



healthwatch
York

Support services for adults with ADHD

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Support services for adults with ADHD - learning from people's experiences

Introduction

This report aims to explore the experiences of adults with ADHD in accessing support services in York. Some of the adults will have been diagnosed when they were children, whilst others will not.

We consider support services to range from getting an assessment and diagnosis for ADHD to getting the help and support that is needed to manage the symptoms. This help can include NHS care and social care support.

In addition we consider the experiences of families, friends and carers who live with and support adults with ADHD. We aim to understand their experiences in accessing information, advice and other relevant support.

What is ADHD?

Attention deficit hyperactivity disorder (ADHD) is one of the most common childhood disorders. It can continue through adolescence and into adulthood. Symptoms include difficulty staying focused and paying attention, difficulty controlling behaviour, and hyperactivity (over-activity).ⁱ There are challenges with diagnosis, since similar but less severe symptoms are common within the 'normal' experiences of childhood.

Half of all individuals with ADHD experience other health issues such as anxiety, depression, obsessive compulsive disorder, learning difficulties, or emotional or neurological problems. These may be secondary, triggered by the frustration of dealing with ADHD, or distinct conditions occurring alongside ADHD.ⁱⁱ

There is no single cause of ADHD, though recent studies indicate genetic factors are important and it does run in families.ⁱⁱⁱ Despite this, and widespread medical acceptance of ADHD as a neurobiological condition, it is still seen as a controversial subject. Parents in particular face stigma, with accusations of poor parenting, and a belief that the

symptoms indicate their failure to restrict the food additives and sugar their child has consumed.^{iv}

ADHD has three subtypes:

- Predominantly inattentive
- Predominantly hyperactive-impulsive (very rare)
- Combined inattention and hyperactive impulsive (most prevalent)

An individual with inattention may have some or all of the following symptoms:

- Be easily distracted, miss details, forget things, and frequently switch from one activity to another
- Have difficulty maintaining focus on one task
- Become bored with a task after only a few minutes, unless doing something enjoyable
- Have difficulty focusing attention on organising and completing a task or learning something new
- Have trouble completing or turning in homework assignments, often losing things needed to complete tasks or activities
- Not seem to listen when spoken to
- Daydream, become easily confused, and move slowly
- Have difficulty processing information as quickly and accurately as others
- Struggle to follow instructions

An individual with hyperactivity may have some or all of the following symptoms:

- Fidget and squirm in their seats
- Talk nonstop
- Dash around, touching or playing with anything and everything in sight
- Have trouble sitting still during dinner, school, doing homework, and story time

- Be constantly in motion
- Have difficulty doing quiet tasks or activities

These hyperactivity symptoms tend to lessen with age and turn into "inner restlessness" in teens and adults with ADHD.

An individual with impulsivity may have some or all of the following symptoms:

- Be very impatient
- Blurt out inappropriate comments, show their emotions without restraint, and act without regard for consequences
- Have difficulty waiting for things they want or waiting their turns in games
- Often interrupt conversations or others' activities^v

The National Institute for Clinical Excellence (NICE) Clinical Guideline for the diagnosis and management of ADHD states that "People with ADHD require integrated care that addresses a wide range of personal, social, educational and occupational needs. Care should be provided by adequately trained healthcare and education professionals."^{vi}

The World Health Organisation estimates that it affected about 39 million people as of 2013.^{vii} ADHD affects 3-9% of all children, and is diagnosed approximately three times more in boys than in girls.^{viii} It is believed that this might be as much about cultural and societal stigma as prevalence, with girls being more likely to have low mood or difficulties socially than display disruptive behaviour that would lead to diagnosis.

About 70% of children with ADHD will continue to have symptoms in adolescence.^{ix} Between 30 and 60% of people diagnosed with ADHD in childhood continue to have symptoms into adulthood and it is thought that between 2 and 5% of adults have the condition.^{x xi}

ADHD and the Criminal Justice System

Studies have shown that adults with ADHD are disproportionately represented in the criminal justice system, with up to two thirds of young

offenders, and up to half of the adult prison population screening positively for childhood ADHD.^{xii} ^{xiii} Childhood ADHD is the second greatest predictor of total offending behaviour behind heroin use, and the greatest predictor of violent offending. Young people with ADHD are more vulnerable to involvement with the criminal justice system as they tend to commit offences that are opportunistic and reactive rather than well planned and organised, making them more likely to be caught. They are less likely to appreciate the seriousness of their actions. Young people with ADHD are less able to cope with arrest, questioning and the court process. They may face difficulties answering questions when experiencing pressure and stress. They are more likely to accept or comply with suggestions from those in authority. This may lead to increased false confession by those with ADHD. They may also struggle to cope with the stress of prison life, resulting in high rates of aggressive behaviour within institutions^{xiv}. Subsequent studies suggest offending behaviour is linked more to conduct challenges, and dealing with emotional adversity, rather than hyperactivity^{xv}. This emphasises the need for supporting young people with ADHD to develop coping strategies and develop emotional resilience.

Key Issues for adults with ADHD

Diagnosis

There is no simple test to diagnose ADHD in childhood. Assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms
- a series of interviews with you or your child
- interviews or reports from other significant people, such as partners, parents and teachers

For adults, similarly, there is no single test to identify ADHD. In some cases, an adult may be diagnosed with ADHD if they have five or more symptoms of inattentiveness, or five or more symptoms of hyperactivity and impulsiveness, listed in diagnostic criteria for children with ADHD.

Under current diagnostic guidelines, a diagnosis of ADHD in adults can't be confirmed unless symptoms have been present from childhood.

For an adult to be diagnosed with ADHD, their symptoms should also have a moderate impact on different areas of their life, such as:

- underachieving at work or in education
- driving dangerously
- difficulty making or keeping friends
- difficulty in relationships with partners

If problems are recent and didn't occur regularly in the past, the adult is not considered to have ADHD. This is because it's currently not thought that ADHD can develop for the first time in adults. ^{xvi}

People with adult ADHD have more trouble with self-management and time, self-organising and problem solving, self-discipline, self-motivation, and self-activation and concentration. In other words they are likely to have more difficulty organising tasks, make careless mistakes, lose things, and struggle to prioritise their daily activities. These symptoms for adult ADHD describe challenges many of us might experience periodically, but may make it seem impossible for an adult to seek employment, hold down a job, or pursue further education unless the person is able to manage their condition. An appropriate diagnosis is essential if a person has the condition, because only with professional care and support will it be possible for them to gain control over their life and integrate successfully and productively.

Additionally, it is common for those with other health issues such as autistic spectrum, anxiety, depression or bi-polar disorder to have symptoms of ADHD. The challenges for 'good' diagnosis are complex and significant, as are the challenges for the individuals and their carers.

Alienation

With limited understanding of the causes and impact of ADHD, many living with the condition face problems with acceptance. The assumption

is that the person could control their behaviour if they really wanted to, and if they had been taught to behave properly.

Adults with ADHD can behave in ways that people do not like, and which are usually associated with 'bad' or 'irresponsible' behaviour. As a result, reactions to this are often negative, aggressive and even more so when the person confronted fails to react 'reasonably' or change their behaviour. Faced with frequent hostility and rejection adults with ADHD can find life traumatic. Defensiveness can become a learned response to others.

Untreated, people with the disorder experience increasing psychological and emotional stress, desperation, and anger, and they can feel alienated. Without the right help it is hard for adults with ADHD to develop coping strategies that present their positive potential and manage those aspects of their behaviour that others find challenging.

Access to services

Across the UK, there are only a handful of places with specialist NHS services for adults with ADHD. These include:

- South London and Maudsley (SLAM) National Adult ADHD Service, the first adult ADHD clinic in the UK;
- Avon & Wiltshire Mental Health Partnership NHS Trust adult ADHD Service, established in 2007
- South West Yorkshire Mental Health NHS Trust specialist adult ADHD Service, established in 2009, with their main base in Wakefield and clinics in Barnsley and Kirklees
- Sheffield Adult ADHD service, one of the first adult ADHD clinics integrated into general adult mental health services
- Leicester Adult ADHD service, operating since 2002, initially as a special interest clinic and since January 2009 as a commissioned service
- The Adult ADHD Research Clinic in Cambridge, founded in 2000 as a joint venture between the Department of Psychiatry,

University of Cambridge and the regional mental health trust,
Cambridgeshire & Peterborough NHS Foundation Trust

- Lothian Adult ADHD service, based at Royal Edinburgh hospital
- Leeds & York Partnership NHS Foundation Trust specialist ADHD assessment and management service^{xvii}

The Tuke Centre is part of the Retreat in York. It has been commissioned since January 2016 by the four Clinical Commissioning Groups (CCGs) across North Yorkshire – Vale of York, Scarborough & Ryedale, Hambleton, Richmondshire & Whitby, and Harrogate & Rural District – to provide an Autism and ADHD assessment Service^{xviii}. However, the clinic is only contracted to offer a limited number of follow-up sessions to help people understand their diagnosis, not provide ongoing treatment.^{xix}

The National Institute for Clinical Excellence (NICE), was set up “...to reduce variation in the availability and quality of NHS treatment and care”^{xx}. The intention was that British people, wherever they live, have equal access to NHS health care. Services for adults with ADHD is one of the services that the Government expects every adult to have available to them if they need it.

NICE guidelines set out expectations that both NHS commissioners (the CCGs) and NHS provider trusts (the local mental health trusts) deliver, “...a person-centred, integrated approach to providing services (that) is fundamental to delivering high quality care (to) people with ADHD.” NICE further says, “commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duty to avoid unlawful discrimination and to have regard to promoting equality of opportunity.”

It is important to note that NHS Vale of York Clinical Commissioning Group (VoYCCG) has lower levels of health funding than many other areas. For every person in the Vale of York area, the VoYCCG has around £1,140 to spend per year. In an area like Liverpool, that amount rises to £1,560^{xxi}. The four North Yorkshire CCGs were the only ones in the country to inherit debt from the Primary Care Trust they succeeded,

originally indicated to be £19M^{xxii}, though the actual figure was later said to be £8.5M^{xxiii}. Although local CCGs wiped out this debt in their first year, Vale of York CCG is currently forecasting a deficit of £28.1M for 2016/17^{xxiv}. It is clear that investing in new services will be challenging given this situation.

Nutrition

An internet search using the words “nutrition” and “ADHD” brings up around 11 million results, mainly dealing with dietary approaches for children and young people. However, there is a lack of consistent advice about good nutrition for people with ADHD. NHS Choices suggests cutting out certain food colours if your child shows signs of hyperactivity or ADHD^{xxv}. There is also reference on a number of sites to “leaky gut syndrome”^{xxvi} which sites like NHS Choices suggest a lack of evidence to support^{xxvii}. A number of websites suggest trying an elimination diet, cutting out allergens one group at a time^{xxviii}. Others recommend dietary supplements^{xxix}, or following a specific dietary programme^{xxx}. NICE guidance, however, contradicts most of these suggestions.^{xxxi}

As such, there is a challenge for people living with ADHD and their families in deciding which advice to follow. There may be a range of things that work for some people, even though they are not supported by current guidance.

Why is Healthwatch York looking at support for adults with ADHD?

Healthwatch York has been made aware of difficulties adults with ADHD have had in finding and accessing support services. The issue has been raised with us in a number of ways:

- At a conference looking at mental health in York, a number of individuals asked questions about diagnosis and ongoing support for adults with ADHD and autism
- Carers have approached us, particularly through Solution Orientated Adult ADHD Carers (SOAAC)
- Individuals living with ADHD have approached us looking for information and advice, and have shared their stories

The majority of people contacting Healthwatch York stated they were not aware of any support available to people living with ADHD in York.

City of York has a population of approximately 200,000^{xxxii}. NICE guidance estimates that 3-4% of the adult population have ADHD^{xxxiii}. Based on an estimate of 3.5 adults in every hundred having ADHD, and just under a quarter of the population being under 19, then York could have around 5,250 adults in the city living with ADHD. However, we cannot state with certainty the actual extent of need/demand in the area.

What we did to find out more

We attended meetings with SOAAC, and supported them with activity to publicise their carers group. They kindly shared their report, which gives detailed insight into the challenges faced by carers and family members of people with ADHD.

Healthwatch York held two focus groups with carers of people living with autism and / or ADHD, to understand their experiences. Whilst this work did not focus solely on adult ADHD there were a number of issues raised that were directly relevant to this work.

We also held one to one meetings with a number of individuals with ADHD.

What we found out

Findings from the SOAAC report

The voices of families and carers are captured in the ADHD Carers SOAAC report “The Impact of Adult Attention Deficit Hyperactivity Disorder on the Individual, their Carers, and on Society”^{xxxiv}.

Here, we reproduce short extracts from the SOAAC report to highlight the sense of frustration at the lack of support available to carers of people with ADHD, and the impact ADHD has had on their lives. All names have been changed.

Tom’s story

“I became aware my son Tom was different from the other children at an early age. He was more sensitive than his peers and found it hard to fit in... Teacher’s would write that Tom “finds it difficult to produce much written work, lacks concentration, lacks patience, is easily distracted, makes mistakes..., is disorganised, needs to learn to listen and follow instructions.” There were also positive comments like, “he is a bright and intelligent boy...”

“He was afraid of things that were unfamiliar... he struggled to apply himself... he would fidget a great deal... he was not obviously hyperactive. I have since learned this is not unusual. People can have ADHD with the hyperactivity manifesting in other ways.”

“I took him to the child development centre when he was five but following a ten minute appraisal, was told there was nothing wrong.”...

“When asked what he would like to be when he grew up Tom said he would like to be a doctor or a rock singer. His teacher responded “You are more likely to end up in prison.”...

“I knew my son was struggling, I knew he was bright, and suspected he had ADHD, but I was not listened to... I believe I was dismissed as an overprotective neurotic mother.” ...

“(At seventeen) we sent Tom for weekly support at the Dyslexia Institute which consisted of tools and strategies geared to his ADHD.... (he) began attending a private clinic where the consultant prescribed methylphenidate, monitoring him at regular intervals...”

“(Tom) wished to continue his education... studying history, law, psychology and sociology. He gained two A’s and two B’s... and went to University to study law. This from a boy who (at school) was told he was not A-level material... Now aged 19 Tom thought he no longer needed (medication) and stopped taking it. He...believed he could manage without support from the university. Without structure to his life of medication, he soon lost focus... I believe he turned to alcohol and drugs as... a means of self-medication and to hide from the growing awareness he was not coping....”

“He ‘dropped out’ of University and came back to York. He moved in with a girl which was the first of four dysfunctional relationships over the next 10 years... After the first relationship failed Tom was devastated. He felt abandoned and desperate. ... An old friend ... came back into his life... a drug dealer ...with a regular supply of cocaine or M-CAT

(mephedrone). Tom said this helped him feel 'normal' ...but... he would sleep most of the day and stay up at night. He became more irritable, aggressive and his mood swings were more marked....”

“There is a tendency to attribute the dysfunctional behaviour of those with adult ADHD to substances and alcohol rather than recognising it as a consequence of this disorder when left untreated. ...”

“Due to his condition Tom found it difficult to deal with everyday problems. He was unable to focus on more than one thing at a time therefore he couldn't hold down a job at the same time as being anxious about a relationship. His self-esteem was poor and his emotions fragile. ...”

“We received a call from the police at 2am telling us our son was in custody. It came as an enormous shock... the judge sentenced them to three years in prison with immediate effect....”

“A business colleague gave Tom a job.... The demise of his existing relationship followed by problems with the subsequent relationship... made it impossible for him to function at work. He would sometimes fall asleep at his desk because he had been awake all night in a state of anxiety...”

“The stress of dealing with our son put a great deal of strain on our marriage and contributed to my husband and I separating for 7 months in 2010. When I returned home Tom's girlfriend told me she wanted him to see his GP, to be referred for a mental health assessment as she was concerned about his behaviour... we eventually persuaded him to see his GP but after explaining his symptoms and behaviour we were told there was nothing wrong. Tom's relationship ended and ... his behaviour deteriorated further.... He would say he wanted to die and that he was going to kill himself... we would go to his house and find mirrors smashed and furniture broken... blood everywhere and cuts on Tom's arms and wrists...”

“As there is so little support for those with Adult ADHD... I feel I am alone with the responsibility of caring for my son... (which) has taken its toll on my physical and psychological well-being. I often go to bed with a heavy heart and find it hard to sleep... sometimes a feeling of rising panic and thinking I might be overwhelmed by it... I am constantly tired... inside I feel trapped and desperate. I feel frustrated and angry with myself for being this ‘pathetic’ human being.... “

“It is not easy to relax... as there is a feeling of guilt that accompanies this. It stems from a conviction that somehow I have let my son down knowing that more could have been done... I feel I was part of the system that failed him.”

Matthew’s story

“Although (Matthew was) an engaging and lively child and an early developer, he had little regard for the consequences of his actions. He didn’t want to stay at school on his first day so he bit the teacher... a few months later he cycled out of the school and straight onto the main road where he hit the side of a passing car.”

“From the age of about 12 he began to develop serious behavioural problems... refusing to go to school... started using alcohol and soft drugs to... help him cope with the difference between the world as he saw it and the expectations of those around him. If asked to do something he didn’t want to do... he would respond with disproportionate violence; throwing bottles or coffee mugs, kicking holes in doors and walls and threatening us with knives. During this phase he was suspended from school for drinking on the premises and ... permanently excluded for possession of a knife. Matthew was also stopped by the police and was arrested on many occasions for various offences....”

“Looking back it is clear Matthew’s inability to link actions to consequences was the underlying reason for his behaviour but... this was never suggested or explored. An intensive session of therapy... focussed exclusively on relationships within the family, and Matthew

himself was **never** assessed by a qualified therapist. Limetrees gave this task to a second-year student who produced a 4-page report saying that he was bright but lazy... The first experienced doctor to be involved diagnosed Matthew's condition as likely to be caused by severe ADHD simply by listening to our descriptions and looking at his old school reports – this of course begs the question as to why his school or GP did not have access to anyone with this experience and knowledge to see this at the time... He was seen and assessed... as having severe ADD and the options for his treatment were outlined. However as adults with ADD don't fit into the remit of any of the services available in York he was unable to follow up any of the recommendations..."

"It is too late for our family, but we hope that by sharing our experience this condition will be picked up.... Even now, the lack of ongoing support for Matthew in adulthood means that he remains at real risk of poverty and homelessness."

The report details the challenges Matthew faces:

- Money – impulse spending, finds budgeting difficult, disorganised and forgets to pay bills, finds saving very difficult – his mother helps by holding his money for him and managing household bills
- Food – inability to plan, shop for and prepare meals, forgets to eat, shops on impulse, cannot cook a meal using more than two sources, e.g. cannot grill sausages, boil potatoes and microwave beans as too much going on
- Hygiene – forgets to bathe, wash hair or shave, wears the same clothes for days or weeks
- Household tasks – doesn't like help from other people, washes up regularly, but other tasks like cleaning, laundry and shopping are sporadic, forgets to buy replacements for things like toilet paper
- Appointments – finds remembering and planning appointments difficult, gets anxious about going somewhere unfamiliar
- Friendships – difficulty in making and sustaining friendships
- Medication – receives support from parents to get repeat prescriptions, leaves some medication with them

Andrew's story

“Following a difficult birth Andrew was an unsettled baby... we did not realise he had problems until I started taking him to toddler groups. Initially we were sent to Limetrees. The main focus was on us as parents which we found patronising and upsetting. They tested Andrew's IQ which was high. Following problems at Primary School Andrew was eventually given an ADHD diagnosis with no further plan. We then saw our GP who advised us to see a Paediatric consultant in London. She assessed Andrew over several hours and diagnosed him with ADHD. He was prescribed Ritalin which seemed to help...”

“Secondary school did not help with Andrew's ADHD. He started to self-harm and became very disruptive. The school dismissed his problems as purely bad behaviour.”

“In year 10... (he) gained new (friends) who had a negative influence on him... He started taking cannabis becoming very aggressive at home and ceasing to try at school. We went to the GP as his problems were escalating. We were referred to Limetrees and he saw a counsellor who seemed to make him more agitated. Violence started to increase.... No one seemed to know what to do. On one evening things became very violent with Andrew smashing two laptops in his room and jumping out of his window. We had to call the police who agreed he needed help but said the only way was for us to agree to him being arrested which we reluctantly did. He was then referred to the Youth Offending Team (YOT). The person he saw had a good influence on Andrew and was very helpful (but) the nurse who works alongside YOT dismissed his ADHD after only one appointment. Andrew soon relapsed, threatening to kill us in our sleep. A social worker started to see him after the YOT order and the police had to be called on several occasions. Andrew's father was too afraid to work away (which is part of his job) fearing what might happen at home... After three months we were told it would be the last visit, despite his problems increasing and the police being more involved.”

“We started to feel very vulnerable and afraid for all our safety including Andrew’s as he regularly threatened to kill himself. He would taunt us with knives when he was angry... We desperately called the manager of child social services on several occasions, sometimes in tears....”

“Social services contacted us and gave us a family intervention worker for problem families... this person said Andrew did not have ADHD and could be easily sorted out also saying they didn’t really see nice families like ours... Andrew had deteriorated and was taking M-CAT. More items were stolen from our house... drug dealers would turn up at our house and we had to call the police frequently... which ended with Andrew having to move to Howe Hill Hostel....”

“Andrew didn’t engage and slept rough and on people’s floors. He was only 16 and getting into more trouble with the police, culminating in him being placed in the custody of the local authority... the foster carers allowing their son to tattoo Andrew’s neck, chest and arm and sending us the bill.... Andrew was also getting cannabis from their son... Other than Andrew’s reviews there was only 2 or 3 visits from social services to see him in 11 months and when the placement collapsed there were no written notes regarding his case. On the day he left we got a call from Andrew at Kings Cross station saying he was sleeping rough so we arranged for him to come home...”

“A week after his 18th birthday Andrew took an overdose in London then ran away from hospital. The police found him... he was sectioned under the Mental Health Act... To our horror he was discharged the next day... he rang us saying he was going to jump off a building... he was sectioned again and sent to the Friarage... but escaped... the following day.”

“Andrew had further stays in hostels, made further calls about taking his own life, self-harmed, got involved with drug dealers, and threatened and intimidated family members.”

“Andrew ended up in Hull prison for 9 weeks... things continued to go badly.... After committing several offences, Andrew was sentenced to 15 months in prison... He is not allowed contact with me until February 2016.... We are so afraid that without some intervention he will continue on this destructive path.

Summary of Issues from the SOAAC Report

In summary, the Solution Orientated Adult ADHD Carers (SOAAC) report indicates that despite a parents' concern:

- a GP may be reluctant or refuse to refer a child for assessment;
- a school may not identify potential ADHD underlying difficult behaviour, and thus not involve an educational psychologist;
- a school psychology service may refer an older child to CAHMS, but long waiting times may lose a vital window of opportunity to intervene when the 'child' or young person may have been willing to grasp an opportunity;
- even when parents resort to private mental health resources and help is found, they face challenges when a child becomes a young adult. When they face a new environment such as university, their previous trusted support relationships are cut off. They enter a new academic environment in which greater independence is expected of all students. Most new students will thrive and make new and lasting relationships with their peers, but for someone with ADHD or other mental health conditions the new life can feel exposed, potentially hostile and hugely challenging.

Voices of Adults with ADHD

A number of adults with ADHD living in York contacted Healthwatch York to share their experiences (all names have been changed):

Xanthe

Xanthe says: “I was only diagnosed in 2005, in my 30s. I came to York as a mature student. I was meant to have care and support transfer with me but this didn’t happen. I have direct payments which allow me to pay for a life coach. This is essential for me. At transfer the payments stopped, I couldn’t see my life coach, and my life fell apart. I went to a GP in York, to ask for help. I knew I needed a referral into Mental Health services. I was anxious, and I lost it on the telephone to the GP – I became irrational and used inappropriate language. I got a letter saying my behaviour was unacceptable. The in-house mental health nurse said the letter was wrong – people who understand ADHD know it isn’t how I would choose to behave but when upset I literally cannot help myself. I want to work. I’ve been unemployed for over 10 years. But to work, I need support. I need help with structuring my life to get the balance right between work, life and home. I take on lots of voluntary projects, throw myself in wholeheartedly doing hours and hours of work every week, and exhaust myself and then need time to recover.”

Xanthe believes that mental health services should be available. She has been told by the NHS in adjacent areas that she should be monitored every 6 months, but has also been told that this impossible in York. Xanthe feels she has been rejected by services because she is not classified as having ‘mental health issues’. She says, “I have trouble fitting service categories”. However, she seems to suggest that as a ‘service user’ or patient she is made to feel at fault because she does not fit. She feels that it is the ‘system’ that defines and redefines categories and sets criteria.

Her social worker, not trained in ADHD, admits not understanding the condition, but wants to. Xanthe wants employment, but is worried about this because of the challenges involved. She has been able to access coaching, which has helped her set boundaries, and gain insight into how others perceive her, which has helped her think about going back to

work. But she is worried that she may not still receive this support if she goes back into employment. However, without proper support she does not believe she has a good chance of making a success of work. Xanthe feels that services make an assumption that she has family support. She is living and coping on her own but feels that everyone “thinks I must have a carer somewhere.”

She provides further insight into living with the condition. She shared that she finds too much input overwhelming. She described it as being like trying to watch TV, read a book, listen to a radio station and hold a conversation all at the same time. She finds it easy to become overloaded:

- I can't go to the CYC offices...they cause sensory overload
- I can't stand the heating system at night... the ticking sound is too penetrating.

Xanthe also confirmed she finds it difficult to form strong relationships, as people can find her behaviour challenging. Xanthe's experience echoes those passed on by carers: the condition caused people to feel bullied. In turn, Xanthe was bullied at school and moved schools often. Xanthe was diagnosed in adulthood. Prior to diagnosis, she frequently felt angry and frustrated. She is clever, but dyslexic, and has found written work and reading a problem. As she grew older, she felt she was seen as a 'misfit'. Without support, she drifted into drugs and poor relationships.

Xanthe needs 'space' to think and process thoughts and feelings. She has had a number of different diagnoses, including being thought to be bipolar or depressed by health professionals. She believes that “doctors don't look for a pattern.” She feels they are looking for symptoms or criteria rather than trying to see the whole person.

Xanthe has offered many other experiences and insights. She is now aware of her condition, and how others perceive her. But she feels that in effect she is just marking time. In order to move forward the services already outlined, and in place in other areas, need to be provided in

York. Xanthe has found real help from a 'life coach' who has helped her to recognise and engage with her condition. But to take the next steps into employment, she needs this support to continue.

James

James contacted Healthwatch York after coming to live in York. James had previously been diagnosed with ADHD and was looking for services in support of his condition. He approached his GP in York and found the experience 'shocking'. He was told “there is no money in mental health” in York, particularly for autistic spectrum disorders and ADHD. He states that his impression was that “the system is in chaos”. James asked for to change to a different medication as he was having side effects. His GP again told him there was no money for a referral to a psychiatrist for a medication review. James states that his appointment went nowhere until he showed the GP a letter from a Maudsley psychiatrist. He was then prescribed more of the old medication. When he once again asked for a medication review, the GP responded with further negative comments about the state of mental health services.

James hopes to find another GP who may give different and more supportive answers. But his negative encounter has left him feeling neglected by the Health Service. James says:

“I am back on the medication that I previously wanted to change from, without any therapeutic support or even any hope of ever getting (it)”.

Sarah

Sarah is a young adult with family responsibilities. She contacted us “at her wit's end”. She informed us that her world had collapsed - her partner had gone, and her children. Sarah has ADHD. She contacted us wanting to know who could help her turn her life around. Sarah was trying to put her “life back together”.

Sarah already had an ADHD diagnosis before coming to York. Fit and active, Sarah has had useful input from a community mental health team in the past. She became ill with glandular fever. She told us that three

GPs had made referrals for social worker support, but that City of York Council refused to provide one. She also states that the Council refused help with a 'managed move', and her attempts to obtain a 'personal budget'. Sarah recounted “repeatedly (being) passed from pillar to post”, and being “misdiagnosed by a CPN (community psychiatric nurse)” who was provided only after her 'breakdown' – a crisis that she feels probably need not have happened if she had been given support to manage her condition appropriately in the first place.

Sarah feels like she has been “treated like dirt”. She says “we are literally going out of our minds”. Sarah is also convinced that the CPN's 15 minute assessment of her mental health situation, which she disputes, now forms part of her recorded medical history. She believes this has affected further decisions that have been made regarding fitness to care for her children. She wanted to understand whether this assessment can be removed from her records.

Sarah actually says little about having ADHD, other than noting that he/she has the diagnosis, but talked about her experiences of rejection when trying to obtain help from all agencies, whether statutory or voluntary and community sector, as she did not fit the criteria. These rejections add to underlying challenges when simply wanting to be, “back at work and enjoying family life”, adding “...is that too much to ask?”

Alex

Alex was recently diagnosed with ADHD at the Tuke Centre, part of the Retreat in York. Despite this diagnosis, he does not believe he has very extreme symptoms. He feels that his condition probably contributed to difficulties with forming or sustaining positive personal relationships.

Alex's GP who made the referral “was brilliant” and the referral resulted in an assessment 12 weeks later.

The Tuke Centre recommended ADHD-specific Cognitive Behavioural Therapy (CBT). Alex was told that the therapy sessions were chargeable, but that the Tuke Centre were confident the costs would be

'covered'. The sessions have since ceased as it became clear that ongoing care and support might be a problem. Alex understands that the Retreat submitted a bid to become a provider of ADHD pathway services in addition to providing diagnosis support across North Yorkshire to the 4 CCGs but this had not been agreed at the time he spoke to us. Alex was also prescribed medication. He tried several types until Alex's GP received a letter from TEWV declining funding for ongoing care for Alex. Alex himself was not copied into this communication.

Alex still seeks CBT and the right medication. In addition he has sought out a 'support group', finding one at Wakefield Pinderfields Hospital. As with others who have contacted us, he stated that being able to be in contact with others 'who get it' is helpful, but Alex feels the Wakefield group is probably geared more to parents of people with ADHD than the individuals directly affected.

Alex concludes that the Government is failing to take ADHD seriously, and as a result incur social and economic costs. In addition, he believes they risk alienating many adults with ADHD who, without help and support, end up with ruined lives. As Alex explains, he has other 'problem behaviour' which he also want to overcome. Alex is angry that although an ADHD assessment/diagnosis service was put in place nearly 2 years ago, he has yet to receive agreement on funding for his ongoing care needs. Alex's GP has sought to obtain further funding for ongoing care, but when the request was passed to TEWV, the Trust declined it. "It took them over 8 months of ping pong to come to that decision!" He believes he is "just another adult with ADHD left high and dry."

Mary

Mary is in her 40s. She feels under pressure to sign on whilst waiting for diagnosis and treatment, probably for ADHD. There is no ADHD consultant in York, she has to get an appointment with Wakefield. (Note: The Tuke Centre at the Retreat has an ADHD consultant, Thomas Elanjithara, and people can be referred to him). It takes 7 weeks to get an appointment. She has no food in the cupboard and no credit on her phone. She needs support with claiming benefits. She wants an

advocate to support with pressure from the Job Centre. She is feeling very overwhelmed by circumstances.

Healthwatch York Focus groups on Autism and / or ADHD, February 2015

Findings from the Focus Groups

We spoke with 13 people across 3 groups. 11 were carers, 2 were professionals working with people with ADHD. It is important to note that the discussion covered experiences of both autism and ADHD, though these two conditions are not always present together. Feedback received from the focus groups has been divided into 3 distinct sections:

1. People's experiences of autism and ADHD
2. Themes and comments on how life for people with autism and ADHD could be improved in the city
3. Gaps identified by a coach with experience of working with people living with ADHD who attended the focus group

1. People's experiences

All names have been changed.

Ellen

Ellen used to go to St John's University, she has Asperger's, but walked out and effectively became a recluse. Her confidence went, and she didn't want any formal support, she just wanted a drop-in space, to take the pressure of support off, 2 years ago. Ellen ended up going home, got so depressed she just couldn't cope, but she feels she was left to get worse. "It's difficult when you get into the mental health system – to understand what issues are due to the autistic spectrum disorder and what actually is mental health."

Ben

"Last week the police came twice for my son, Ben, because he didn't want to go back to his flat, ended up in the police car having a 'meltdown'. Police asked "what has happened since we were here last? What support is in place?"

"He has gone missing for over 8 hours, and suddenly he's the family's problem. He's at the family home more than at his own home. He has a

specific number of hours of care, mainly delivered by young girls of around sixteen. He's never given choice in this and he probably finds them quite intimidating."

Mark

"Mark will be 29 this year, we're worried we will have to move him to somewhere else, due to behaviours and rituals. He previously lost his job. He had a job at a shop, he was then sacked as he was taking too long. This was five years ago. He got really depressed, no intervention at this time, hadn't declared his Autism to his employer, he didn't work fast enough – very meticulous, felt he couldn't explain the condition. His mental ill health led to paranoia. Services will only provide support at crisis."

Jason

"It feels like there is very little provision for those with ADHD. What's happening to address this? Jason was placed with a provider outside York aged thirteen, he's now twenty two. At eighteen we received a letter from City of York Council telling the family they had provision for him now, in York, in a flat that hadn't yet been built. Jason's current provider has become his whole world, it's very scary to think it could all be stopped. It sometimes feels like bullying tactics – that they can withdraw provision if you protest too much. When Jason heard about it he said "I don't want to go back there, they don't understand me." It feels like it always comes down to money – is bringing our child back about saving money?"

"Jason has a care plan, but I'm not sure if it's used. There's no prompting, he's not learnt to go shopping or prepare food. I would like him to have personal assistants who would work one to one to support him. He needs life preparation support. We've not been offered 'personalisation', would be willing to be part of developing a personalised plan for Jason, testing activities to see what works."

Nathan

“I would like to see lots of opportunities for young people to do things in York. It feels like there is a difference between mainstream children and people with autism. It’s particularly challenging for those who are high functioning- where do they fit? My son doesn’t see himself as disabled but mainstream schools are not a supportive environment.”

“This leads to a decline in mental health. There is no open door policy with Limetrees, so we’re back to the beginning as a re-referral when he has a dip. My son is nearly 14. He has dips - peaks and troughs, and the lows happen in a split second, with very little warning. He has medication which could enable him to take his own life. At that stage we want significant intervention from Limetrees. But when it happens, they say he’s been OK for a period beforehand, then he’s a closed case. Which means we have to go back to our GP, have to wait for support to be available, and by the time we get back in to services, we’ve sorted it out. But at an emotional and physical cost to us each time.”

“With interventions you maybe get 3 months of support, and then things are checked 6 months later. If all is OK they close the case. It’s a really challenging situation for the whole family. There’s no consistency - staff have moved on, so you have to start again, building new relationships which is one of the real challenges for our children. So we as a family sort it ourselves, but we worry about the impact on our other children. It’s exhausting, just existing. We both still have to go to work, sometimes we leave him with others looking after him and all we can do is hope he’s OK. Realistically when he has these dips we need a response and support within a couple of days. We’re not the only ones – we’re connected with a big group of people going through the same thing.”

“Someone last year couldn’t cope and took his own life. We want something ongoing to help with maintaining mental wellbeing. But we’ve been told this doesn’t exist.”

“School has been great - looking at 1 to 1 support with a Personal Assistant to do something and they’ll allow him time out of school. He’s

looking at yoga, looking at self-care and how he can help himself. But he struggles with social skills.”

“As parents we’re on suicide watch but we get no training. It feels like they make you look after everything yourselves and it’s a struggle to maintain normal family life whilst crises are happening around you. You juggle work whilst thinking of ways to bring him out of it. Sometimes it feel like I don’t know my son at all. He doesn’t talk. So I’ve no idea what’s in his head, sometimes.”

“Because my son has an autism label, it’s an excuse for the challenges, so I feel like he’s not seen as in as great a need as a one-off incident when he experiences mental ill health as it would be for, for example, a “normal” 15 year old. A staff member at Limetrees once said to me “The parents become better equipped to deal with it.” My daughter now has a really good support network through Young Carers at the Carers Centre but it took time and effort to get this in place.”

“I’m worried about transition. I know other parent carers who say “you’re where we were 10 years ago.” I think that Limetrees don’t know enough about autism. But it’s not their fault, they are very stretched. You have to be in crisis to get support.”

“It’s great to hear about psychiatric liaison in A & E. But I don’t want to get to that point. My son tried to kill himself at 13 years old. He threw himself under a bus. As a parent, you always have this hanging over you.”

“In school the Physical Disability Specialist teacher did a big programme of social activity. But autism speciality teachers are too stretched - so I feel like those with social challenges rather than a physical impairment are not getting the same deal.”

“Some interventions are amazing but they’re not a permanent fix. When I said this I was told he’ll need to learn to cope, and our family does too. I

was also told children with autism have dark moments but they're not really suicidal."

"Nathan says he doesn't see the point in referrals. He will have an experience, then he'll get the intervention but then it will all come to an end and he'll be back without support."

"The good thing is that all the interventions he's had have been age appropriate, so for example, when he was 10, he talked about what's happening in the brain, drew pictures of his brain and how he feels. It's all good person centred stuff. But what next? I'm always trying to think of the next thing that might help. But I've no experience of where he goes next. We've been offered different therapies to deal with aftermath. But I actually want training on what to do when things start to fall apart. What's 'usual?' I've never had a fourteen year old boy before. What's hormones? What's Autism?"

"This all has an impact on health – feeling exhausted and anxious. We're in a constant vicious circle of services. I'd like a holistic approach. I need advice, training, and guidance to plan for what comes next. There can be triggers, usually around school, bullying at school, and his behaviour takes a dip, but the school is very supportive. Sometimes though, there's no indication why."

"With some of the options we're offered Nathan asks "Why would I go there? It's full of disabled people, I'm not used to them." But he also can't go to some other groups as "they talk too fast and I can't process it."

"Nathan says "All I want to do is fit in, I don't want to be singled out. I want to fit in, want to 'blend' in and not be the person that has a meltdown." Nathan will try anything, he's not scared of doing things. Last week, when he felt better, we went shopping. He said he wanted to look 'less different.'"

“We get a direct payment. But it’s a struggle to find individuals of the right age. He had a Personal Assistant recently who had a friend with Autism. They both used to sit and not speak for a while.”

“He went on a residential recently. But the next youngest person was seventeen. He loved it but he couldn’t cope in the canteen, so he sat apart from everyone else. He feels damned if he does and damned if he doesn’t. He doesn’t want to exclude himself but he can’t cope.”

“I spoke to one of the specialist teachers, sharing my view that we first need to look at the social side. It’s the biggest area where support is needed. When you are doing this with young children, you need to keep revisiting this for children who are high functioning.”

“I’ve been told things that aren’t right. I’ve been told he wouldn’t get sarcasm. He does. We’re a very sociable family. Nathan is sharp, witty, quick, but take him out and the barriers he has get in the way. He won’t allow his friend to come round. He needs people he trusts around. It’s taken a long time to build that trust. He’s an intelligent, talented chap, but struggles to show this outside of the house.”

“We keep looking for positive stuff. We started off years ago with the sports directory. He tried everything but he’s not sporty. He likes TV and Youtube. But he’s looking at Yoga to do with his Dad. He’s decided he could have a Facebook account. He wants very limited public exposure, so he’s looking at IT, at non-direct contact. He’s looked at clubs at school, but it’s outside his comfort zone.”

“If we were was starting over, back at Primary school then I’d focus on social interaction. He did the programme about social interaction, but I would do so much more with children with autism then. That’s the time when they are still having some social capacity with their peers. They need Emotional Intelligence and support at this point. I’d also want to see more support for parents – we went on the ASSEND course, but we had already read a lot. It was good to meet parents though.”

“There used to be a siblings group at Limetrees. When Nathan was diagnosed with Autism they had a group that met with siblings to help them through it. Just for siblings. But then the rate of referrals increased, so they had to redirect funding to diagnosis work. So all peer support stopped. Peer support can help but it is not enough, they need professional intervention.”

“You can access City of York Council Workforce Development Unit training as a parent. CANDI (now York Parent Carer Forum) set this up. Does it still apply? But it would be good if they could provide training around managing specific behaviours through Mental Health. We’ve had some really good training, for example about sensory processing. But for us it’s all about social skills and mental health.”

2. Themes and comments on how life for people with autism and ADHD could be improved in the city

Understanding the potential links between autism and other conditions

One parent felt it was important to understand that for many people with autism, there are usually a minimum of two things going on. These could be for example ADHD, Dyspraxia, learning difficulties, Mental Health Conditions, which are experienced alongside and as well as an Autistic Spectrum condition. The parent emphasised that for her child, change is difficult. With this in mind, she invited us to imagine how people with autism feel when they have to leave York because there is no provision here. She feels that they are removed from everything familiar. But she is aware that we don’t have the services here to support them.

What is missing and what people would like to see

The focus group came up with a number of issues highlighting improvements that could be made

- People need reminders for medical care, from health checks and dental appointments, through to remembering to brush your teeth.
- There are challenges around access to information. It’s hard to find any help about what is available in the city.

- We need easy access to services, including low level support such as Millers Yard.
- There is a need for structure. A timetable, with a range of meaningful activities.
- There needs to be initial investment in early support to reduce the challenges in later life.
- We need someone realising when things aren't working.
- Children's Services have an independent reviewing officer - completely independent, reviews things every year – what's working, what isn't. Can we have this in Adult Services?
- We need to look at how we can nurture and support creativity, skills and employability? Everyone has skills, it is how you use them e.g. a person who enjoys ripping up paper can help create mosaics.

Medication

Participants made a number of comments on medication for ADHD:

- Medication – this can be a major breakthrough
- Anxiety management is a big issue – they don't seem to change medication for this if it's not working.
- Reviewing the use of anti-psychotic medications – by impact. These may help short term but should not be used long term.

Care and support

The focus group identified the following issues around support

- People need a keyworker, who knows about their condition, to support with structure, understand what they really want, and help them establish routines.
- It takes years to build relationships of trust with professionals working with your child.
- Good care workers: need patience, don't raise their voice, must be factual and give details such as timings, get to know people, don't overwhelm them, stay calm, motivate people, are good at reading body language, are positive, avoid intimidation.

- Care workers need training. United Response are good, they have specialisms, their staff stay longer, they enjoy the job and are paid more for specialist skills.
- Some staff who work with people with autism show a lack of awareness.

Other issues raised by the group

- Where does the strategic responsibility for Autism and ADHD sit in York? It would be good to have clarity over where issues can be raised and who to hold to account.
- The economic impact of failing people with Autism and ADHD needs to be taken into account. Where is the money for people with these conditions? The challenges of austerity are reducing inclusive practice.

3. Gaps identified by a coach with experience of working with people living with ADHD in York

There needs to be more focus on adults who may not have been diagnosed. They are on the periphery. I've been approached by parents of adults in their twenties, who wanted specific help for their social skills, anxiety. I am not qualified to provide this. There is no training on how to work with people. I'm a bit at a loss on where to signpost to.

There are recommendations on how to work with people with Autism. A lot of standard psychotherapy is not helpful, and can actually make things worse. A structured approach is more beneficial. Another gap is support for couples, who need counselling, where one partner is on the spectrum and they are experiencing difficulties. I am looking at and willing to co-ordinate a partners group in York. There are gaps in information and emotional support. We need to increase understanding of the effects of Autism on adult relationships. How do we identify if this is due to Autism and where can support be found? There's just not enough support out there. Currently the nearest support groups are in Halifax. Everyone involved in education needs training in disability awareness, equality and Autism awareness before they start to work in schools.

Conclusion

Drawing on all the information the testimony above describes a poor picture, both for adults and for families living with ADHD in York. If an adult sees their GP because of concern about whether they might have ADHD, there is no guarantee that this visit will lead to a referral for an assessment. These stories indicate some GPs remain sceptical about ADHD as a medical condition.

If they do receive a referral for assessment and possible diagnosis, there is still limited access to ongoing support.

It is clear that in order for this to change, there needs to be a consistent pathway and options for treatment and support. The financial, emotional and societal costs of failing to do so are evident from the experiences people have shared with us.

Recommendations

Recommendation	Recommended to
Commissioners and Providers commit to working together with people with ADHD to find a creative (if necessary) and sustainable solution to provide support services for adults with ADHD in the York area. This should include considering the needs of people with ADHD in newly emerging pathways around low level / community based support for people experiencing mental ill health.	NHS Vale of York CCG (VoYCCG) Tees Esk & Wear Valleys NHS Foundation Trust (TEWV) City of York Council (CYC)
Consider the creation of a multi-agency task group to look at how a 'system wide' pathway to provide the efficient and effective pathways regarding support for people with ADHD and their carers can be developed.	VoY CCG TEWV CYC The Retreat SOAAC
A patient/service user reference group should be established with links to the task group to embed co-production approaches and to develop peer support networks locally.	Health & Wellbeing Board
Consider creative approaches to personal budgets and personal health budgets to support those with ADHD having access to a wider range of potential support services.	VoY CCG CYC
Clarify where responsibility sits in York for Autism, and where concerns about the implementation of the National Autism Strategy can be raised	Health & Wellbeing Board

Appendix 1 - Information and Support providers

NHS Choices provides information on diagnosing and managing health conditions. This page is mainly about ADHD in children, but provides links to a wide range of information.

<http://www.nhs.uk/conditions/Attention-deficit-hyperactivity-disorder/Pages/Introduction.aspx>

The ADHD Foundation, in partnership with individuals, families, doctors, teachers and other agencies, works to:

- Build a positive foundation for life.
- Improve life chances through better understanding and management of ADHD.
- Raise awareness & understanding of ADHD - change the negative perception of ADHD into positive.
- Bring about positive change and inclusion within policy and practice.
- Support schools, GP's, youth justice services and other professionals who work with people living with ADHD.
- The ADHD Foundation supports achievement, educational attainment, mental health and employability.

The Foundation works in partnership with those living with ADHD, enabling them to understand and manage ADHD.

<http://www.adhdfoundation.org.uk>

ADHD Together is a resource to help parents, carers and teachers from across Europe work together in supporting school-age children with ADHD. The following sections have been developed to cover the key steps needed to encourage them to thrive both at home and in the school environment.

<http://www.adhdtogether.com>

ADDISS, The National **A**ttention **D**eficit **D**isorder **I**nformation and **S**upport **S**ervice provides people-friendly information and resources about Attention Deficit Hyperactivity Disorder to anyone who needs

assistance - parents, sufferers, teachers or health professionals.
Whatever you're looking for in ADHD, they'll do their best to help.

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

The Hyperactive Children's Support Group

HACSG aims to provide information and advice to Parents, Carers and Professionals seeking solutions for children and young people who may be affected by Hyperactivity and/or ADHD.

The HACSG is unable to offer diagnosis or medical advice. We are more than happy to talk over any concerns Parents, Carers or Professionals may have and will do our best to investigate a dietary and nutritional approach.

<http://www.hacsg.org.uk/>

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 - xx <https://www.nice.org.uk/about/who-we-are>
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York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

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www.healthwatchyork.co.uk

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