# ADHD:

## PAYING ENOUGH ATTENTION?

A RESEARCH REPORT INVESTIGATING ADHD IN THE UK

# FOREWORD

Attention Deficit Hyperactivity Disorder (ADHD) is a real condition which, if not diagnosed and treated, can have a significant impact on the lives of both the person with the disorder and their family. However, despite our growing understanding of the condition, many children still remain undiagnosed or are not receiving the most appropriate care and treatment. This means that many people do not have access to the support that they need to cope with a disorder that can affect all aspects of their lives.

ADHD is a complex disorder and its management involves a wide range of organisations and individuals. Although awareness of the need for early diagnosis and effective treatment of ADHD is increasing across the fields of medicine, education and social services, there are still many areas where improvements can be made to ensure that people with ADHD do not slip through the net. Initiatives and policy changes such as the Special Educational Needs Code of Practice and the forthcoming National Service Framework for Children may go some way to address these areas but there is still much progress needed.

Given the right support and education, children with ADHD can really succeed, which makes it even more frustrating that this is not happening at the moment.

This report conveys new survey findings which provide a fresh insight into current understanding and management of ADHD in the UK. I hope that it will underline the need to give ADHD our full attention.

**Andrea Bilbow,** Founder and Director of ADDISS (The National Attention Deficit Disorder Information and Support Service)

ADDISS
ADHD INFORMATION SERVICES
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ADDISS is a registered charity (1070827), which provides information, training and support for parents, sufferers and professionals in the fields of ADHD and related learning and behavioural difficulties. For more information call 020 8906 9068, email us at **info@addiss.co.uk** or view the ADDISS website at www.addiss.co.uk.

# CONTENTS




**This report is supported by an educational grant from Eli Lilly and Company Limited.**

# 01 INTRODUCTION

This report aims to communicate the reality of ADHD and the impact it has on all aspects of the lives of those who have the disorder. The report outlines the facts about ADHD and draws on a wide range of evidence, including published documents and opinion from medical and educational experts. New research among child and adolescent psychiatrists and paediatricians is also presented, which demonstrates how those who diagnose and treat the disorder perceive the current situation in the UK.

# 02 WHAT IS ADHD?

## DEFINITION

Attention deficit hyperactivity disorder (ADHD), also sometimes referred to as attention deficit disorder (ADD) or hyperkinetic disorder (HKD), is a neurobiological disorder caused by an imbalance of some of the neurotransmitters found in the brain, called norepinephrine and dopamine.[1]

## SYMPTOMS

ADHD is one of the most common disorders of childhood and adolescence[2] and is characterised by symptoms of impulsivity and hyperactivity and/or inattention. The symptoms are not seen to the same degree in all people diagnosed with the disorder and healthcare professionals recognise that there are 3 main combinations of symptoms:

- Some people have predominantly (mostly) hyperactive-impulsive type
- Some have predominantly (mostly) inattentive type
- And some have a combined type (this makes up the majority of ADHD cases)[1]

Hyperactive or impulsive behaviours may include: fidgeting, having trouble playing quietly, interrupting others and always being 'on the go.'[3] Symptoms of inattention may include: being disorganised, being forgetful and easily distracted and finding it difficult to sustain attention in tasks or play activities.[3] Whilst ADHD behaviours occur to some extent in all of us, the difference between ADHD and normal behaviour is the degree of the problem and the difficulties it causes.[1] Children with ADHD show this behaviour to a significantly greater extent and severity.

Children with ADHD may exhibit behaviours that cannot be explained by any other psychiatric condition and are not in keeping with the child's age and intellectual ability.[1] Mood swings and 'social clumsiness' are common. Parents and teachers may report that these children often misread the accepted social cues, saying or doing inappropriate things. Social problems often hit a peak in primary school and start to ease in secondary school, although in adolescence any remaining insecurities make the normal social uncertainties of this age even greater.[1]

## PREVALENCE

According to medical guidelines, ADHD affects 5% of school-aged children[4] and the male to female ratio in diagnosed ADHD prevalence is at least 4 to 1.[5] The observed prevalence of ADHD in boys and girls is skewed by the fact that symptoms of hyperactivity and impulsivity are more common in boys, whereas girls with ADHD more commonly have inattentive symptoms.[1,3]

Many girls remain undiagnosed as they tend to be less disruptive. But while they may not be referred to a clinic, they may still be failing at school[1] and experiencing other problems due to their ADHD. ADHD in girls (who have ADHD with hyperactivity, either combined type or hyperactive type), is associated with more severe cognitive and language problems and greater social problems.[6]

"The estimated prevalence of all ADHD is… around 5% of school-aged children. Not all children who might meet the diagnostic criteria for ADHD are diagnosed… It has been estimated that approximately 1% of school-aged children meet the diagnostic criteria for… severe combined type ADHD."

**National Institute for Clinical Excellence (NICE) Guidance[4]**

5% of school-aged children in the UK equals 500,000 children.[7]

Whilst ADHD is perceived to be largely a childhood disorder, research suggests that up to 2 out of 3 children diagnosed with ADHD (65%) continue to experience symptoms into adulthood.[2]

"While there is controversy around the prevalence of ADHD, when you put the figures cited by NICE into real terms, particularly in a school setting, it is clear that these are valid. On average, in every school year of 100 children, it is generally found that there is 1 child with severe ADHD and a few more with less severe symptoms."

**Fintan O'Regan, Education Specialist and former Head of the Centre Academy**

ADHD is a strongly hereditary (or genetic) condition.[1,3] If a family has 1 child with ADHD, there is a 30-40% chance that another brother or sister will also have the disorder.[1] If the child with ADHD has an identical twin, the likelihood that the twin will also have the disorder is about 90%.[1]

## DIAGNOSIS

"In the UK, the assessment and diagnosis of ADHD is carried out by specialists. There are protocols for these processes and for further management. Although some voices have expressed fears of overdiagnosis and overtreatment, there is no evidence that this is happening nationally. No specialist would want this to happen and the guidance on good practice that exists will in any case prevent it."

**Professor Peter Hill, Consultant Child and Adolescent Psychiatrist at Wimpole Street Clinic**

In order to ensure an accurate diagnosis, only specially trained healthcare professionals (normally child and adolescent psychiatrists or paediatricians) can officially diagnose ADHD. The methods employed by specialist healthcare professionals in diagnosis are robust and a rigorous assessment will be carried out before a diagnosis of ADHD is made.[1] There are 2 main medical guidelines which detail the criteria for diagnosis – the American Psychiatric Association DSM-IV[3] (The Diagnostic and Statistical Manual of Mental Disorders) and the World Health Organisation ICD-10 (The International Statistical Classification of Diseases and Related Health Problems).[8]

Diagnosis will also take into account a significant amount of information from other sources, including parents, teachers, social workers and the GP. Diagnosis of ADHD can be difficult because other problems (such as autism, Asperger's Syndrome, epilepsy, depression, brain injury or family dysfunction) can result in behaviour similar to ADHD. ADHD can exist in conjunction with many other conditions whose symptoms can overlap and mask those of ADHD, therefore behaviour due to a separate condition needs to be excluded during diagnosis.

# 02 WHAT IS ADHD?

## 3 STEP PROCESS FOR DIAGNOSING ADHD[1]

**1. THE HEALTHCARE PROFESSIONAL WILL LOOK FOR INDICATORS OF ADHD**

- Significant under-performance at school, despite a normal intellect and no major specific learning disabilities
- Behavioural problems which are considerably worse than would be expected for the standard of parenting and home environment

**2. THEY WILL EXCLUDE BEHAVIOURS OR CONDITIONS THAT COULD BE MISCONSTRUED AS ADHD**

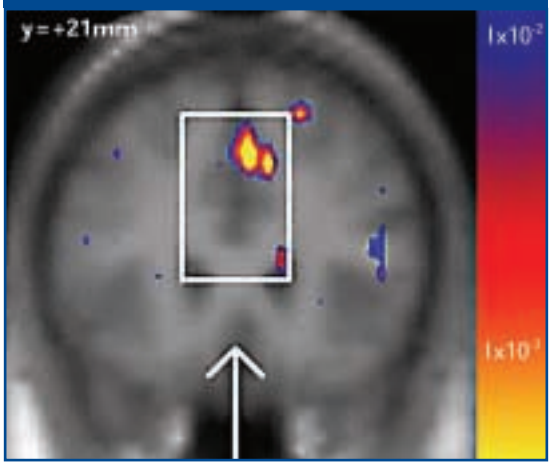
- Intellectual disability; hearing impairment; specific learning disabilities; behaviour attributable to a normal active pre-school child; autism; Asperger's Syndrome; epilepsy; depression; brain injury or family dysfunction

**3. THEY ALSO USE OBJECTIVE ASSESSMENT TOOLS**

- DSM-IV or ICD-10 criteria[3,8]
- Questionnaires completed by the specialist, parents and teachers e.g. Conners Teacher and Parent Rating Scales
- Tests which measure the length and type of mental process (psychometric tests and profiles)
- Tests of attention and persistence e.g. Continuous Performance Test

In the future, technology may also play a part in the diagnostic process. Brain structure and imaging studies, such as Magnetic Resonance Imaging (MRI), have found differences between ADHD patients and individuals who do not have ADHD.[9] MRI studies have shown that children with ADHD have 'underactive' parts of the brain, when involved in specific activities such as a task that involves executive functioning, and that the differences (between the brains of children with ADHD compared to those of other children) remain consistent over time.[10, 11, 12]

**BRAIN WITHOUT ADHD**




**BRAIN WITH ADHD**

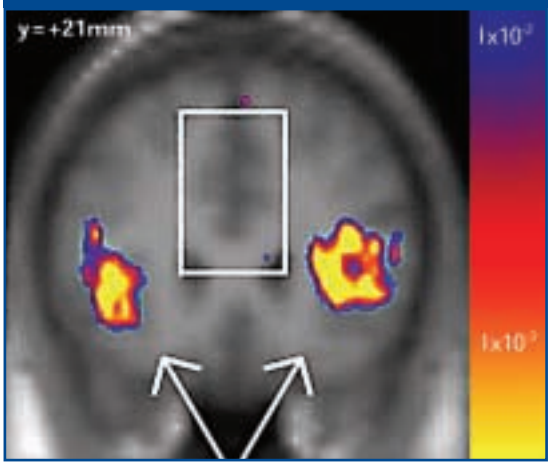



**Diagram 1:** The pictures above show the differing activation of the brain in people with and without ADHD under specific test conditions.[10]

# 03 ADHD TODAY

A recent survey was carried out amongst child and adolescent psychiatrists and paediatricians in the UK in order to investigate their views on ADHD and the current situation regarding diagnosis and treatment of this condition in the UK.[13]

## IMPACT OF UNDIAGNOSED AND UNTREATED ADHD

"The consequences of severe ADHD for children, their families and for society can be very serious. Children can develop poor self-esteem, emotional and social problems and their educational attainment is frequently severely impaired. The pressure on families can be extreme."

**National Institute for Clinical Excellence (NICE) Guidance[4]**

## PAYING ENOUGH ATTENTION? KEY SURVEY FINDINGS

Survey participants highlighted the potential impact of undiagnosed and untreated ADHD.

- ADHD was rated as having as great an impact on a child's development as depression, Tourette's Syndrome, anxiety or dyslexia. 80% of specialists surveyed rated ADHD as having the greatest or second greatest impact of these conditions on a child's development
- 98% of those surveyed believed undiagnosed ADHD has a serious impact on a child's academic progress
- 97% stated that children with undiagnosed ADHD are more likely to drop out of school several years earlier than their peers
- Over 90% said that undiagnosed and untreated ADHD:
  - Has a serious impact on a child's relationships with their parents, siblings and peers
  - Can result in children feeling excluded from their peers, impacting their ability to make friends and leading to very low self-esteem due to their exclusion
  - Can lead to a variety of social problems, such as difficulties finding and keeping a job and criminal behaviour (such as stealing, shoplifting and vandalism)
- 85% said they believe that not treating childhood ADHD could lead to adult mental health problems such as depression and even suicide[13,14]

The recently published International Consensus Statement, signed by 86 psychiatrists and psychologists, also confirms that untreated ADHD can lead to 'impairments in major life activities,' which can include: increased teenage pregnancy; substance misuse; engaging in antisocial behaviour and excessive speeding or multiple car accidents.[15]

The International Consensus Statement states that the view that ADHD does not exist (which is sometimes quoted in the media) is the opinion of only a handful of non-expert doctors and these views contrast against those of mainstream science.[15] Dr Carol Cooper, a GP who writes for the media, comments on their role: "There are still some groups of people in the UK who do not believe in the validity of ADHD, as well as other psychological disorders. Whether professionals or not, these people are happy to provide quotes for sensationalist articles which perpetuate the stigma around disorders such as ADHD. The end result is a huge disservice to sufferers and their families. ADHD does exist and it has a significant impact on the lives of a person with ADHD and their family."

Families who have children with ADHD have been found to experience increased levels of parental frustration, marital discord and divorce.[16]

It has been shown in international literature that ADHD is associated with increased use of healthcare and other social resources, although many of these costs are not quantified.[17] Social resources can include education, social services, unemployment benefits and the Youth and Criminal Justice system.

Providing treatment (both behavioural and pharmacological) for children with ADHD is important in order to help people with ADHD manage their disorder and live a full life.[18]

"Bringing up a child with ADHD can be very rewarding, but can also have many challenges. These are made more difficult by the fact that some newspapers refer to children with ADHD as just naughty, and accuse parents of forcing diagnosis on their children. Raising a child with ADHD is also made more difficult as there is so little help and information available from the health and education authorities. I knew Yasmin was different from very early on, but she wasn't diagnosed until she was in infant school. However, once Yasmin was diagnosed I felt relief, because at last I would get some help for my daughter."

**Sharon O'Dell, mother of Yasmin, 12, who has ADHD**

## ACCESSING THE SYSTEM AND ACHIEVING A DIAGNOSIS

According to NICE guidance, the prevalence of ADHD is 5% of school-aged children. Also according to NICE, ADHD is currently underdiagnosed in the UK.[4] 1% of school-aged children meet the diagnostic criteria for severe combined type ADHD and should receive treatment[4] (this equates to approximately 100,000 children in the UK).[7] However only 70,000 children are currently receiving medication for their ADHD.[19] Over half (54%) of the child and adolescent psychiatrists and community paediatricians recently surveyed also stated that ADHD is currently underdiagnosed in the UK.[13]

## PAYING ENOUGH ATTENTION? KEY SURVEY FINDINGS

The survey participants were asked what they thought the main barriers to effective identification and diagnosis of ADHD in the UK were. Reasons given included:-

- Too few child and adolescent psychiatrists or paediatricians with an interest in mental health (85%)
- GPs are unsure of which patients to refer (57%)
- Parents are not aware of ADHD so don't go to their GP (53%)[13]
- For those aware of a problem, research conducted among children and parents on the subject of children's mental health found that the most common reasons parents gave for not contacting any services about their child's mental health problems included fear of being branded a failure or blamed (29%)[20]

The role of primary care in initial identification of ADHD and referral to secondary care specialists (child and adolescent psychiatrists and paediatricians) was highlighted by the experts surveyed.

- Over two thirds of specialists (72%) felt that GPs should have a key role in preliminary screening of patients who may have ADHD
- 88% felt that GPs would benefit from increased education to improve their understanding of ADHD and thus improve the level of accurate referral[13]

Reports show that there is currently a delay of between 9 months and 5 years between a family first approaching their GP for help and advice and when they reach diagnosis by a specialist.[21]

"It is vital that primary and secondary care work effectively together to manage ADHD. Improved education is key to improving the referral process and helping children with ADHD access secondary care specialists."

**Dr Amanda Kirby, a GP with a special interest in mental health**

Teachers were also highlighted as having a potential role in initially recognising ADHD in the classroom. 43% of medical experts surveyed believe that a major barrier to diagnosis of ADHD is that teachers are not aware and therefore do not realise that children should be referred to a medical professional.[13]

# 03 ADHD TODAY

"It is possible that some of the children with ADHD excluded from school could still be in mainstream education had they been identified and treated earlier. It is impossible to emphasise enough the importance of identifying and treating ADHD as early as possible."

**Dr Joanne Barton, Consultant Child and Adolescent Psychiatrist, University of Keele**

Levels of identification and diagnosis may be negatively impacted by the range of different professionals and services involved (including medical, educational, psychological and social services). Recent guidelines for successful multi-agency working state that there are significant differences between the various professional groups that can result in confusion, misunderstandings and conflict and that the operation of a true multi-disciplinary structure is 'likely to be constrained by resource, practical and logistical factors'.[22]

Linda Shepherd, founder of the ADHD in Suffolk group, explains: "We have in our area a multi-agency group of professionals who invited us to sit on the various panels, including CAMHS. The group produces information for parents, teachers, healthcare professionals and local MPs in order to share best practice and develop policies. Our specialist healthcare professionals have even arranged shared care prescribing arrangements with GPs. This joint working, especially with the health professionals involving groups such as ours, has been really successful and we think multi-agency working is vital to improving services for those with ADHD. However, government must make more adequate funding available if this is to proceed to common practice."

Levels of specialist service provision also impact on the ability to diagnose and manage ADHD effectively. Provision of child and adolescent mental health services across the UK is variable, with long waiting times in some areas.[4] The amount spent by health authorities on specialist CAMHS (Child and Adolescent Mental Health Services) has been found to vary by a factor of 7 (per head of child population aged 18).[23]

### PAYING ENOUGH ATTENTION? KEY SURVEY FINDINGS

- Over half of community paediatricians (53%) and over a third of child and adolescent psychiatrists (38%) surveyed believed that their patients with ADHD would benefit from more regular reviews
- On average, specialists would like to see their patients with ADHD 20% more frequently
- 22% of specialists would like to see their patients with ADHD at least twice as often as they currently do
- Currently 25% of specialists see their patients 4 times a year (i.e. once every 3 months)
- 85% of child and adolescent psychiatrists and paediatricians felt that there are too few child psychiatrists or paediatricians with an interest in mental health and that this is a barrier to identification and diagnosis of ADHD. Additionally specialists felt the shortage of staff is an obstacle to regular reviews of patients with ADHD[13]

"It is vital that children with ADHD are given access to the range of management strategies available as, without this, children with ADHD are simply learning to fail."

**Dr Val Harpin, Consultant Paediatrician, Sheffield Children's Trust**

## TREATMENT

Almost all (98%) of the child and adolescent psychiatrists and paediatricians surveyed stated that a combination of behavioural therapy and pharmacological therapy together is the most effective treatment for ADHD.[13] This is reflected in a number of published studies with most experts agreeing that the most effective way to treat ADHD is with a variety of different approaches.[1,4]

- Despite this, only one third (34%) of specialists surveyed who regard this as the best approach use it for all their patients. Child and adolescent psychiatrists and community paediatricians surveyed believed that the key barriers to the use of behavioural therapy and drug therapy together are parental concerns about medication (35%) and limited resources (25%)[13]

"It is recognised that ADHD and HKD cause considerable morbidity and should be treated."

**Scottish Intercollegiate Guidelines Network[5]**

The range of treatments available for ADHD include: behavioural therapies (including therapy for families or individuals); school-based training (including counselling and help with learning skills); social skills training; sensory-motor integration (or coordination training); parenting support and pharmacotherapy.

Psychostimulants are the standard pharmacotherapy for ADHD. Whilst stimulants are effective for many patients, a significant number of children still experience side-effects or a lack of efficacy.[5,24] Additionally there is some public concern that there is a gap between what is known about psychostimulants and how they are used.[25]

"Effectively treating ADHD symptoms can provide the opportunity for people with ADHD to overcome the disorder, interacting better with family and peers and having the opportunity to achieve their potential academically, in employment and in life. It is important that those who need treatment for this disorder have access to treatment."

**Professor Eric Taylor, Consultant Child and Adolescent Psychiatrist, MRC Child Psychiatry Unit, Maudsley Hospital, London**

## WIDER SUPPORT

ADHD is not simply about diagnosing the disorder and treating it with a single, or combined, therapy. The nature of the disorder, whether undiagnosed and untreated or recognised and managed by health services, requires greater input from a range of different sources to ensure continued support. The most critical points for a young person are:-

- Parents and the family network
- Education and schooling
- Social services and, where appropriate, the Youth and Criminal Justice system

If optimal management of the disorder is to be achieved, then all parties need to be able to provide the relevant support for people coming to terms with living with ADHD.

"We believe that every individual must be given the opportunity to achieve his or her potential in learning and educational systems. For this to happen it is important that pupils with ADHD are identified as early as possible in their schooling so that they can receive appropriate support.

"Increased understanding of ADHD, plus help negotiating the routes through the statementing and diagnosis process for both parents and teachers, is essential to aid children with ADHD in receiving the educational support they need. This requires more effective joined up working – with guidance and advice – between all the parties involved."

**Jean Gemmell, General Secretary, Professional Association of Teachers (PAT)**

The DfES (Department for Education and Skills) has recently produced guidance in the form of a Special Educational Needs (SEN) Code of Practice in order to try to improve the support provided to children with SEN within the education system. This Code states that Local Education Authorities are required to build collaborative relationships with health services, parent groups, social services and voluntary organisations, utilising joined up working between agencies to ensure provision of integrated care for children with mental health problems.[26] However, ADHD is not mentioned specifically in the SEN Code of Practice.

"The DfES provides guidelines for schools, but these policies do not translate into reality in practice. ADHD is a complex disorder and the lack of understanding around ADHD means that teachers would benefit from policies that provide more clear and definitive guidance regarding ADHD in the classroom. Only then will the joined up thinking the DfES promotes be translated into effective joined up working."

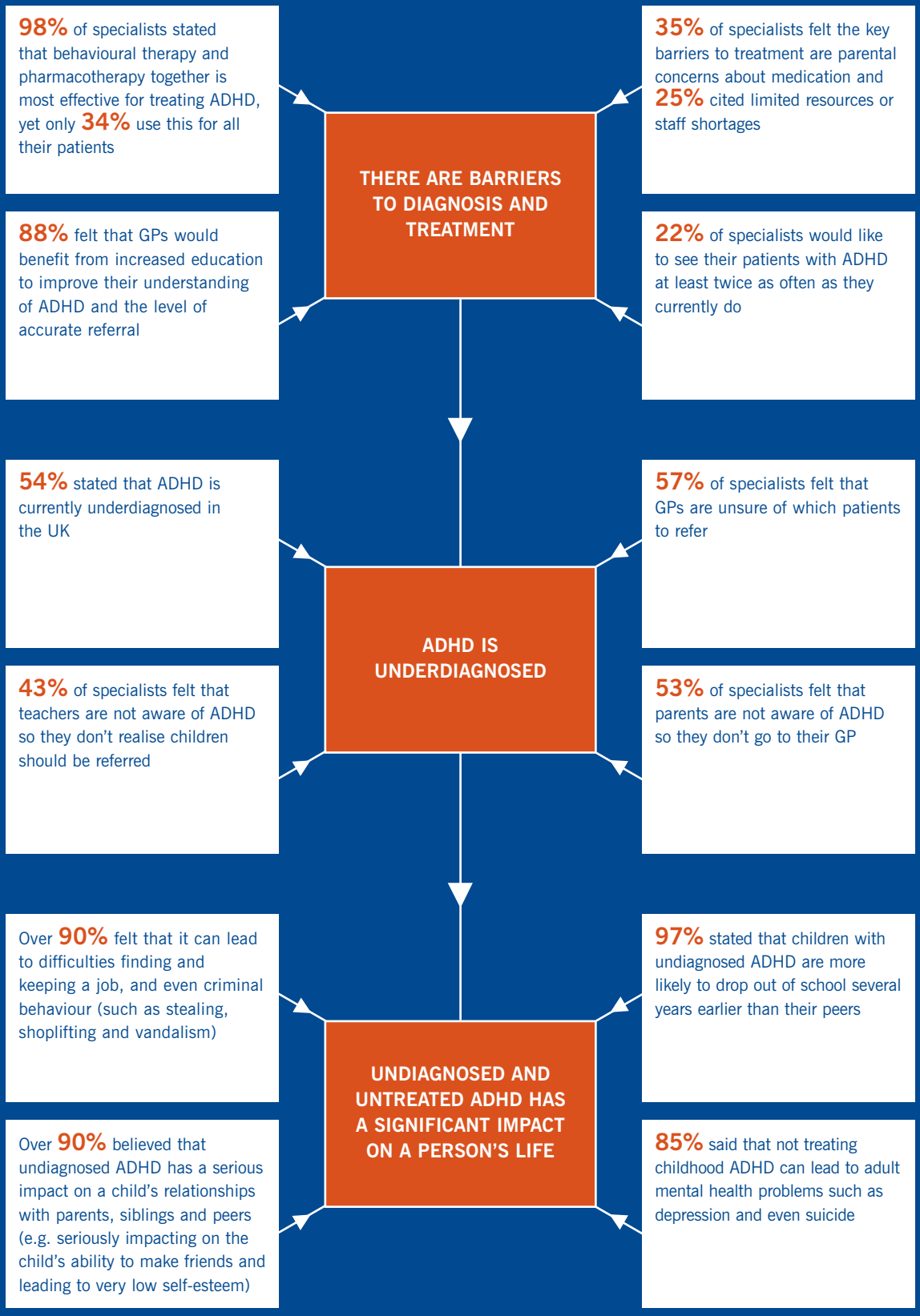
**Fintan O'Regan, Education Specialist and former Head of the Centre Academy**

Results of a 3 year study, by the Office for National Statistics, has shown that having a persistent hyperkinetic disorder increased the odds of a child having been excluded from school by 11 times (compared to those without the disorder).[20] Additionally, 20% of children with a mental health condition had taken 6 or more days off school in the past term (with one of the reasons for absence being refusal by the child to attend school). This was compared to 8% of children without the disorder.[20]

"In addition to the education system, social services also have a valuable role to play in providing support to families with a child with ADHD, and the Youth and Criminal Justice system may also become involved," according to Margaret Alsop, head of the Dorset ADHD Support Group. "However, both the social services and the Youth and Criminal Justice system are over-stretched, and within the system there is still under-recognition of ADHD. At a recent Parent Convention, only 1% of the parents had received positive support from the social services. We need to increase education and develop better ways of working together to ensure that these systems are able to provide the support which is so greatly needed."

The Youth and Criminal Justice system may become involved if a child has broken the law. According to the British Medical Association (BMA), lack of recognition and early diagnosis of ADHD have forced up the national crime figures. These figures suggest that 23% of all crime is due to children in care homes not receiving the appropriate assessment on the possible diagnosis of ADHD and hidden disabilities and 48% is due to medical disorders and other mental health related conditions associated with ADHD.[27]

## KEY SURVEY FINDINGS AT A GLANCE



# 04 ADHD TOMORROW

## RECOMMENDATIONS FOR THE FUTURE

**1.** Teachers need increased education, resources and support

- To enable them to understand ADHD, to manage the child in the classroom appropriately and to provide advice to parents on how to access the healthcare system

**2.** GPs should receive education about ADHD

- To improve levels of appropriate referral to secondary care for diagnosis and to ensure they can provide the ongoing observation and support needed for the child if a diagnosis is made

**3.** Secondary care needs additional specialists

- To ensure that the waiting time is shortened for a first referral and that they can see patients more often

**4.** Patients should have access to the most effective management strategy

- This currently does not happen in part due to some parental concerns about medication (35%) and limited resources (25%)[13]

**5.** There needs to be increased understanding of ADHD amongst the general public and the media

- In order to remove the fear of being blamed or branded a failure which can be a barrier to parents and families accessing support[20]

**6.** There needs to be increased information for parents

- To increase their understanding and ensure they seek help from their GP

## CONCLUSION

This report highlights that the current identification and management of ADHD is not adequately supporting those children who have ADHD. The disorder is underdiagnosed and, even for those who manage to navigate the system successfully, it can take years to obtain a diagnosis, by which time the child may have been excluded from school. It is imperative that the management of ADHD is improved and that the 'call to action' involves all parties. There needs to be joined up thinking in the way that healthcare professionals, education professionals and parents of children with ADHD work to ensure that these children receive the support and attention that they need.

**Andrea Bilbow, Founder and Director of ADDISS (The National Attention Deficit Disorder Information and Support Service)**

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