



# Born to Be **ADHD**

## A Lifetime Lost, or a **Lifetime Saved**

Attention Deficit Hyperactivity Disorder (ADHD) in children across the UK. A look at its impact and what must be done to achieve equity for these particularly vulnerable children, so they might be able to reach their exceptional potential as they progress into adulthood.

The recommendations in this report are supported by:



This report was developed following review of survey findings, collation of available data on ADHD and general consultation and workshop input by the Expert Panel: Fintan O'Regan, Dr Matthew McConkey, Poppy Ellis Logan and Dr Tony Lloyd. This workshop was facilitated by Reynolds-MacKenzie; Shire did not attend this workshop. Shire has reviewed the report for factual accuracy and compliance with the ABPI Code of Practice for the Pharmaceutical Industry.

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# Impact of ADHD: the facts

UP TO 30% OF CHILDREN WITH ADHD MAY HAVE A SEPARATE SERIOUS MOOD DISORDER LIKE **DEPRESSION**<sup>1</sup>, AND UP TO HALF OF GIRLS WITH ADHD MAY ATTEMPT SELF-HARM<sup>2</sup>

DATA SUGGEST AROUND HALF OF CHILDREN WITH ADHD IN THE UK **DO NOT FEEL SUPPORTED** BY THEIR SCHOOL<sup>7</sup>

UP TO 30% OF CHILDREN AND OVER HALF OF ADULTS WITH ADHD ALSO SUFFER FROM AN **ANXIETY DISORDER**<sup>3</sup>

ADULTS WITH ADHD ARE NINE TIMES MORE LIKELY TO END UP IN PRISON, THAN THOSE OF A SIMILAR AGE AND BACKGROUND WHO DO NOT HAVE ADHD<sup>8</sup>

- THEY ALSO EXPERIENCE GREATER FINANCIAL INSTABILITY<sup>9</sup> AND ARE MORE LIKELY TO HAVE BEEN FIRED FROM A JOB<sup>10</sup>

UP TO 20% OF INDIVIDUALS WITH ADHD MAY SHOW SYMPTOMS OF **BIPOLAR DISORDER**<sup>3</sup>

AROUND A THIRD OF PEOPLE WITH ADHD ARE THOUGHT TO HAVE TO **WAIT OVER TWO YEARS** BEFORE THEY ARE FORMALLY DIAGNOSED<sup>7</sup>

ADULTS WITH ADHD HAVE A **HIGHER MORTALITY RATE** THAN THOSE WITHOUT ADHD<sup>4</sup>

RESEARCH SUGGESTS THAT CHILD AND ADOLESCENT ADHD PATIENTS IN THE UK MAY EXPERIENCE THE **LONGEST WAITING TIMES ANYWHERE IN EUROPE** WHEN LOOKING AT TIME FROM INITIAL MEETING WITH A DOCTOR TO FORMAL ADHD DIAGNOSIS<sup>11</sup>

CHILDREN WITH UNTREATED OR POORLY CONTROLLED ADHD ARE:

- MORE THAN FIVE TIMES MORE LIKELY TO PARTICIPATE IN FIGHTS<sup>5</sup>
- MORE THAN TWICE AS LIKELY TO FEEL FRUSTRATED AT SCHOOL<sup>5</sup>
- THREE TIMES AS LIKELY TO HAVE A READING DISABILITY<sup>6</sup>

IN A RECENT SURVEY, 22% OF PATIENTS AND PARENTS AND CAREGIVERS OF CHILDREN WITH ADHD (n=104) NOTED THEIR

**GP EXPRESSED DOUBT** ABOUT WHETHER ADHD IS REAL<sup>7</sup>

# Preface



**Helen Whately -  
MP for Faversham  
and Mid-Kent  
and Chair of  
the All-Party  
Parliamentary  
Group (APPG) for Mental Health**

About a year ago a mother from my constituency called my office in great distress. Her little boy Michael (not his real name) had ADHD, and had been excluded from school. His behaviour became more challenging for the school after a particularly supportive teaching assistant left. Michael was now having lessons in a draughty cupboard room at another school, outside normal school hours, and becoming ever more isolated from his peers. A few months later he was offered a place at a special school some 90 miles away from his own – an unacceptably long daily journey for such a young boy. Eventually the county council agreed to find a school place for him in the Independent sector.

I've heard many stories like Michael's, both from constituents who come to my advice surgeries and as Chair of the APPG for Mental Health. As this report shows, children with ADHD are experiencing patchy or inadequate support, struggling to access the right services and waiting too long for a diagnosis. Given that around 300,000 children in school today – one in every classroom – have ADHD, we must do better.

What's clear from this report is that people with ADHD are still facing a stigma, even among the medical community. Too often ADHD is written off as simple bad behaviour or bad parenting. I was shocked to read that 22% of patients or their parents or caregivers experienced doubt from their GPs about whether ADHD is a real condition. This just adds to the distress of children and their families and leads to worse outcomes.

Children with ADHD are often brilliant creative thinkers who flourish with the right support: Michael was doing well before a change of staff at his school. But untreated ADHD can have a lifelong impact. As this report shows, 68% of children with ADHD feel frustrated at school and people with ADHD are more likely to have difficulties reading. Adults with ADHD experience greater challenges finding work, are nine times more likely to end up in prison and have a higher mortality rate than those without.

So I welcome this report and its positive recommendations for how we can improve treatment for people with ADHD. I hope the Government, schools and the NHS will take these on board. There has never been a better time to be a mental health campaigner; the head of a major charity has said to me this is a 'golden moment'. With strong Government support for fighting stigma, and a route map set out in the NHS Five Year Forward View, now is a chance to transform treatment for all mental health problems including ADHD.



# Foreword

An absolute core of our society is the innate responsibility we have to protect and nurture the children within it. Keeping those who are most vulnerable safe from harm and helping every child to reach his or her potential is a fundamental responsibility shared by parents, teachers, healthcare professionals and politicians alike. Where we see shortcomings in our care we must ask why, and enact change so that failures become successes. For one of the most common mental health disorders affecting young people in the UK – Attention Deficit Hyperactivity Disorder (ADHD) – we are failing. To ensure that our generation of children are given the chance they deserve to reach their full potential, action must be taken.

Across the UK there is currently a powerful drive to reduce stigma around mental health. Alongside high-profile campaigners, widespread political commitment to improving mental health support, particularly for children, makes now a pivotal time to ensure we address the needs of those most at risk. This means looking at every mental health disorder in proportion to ensure stigmatised neurodevelopmental conditions like ADHD are given weighting based on their prevalence and the impact they have on individuals and society. ADHD was only appropriately ‘labelled’ in the 1980s and remains poorly understood by large parts of society. There are few ADHD advocates in comparison to other mental health disorders, it receives little representation at a policy level and in areas of jurisdiction or social governance, and its own symptoms repress the voices of those it affects. It has since been consistently neglected and deprioritised across UK health and social care, which has damaged future life chances for people with ADHD.

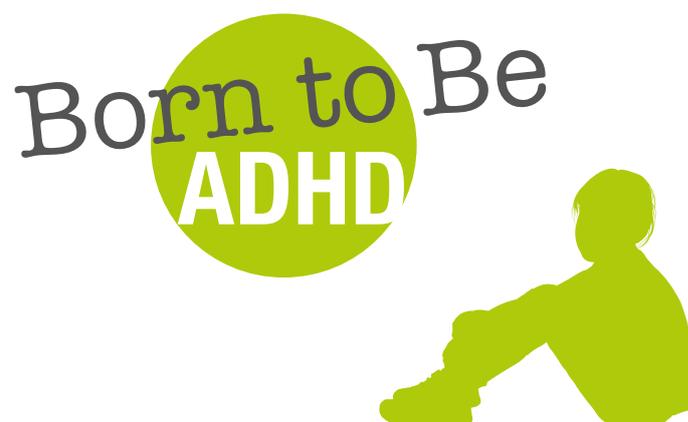
In mental health - and particularly in neurodevelopmental disorders – there is no doubt that, if we get the combination of understanding and care right, the benefits to individuals and society are clear; if we get them wrong, results can be dramatic. This is exemplified across ADHD: with the right support, given from an early age, there are few limits to what those who live with this condition can achieve. Olympic athletes, Michelin-starred chefs, entrepreneurs, doctors, artists and many other outstanding professions all boast individuals with ADHD among their elite. However, too often delay, ignorance, stigma and inequity of care result in thousands of children and their families being left to fend for themselves. The typical long-term consequences of this are not only limited school achievement, a chaotic adult life, low self-esteem, depression and anxiety, they often include less well-known, but far starker extremes such as self-harm, imprisonment, homelessness and substance abuse.

The contrast is stark and provides a clear reminder of how vital it is that we get this combination right.

We fully believe that each and every child with or without ADHD has endless potential. However, the statistics included in this report provide just a snapshot of our challenge; and it is no small one. Despite over two decades of scientific and clinical research confirming that ADHD is not only a very real condition, but one that is highly prevalent and treatable, alarming numbers of people continue to question its very existence. What is perhaps most concerning is that these are not simply minorities of people on a periphery, but those on the front lines of child development – teaching staff, doctors and policy makers. Meanwhile the impact of unrecognised ADHD becomes clearer by the day – from increased adolescent pregnancy and school exclusion through to likelihood of imprisonment, suicide and even levels of general mortality across the UK.

Small, achievable steps towards changing attitudes, understanding and practice will make a huge difference to the lives of children living with ADHD. By reviewing the calls to action in this report, getting involved in the conversation and enacting change we can ensure that we create an environment where a generation of children can achieve great things, and are not left looking back on a lifetime lost.

## #BornToBeADHD



**ADHD is found in up to 5% of children. In the UK that's over 300,000 cases – one in every classroom.<sup>12,13</sup>**

# The panel



**Fin O'Regan**

Special Education Needs (SEN) and Behaviour Consultant for the Schools Network and an associate lecturer for Leicester University, the National Association of Special Needs, Tribal Education and the Institute of Education. He is currently the Vice Chairman of the UK ADHD Partnership (UKAP) and a member of the European ADHD Alliance

*Fin O'Regan*



**Poppy Ellis Logan**

Full-time ADHD advocate and activist, founder of #AttentionUK, frontline officer at Mind in the City, Hackney and Waltham Forest, freelance ADHD Consultant for Higher Educational Institutes, and young persons' representative on the NICE Guideline Committee for ADHD

*PoppyEllisLogan*



**Dr Tony Lloyd**

Chief Executive Officer at the ADHD Foundation

*Dr Tony Lloyd*



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*Matthew McConkey*



# ADHD: what it is and why it matters

## ADHD is real

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder that results in a group of behavioural symptoms including inattentiveness, hyperactivity, and impulsiveness.<sup>14</sup> Many children go through phases when they're restless or inattentive – this is completely normal and doesn't necessarily mean they have ADHD.<sup>14</sup> People with ADHD have symptoms of hyperactivity, impulsivity and/or inattention in multiple settings - to such an extent that it consistently impacts their development, education and family life.<sup>14,15</sup> ADHD is caused by structural and functional abnormalities in the brain that have been clearly identified. These abnormalities vary between individuals, which accounts for the diverse presentation of the disorder.<sup>16</sup> Up to 90% of cases are estimated to be caused by genetic factors and around one in three people with ADHD have at least one parent with symptoms.<sup>12</sup> There are different subtypes of ADHD – predominantly hyperactive, predominantly inattentive and a mixture of the two.

## The lifetime impact of ADHD

Without effective management, ADHD will often have a substantial impact on academic and work-related outcomes. Several published studies have found significant differences in academic performance, relationships with siblings and behavioural and conduct problems in children with ADHD compared to those without the condition.

- More children with ADHD felt frustrated at school compared to those without ADHD (68% vs 25% respectively)<sup>5</sup>
- Cumulative incidence of reading disability by the age of 19 years was significantly higher in children with ADHD (51% in boys, 46.7% in girls) compared with those without ADHD (14.5% in boys, 7.7% in girls)<sup>6</sup>
- Fewer children with ADHD had good relationships with their siblings (54% vs 74% respectively)<sup>5</sup>
- Children and young people with ADHD were reported to have significantly higher incidence of behavioural and conduct problems, including participation in fights (22% vs 4% respectively) and consumption of excessive amounts of alcohol (11% vs 5% respectively)<sup>5</sup>

While the disorder is often associated with children and young people, up to two thirds of cases persist into adulthood.<sup>18,19</sup> The Lifetime Impairment Survey found that adults with ADHD reported significantly greater difficulties at work and in many aspects of social functioning.<sup>20</sup>

Symptoms of ADHD have been associated with relatively high rates of arrests and imprisonment in adulthood<sup>21,22</sup> with those living with ADHD nine times more likely to end up in prison than those without.<sup>8,23</sup>

- Adults with ADHD are more likely to be dismissed from employment and experience more interpersonal difficulties in the workplace,<sup>10</sup> data suggest they are more likely to have been fired from a job<sup>10,23</sup>
- Adults with ADHD experience more relationship difficulties<sup>20</sup>
- Adults with ADHD have a higher mortality rate – which is even more pronounced if diagnosis was delayed until adulthood<sup>4</sup>

## There is a serious financial cost, as well as a human one

In addition to creating problems with personal development and relationships, ADHD can have serious economic implications for both the individual as well as society as a whole.<sup>9</sup> A lower income later in life, due to a lower academic performance and achievement as a child, as well as occupational instability and more frequent financial difficulties all contribute to the financial burden of ADHD on these individuals.

ADHD also has an economic impact on wider society – for example, when looking at tax rates and social insurance contributions, one study in Germany found that ADHD individuals contributed €80,000 less than their non-ADHD counterparts to lifetime net tax revenue.<sup>24</sup> Additional costs to wider society include managing comorbidities, increased criminality, work loss, and increased rates of accidents in individuals with untreated ADHD.<sup>9</sup>

## Just hyperactive boys? Think again

Research suggests that the ratio of ADHD prevalence in boys compared to girls is around 2:1.<sup>25</sup> However, compared with boys, girls tend to present with fewer disruptive behaviours, which can be more difficult to recognise; as a result, this, in combination with gender expectations, could lead to a gender bias in ADHD in terms of identifying patients and initiating referrals.<sup>26</sup> This gender bias can have an impact in later life on girls compared to boys if ADHD is not correctly identified and managed. While girls and boys have a similar pattern of risk for comorbid disorders, girls tend to internalise their ADHD which results in higher rates of depression, anxiety and self-harm as adults compared to men with ADHD.<sup>27</sup>

## People with ADHD are not different, they are exceptional

While ADHD may be challenging, people with ADHD are often highly creative, divergent thinkers, and excellent problem solvers.<sup>28</sup> Research has shown that in certain situations individuals with ADHD outperform individuals without by generating more creative ideas and thus are more likely to find a correct solution to a problem.<sup>29</sup> People with ADHD have incredible potential and, when given the correct care and support, can go on to become important and creative contributors to society. Unfortunately, too often children, young people and adults with ADHD experience barriers in accessing care, due to prevailing stigma and a lack of understanding of the condition.

With support, people with ADHD have great potential

“If managed properly, ADHD can be an amazing asset. The spontaneity, energy and creativeness it offers mean those with the condition can set and achieve outstanding goals. Yet, if it is not identified early children will spend crucial years when they should be learning academic and social skills confused, alone and fighting against these same symptoms Every month where ADHD is not diagnosed and acted on has the potential to make this worse.”

DR TONY LLOYD



# ADHD in the UK today: time to pay attention

Around three to five in every 100 school-aged children in the UK have ADHD.<sup>12</sup> That's well over 300,000 children in classrooms today.<sup>13</sup> By comparison, autism affects one in every 100 people while type 1 diabetes affects 0.02 of every 100 children aged from 0-14.<sup>30,31</sup> Despite its wide prevalence, ADHD remains chronically underdiagnosed and access to services and treatment in the UK is limited and inconsistent.<sup>32,33</sup> The impact of this can have a significant impact on both individuals with the condition and on society in general. Delays in diagnosis have been clearly shown to be detrimental to a child's development, exaggerating poor educational, behavioural, and psychological outcomes, and greatly increasing the risk of depression and low self-esteem in the long-term.<sup>34</sup>

A recent online survey, initiated by Shire in partnership with the ADHD Foundation, has further highlighted the stigma and challenges children and their parents or caregivers face when seeking information and support on ADHD. The survey research involved 72 parents/guardians of children with ADHD and 32 adult patients with ADHD.<sup>7</sup>

**“There is a clear postcode lottery of care for people with ADHD across the UK. We need to ensure that we are prioritising and organising access to support based on an individual's needs. This is critical in ensuring that those with ADHD are able to perform to the best of their ability and are confident that they have the support they need to do so.”**

FIN O'REGAN

## The UK falls behind in ADHD diagnosis

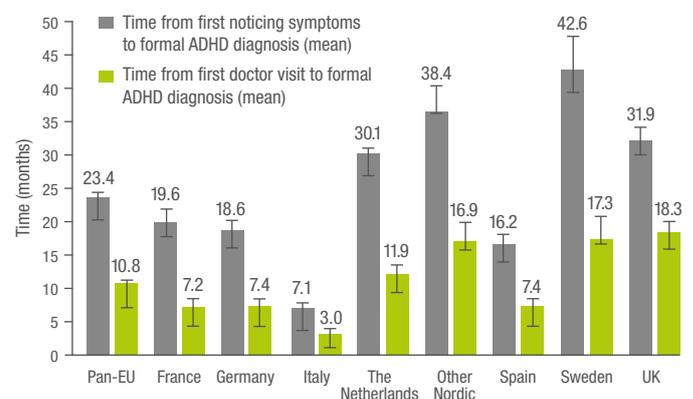
Survey data reinforced the significant variability in the number of visits to the GP that are required before receiving referral to a specialist:

- Over a third (38%) of surveyed adults and children diagnosed with ADHD had to visit their GP at least 3 times before being referred to a specialist, with a similar proportion (28%) waiting two or more years before receiving a diagnosis<sup>7</sup>
- Less than one third (27%) of surveyed adults and children diagnosed with ADHD were referred straight to a specialist during their initial GP appointment<sup>7</sup>
- A separate survey has also shown that people with suspected ADHD can wait anywhere between 2 weeks and 55 weeks from referral to a first appointment with a specialist.<sup>35</sup>

A further recent study involving ADHD caregivers in Europe, found that, compared with many other comparable countries in Europe:<sup>11</sup>

- In the UK, people with ADHD symptoms see the highest number of different doctors (on average) en-route to diagnosis
- The UK had the highest number of caregivers reporting difficulty in obtaining a specialist referral

## Time to formal diagnosis obtained from the European CAPPA\* study



Adapted from Friedman M et al 2017<sup>11</sup>

\*The Caregiver Perspective on Paediatric ADHD (CAPPA) survey



## Once diagnosed, UK patients are not getting the specialist care they should

Difficulties in obtaining care continue beyond achieving a diagnosis.

An analysis conducted between 1999 and 2004 found that around half of children with ADHD had not been provided with access to specialist healthcare services, despite National Institute of Health and Care Excellence (NICE) guidelines recommending that suspected cases get referred to specialist services who can perform diagnostic assessments and, if necessary, initiate pharmaceutical treatment.<sup>36</sup>

With few clear-cut routes to an ADHD diagnosis, lack of understanding of ‘what to do next’ is a key area of concern. From GPs, paediatric services, Child and Adolescent Mental Health Services (CAMHS) and beyond, knowledge of where to send children can be sparse.

**“I experienced delays in repeat prescriptions with my GP – this left me without medication for a week, where I ended up in A&E. As a result, I experience constant anxiety about not getting my medication on time. I haven’t been offered any other kind of support other than medication.”**

ADULT ADHD PATIENT

## The myth that ADHD is overmedicated

NICE recommends that pharmaceutical treatment (prescription medicines) should be considered for children with severe symptoms and impairment, and for children with moderate impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment.<sup>15</sup> The Scottish Intercollegiate Guidelines Network also recommends medication for moderate to severe ADHD.<sup>19</sup>

In contrast to the common idea that ADHD is far too often medicated in the UK, a recent study found that among other countries such as the USA, the Netherlands and Germany, the UK shows one of the lowest estimates in ADHD drug prescribing rates in children – for example, prescribing rates in the UK were around 2-5 times lower than those in Germany in 2006 and 2007.<sup>37</sup>

In the UK, there is a clear gap between best practice guidelines and implementation of these recommendations in ‘real-world’ practice.<sup>38</sup> In the recent parent and patient survey initiated by Shire, patients and caregivers report further discrepancies in support offered following diagnosis:

- Over three quarters (78%) of adults and children diagnosed with ADHD that were surveyed (n=104) were not offered psychiatric counselling or therapy<sup>7</sup> – despite NICE guidelines recommending a comprehensive treatment plan that includes psychological support (either at a group-level or individually)<sup>15</sup>
  - Scottish Intercollegiate Guidelines Network (SIGN) guidelines also recommend a combination of medication and behavioural treatment and that all children with ADHD should have an individualised education plan<sup>19</sup>
- 87% of patients surveyed (n=104) were not offered additional support in school/college settings after their first consultation with a specialist<sup>7</sup>
- One in eight (13%) of patients surveyed (n=104) were offered no support at all following their first ADHD consultation<sup>7</sup>

**“I have repeatedly requested cognitive behavioural therapy for my child, but my health service was unable to provide this due to lack of funding. I have heard other services have a two year waiting list for cognitive behavioural therapy (CBT) which is unacceptable.”**

PARENT OF A CHILD WITH ADHD

## **Embedded stigma is preventing children getting the diagnosis and care they need**

Accessing information and services that support prompt ADHD diagnosis and provide adequate follow-up care through childhood and adolescence is a challenge. Despite the long-term efficiency of treating ADHD (when compared to dealing with the longer-term consequences), constraints on time and budget are commonly cited by healthcare and school systems as limiting factors. However, this masks a far more disturbing issue that runs deep through the very systems designed to protect children – stigma that ADHD is simply poor behaviour or bad parenting, and even total disbelief that this scientifically-proven neurodevelopmental condition exists.



**“Prior to official diagnosis of my son, our family received no support or information from medical practitioners. Our GP was very sceptical and we were repeatedly turned away or told to wait to see if his symptoms improved, or that he would grow out of it. His school was equally unhelpful; as a result, any information and support we gathered we had to find ourselves through the internet. We practically had to beg to be referred to a specialist.”**

PARENT OF A CHILD WITH ADHD

Findings from the recent parent and patient survey (n=104) reveal startling experiences of patients and caregivers interacting with healthcare professionals.<sup>7</sup>

- Almost one in four (22%) experienced doubt from their GPs about whether ADHD is a real condition
- Two thirds (66%) felt as though they had little or no positive support from their GP about their/their child's ADHD symptoms
- Only one quarter (25%) felt their GP had a good understanding of the condition

Feelings of dismissal are common among parents and caregivers of children with ADHD, and align with previous research in this area.<sup>39</sup> Stigmatising beliefs about life-long mental illness, including individuals with ADHD, have created a “culture of suspicion” about mental health treatment, especially when involving a child.<sup>39</sup> This kind of stigma, reinforced by the dissemination of myths and incorrect information around ADHD, is a recognised barrier to patients and caregivers when trying to access support from either healthcare professionals or the education system.

**“We have made major strides in addressing the stigma around mental health conditions. However, one of the biggest problems with ADHD is that it is rarely discussed or not even recognised as a mental health condition by the very campaigns that seek to challenge mental health stigma. We need to ensure that more mental health training is carried out in schools to distinguish ADHD from learning disabilities such as Downs Syndrome and Specific Learning Difficulties such as Dyslexia. We must educate and raise awareness around the condition throughout society in general.”**

POPPY ELLIS LOGAN



Additional survey results (n=104) show that these dangerous misperceptions continue to run through the education system, where children and parents look to staff for guidance and support:<sup>7</sup>

- Four in every 10 parents (38%) were criticised by school teaching staff who blame the condition on parenting skills
- Nearly one quarter (23%) were specifically told by teaching staff that ADHD is over-diagnosed - despite recent research which found that more than half (54%) of paediatricians and child and adolescent psychiatrists believe ADHD to be currently under-diagnosed in the UK<sup>33</sup>
- Almost half (49%) of those surveyed felt that they have received a below average or poor level of support from their school
- Only 8% of those surveyed claim to have received an excellent level of support from school teachers and school nurses

**“The only support my son was offered was medication from his specialist – there was no support offered by his school. His school staff are not trained sufficiently to deal with ADHD-related needs; they lack empathy and a fundamental understanding of the condition.”**

PARENT OF A CHILD WITH ADHD

## **Periods of change carry the biggest risks**

Transitional periods are commonly stressful for children and young adults. Whether moving from school to college, college to university, or from paediatric to adult NHS care, uncertainty and anxiety are commonplace. For those with ADHD this stress is heightened significantly and many battling undiagnosed or mismanaged ADHD will face periods of real danger.



For people with ADHD, stressful transitional periods are when many experiment with drugs and alcohol. Disruption or a failure to recognise the need for additional support during these periods are likely to have longer lasting effects on the individual's development and lifelong potential.<sup>40</sup>

In the UK, the needs of children with ADHD through these transitional periods are poorly addressed.<sup>41</sup> In general, schools and universities do little to provide additional pastoral care while NHS care services often simply remove regular care for teenagers and young adults overnight. Furthermore, the transition away from the school-day timetable and term structure to total independence – either in employment or an un-timetabled university lifestyle – makes it even harder to manage ADHD symptoms, leaving individuals more impaired than ever by the disorder at this stage in their life.

**“There is a prevailing culture of chronic ‘short term-ism’ in the NHS. Short-term solutions are put in place without thinking of longer-term consequences. Often this can exacerbate other issues in services. For example, increasing diagnostic services in child and adolescent services will help in meeting short-term targets; however, without also increasing provisions to adult care, this can result in a bottleneck of services down the line when the children need to transition to adult care – resulting in many adolescents falling through the gap.”**

DR MATTHEW MCCONKEY

The recent survey findings of 32 adult patients with ADHD indicate:<sup>7</sup>

- Only 9% of those with ADHD who were receiving paediatric care had a reassessment by their current specialist to establish if they needed continued support into adult services
- Just 16% of patients had a formal meeting with the child specialist to discuss the transition from paediatric to adult services
- Only 16% of patients had an introduction and assessment by an adult specialist
- While transitional units exist, these are few and far between: only 13% of adult patients surveyed received a referral to a specialist transitional unit for ADHD

## **NHS guidelines are comprehensive, but rarely followed**

Despite the publication of NICE guidelines<sup>15</sup> and Health Improvement Scotland recommendations<sup>42</sup> that advise clear transitional arrangements from child to adult services, the implementation of these recommendations is widely varied across the UK, mainly due to significant variation in the ways that services are organised across the country.<sup>40</sup> Often this means there is either a gap between when care for adolescents ends and care from adult services begin, or these services overlap;<sup>40</sup> as a result, there is disparity in the belief about when care should be passed from adolescent to adult services,<sup>40</sup> causing distress and disruption for patients.<sup>43</sup> For adults, care can be somewhat of a ‘postcode lottery’ with some regions having no or little care for those living with ADHD and very long waiting times where services do exist.



# Change is possible - and it starts now

Children with ADHD, and their parents, too often battle with the symptoms for years before a formal diagnosis. Once diagnosed, there are often further delays before treatment or an effective management plan is put in place. Even then, support given across health and school settings remains inconsistent at best, and negligent at its worst. The reasons behind this are multi-faceted. Yet, despite these additional challenges and barriers there remains great cause for optimism so that people with ADHD can reach their full potential.

Ensuring ADHD is a core part of the mental health reform being committed to across the UK could be a pivotal moment for igniting positive change. Specifically:

## General actions for the governments of the four UK nations in 2017-18

- Provide clarity on how reforms under the Five Year Forward View for Mental Health<sup>44</sup> in England, and the Scottish Government Mental Health Strategy<sup>45</sup> will address the needs of children and young adults with ADHD specifically
- Urgently investigate the extent and cause of the postcode disparity being seen across the UK with regards to NHS ADHD care and provide a statement of intent to address this
- Issue a mandate to public services to ensure that ADHD is routinely acknowledged within information or guidance on mental health.

## Considerations for the NHS

### Prompt diagnosis means understanding the referral pathway

- All primary care practitioners should be aware of what ADHD is, its prevalence, the symptoms and the extent of stigma amongst GPs. Practitioners should also know the best route of referral for someone with suspected ADHD in their area, so that specialist care can be given with minimal delay
- Each Clinical Commissioning Group (CCG) and Health Board should be requested to work with local Child and Adolescent Mental Health Services (CAMHS), community paediatric units and schools to develop a local 'optimal referral pathway' for ADHD and ensure that this is widely communicated within primary care and education services
- Services should evaluate if enabling medication reviews to take place in primary care could support improvements in patient welfare and enable cost and time savings.

### Challenge myths and misperceptions wherever they arise

- Stigma and misperceptions around ADHD continue to run deeply through primary care and mental health commissioning. This must be acknowledged and addressed as part of initial and ongoing GP training on mental health, particularly training aimed at the care of children.



## Considerations for schools and the education system

### Understanding of ADHD and how to engage with children and parents requires regular training

- ADHD must be a core part of mental health training within the Social, Emotional and Mental Health section of the Special Education Needs (SEN) Code of Practice and their equivalents in the devolved nations, from initial teacher training through to continual professional development
  - Training on ADHD, including effective teaching techniques, must be considered for all staff who interact with pupils on a daily basis and should not be limited to Special Educational Needs Co-ordinators (SENCO) or other 'designated' personnel
- Training for all teachers and educational psychologists should address:
  - Identifying the signs of undiagnosed ADHD and understanding the realities of the disorder
  - Advice on how to best approach and discuss the topic with parents
  - Local appropriate referral pathways to ensure that children are given the best chance of a prompt diagnosis
  - The most effective teaching techniques for children with ADHD, to help them reach their fullest potential

## Supporting children and young adults through periods of transition

### In schools:

Schools, CAMHS and NHS services that treat ADHD should develop a multi-disciplinary plan to support children and young people with ADHD through periods of transition, such as starting a new school either at a common entry-point (e.g. first year of secondary school) or at other entry points (e.g. as a result of exclusion from a previous school), and through transition to further or higher education.

### From paediatric to adult NHS care

The NHS should commit to a formal review into providing separate transitional services delivered specifically for 16-25 year olds as part of standard ADHD care across the country.

# End note

One of the most crucial elements to improving care and outcomes for people with ADHD is starting early, before problems begin to get out of control. If we get this combination right we not only help those with ADHD reach their full potential, but we improve things for parents, teachers, classmates and society. We reduce the burden on the NHS, on the criminal justice and benefit systems and support exceptional people to thrive and improve our society.

Our society today understands and accepts several mental health disorders and many different types of neurodiversity, meaning that disorders such as depression, dyslexia and autism - which in previous years may have been marginalised, trivialised and even disbelieved in the way that ADHD is today – are now accepted. We vehemently believe that in future years, we will not only destigmatise ADHD, but celebrate it as a route to creativity, passion and ingenuity. This won't be easy, and will rely on the help and dedication of many people, but a few simple steps can set us off on the right path.



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