Your Attention Please: The Social and Economic Impact of ADHD

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DEMOS

Shire

PARTNERS CREDITS

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Any errors and omissions remain my own.

Simone Vibert

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EXECUTIVE SUMMARY

Attention deficit hyperactivity disorder (ADHD) is a frequently stereotyped condition, but contrary to common misconceptions, ADHD does not only affect young boys, nor does it reflect a simple inability to behave. It is a chronic condition that affects people from all backgrounds and frequently persists into adulthood. Many people grow up with ADHD and become adults without ever being diagnosed, receiving little or no support; the true impact of this is not well understood from a research perspective.

At a time when mental health services are under the spotlight, the aim of this Demos report is to shine a light on the socioeconomic impact of undiagnosed and untreated ADHD on individuals, the people around them and wider society. We also sought to assess the evidence base for the impact of ADHD and to identify gaps.

Methodology

Research for this project took place between August and October 2017. It consisted of:

- conducting a rapid evidence assessment (REA) of academic literature
- supplementary desk research
- holding interviews with people diagnosed with ADHD in adulthood
- examining written submissions from people diagnosed with ADHD in adulthood
- holding interviews with professional experts and stakeholders

What is ADHD?

ADHD is a neurodevelopmental disorder characterised by excessive activity, problems paying attention and problems controlling one's behaviour. It is one of the most common disorders of childhood and adolescence: estimated prevalence among 5–15-year-olds in the UK is 3.62 per cent of boys and 0.85 per cent of girls.[1] Although symptoms often improve, ADHD usually continues to affect people in adulthood.

ADHD cannot be cured. However, medication can be used to relieve the core symptoms, with stimulants being the most frequently prescribed

type of medication. Non-pharmacological treatment, such as parent training, patient therapy and psychoeducation, can also have an important role in equipping people with the skills they need to control the impact of ADHD symptoms on their lives.

ADHD frequently co-occurs with other psychiatric conditions, such as depression, anxiety, conduct disorder and oppositional defiant disorder. The high comorbidity rate can make diagnosis and treatment of ADHD challenging.

Policy context

In recent years, there has been a flurry of government activity in the mental health sphere. Reports such as *Future in Mind* and *The Five Year Forward View for Mental Health* have shone light on the failings of mental health services, particularly for children and young people, and sparked new programmes and initiatives aimed at their improvement.[2] Furthermore, no longer seen as just a matter for health professionals, mental health is increasingly becoming part of the remit of schools and teachers, too, with a number of initiatives aimed at improving joint working between the two sectors.

It remains to be seen how these developments will affect the everyday experience of people with ADHD. As things stand, children with ADHD are frequently unable to access Child and Adolescent Mental Health Services (CAMHS) as the challenges they face do not typically present as acutely as problems such as eating disorders and self-harm, and evidence suggests that knowledge of ADHD is poor among teachers. Furthermore, despite growing awareness among clinical and academic circles of the fact that ADHD frequently persists into adulthood, services for adults have yet to catch up, with specialist ADHD psychiatrists in significant demand and access to specialist ADHD clinics a postcode lottery. Without dedicated attention and investment, people with ADHD may feel little benefit from general developments in mental health policy.

Key findings

There are significant gaps in the evidence concerning the socioeconomic impact of undiagnosed and untreated ADHD. Research into the impact of undiagnosed and untreated ADHD is challenging and remains in its infancy. Our research identified two particularly significant gaps in the existing evidence base:

- There are very few studies that monetise the impact of ADHD.

- Most studies explore the impacts of diagnosed and treated ADHD, rather than undiagnosed and untreated ADHD.

Despite the gaps in the evidence, it appears that undiagnosed and untreated ADHD imposes a significant socioeconomic burden. ADHD can have a far-reaching and pervasive effect across all areas of day to day life. We found evidence of ADHD's impact on daily routines, health and wellbeing, education, work, personal relationships, risk-taking and crime.

The economic evidence taken together suggests that for a country of the UK's size, the annual cost of ADHD could run into billions of pounds. Although most of the research focuses on the costs of diagnosed ADHD, it is likely that the costs of undiagnosed ADHD are higher.

Surprisingly, the evidence appears to suggest that most of the costs are associated with adults with the condition – not children – and that the impact on work could be the single biggest cost component.

Evidence suggests that adults with ADHD are less likely to be in full-time, paid work than those without the condition, and that their on-the-job productivity may also be reduced. This has implications for individuals, employers and the state, as a result of reduced tax-take and increased expenditure on welfare benefits.

Awareness and understanding of the condition is poor, inhibiting early diagnosis and intervention.

There is good reason to believe that early diagnosis and intervention could play an important role in helping people with ADHD to lead successful and fulfilling lives – but a good knowledge of ADHD is needed for this. Unfortunately, awareness and understanding of ADHD is currently very poor, and not just among the general public – evidence has shown that parents, teachers and healthcare professionals also frequently fail to grasp the basic facts of the condition.

Recommendations

People with ADHD can be creative, energetic and dynamic. But as things stand, too many people with the condition are going through life without receiving the diagnosis or support they need to be happy and fulfilled, and to make the most of their talents. Many people with the condition suffer immensely in all areas of their lives, including education, work, relationships and more, with implications for their friends and family, wider society and the public purse too.

Reducing the socioeconomic burden of ADHD will be a complex task. It will require change and joined up thinking across a number of different

sectors and services, including health, education, employment and research – as reflected in our recommendations below. But the green paper on children's mental health represents an important opportunity for the government to lead the charge.[3] Policy-makers must use the green paper as a springboard to implement a convincing and transformative strategy to ensure that people with ADHD are left behind no longer.

Recommendations for policy and practice

We make the following recommendations for policy-makers and practitioners:

- The government should work with people with ADHD and the media to develop an awareness-raising campaign, aiming to make ADHD visible to a wider audience and promote better public understanding of the condition.
- Mental Health First Aid (MHFA; https://mhfaengland.org/) should develop its government-sponsored schools programme to include advice on ADHD.
- Initial teacher training (ITT) providers should clearly focus on supporting children with ADHD in their programmes, in meeting the new requirement for special educational needs and disabilities (SEND) training to form a core part of all ITT courses from 2018.
- NHS England should work with clinical commissioning groups (CCGs) to ensure that they prioritise data collection and use as part of a drive to improve their commissioning of health services for people with ADHD.
- Health professionals treating children and young people with ADHD should work with other professionals (such as the proposed designated senior leads for mental health in schools) to create transition plans ahead of key changes in the individual's life.
- Department for Work and Pensions (DWP) work coaches and employers should signpost people with ADHD to Access to Work.

Recommendations for policy and practice

We recommend that the following work is prioritised by researchers and research funders:

- Explore the difference made by early access to diagnosis and treatment to the long-term outcomes and costs of people with ADHD.
- Compare outcomes for adults with ADHD treated in general psychiatric clinics with outcomes for those treated in adult ADHD clinics.
- Explore under-researched social and economic impacts of ADHD.
- Separate the impacts of ADHD from the impacts of other psychiatric conditions that frequently co-occur with ADHD.

INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is frequently stereotyped. For many, it conjures up an image of an uncontrollable, primary-school-aged child – usually a boy – who climbs the walls and just will not do as he is told.

But ADHD does not only affect young boys, nor does it reflect a simple inability to behave. It is a chronic condition that affects people from all backgrounds and frequently persists into adulthood. ADHD can make daily life a struggle and relationships chaotic. It can lead to significant problems in education and work, and put people at risk of serious harm through drugs, alcohol and other risk-taking behaviour. Yet many people grow up and enter adulthood without ever being diagnosed, unaware of the reasons behind the problems they are experiencing, and receiving little or no support – to the detriment of their own lives, the people around them and wider society.

This research

From a research perspective, the true impact of ADHD is currently poorly understood. The aim of this research was to explore the socioeconomic impact of undiagnosed and untreated ADHD on individuals, the people around them and wider society. At a time when mental health services are under the spotlight, Demos has sought to find out exactly what is at stake when people with ADHD are not properly identified or supported. We also sought to assess the evidence base concerning the impact of ADHD and to identify gaps.

There have recently been developments in the diagnosis and treatment of ADHD so it is an especially good time to explore the wider implications of the condition and create a strategy to reduce its burden. The growth of specialist adult ADHD clinics could offer better care to people with the condition beyond childhood. The development of new assessment tools (such as Qb testing) is creating the possibility of faster and more reliable diagnosis. Furthermore, a new guideline from the National Institute for Health and Care Excellence (NICE) due this year could provide the impetus for services to be stepped up and improved. Building on these developments, now is the time to reflect on what ADHD means for people living with the condition, their friends and family, and wider society, so that we can encourage and facilitate those in a position to lead change to do so.

Methodology

Research for this project took place between August and October 2017. It consisted of:

- conducting an REA of academic literature
- supplementary desk research
- holding interviews with people diagnosed with ADHD in adulthood
- examining written submissions from people diagnosed with ADHD in adulthood
- holding interviews with professional experts and stakeholders

The REA

We conducted an REA of existing research into the socioeconomic impact of ADHD. In this review we analysed research from the UK and elsewhere that explored the impact of ADHD on individuals living with the condition, the people around them, and society as a whole. The review gave us a series of important research findings and, importantly, enabled us to assess the quality of the overall body of evidence and to identify gaps. A detailed explanation of our approach to this REA can be found in appendix 1.

Additional desk research

In addition to our core REA, we reviewed wider literature to gather evidence on two topics related to ADHD's socioeconomic impact: the extent to which ADHD is understood and recognised by different groups, and the current policy framework for identifying and supporting people with ADHD. This desk research encompassed academic, policy-oriented and grey literature, from the UK and elsewhere.

Interviews with people diagnosed with ADHD in adulthood

We conducted five one-to-one, semi-structured telephone interviews with people with ADHD. We considered a range of demographic factors during recruitment, to ensure some variety of gender, age, location and other background characteristics among interviewees. We also restricted recruitment to people who had been diagnosed in adulthood – this allowed us to capture the impact of undiagnosed ADHD in particular, by asking retrospective questions exploring participants' pre-diagnosis experience. We asked further questions exploring diagnosis, including what led to diagnosis and possible improvements to the process, and the difference made by diagnosis and treatment (where relevant).

We have changed the names of interviewees and some of their details in order to protect their anonymity.

Written submissions from people diagnosed with ADHD in adulthood

We invited a further group of people diagnosed with ADHD in adulthood to submit written evidence, exploring the same questions used in our interviews in less depth. Five people responded to this call for evidence by submitting a response.[4]

Interviews with professional experts and stakeholders

Finally, we conducted five telephone interviews with professional experts and stakeholders drawn from academia, journalism, psychiatry and the third sector. The content of each interview varied, but collectively these interviews helped us to sense-check the results of our REA and desk research, gain further detail where the evidence had been lacking, and help us generate recommendations for research, policy and practice.

This report

This report is structured as follows:

- Chapter 1 provides background context, outlining what ADHD is and relevant policy developments.
- Chapter 2 assesses the quality of the evidence on the socioeconomic impact of ADHD, on which many of our findings are based. We present an overall assessment and identify key gaps.
- Chapter 3 presents the available evidence on the overall socioeconomic impact of ADHD. It summarises the vast array of social and economic impacts that have been associated with ADHD, and estimates the costs of ADHD in monetary terms.
- Chapter 4 explores in greater depth the social and economic impacts of ADHD outlined in the previous chapter, focusing on impacts on the individual, the people close to them (partners, friends and family) and society as a whole (including the public purse). It considers many different aspects of life, specifically: education, work, health and wellbeing, daily routines, personal relationships, risk-taking and crime.
- Chapter 5 considers the extent to which ADHD is understood and recognised as a condition by the general public, teachers, healthcare professionals and parents.
- Chapter 6 presents five personal stories we have collected through our interviews from people diagnosed with ADHD as adults. These stories explore what it was like to live with

undiagnosed ADHD, the impact of diagnosis and feelings about the future. The stories demonstrate that ADHD comes in many forms and affects people from all walks of life.

- Chapter 7 presents our conclusions and recommendations for research, policy and practice.
- Finally, the appendix outlines our methodology for the REA.

1 UNDERSTANDING ADHD

To provide context for the rest of this report, this chapter provides a summary of what is known about ADHD and its position in the current policy landscape.

What is ADHD?

ADHD is a neurodevelopmental disorder characterised by excessive activity, problems paying attention and problems controlling one's behaviour. The problems arising from ADHD are separated into two groups of symptoms: inattentiveness, and hyperactivity and impulsivity. Normally people experience both types of problem – this is known as 'combined type ADHD'. However, some only experience one symptom set, and are therefore diagnosed with 'inattentive type' or 'hyperactive-impulsive type ADHD'. Although all people experience inattention and hyperactivity on occasions, particularly very young children, for those with ADHD the symptoms are impairing and inappropriate for their developmental stage.

ADHD is one of the most common disorders of childhood and adolescence. Prevalence figures vary but estimates suggest a prevalence of 5 per cent among children and adolescents and 2.5 per cent among adults worldwide.[5] Prevalence among 5–15-year-olds in the UK has been found to be slightly lower than the worldwide estimate, with 3.62 per cent of boys and 0.85 per cent of girls thought to be affected.[6] Evidence suggests the majority do not seek or receive treatment.[7] Although symptoms often improve, ADHD usually continues to affect people in adulthood. Research has shown that approximately 65 per cent of children with ADHD continue to experience at least some symptoms and associated impairments at age 25, if not a full diagnosis.[8] However, the way in which ADHD presents itself may change as someone grows up – see box 1.

The causes of ADHD are not fully understood, but existing research suggests that there is a strong genetic component. ADHD often runs in families – research shows that parents and siblings of a child with ADHD are four to five times more likely to have ADHD themselves. A range of other possible causes have been identified, including brain structure, brain damage early in life, low birthweight and being born prematurely.[9]

ADHD cannot be cured, but medication can be used to relieve the core symptoms, with stimulants being the most frequently prescribed type of medication. Non-pharmacological treatment, such as parent training, patient therapy and psychoeducation, can also have an important role – these do not reduce the core symptoms of ADHD, as medication does, but equip people with the skills they need to control the impact of ADHD

symptoms on their lives. A combination of medication and non-pharmacological treatment is often most effective.[10] However, the draft version of the forthcoming revised NICE guideline on ADHD states that combining the two does not offer 'the best balance of benefits and costs', and should only be considered 'when medication has offered some benefit but symptoms continue to have a significant effect on everyday life'.[11]

Finally, it should be noted that ADHD frequently co-occurs with other psychiatric conditions, such as depression, anxiety, conduct disorder and oppositional defiant disorder. Only around a third of children are diagnosed with ADHD alone,[12] and evidence suggests that as many as half of children with ADHD also have conduct disorder or oppositional defiant disorder.[13] The high comorbidity rate can make diagnosis challenging, as many of these conditions have overlapping symptoms. The relationship between ADHD and other psychiatric conditions is complex, but these other conditions may be less likely to develop if ADHD is identified and managed at an early age.

Box 1 People with ADHD who may be at particular risk of not being diagnosed or supported

The way in which ADHD presents can vary from person to person. It is important to take this into account when diagnosing and supporting people with ADHD. Evidence suggests that the following groups are at particular risk of not receiving a diagnosis:

- people who do not experience hyperactive-impulsive symptoms
- girls and women
- adults who were not diagnosed as childhood

People who do not experience hyperactive-impulsive symptoms

There is a common misconception that all people with ADHD experience hyperactivity, but this is not the case. People with inattentive type ADHD do not experience hyperactivity, but instead face problems such as forgetfulness, disorganisation, difficulty focusing and excessive daydreaming. Research has shown that children with predominantly inattentive symptoms tend to be referred and diagnosed with ADHD at an older age than those with the combined type.[14] Inattentive type symptoms may be less obvious or produce less disruption in classrooms and other settings than hyperactivity.

Girls and women

As shown earlier in this chapter, it is thought that ADHD is more prevalent among males than females.[15] This can lead to girls and women with ADHD slipping through the net, as professionals are more alert to the possible presence of ADHD among boys and men. Research has shown that girls are less likely to be referred to CAMHS than boys.[16] Yet, like boys, girls diagnosed with ADHD in childhood are at risk of a range of poor outcomes, including low educational attainment, unplanned pregnancy, body mass index and clinician-rated impairment,[17] raising questions about what happens to those who do not receive a diagnosis. It has been suggested that females are more likely to experience predominantly inattentive symptoms than boys, which may be part of the reason why ADHD among females can be missed.[18]

Adults who were not diagnosed at childhood

It has only fairly recently been recognised that ADHD is not simply a disorder of childhood, but normally persists to a greater or lesser extent into adulthood. While this is true, it is important to note that ADHD often presents differently in adulthood than childhood. There is some evidence to suggest that inattentiveness may be more likely to persist into adulthood than hyperactivity (although the quality of evidence is poor[19]). Furthermore, inattention becomes more problematic for individuals as they become independent and the demands of daily life increase, such as managing a home or a job.[20] Because ADHD in adults can present differently from how it often presents in children, people who are not diagnosed in childhood are at risk of not being diagnosed in adulthood either. Given the difference in presentation, some have argued that there is a need to develop age-adjusted diagnostic criteria, although the 2008 NICE guideline development group concluded that there was insufficient evidence to justify this.[21]

Policy context

ADHD is a neurodevelopmental disorder, a category that also includes autism. Neurodevelopmental disorders are distinct from mental health conditions. Children with ADHD who receive treatment may do so through CAMHS but they might also be treated through paediatric clinics. Nevertheless, people with ADHD often experience mental health problems, and ADHD is most frequently discussed in a policy context in discussions around mental health. Therefore, this section focuses on the

policy landscape for mental health, drawing out implications for people with ADHD.

There has recently been a flurry of government activity over mental health has been the subject of a flurry of government activity. Recognising mental health services to be of poor quality and waiting times too long, the coalition government made a commitment to achieve parity of esteem between physical and mental health services by 2020.[22]

There has also been ever-increasing discussion of the importance of prevention and early intervention. This is partly in response to an ever-growing body of evidence showing that people do better in life when mental health problems and related conditions, such as ADHD, are tackled early. Diagnosed and treated ADHD is still likely to have an impact on a person's life, but the costs of late-diagnosed ADHD are likely to be far greater – let alone the costs when someone never receives a diagnosis. Recognising the importance of early intervention, recent government policy has had a particular focus on improving children and young people's mental health.

Health

In September 2014 the Children and Young People's Mental Health Taskforce was established, resulting in the publication of *Future in Mind* in 2015 – a report which recommended making better links between schools and specialist services, tackling stigma, improving access and waiting time standards, and establishing one-stop-shop support services in the community.[23] The need for progress on services for children and young people in particular was made even clearer by a Health Committee report published in 2014 outlining significant failures in CAMHS.[24] In the March 2015 budget, the government announced £1.4 billion of funding over the next five years from 2015/16 to improve mental health services for children and young people.[25]

Paul Farmer of Mind led the Mental Health Taskforce, which explored mental health services for people of all ages, and published *The Five Year Forward View for Mental Health* in 2016.[26] In addition to calling for the recommendations made in *Future in Mind* to be implemented in full, it set out its own vision for the future of services, requiring changes in service delivery models, workforce development, access standards and more. The report was accepted in full by all relevant NHS bodies. Sustainability and transformation partnerships, announced in December 2015 to help deliver the vision set out in *The Five Year Forward View for Mental Health*, are being developed by NHS organisations and local authorities to plan the future of health and care services in local areas. Despite the increased focus on the mental health of people of all ages, there is a question of how far developments in health policy are leading

to tangible improvements – especially for people with ADHD. It has been argued that new funding announced for mental health is often not reaching the frontline.[27] In the context of tight budgets, another key area of concern is how services are being rationed. Phase 1 of the Care Quality Commission's thematic review of children's mental health services found that just 25 per cent of children and young people in need of treatment for a mental health problem are able to access it.[28] In October 2017 the Children's Commissioner Anne Longfield took the unprecedented step of writing an open letter to Simon Stevens, Chief Executive of NHS England, in which she attacked the unacceptable quality of mental healthcare and accused Stevens of ignoring the frustrations and concerns of young people and their parents.[29]

Lack of access to services is particularly a problem for children with ADHD. In many areas, only children with the most severe, often life-threatening, problems such as self-harm and eating disorders are offered support – not children with ADHD, whose challenges may not present as starkly, despite the significant impact the condition has throughout the life-course (as demonstrated in chapter 4). For example, a recent report highlighted two CAMHS services that do not provide services to children with ADHD or autism.[30] Furthermore, although there is increasing attention to the need to improve services for adults, too, there is not yet evidence of there being significant improvements in those services for adults with ADHD. Access to an adult ADHD clinic is a postcode lottery, with many people only able to access general psychiatric services, which may lack experts to diagnose or treat ADHD. We heard from one of our expert interviewees that there are waiting lists of up to seven years for adult ADHD clinics, and some clinics only diagnose or provide minimal support owing to the level of demand they face.

Education

As well as focusing on health, recent policy has also addressed the role of schools and education in improving mental health and wellbeing among children and young people. There is a particularly good opportunity to intervene early through schools in the case of ADHD, as it is widely accepted that the condition emerges in childhood, unlike other conditions which may only emerge in adolescence or adulthood, and that problems often present for the first time at school.

Following the Children and Families Act 2014, which overhauled the special educational needs (SEN) system, a new SEN code of practice was published, which replaced the previous category of 'behavioural, emotional and social difficulties' with 'social, emotional and mental health'.[31] This encouraged teachers and other educational professionals to reflect on what might be causing problem behaviour among their students, to reduce the likelihood of underlying mental health problems

and other conditions being missed. This could benefit those children for whom ADHD presents as behavioural challenges. The Department for Education also published new guidance in 2014 (updated in 2016), advising how and when teachers should refer pupils to CAMHS and how pupils with mental health problems can be supported in the classroom.[32]

Looking specifically at how to make health and education services more joined up, a pilot was announced in December 2015 to test the introduction of single points of contact in 255 schools and in 22 pilot areas. Better collaboration between health and education services in relation to children's mental health has also been the focus of a joint committee inquiry in 2017.[33] An evaluation of the link trial pilots in February 2017 was generally positive, pointing to improved clarity of pathways to specialist services and more engagement between school and CAMHS staff. However, it also found that substantial investment would be needed in order to deliver the model across the country.[34] Furthermore, as previously indicated, children with ADHD are often judged not to have sufficient needs to be offered support through CAMHS, so the link trials could offer limited benefits to this group. A key theme of the children's mental health green paper released in December 2017 is boosting joint working between health and education professionals further still.[35]

One of our expert interviewees commented that while some progress has been made in providing better support to children with mental health needs or SEN (a category into which many children with ADHD fall), there is a disconnect between different sets of education policies, which is inhibiting progress. For example, the SEN reforms introduced a stronger focus on outcomes, but efforts to ensure this delivers benefits to children are undermined by a highly demanding examination regime, and insufficient focus on inappropriate use of exclusions and quality of alternative provision. As discussed in chapter 4, children with ADHD have been shown to be at a much higher risk of being excluded and placed in alternative provision.

The same expert also noted that an increased role for schools in addressing mental health problems among their pupils has not been met without opposition, as made clear by one of our expert interviewees who pointed to the concerns expressed by school teachers themselves. At a time when teachers are reporting overwhelming levels of stress and high workloads,[36] some argue that their role in pupils' mental health should be very limited and that they are being given too much responsibility in this area. Lack of time may lead teachers to pay attention to those with the most obvious needs, rather than children with ADHD who may internalise their problems or simply be labelled as troublemakers.

Looking ahead

There are no signs that the government has any intention to focus squarely on the specific challenges of ADHD, although the agenda around mental health, particularly children and young people's mental health, continues to grow. In January 2017, May outlined a new set of reforms and policies, including: [37]

- mental health first aid training for every secondary school
- a thematic review of children and young people's mental health services across country, led by the Care Quality Commission, to identify what is working and what is not
- support for NHS England's commitment to eliminate inappropriate inpatient beds by 2021
- a new pilot programme of peer support for young people
- a new green paper on children and young people's mental health, to set out plans to transform services in schools, universities and for families; published in December 2017, this paper focuses on improving services for those experiencing problems and boosting preventative work

It remains to be seen how much impact these initiatives and policies will have on the everyday experience of children experiencing mental health problems – especially those with ADHD.

2 ASSESSING THE QUALITY OF THE EVIDENCE

This chapter presents our assessment of the quality of the evidence available on the socioeconomic impact of undiagnosed and untreated ADHD in the UK. A key aim of this project was not only to identify what existing research tells us about the nature and scale of this impact, but to assess the quality of the evidence base. We considered this an important aim because research into the social and economic impacts of other untreated health conditions has played an important role in justifying greater investment and intervention. For example, a 2016 study led by the World Health Organization that explored the cost of untreated depression and anxiety to the global economy found that every US$1 invested in scaling up treatment for these conditions leads to a return of US$4 in better health and ability to work.[38] Research like this, which clearly demonstrates the economic benefits to be gained by greater investment in services, is very powerful at a time when public finances are tight.

The approach we took to the REA is set out fully in appendix 1. In brief, we consulted four databases and identified 76 relevant studies from the UK, US, Australia and Europe for detailed assessment. For each study we completed a data extraction form, in which we summarised the key findings and our assessment of the quality and relevance of the study. Below we present our overall assessment of the entire evidence base. The limitations of the evidence base are unsurprising given the clear methodological difficulties in quantifying and monetising the impact of a condition when it is undiagnosed, particularly one that affects so many aspects of a people's lives, as ADHD does.

Two major gaps in the evidence

ADHD is a complex condition, and although important progress has been made, research into the impact it has when undiagnosed and untreated is in its infancy. Our REA identified two major gaps in the existing evidence base:

- there are very few studies that monetise the impact of ADHD
- most studies explore the impacts of diagnosed and treated ADHD, rather than undiagnosed and untreated ADHD

Few studies monetise the impact of ADHD

It is clear that ADHD can affect a person's life, those around them and wider society in a myriad of ways. Some of the impacts of ADHD are difficult or impossible to monetise, such as the effect it can have on an individual's self-confidence, or the strain that bringing up a child with ADHD can put on a couple's marriage. But many of the impacts can in theory be monetised, such as loss of earnings and welfare expenditure – yet few studies exist that aim to capture these costs.

Studies that have attempted to monetise the costs of ADHD to some extent are explored in the next chapter. While these efforts constitute important first steps in developing the evidence base, more work is needed to verify their findings and to overcome the limitations that tend to affect work in this area (see below). This is demonstrated by the fact that the estimates produced by existing research vary significantly.

Most studies explore the impacts of diagnosed and treated ADHD, rather than undiagnosed and untreated ADHD

The majority of studies looking at the impact of ADHD focus on diagnosed and treated ADHD – something that is unsurprising given the obvious practical difficulties in exploring the impact of the condition among those who do not know they have it. Yet it is highly plausible that the social and economic impacts of undiagnosed and untreated ADHD are worse than the impacts of the condition when it is identified and treated, making the general lack of research into the impacts of undiagnosed ADHD highly limiting and problematic.

Some researchers have attempted to overcome the difficulties of exploring undiagnosed ADHD by undertaking a random sample of the community and using diagnostic criteria and scales to identify those people within the sample who have ADHD. However, the impacts of ADHD have not been monetised in these particular studies. Another approach has been to explore the impact of ADHD among people who were diagnosed in adulthood. Indeed, Daley et al costed the impact of late-diagnosed ADHD in Denmark using this technique.[39] While the approach has limitations, it represents important progress in capturing the profile of costs experienced by those whose ADHD is not identified or treated until later in life (see chapter 3 for an explanation of the findings of this study). More work is needed to build on these findings and further address this gap in the evidence.

Further limitations of the evidence

In addition to the two major gaps identified in the evidence above, we found additional limitations in the evidence base that further restrict the

conclusions that can be drawn about the socioeconomic impact of ADHD in the UK, which we discuss below.

Not controlling for comorbidities

It was noted above that people with ADHD often suffer from additional psychiatric problems or 'comorbidities'. If comorbidities are not properly controlled for then outcomes that are a result of conditions other than ADHD, or the interaction between ADHD and another condition or conditions, may be wrongly attributed to ADHD alone. While some studies controlled for comorbidities, many did not.

Not exploring the impact throughout the lifespan

Many studies explored the impact of ADHD on people until they reached adolescence or early adulthood, but few looked beyond this point to explore the impact in middle–late adulthood.

Certain kinds of impact are neglected

The impact of ADHD on certain aspects of life are under-researched. For example, it has been suggested that ADHD creates significant costs as a result of substance abuse, crime and traffic accidents, but these cost categories are rarely taken into account in monetised assessments of the impact of ADHD.

Variability in study design

Most of the studies we analysed were observational studies or meta-analyses. The observational studies varied in design enormously, including cohort studies, case-control studies and cross sectional studies, and even when the design type was similar, other features of the study vary significantly, e.g. the time between following up subjects in a cohort study. The meta-analyses tended to recognise the heterogeneity in study design and conclusions are therefore limited.

Lack of developmental sensitivity

The way in which ADHD manifests often changes as people grow up. As a result, when researching the impacts of ADHD, different outcomes need to be measured at different ages. Some longitudinal studies failed to account for this in their design, assessing the same outcomes at different developmental points.

Reliance on international evidence

As the evidence base on the socioeconomic impact of ADHD is so small, we decided not to restrict our review to studies only from the UK, opting instead to explore evidence from the US, Europe and Australia as well. Countries vary from each other in a number of ways, which could affect

the size and of the socioeconomic burden and whether it is borne by the state or the individual, including the way that ADHD is defined and treated, the nature of the healthcare system (eg publicly or privately funded, role of primary care physicians as gatekeepers), the nature of the welfare system and more. Therefore, findings from international research may have limited applicability to the UK.

Conclusions

This chapter has presented our overall assessment of the evidence base on the socioeconomic impact of ADHD, providing some important caveats for the chapters that follow. Our review identified some high quality and ambitious work on this theme, but our general conclusion is that the evidence base is currently weak. This likely results from a lack of focus on key issues relevant to our remit, in particular the specific impacts of undiagnosed and untreated ADHD, and in monetising these impacts. Furthermore, it should be noted that the complexities of ADHD as a medical condition make research in this area exceptionally challenging – e.g. its changing presentation over time, and the prevalence of comorbidities.

Further research is needed for us to understand the scale of the problems posed by undiagnosed ADHD and to identify the best ways of minimising this burden. In the final chapter we recommend the areas in which further research would add most value (and make recommendations for policy and practice).

3 THE BIG PICTURE

This chapter presents our key findings on the impact of undiagnosed and untreated ADHD in the UK. These findings must be considered in light of the comments made in the previous chapter on the limitations of the evidence base, which suffers from a number of gaps. Nevertheless, there are clear indications that undiagnosed and untreated ADHD imposes a significant socioeconomic burden. The chapter begins by setting out the myriad of ways in which ADHD can impact on a person's life, those around them and wider society. It then presents the cost estimates that have been produced that attempt to monetise the burden.

We present some findings specific to the burden of undiagnosed and untreated ADHD, but as the evidence on this is sparse, we also explore the literature on the burden of diagnosed and treated ADHD. It is highly plausible that costs are highest for those who are never diagnosed, followed by those who were diagnosed as adults and lowest for those diagnosed as children, as treatment aims to reduce ADHD symptoms and associated impairments, and possibly delivers cost savings across many areas of people's lives. Thus, studies that look at the costs of *diagnosed* ADHD are a helpful indicator but possibly underestimate the real costs of *undiagnosed* ADHD.

It is worth noting here that although this report is focused on the costs of ADHD, many people with ADHD consider there to be a number of upsides to their condition. For example, those who participated in our research associated the following positive traits with ADHD: abstract thinking, spontaneity, sense of fun, and the ability to focus intensely on certain things. However, participants were keen to stress that the difficulties caused by their condition normally outweighed the benefits – even if they would not change the fact that they had ADHD.

The diverse range of social and economic impacts that may result from undiagnosed and untreated ADHD

One of the most striking aspects of ADHD is the number of ways in which it can affect a person's life. Success in daily life, particularly as adults, often demands that we are patient, organised, cautious and able to focus. The core ADHD symptoms of inattentiveness, hyperactivity and impulsivity may not on the surface appear as destructive as the symptoms of other medical conditions, but they can have a particularly far-reaching and pervasive effect across all areas of day to day life – from education, to work, to personal relationships and more.

Furthermore, ADHD has implications not only for the individual with condition, but for their friends and family, and wider society too.

Though little work explores the specific impact of undiagnosed ADHD, and even less monetises it, there is a large body of evidence exploring the impact of ADHD in different areas or 'domains' of life. Table 1 documents the range of possible social and economic impacts of ADHD discussed in the literature on three levels: the individual, people around them, and the wider economy. Note that as our focus here is on undiagnosed and untreated ADHD, we do not include the costs involved in identifying and managing ADHD (e.g. costs of psychiatric services). Furthermore, the strength of the evidence for these impacts varies – for example, the relationship between ADHD and criminal behaviour is highly contested, while the link between ADHD and poor academic performance is widely accepted. We explore these impacts in greater depth and comment in more detail on the strength of the evidence in the next chapter.

Table 1 Potential social and economic impacts of undiagnosed ADHD on individuals, people around them and the economy

	Individual	People around them (partner, friends, family, co-workers, classmates, etc)	Economy
Health and wellbeing	▪ comorbid health conditions, mental and physical ▪ substance abuse – alcohol and drugs ▪ poor self-esteem, self-confidence and wellbeing	▪ wellbeing of close friends and family can be affected	▪ cost of treating comorbid health conditions
Education	▪ being absent from school from exclusion or truanting ▪ repeating academic years ▪ poor academic performance ▪ few qualifications	▪ classmates' learning may be disrupted ▪ teachers' attention disproportionately focused on managing children with ADHD	▪ poor education so children with ADHD are less prepared to succeed in work ▪ costs involved in school placement breakdown

Work	▪ not being in full-time work ▪ low pay ▪ low disposable income ▪ poor job stability ▪ poor career planning ▪ lower on-the-job productivity	▪ parents distracted from work by supporting child with ADHD, e.g. attending school meetings in work hours ▪ work colleagues taking on more duties to make up for lower productivity of individual with ADHD	▪ lower tax returns from under-employment of people with ADHD ▪ provision of income replacement benefits
Personal relationships	▪ impact on relationships between individual with ADHD and family members, when growing up and in adulthood ▪ difficulty establishing or maintaining friendships ▪ tension with classmates and co-workers	▪ strained relationships between people close to someone with ADHD, e.g. parents of a child with ADHD may experience marital strain	▪ provision of social care services or respite
Risk-taking	▪ gambling and reckless spending ▪ risky sexual behaviour and unplanned pregnancy ▪ accidents and injury	▪ personal relationships damaged ▪ effect on family finances of gambling and substance abuse	▪ cost of providing health and care services associated with these behaviours
Daily life	▪ difficulty with daily tasks associated with independent living, e.g. paying bills, housework ▪ difficulty with driving, including health and financial costs of traffic accidents	▪ partners, family or housemates have to overcompensate by taking on more of these tasks themselves ▪ health and financial costs of traffic accidents experienced by those involved	▪ cost of attending to traffic accidents

Crime	▪ time spent in criminal justice system ▪ higher likelihood of being victim of a crime	▪ members of the public become victims of anti-social behaviour or crime ▪ impact on friends and family of individual entering criminal justice system	▪ cost of administering criminal justice system ▪ cost of prison places

Monetising the impact

As discussed in the previous chapter, there is very little research into the socioeconomic burden of ADHD, and no single study that monetises the specific burden of undiagnosed and untreated ADHD in the UK. Therefore, only tentative conclusions can be drawn from the available evidence. With these caveats in mind, in this section we explore the four most relevant studies that attempt to monetise the impact of ADHD, in order to provide a rough estimation of the scale of the burden that undiagnosed ADHD in the UK is likely to have. We list the studies from most to least relevant.

Key characteristics and findings of the four most relevant studies

D Daley et al, 'Costing adult attention deficit hyperactivity disorder: impact on the individual and society' (2015)[40]

- This was the only study we found in our REA to focus specifically on costs related to individuals who were undiagnosed and untreated until adulthood.
- It used Danish medical registers to identify individuals in Denmark who had been diagnosed with ADHD in adulthood, and compared their performance with their siblings (where the siblings did not have ADHD) to estimate the costs of ADHD to the individual and the state.
- The study found that compared with their non-ADHD siblings, individuals diagnosed with ADHD as adults experienced private costs of approximately €8,600 per person, per year, of which over €7,900 resulted from the adults with ADHD having lower disposable income. Public costs amounted to around €9,000, most of which is accounted for by loss of income tax revenue and provision of

income replacement benefits. *Thus, the total yearly costs to the individual and state combined were found to be €17,769 per person, per year.* Aggregating this figure up, the study finds that the total costs of ADHD diagnosed in adults is €337 million, with costs to individuals of €163 million and costs to the state of €174 million.

- Although the analysis concerns the cost of ADHD for people living in Denmark, rough calculations were made to extrapolate the findings to other countries. When applying the prevalence rate and costs found in the study to the UK, it was calculated that the combined private and state costs of ADHD diagnosed in adulthood are *over €4 billion per year* (around £3.6 billion[41]).

JA Doshi et al, 'Economic impact of childhood and adult attention-deficit/hyperactivity disorder in the United States'[42]

- This article was a systematic review of 19 US studies on the costs of children, adolescents and adults with ADHD and their family members.
- Estimates of the annual incremental costs to society of ADHD (the excess costs over and above those of individuals without ADHD) *were found to range from $143 to $266 billion.*
- About three-quarters (73–74 per cent) of the costs were attributable to adults with ADHD or to adult family members of patients with ADHD. This is significant as most of the literature focuses on the costs attributable to children and adolescents alone.
- For adults with ADHD, the largest cost component (71–83 per cent) was found to be productivity and income losses – a finding which supports Daley et al. For children with ADHD, the largest cost component was healthcare (56–61 per cent), followed by education costs (35–40 per cent).
- Spillover costs were found to be substantial, with up to a quarter of the costs borne by family members rather than the person with ADHD, in the form of greater healthcare costs and losses in productivity.

HH Le et al, 'Economic impact of childhood/adolescent ADHD in a European setting: the Netherlands as a reference case' (2013)[43]

- Following in the footsteps of Doshi et al's 2012 study, Le et al sought to explore the economic burden of ADHD in Europe, taking the Netherlands as a reference case. A similar

methodology was used – the study took the form of a systematic review of the available evidence. However, the European evidence base was found to be much more limited than the US evidence base, with only seven relevant studies identified, none of which explored the costs of adult ADHD – only costs related to children and adolescents with the condition.

- It was found that the *annual cost of ADHD in the Netherlands could range from €1,041 million to €1,529 million.* This is smaller than the estimates made by Doshi et al in 2012, since the population of the Netherlands is considerably smaller than the US. The study considers just children and adolescents with ADHD rather than adults, too, and reported prevalence of ADHD is higher in the US than in the Netherlands.
- Similar to Doshi et al and Daley et al, the study found that most costs lay outside the healthcare sector: the biggest cost sector was education (42–62 per cent), whereas healthcare for the person with ADHD accounted for 8–25 per cent of costs.
- The study was also consistent with Doshi et al (2012) in finding that a substantial proportion of costs were borne by family members (29–33 per cent).

C Telford et al, 'Estimating the costs of ongoing care for adolescents with attention-deficit hyperactivity disorder' (2013)[44]

- This study was one of the seven examined by Le et al. It is worth considering in its own right for our purposes, as it is the most relevant study that focused on the burden of ADHD in the UK.
- The study estimates the additional education, health and social care costs among adolescents in the UK diagnosed with ADHD, but does not explore the specific economic burden associated with adults or those who are undiagnosed.
- Participants in the study were drawn from the Cardiff Longitudinal ADHD Study – a cohort of young people who were followed up five years after being diagnosed with ADHD by CAMHS and paediatric clinics in north and southwest England and Wales. Service use over the previous year was measured using the Children's Service Interview (a brief measure of service use related to mental health problems) with parents, and combined with unit cost data from national sources to calculate costs per person.
- The results showed that the mean cost per adolescent for NHS, social care and education services used in a year related to ADHD was £5,493. Education resources accounted for the greatest amount of costs (76 per cent), followed by NHS resources (24 per cent). Using estimated prevalence figures, *the study*

suggests that the annual cost of ongoing care for adolescents with ADHD in the UK is £670 million.

What can we conclude about the socioeconomic burden of ADHD from these studies?

The studies explored above vary significantly in their aims, design and findings. Nevertheless, they suggest that two tentative yet interesting conclusions can be drawn.

First, all of the evidence suggests that the economic burden of undiagnosed and untreated ADHD in the UK is likely to be very large indeed. For a country the UK's size, the estimates above suggest that the annual costs of ADHD could run into billions of pounds. Although most of the research focuses on the costs of diagnosed ADHD, we can assume that the costs of undiagnosed and untreated ADHD are likely to be higher as diagnosis and treatment aims to reduce the core symptoms of ADHD, improve functioning and decrease impairment.

Second, a surprising conclusion is that healthcare costs do not appear to be the biggest contributing factor to the economic burden of ADHD. Both the studies that looked at ADHD in adults as well as children found that income and productivity losses for adults with the condition were the biggest component of the overall economic burden. Even among children, education costs were found to be greater than healthcare costs in two of the three studies set out above. Furthermore, healthcare costs are likely to be even lower among children whose ADHD goes undiagnosed, while costs in other sectors (such as income and productivity in later life) are likely to be higher.

4 EXPLORING THE SOCIAL AND ECONOMIC IMPACTS OF UNDIAGNOSED ADHD IN GREATER DEPTH

This chapter explores the social and economic impacts outlined in the previous chapter in greater depth, demonstrating how ADHD can affect various aspects of a person's life, their friends and family, and wider society – particularly when the condition is undiagnosed and unmanaged. The chapter draws on the wider literature and expert interviews while also illustrating the lived experience through our evidence from people with ADHD.

Some of the poor outcomes we describe are still observed even when all other outcomes are kept constant. Although we discuss the impacts on different aspects of life separately, it is important to stress that the impacts are in many cases mutually reinforcing. Put simply, difficulties in one aspect of a person's life can cause, or be caused by, difficulties in other areas of life. For example, poor self-esteem can cause difficulties in forming good quality personal relationships, and it can be caused by the experience of consistently failing in education and work. The fact that ADHD can affect so many different aspects of life, and that the impacts are so often mutually reinforcing, is part of the reason why the condition can be so highly damaging (and costly) – if something begins to go wrong in one area, then it can lead to many other things in other areas of a person's life going wrong too. But by the same coin, improvements in one aspect of a person's life can lead to drastic improvements in other areas that might seem disconnected. In particular, improving education outcomes is widely considered to be something that can lead to improvements in many other areas of people's lives – including people with ADHD – thus strengthening the case for early diagnosis and intervention.

Education

The relationship between ADHD and experiencing problems at school has been the subject of much research. This is likely to be in part a response to the fact that a large body of evidence suggests that above all factors, a good education is pivotal in shaping a person's life chances.[45] This raises the possibility that if children with ADHD are supported to succeed in education, this may go very far in helping them to avoid negative outcomes in many of the other areas of life discussed below. However, evidence suggests that currently children with ADHD do not generally perform well at school, with teachers often not realising that they have the condition (as discussed further in chapter 5).

School is normally the first point at which problems associated with ADHD begin to emerge. In primary school, hyperactivity and impulsivity can

lead a child to be a highly disruptive presence in the classroom, while inattentiveness can make them unable to concentrate and keep up with what the teacher is saying. The problems tend to become even greater at secondary school, where more demands are made of students, for example managing their time, being organised and coping with a greater workload. Summarising the evidence on the impact of ADHD on success in education, in 2015 Arnold et al found that children with ADHD typically do worse in their academic achievement (information and skills learned, as measured by standardised tests) and academic performance (success within the school setting, as measured by grades, years of schooling completed and so on) than other children.[46] There is evidence to suggest that children with inattentive type ADHD are at particular risk of poor academic achievement.[47]

When difficulties at school begin, a vicious cycle can quickly develop, which is difficult to break out of. A recent study of 766,244 children attending primary, secondary and special schools in Scotland between 2009 and 2013 found that those being treated for ADHD experienced higher rates of unauthorised absence, and were more likely to be excluded, and to leave school before 16.[48] Many of the people we spoke to with ADHD said that the school was a real struggle and demoralising experience. One of our interviewees described how her teachers would make comments such as 'nice of you to turn up' if she was late, which made her 'not want to go back again' (Jenny, London, 36, diagnosed at 31). This led her to begin truanting. Another interviewee began missing school at the age of 14 as the hustle and bustle of a big school environment made her feel physically and mentally exhausted, despite having performed well at school until that point:

> *I didn't drop out of school because of the schoolwork… I didn't underachieve in the classic sense, I couldn't cope with going to school.*
>
> Emma, Yorkshire, 49, diagnosed at 43

The effects of ADHD can be a serious blow to the self-esteem of someone with the condition – many of the people we spoke to saw school as the beginning of a series of failures in their lives, and on diagnosis as an adult one interviewee said she found herself 'grieving the loss of her education' (Emma, Yorkshire, 49, diagnosed at 43). A poor academic record can also limit one's future earning potential – an issue we turn to in the next section.

Not all people with ADHD find school such a struggle – at least on the surface. According to a consultant psychiatrist we spoke to, those who are less severely affected by ADHD can 'coast' their way through the system, able to perform adequately despite their symptoms. However, those who go on to university often find that their symptoms prevent them from succeeding or achieving their true potential. This was demonstrated in our interviews with people with ADHD. Two described having to repeat years as a result of ADHD, for reasons such as difficulties with organisation. One interviewee had to resit his first year three times, while another described how he focused all of his attention on a small number of assignments, which led to him underperforming in other areas. This phenomenon is known as 'hyperfocusing' and is common among people with ADHD:

> *I started my PhD at 36 so that should give you an idea, you know, about the effect it has. Procrastination was a really, really difficult thing in university. Just basic time management skills, trying to organise time… in my undergrad I missed a lot of deadlines.*
>
> Ben, South West, 40, diagnosed at 36

The immense challenges faced by people with ADHD in education have significant implications for other students, too. Unmanaged ADHD can be a source of significant disruption in the classroom, placing great demands on the time of the teacher and slowing down progress among others in the class. The most disruptive children may be at risk of exclusion, which is also costly to the state: the average cost of alternative provision for an excluded pupil is £11,536 per year compared with £4,355 for a mainstream secondary school place – a difference of £7,181 per year.[49]

The difficulties experienced by some people with ADHD when moving from school to university (along with those who experience problems when moving from primary to secondary education) raises broader questions about how well we are supporting people with ADHD to cope with transitions. Another transition that people with ADHD can find difficult to navigate is the transition from school to work.

Work

The evidence base concerning the impact of ADHD on employment and success in work has grown in recent years, as awareness of the continued impact of ADHD in adulthood has increased. Indeed, it was

suggested in the previous chapter that income and productivity losses in adulthood may be the most significant components of the economic burden of ADHD.

It is widely established in the literature that ADHD affects the likelihood of a person being in work and their earnings. For example, Fletcher showed that being diagnosed with ADHD in childhood reduced employment in early adulthood by 10 per cent and earnings by 33 per cent.[50] Reduced employment and wage income has important implications for the individual's level of disposable income, as well as for the state through reduced tax revenue and the cost of providing income replacement benefits, such as Job Seeker's Allowance and Employment and Support Allowance. Fletcher found that welfare benefit receipts were increased by 15 per cent for those diagnosed with ADHD.[51] One respondent to our call for written evidence said that she had been on benefits since 2003 and that there was no possibility of her getting paid work (Woman, Yorkshire, 43, diagnosed at 31), while an interviewee told us that she had been struggling to cope in a new role as a volunteer in an office environment, with all its noise and distractions, until she had been diagnosed and treated for ADHD (Jenny, London, 36, diagnosed at 31).

Even those in paid work appear to suffer significantly as a result of ADHD. According to a quantitative survey of 880 people in Europe and the US, ADHD was associated with poorer workplace productivity according to a range of measures, including absenteeism (days missed due to ill health), presenteeism (impairment experienced at work due to ill health) and overall work impairment (combined absenteeism and presenteeism). The study does not indicate how much of this lost productivity was a result of ADHD, which is significant as 71 per cent of the sample have at least one comorbidity, but the results are directionally similar to other studies exploring the impact of ADHD on productivity. Looking specifically at the UK, overall work impairment for people with ADHD was 60.8 per cent, compared with 24.4 per cent for people without the condition.[52] This rate of impairment is greater than that for rheumatoid arthritis with severe functional disability (47 per cent).

Lower productivity may lead to people with ADHD working longer hours or losses accruing to their employer. ADHD can also be associated with lack of career planning and increased job instability;[53] this was reflected strongly in our interviews and written feedback from people with the condition. One respondent wrote:

I found it difficult to stay employed, I've never maintained a job for longer than a year.

Man, North West, 25, diagnosed at 23

Another interviewee observed:

I learn the things and do the things I find interesting at the time, but it's not building up to a coherent whole. My lack of understanding the rules means I've got no career momentum.

Harry, East of England, 47, diagnosed at 43

Employment and productivity among individuals who know people with ADHD may also be affected. Able et al report that 63.3 per cent of UK participants in their study who had been diagnosed with ADHD felt that the condition affected their relationships with their co-workers.[54] Furthermore, productivity and employment levels among parents may be impacted as a consequence of needing to devote significant time to supporting children with ADHD,[55] particularly when support from healthcare services or schools is not forthcoming.

The accumulated problems people with ADHD often experience in education and work can be highly damaging to their self-esteem and confidence, as explored in the next section.

Health and wellbeing

The evidence strongly suggests that people with ADHD are at greater risk than others of suffering from a range of additional mental and physical health problems, as well as poorer quality of life and sense of wellbeing.

The vast majority of the people with ADHD who participated in this research indicated either explicitly or implicitly that their wellbeing had suffered significantly as a result of living with undiagnosed ADHD. Common themes to emerge included low self-esteem, lack of confidence, the sense of being a failure, and a feeling of being different from other people. Diet and sleep, particularly the latter, were often reported to have been affected as well:

Wellbeing has never been part of my life. A consultant once asked me to think back to when I last felt really well and I was able to say to him with all honesty, that I had no recollection of this as far back as childhood.

Woman, Scotland, 62, diagnosed at 61

Although we did not collect evidence directly from friends and family of people with ADHD, those diagnosed with the condition frequently commented on how they thought the condition had affected the wellbeing of those around them, often suggesting that they felt they were (or had been) difficult to live with. Research has shown that children growing up with a sibling with diagnosed ADHD are substantially less happy with their family and life overall than children who are not.[56] Matza et al note that having a child with ADHD can lead to disturbance in parents' marital functioning and extremely high parental stress.[57]

The additional mental health problems many people with ADHD experience meet the diagnostic criteria to be considered separate psychiatric conditions in their own right. Indeed, Daley et al found that people in their study who had been diagnosed in adulthood had on average 4.3 comorbid psychiatric disorders, such as conduct disorder, anxiety, depression and disorders arising from substance abuse.[58] The causes of ADHD and its common comorbidities are complex, as is the relationship between them. On the one hand, as one of our expert interviewees explained, ADHD and many of its frequently comorbid conditions are thought to co-occur commonly as they share certain genetic causes, suggesting that the treatment of ADHD would not directly affect whether other conditions emerge (as the genetic causes would still be there, regardless of whether or not the ADHD is addressed). On the other hand, comorbidities might develop as a result not just of the genetic base, but because the experience of living with ADHD is difficult. There was a clear consensus among the experts we consulted that the experience of having the disorder and all the problems that can follow in education, work and so on can be the cause of the development of comorbidities. If true, it is possible that the development of comorbidities might be curtailed to some extent by ensuring that ADHD is properly addressed:

> *The levels of anxiety that go with that kind of neurology on a day to day basis, particularly in schools, means that you have children who can experience a great deal of anxiety.*

Academic

A lot of the anxiety is actually about being unable to do things and complete things or they feel depressed. So the mental health comorbidity they're having, in my opinion, is a consequence of their underlying ADHD.

Consultant psychiatrist

This was a point reinforced by a number of the people with ADHD who contributed to our research: as one participant put it, 'untreated ADHD is depressing' (Emma, Yorkshire, 49, diagnosed at 43). Indeed, several people we heard from described extremely frustrating periods when GPs and psychiatrists had only diagnosed depression or anxiety, and refused to see what they considered to be the root cause of ADHD:

I'd have never been diagnosed if it was left to a GP, I'd have just been told it was depression, and so did the access team. They said, 'It's depression and you don't really need any support.' But I was sick of telling people 'I am not depressed.'

Jenny, London, 36, diagnosed at 31

People with ADHD may experience physical comorbidities as well as psychiatric comorbidities, although the former have been much less thoroughly researched than the latter. For example, it has been argued that there is a possible association between ADHD and obesity. Summarising the evidence so far, Cortese and Tessari find that although the evidence is mixed, meta-analysis suggests that people with ADHD appear to be at greater risk of obesity, and that recent longitudinal studies support ADHD having a causal role in this process.[59] Other physical comorbidities discussed in the literature include asthma, hypertension and irritable bowel syndrome.

Comorbidities that require treatment, whether mental or physical, have an effect on the state as well as the individual through increased healthcare costs.

Daily life

To someone unfamiliar with the condition, the core symptoms of ADHD and the ways in which they are manifested in daily life might seem fairly innocuous. Losing one's keys or forgetting a meeting might be considered minor annoyances rather than major problems. Indeed, existing research into the impact of ADHD is rarely concerned with the

day to day frustrations and difficulties caused by ADHD, focusing instead (perhaps understandably) on the more overtly problematic impacts such as poor outcomes in education, work and health.

Nevertheless, the supposedly minor inconveniences experienced daily as a result of ADHD warrant brief discussion, as in our conversations with people with ADHD they were often the first things they raised. Typical comments included:

> *There's always things left half-started and half-finished, I'd forget things like PE kits and stuff like that, I was always tracking back on myself.*
>
> Jenny, London, 36, diagnosed at 31

> *Usually I am quite late on a regular basis to anything. Doesn't matter what it is. I miss trains and buses and so and so. That ends up being down to... I mean to ridiculous things like leaving keys, leaving train tickets, or leaving my wallet, or forgetting to bring what I need.*
>
> Jason, North East, 24, diagnosed at 21

> *I would often lose things.*
>
> Man, North West, 25, diagnosed at 23

While they may be major problems in themselves, the daily problems experienced by people with ADHD can have great personal and social significance, particularly over time. Our qualitative evidence suggests that low confidence and self-esteem among many people with ADHD is perhaps most fundamentally linked not to lack of success in education and work, but being incapable of coping with the most basic of tasks in life:

> *It took me [until] really late to develop a lot of skills that people took for granted like driving for example.*
>
> Ben, Southwest, 40, diagnosed at 36

Things like getting out of bed, brushing your teeth, getting washed and dressed, eating, dealing with the very ordinary… sometimes it is really painful to do them and you don't know why you are struggling like that.

Emma, Yorkshire, 49, diagnosed at 43

As well as causing people to reflect on their own self-worth, difficulties with managing basic daily tasks can also damage the relationships of people with ADHD, particularly with those they live with. People living with the condition often develop coping strategies, which might seem strange or be frustrating to a partner or close friends in the same household. Indeed, one of our interviewees described how he needed to block out vast amounts of time to do housework or similar tasks, in order to allow time for procrastination, which he felt incapable of controlling. According to the consultant psychiatrist we interviewed, people with undiagnosed ADHD often seek help at points when their living arrangements change – e.g. when they move in with someone new, or marry. The impact of ADHD on a person's relationships are explored further in the next section.

Personal relationships

The core ADHD symptoms and behaviours can be a highly disturbing influence on an individual's personal relationships, from childhood through to adolescence and adulthood. When ADHD is undiagnosed it can make things even more difficult as, lacking any explanation, it might be falsely assumed that the individual's behaviour is simply a result of them being lazy or careless. Children growing up with undiagnosed ADHD may find themselves in conflict with their parents for this reason:

It's impacted on my home life, I ended up leaving home at 16 because of what struggles it put on the family… they wanted me to go to school and I didn't.

Jenny, London, 36, diagnosed at 31

I think there's more of an understanding now that they know it was ADHD as opposed to just me being rude.

Jason, North East, 24, diagnosed at 21

Sibling relationships may also suffer as a result of one child having undiagnosed ADHD. In 2016 Peasgood et al found that children with a sibling diagnosed with ADHD were more likely to report calling their sibling names or taking their belongings, while the children with ADHD themselves were more likely to take their sibling's belongings, than in households where no child had diagnosed ADHD.[60]

It was noted in the introduction that there is a strong genetic component to ADHD and that it often runs in families. Several participants in our research noted that they had family members with an ADHD diagnosis, or who they suspected had ADHD. In some cases this was seen as a challenge for personal relationships, with one participant commenting that her mother had to cope with bringing up three children with ADHD on her own. In other cases, more than one person in the family having the condition was seen in a more positive light – for example, one interviewee commented that those with ADHD in his family understood each other, even though their family life was chaotic.

Several studies have shown that people with ADHD are more likely to be single than those without the condition. For example, Able et al found that 51.5 per cent of UK participants in their survey with ADHD were married, compared with 66.5 per cent of those without ADHD.[61] Furthermore, 61.4 per cent of those with ADHD said that they felt ADHD had a negative impact on their relationship with significant others. In addition to challenges around managing basic tasks in a shared home (as outlined above), more fundamentally, poor listening skills and being easily frustrated can reduce intimacy between people with ADHD and their partners.

The challenges of developing and sustaining romantic relationships experienced by many people with ADHD was reflected in our interviews and written submissions. We received a written response from someone who said that they had not been in a relationship for 11 years (Woman, Yorkshire, 43, diagnosed at 31). Furthermore, one of our interviewees said that he and his partner found the early stages of their marriage stressful, commenting, 'I am sure it's not easy if your partner has ADHD' (Ben, South West, 40, diagnosed at 36). Indeed, the psychiatrist who participated in our research said that one of the triggers that brought people to his service was when they experienced relationship difficulties.

Here an interviewee describes how ADHD can prevent him from focusing on what his partner is saying:

> *If I'm deep in thought about something and my partner and I have a serious conversation, it's a real effort to focus and hear what she's saying, when my brain's still doing the thinking.*

Harry, East of England, 47, diagnosed at 43

Finally, our research suggests that ADHD can prevent people from making or sustaining friendships. One of our interviewees explained that she found it incredibly difficult to pay attention to things not in her immediate environment, so keeping in touch with friends and arranging to meet up was a huge challenge for her. Combined with poor self-esteem, lack of friendships can contribute to a pervasive sense of isolation and feeling disconnected or separate from other people:

> *I kind of started seeing myself as someone who couldn't be relied upon or depended upon.*

Ben, Southwest, 40, diagnosed at 36

Risk-taking

The core ADHD symptoms, particularly impulsivity, make people with the condition prone to taking risks. This can affect many aspects of a person's life, including those already explored in this chapter – for example, someone may find themselves quitting a job without having another one lined up, and acceptance risk can play an important part in someone's abuse of alcohol or drugs.

A range of further risk-taking behaviour is associated with ADHD in the literature. Evidence suggests that people with ADHD are more prone than others to accidents and injury. This may be linked to risk-taking (although it could also be linked to other impairments resulting from ADHD such as poor planning skills, lack of sleep, and slower psychomotor speed and response times[62]). A child with ADHD may not think twice about jumping from a tree, and adults with ADHD have been shown to be at greater risk of being involved in traffic accidents.[63] It is therefore unsurprising that a link has been demonstrated between ADHD and increased mortality rates. One study used Danish registers to follow nearly 2 million people, including over 30,000 with ADHD, over a period of 32

years. It found that the mortality rate among ADHD participants was 5.85 per 10,000 person years compared with 2.21 per 10,000 person years in people without ADHD. The highest rate of mortality was found in people diagnosed with ADHD in adulthood, 'The excess mortality in ADHD was mainly driven by deaths from unnatural causes, especially accidents.'[64] Interestingly, despite much discussion of the link between ADHD and injuries in the literature, none of our research participants with ADHD noted injuries and accidents as being impacts of their condition.

Gambling and reckless spending has also been linked to ADHD. In a large quantitative study in the US, individuals with ADHD were shown to be significantly more likely than the general population to develop problems with gambling or spending too much (22.53 per cent vs 5.54 per cent). This was reflected in several of our interviews and written responses, with one person commenting, 'What I now know to be impulsivity caused me to struggle with money and rack up huge debts' (Man, North West, 25, diagnosed at 23). Another commented, '[Before diagnosis] I was in a lot of debt, which I'm sorting out still' (Jenny, London, 36, diagnosed at 31), although it was unclear whether this debt was a result of low income or high spending.

Another participant in our research said that her ADHD had led her to engage in risky sexual behaviour. Some research has sought to explore possible links between ADHD and risky sexual behaviour, using indicators such as acquisition of sexually transmitted diseases, number of partners, condom use and unplanned pregnancy, but this possible manifestation of risk-taking behaviour is less well studied than others. This is particularly the case in relation to the association between ADHD and unplanned pregnancy – perhaps a result of ADHD in women and girls being less studied in general, although a small study recently pointed to a link between the condition and unplanned pregnancy.[65]

Risky behaviour and its consequences can have devastating implications for friends, families and wider society as well as individuals. As an example, problematic gambling can lead to increased arguing between an individual and their loved ones, preoccupation and inability to focus on things other than gambling, lying about losses and even stealing to fund the habit.[66] It may be left to the state to pick up the pieces when an individual engages in risky behaviour by providing health and care services.

Crime

Finally, we turn to the possible impact of ADHD on levels of anti-social behaviour and crime – a relationship which is contested in the literature.

It is intuitively plausible that some of the key symptoms and behaviours which can be associated with ADHD may increase the likelihood of a person committing crime. Symptoms of impulsivity may make a person with ADHD less able to restrain themselves, or think through the consequences of criminal behaviour, than others. One of our research participants indicated that they had been involved with crime, that they 'got into drugs, the criminal world' as a result of ADHD and were 'nearly in prison' (Woman, Yorkshire, 43, diagnosed at 31).

Furthermore, numerous studies have pointed to the high prevalence of ADHD within the prison system: among adult prison inmates, estimates of adult ADHD prevalence are 23–45 per cent.[67] Even if the true prevalence rate of ADHD among the prison population is towards the bottom of this range, it suggests that the number of people in prison with ADHD is highly disproportionate, as adult ADHD in the general population is estimated at 2.5 per cent. Some research has gone further than observing ADHD rates in prisons, looking directly at the rate of criminal behaviour among people with a diagnosis. Using Swedish national population and crime registers, Lichtenstein et al found that among the 25,656 people with an ADHD diagnosis, 27 per cent of men and 15 per cent of women had been convicted of at least one crime.[68]

If there is indeed a relationship between ADHD and crime, this represents a significant cost to the state. The average cost of a prison place in 2015/16 was £35,182.[69] Aside from the cost of administering the punishment itself (whether prison or a community sentence), the extra costs of administering the criminal justice system must be accounted for – not to mention the costs to victims, which may be very significant indeed (and difficult to quantify). The costs of crime committed as a result of ADHD are rarely included in calculations of the socioeconomic burden of the disease – an area in which much more research is needed.

An issue of some debate in the research is how far criminal behaviour results from ADHD and how far it results from comorbidities. More specifically, it has been hypothesised that conduct disorder (a condition characterised by repeated and persistent patterns of anti-social, aggressive or defiant behaviour, which is frequently comorbid with ADHD) may also have a causal role in criminal behaviour.[70] Furthermore, even if ADHD has an independent effect in increasing the likelihood that someone commits crime, this may be a result of not simply the core ADHD symptoms, but also the wider impacts of the condition. One of the experts we spoke to pointed to the possibility of people with ADHD falling into negative peer groups as a result of leaving school early, which may be a driver of ADHD behaviour in addition to the core symptoms. Lack of employment may also lead to greater levels of anti-social behaviour and

crime among this group. If the problems partly stem from deep-rooted causes such as poor educational and employment outcomes, then early intervention may be needed in order to break the cycle of crime. Nevertheless, a significant finding from Lichtenstein et al was that when people took ADHD medication they were 32–41 per cent less likely to be convicted of a crime than when they did not take medication for six months or more, suggesting that controlling the key symptoms of ADHD may have a significant effect in preventing crime.[71]

The value of early intervention

This chapter has shown that people with ADHD are at risk of poor outcomes in many different areas of their lives, with potentially devastating consequences for themselves, people close to them and wider society. Even though ADHD symptoms emerge in childhood, most of those affected reach adulthood without being diagnosed with the condition. This naturally raises the question of what difference it would make to people's lives if they were diagnosed at an earlier point.

The evidence base concerning the difference made by early intervention for people with ADHD is evolving. The realisation that most children do not simply grow out of ADHD and that it frequently persists into adulthood is still recent. This may be one reason why there is limited research on how early intervention might alter the long-term trajectory of people with ADHD, perhaps enabling them to achieve better outcomes than those outlined above.

Nevertheless, there are reasons to believe that early diagnosis and treatment could make a significant difference to those affected by the condition. Speaking about the value of just diagnosis in itself, a clinical psychiatrist we spoke to said:

> *Patients would describe that they finally have some understanding of why they're struggling in the way that they are. They're able, for the first time, to understand that it might not be that they're just lazy and stupid – which is what they've been told and their own self-perception of themselves.*

The immense value in getting a diagnosis was widely reflected by the people with ADHD we consulted. Although the experience was clearly very emotional for many of them, there was almost always a sense that the diagnosis allowed them to give themselves a break for difficulties which they thought were simply a result of their own inadequacies as people – not a medical condition:

> *It very much helped me understand my path so far and why I dropped out of school and things like that – why I left home early. It gave explanations.*
>
> Jenny, London, 36, diagnosed at 31

When asked to reflect on the value of treatment, several described it as life changing. Simple things such as being able to concentrate on work, or even just organising the house, often became much easier for those who were able to access medication, therapy or both. The short-term benefits of treatment on immediate impairment and reduction of severe ADHD symptoms are relatively well documented in the literature.

In contrast, the evidence on the long-term impacts of treatment on key outcomes, such as education and work, is less well studied and findings not as conclusive. A notable systematic review by Shaw et al found that treatment may reduce the negative impact that untreated ADHD has on life functioning, but does not usually normalise patients.[72] Furthermore, the evidence for treatment being beneficial varied according to the outcomes being studied. For example, treatment of ADHD was most beneficial for outcomes related to driving and obesity, followed by those related to self-esteem, social function and academic attainment. Outcomes related to drug use and addictive behaviour, anti-social behaviour, services use and occupation appeared to be the least responsive to treatment. An academic we consulted said that his top priority for further research in this area would be more work demonstrating the difference made when people with ADHD had access to care.

5 LACK OF UNDERSTANDING AND AWARENESS OF ADHD

The previous chapter showed that people with ADHD are at risk of poor outcomes in many different areas of their lives. Although the evidence is lacking, there is reason to believe that early diagnosis and intervention could play an important part in reducing the risk of poor outcomes, enabling more people with ADHD to live happier and fulfilled lives.

A key factor determining access to diagnosis and treatment is how far people are aware of, and understand, the condition. Unfortunately, awareness and understanding of ADHD is currently very poor. The very existence of the condition is still frequently a topic of debate, fuelled by observation of the fact that the number of prescriptions being dispensed for drugs commonly used to treat ADHD has increased enormously in years, more than doubling between 2004 and 2015.[73] These views are at odds with the research, which suggests that ADHD is under-diagnosed rather than over-diagnosed in the UK. A science journalist pointed out that the little media output there is about ADHD, such as Rory Bremner's documentary 'ADHD With Me Rory Bremner' on the BBC series *Horizon*, which aired in 2017, often generates 'vitriolic' responses from people who say that those diagnosed with the condition should 'stop whingeing as of course the thing doesn't exist'.

Public awareness of ADHD contrasts significantly with awareness of autism. Similar to ADHD, autism is a neurodevelopmental disorder, which manifests in a variety of ways, and it may not be obvious that someone suffers from the condition. However, public awareness of autism seems to be much greater than awareness of ADHD. For example, autism has become increasingly familiar to large, mainstream audiences through programmes such as 'The A Word', 'The Autistic Gardener' and 'Pablo'. Perhaps even more powerfully, characters with autism increasingly feature in television shows not specifically focused on the condition, such as *Holby City*. All the major cinema chains now hold autism-friendly screenings, 5,000 shops signed up to an 'autism hour' in 2017, and several large companies including Microsoft now advertise recruitment programmes focused on hiring those with the condition. As well as helping those with the condition to overcome disadvantage, these initiatives are often heavily promoted and have significant awareness-raising value.

Although there is still a way to go in improving public understanding of autism, awareness at least appears to be improving, and one of our experts suggested that much could be learned from the way in which autism has become more visible to the public. One of our expert interviewees pointed to the fact that there appear to be far more autism charities than ADHD ones – indeed, the 'autism hour' was planned by

the National Autistic Society – which may partly explain why there have been more improvements in awareness of autism than ADHD.

Evidence suggests that even among those who accept that ADHD exists, misconceptions and poor understanding of the condition are rife. People are often unaware of the causes of ADHD, neglecting the importance of genetic factors and falsely claiming that it is a product of poor parenting. Symptoms of ADHD are frequently misunderstood, with ADHD being strongly associated with hyperactivity but not inattentiveness, increasing the risk of people with inattentive type ADHD being missed – particularly girls who are more prone than boys to inattentiveness. Indeed, many still see ADHD as a 'boys' condition' further compounding the risk that girls go undiagnosed. The idea that people grow out of ADHD is still prevalent. Furthermore, views about the use of medication to treat ADHD are still often very negative. According to the current NICE guideline,

> *Drug treatment is not indicated as the first-line treatment for all school-age children and young people with ADHD. It should be reserved for those with severe symptoms and impairment or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to parent-training/education programmes or group psychological treatment.*[74]

Thus although best practice dictates that drug treatment should not be used in the first instance in less severe cases of ADHD, it has a role in the treatment of those with more severe symptoms and impairments. The level of scepticism around the value of medication is perhaps out of step with its role in guidelines for best practice in ADHD management.

The lack of understanding and awareness of ADHD is striking as it is one of the most common disorders of childhood and adolescence. It is reflected in research showing that people experience lengthy delays in getting a diagnosis, if they are diagnosed at all: in a study using the Cardiff Longitudinal ADHD Study cohort, Ford et al found that the median time of parents first contacting a professional about their concerns and their child receiving a diagnosis was 2.5 years.[75]

Below we summarise the evidence of knowledge about ADHD among different groups.

Healthcare professionals

As ADHD is a medical condition, it would be reasonable to expect healthcare professionals to have a good level of knowledge about the condition, but evidence suggests that this is not always the case.

In the UK, GPs occupy a gatekeeper role – they do not engage in ADHD diagnosis or management themselves, but are responsible for referring patients to specialist secondary services – paediatricians or psychiatrists who can make the diagnosis and initiate treatment. Thus, it is critical that GPs have sufficient understanding and awareness of ADHD to refer when appropriate.

Unfortunately, research suggests that knowledge of ADHD among GPs can be lacking. In 2016 Tatlow-Golden et al explored the literature on attitudes and knowledge among GPs in the UK, Europe and Australia. They found that across the diverse range of studies they explored, misconceptions persisted in many GPs' views regarding causes, treatment and their role in ADHD.[76] Although GPs tended to express biomedical views of the causes of ADHD, these were often found to be 'overlaid with a (sometimes more prevalent) focus on the impact of parenting'. Furthermore, although the evidence was insufficient to make decisive conclusions, a number of studies found GPs to question the validity of ADHD as a condition and to express negative attitudes to medication. Participants in our research reported having mixed experiences of GPs, which often required them to 'shop around' until they found a GP who was willing to make a referral:

> *It was a really awkward thing to sort of go to my GP and be like, 'I'm having some problems, I think it's ADHD. Can you refer me?' Initially the first GP I spoke to was sceptical, and this is a really good GP I have a good relationship with.*
>
> Jason, North East, 24, diagnosed at 21

Indeed, we heard of some people paying significant sums to access private healthcare in order to bypass unhelpful GPs (although also to avoid long waiting lists for specialists in some cases).

Although there is little research on the subject, the level of understanding about ADHD among paediatricians and psychiatrists themselves has been brought into question. Tatlow-Golden et al found that competing ideologies regarding ADHD and its treatment have led to inter-professional tensions in CAMHS services,[77] most likely with implications for

the quality of treatment received by children and young people in their care.

Similarly with regard to adults, there are concerns about how far the condition is understood by general psychiatrists. A specialist adult ADHD psychiatrist we spoke to thought that adult ADHD clinics were necessary for the very reason that knowledge among general psychiatrists is patchy. Currently, adults with suspected ADHD may be treated in a specialist adult ADHD clinic or general adult psychiatric service depending on where they live in the country. Previous research has recommended that specialist adult ADHD clinics be developed.[78]

Teachers

Teachers also play a critical role in enabling children to receive a diagnosis and support. Problems resulting from ADHD may first become apparent in a classroom setting. Ford et al found that when they have concerns about their child nearly half (46 per cent) of all parents of children with ADHD tend to approach teachers first, followed by a GP (33 per cent).[79] Similarly, Sayal, Ford and Goodman found that in 2004 parents of three-quarters of children with ADHD had been in contact with education-based professionals in the previous year about their concerns, with a lower proportion in contact with mental health services.[80] As outlined in chapter 1, the role of schools in tackling mental health problems is becoming an increasing focus of policy.

Nevertheless, a substantial body of evidence finds that knowledge about ADHD among teachers is poor, which is not surprising as understanding is lacking even among healthcare professionals. In a recent ComRes survey of primary and secondary school teachers in the UK, 1 in 5 did not agree that ADHD is a mental health condition. Many did not recognise symptoms of ADHD, including impulsive behaviour (41 per cent failed to recognise) and difficulty with organisation (74 per cent).[81] One of our expert interviewees said that he thought that one of the two things that would make the biggest difference to reducing the impact of the condition would be better understanding of ADHD, and discussed this particularly in relation to schools:

> *As long as stigma is about then it's going to be a massive barrier to children getting access to services, or even people accepting that they might have a condition that needs accessing. School awareness is a massive issue, and I still think it's very, very patchy in relation to ADHD, particularly in relation to the inattentive ADHD, which is missed a hell of a lot.*

Previous research has suggested that teachers particularly lack knowledge of the most appropriate forms of treatment and management of ADHD. For example, in a study of primary school teachers in the UK, Moldavsky and Sayal found that teachers considered medication a 'last resort'.[82] Although this overlaps partially with NICE guidelines, which dictate that severity should be taken into account when deciding treatment, some teachers expressed a view that medication should never be used to treat ADHD. Furthermore, in the ComRes survey, 23 per cent of teachers said they would not refer a child they suspected of having ADHD to a healthcare professional.[83] This is worrying given findings from Ohan et al, which suggest that teachers with greater knowledge of the condition were more likely to acknowledge the need for help from other professionals to support a child with ADHD, while those with less knowledge of the condition were more likely to say they could handle the student's problems on their own.[84] Teachers with poor knowledge of ADHD who take the opposite approach and refer too hastily can also create problems: one of our expert interviewees told us that in some areas, vast numbers of children were being referred for suspected ADHD when they did not have the condition, thus creating unnecessary costs to the NHS.

In 2018, a new core content framework for ITT will take effect.[85] For the first time, it will be a compulsory part of ITT courses for trainee teachers to be taught how to support pupils with SEND. It is hoped that this may lead to an improvement in teachers' understanding of SEND, but whether their knowledge of ADHD in particular will improve remains to be seen.

Parents

Parents clearly have an important role in diagnosing and managing ADHD. The process of receiving a diagnosis can be much quicker if parents recognise the signs of ADHD, proactively raise their concerns with professionals, and push for a referral to secondary services if necessary. Indeed, with mental health services under such strain, with high thresholds for accessing care and increased rationing, it can often be necessary for parents to battle for their child to be assessed and to be given the support they need, possibly putting those with more social capital and resources at an advantage.

The important role of parents is recognised in the research. In contrast to previous studies, which suggested that the primary barrier to diagnosis of ADHD was lack of GP recognition, in a study using an epidemiological sample of children with ADHD, Sayal et al found that the main problem was parents not consulting their GP about their concerns, even when they realised there was a problem.[86] This was at least partly a result of poor ADHD awareness among parents: although the majority realised

that there was a problem, many did not construe their child's behaviour as hyperactivity, often thinking instead that she or he had a learning difficulty. Only one-third of children with ADHD in this study had accessed specialist services.

Parents may also wait (or never) flag their concerns with professionals on the basis of the stigma associated with the condition. The fact that people tend to believe that ADHD is a result of bad parenting may lead them to blame themselves for their child's problems, which may in turn make them reluctant to raise their concerns with a teacher or GP. Indeed, a science journalist we spoke to said that parents of children with an ADHD diagnosis were often reluctant to take part in TV or radio programmes about the condition as they had kept the condition a secret, as they were worried about what their friends or family would think about them or their child. Furthermore, the problems their child experiences may present outwardly as annoyances or minor impairments rather than major challenges, thus leading the parent to the view that they are not serious enough to raise with a professional. These factors may explain why Ford et al found that although half of parents reported discussing their concerns with a professional within six months of first becoming worried about their child, some waited several years to do so.[87]

Priorities for better understanding and awareness

This chapter has demonstrated that poor understanding and awareness of ADHD remains a significant problem. Lack of knowledge of ADHD impedes early diagnosis of the condition, and it also makes effective management of symptoms more difficult – ADHD is a complex condition and successful management requires different agencies and parents to work together, a process which can be frustrated if there is no agreed plan of action. Thus, poor understanding prevents children from being properly identified and supported, which represents a missed opportunity to reduce the socioeconomic impacts outlined in the previous chapter.

There is a clear need to increase understanding among those in a best position to identify or support ADHD, including teachers, healthcare professionals and parents. But the need to improve understanding among the general public should not be underestimated. The lack of an accurate public dialogue about ADHD may fuel lack of understanding among teachers, healthcare professionals and parents, and those who are diagnosed may disengage from services if they experience high levels of stigma or bullying.

6 PERSONAL STORIES FROM PEOPLE DIAGNOSED WITH ADHD IN ADULTHOOD

This chapter tells the stories of five people's experiences of living with undiagnosed ADHD and the difference made by diagnosis, drawing on our interviews with people diagnosed with the condition later in life. Together these stories illustrate the wide range of impacts described in chapter 4. They demonstrate that ADHD can affect people from all backgrounds and the way in which it presents can vary enormously – something which must be taken into account when identifying and supporting people with the condition.

Ben's story

Ben is 40 years old lives in the South West of England with his wife. He is currently working on his PhD and teaching part time at the university. He was diagnosed with inattentive type ADHD at around the age of 36.

Throughout his life, Ben has found it difficult to cope with normal, everyday things like housework, keeping track of his commitments, and general administration like paying bills. In order to cope with these tasks, he developed a number of strategies such as blocking out large chunks of time to do them, to compensate for the time he would lose through procrastination. However, when he got married these coping strategies caused friction as his and his wife's schedules became linked and his chronic procrastination began to more heavily impact on her. It also made his ADHD become more obvious. Other relationships also suffered for Ben before his diagnosis – he used to see himself as someone who could not be relied on, which made him reluctant to meet new people and foster long-lasting friendships. Furthermore, although Ben has achieved a high level of education, it has been an enormous struggle at times. Poor time management has made it difficult for Ben to work towards and meet deadlines, and he has had a tendency to focus intently on a small number of assignments instead of devoting equal attention to all aspects of his course.

The initial teething problems experienced in his marriage were one factor among several which led Ben to try and get to the bottom of why he faced certain challenges in life. He had not considered ADHD before, associating it with hyperactivity, which is a problem Ben had not experienced – he was always reading books and watching films without feeling restless. However, he found out about ADHD online and aspects of what he read resonated with his own experiences, which led him to talk to his GP about his concerns. As it happens, an adult ADHD clinic was being set up in his area at the time. His GP referred him to that clinic and he was diagnosed relatively quickly.

Once he had the diagnosis, Ben felt relieved as it gave him the explanation he had been looking for, but was only offered medication rather than a combination of medication and therapy. He found that the medication helped, but he thinks that therapy would have been very valuable in helping him to come to terms with the huge impact that undiagnosed ADHD has had on his confidence, self-esteem and self-identity. Furthermore, Ben is currently not taking medication and has no plans to begin taking it again, as he had problems with taking the correct dose and it interacted badly with other medication he was on, so he is currently receiving no treatment. He says he would 'jump at the chance of therapy'.

When he first got the diagnosis, Ben's mother refused to believe that he had the condition, saying that she would have realised if there was a problem. Other members of his family have been more supportive. Indeed, Ben believes that ADHD is widely spread within his family. One of his brothers was diagnosed in adulthood, and others in his family recognise the symptoms in themselves without having a diagnosis, so there is a certain level of understanding between those within the family who are affected by the condition.

Emma's story

Emma is 49; she is single and lives alone in the Yorkshire. She was diagnosed with combined type ADHD five or six years ago and began taking medication. More recently she was referred to a psychologist, who she now sees regularly.

Emma first started to struggle with her ADHD in secondary school, as she found the number of people and size of the environment too much too deal with, and constantly having to move between classrooms made it hard to settle to things. This contributed to her becoming very depressed; she started skipping school from the age of 14, even though until that point she had been top of her class in almost every subject. She went to university later in life as a mature student, but struggled to look after herself, becoming so exhausted that she was unable to continue and consequently dropped out. Her debilitating fatigue was later diagnosed as Myalgic Encephalomyelitis (ME).

Emma describes her life before diagnosis as 'horrible' and 'very very hard work'. One of the worst things for her was not knowing why she found basic tasks such as washing and dressing so difficult, when others seemed to deal with them as a matter of course. Her relationships with people close to her have also suffered – given that just managing the basics of life is so difficult for Emma, keeping in touch with people who are not in her immediate environment rarely makes the top of her 'to do'

list. Emma also suffers from a recurrent depressive illness. Although she eventually recovered from ME, she believes that untreated ADHD was the root cause of her physical illness and a major factor in perpetuating her depressive illness, as well as being an impediment to effective treatment.

Emma approached her GP after reading about ADHD and recognising the condition. A local psychiatrist appeared to be uninterested in the condition so she paid to go private in order to get a formal diagnosis and support. Medication has helped her to feel less exhausted and balance out her emotions, but she says that psychological support has been crucial too in helping her to develop more effective coping strategies. Nevertheless, Emma has found the process of coming to terms with ADHD painful – she was in floods of tears when she first read about the condition and recognised it in herself, and is grieving for a life that might have been different.

Emma is unemployed at the moment. She thinks that people with ADHD can be very valuable for employers when given the right support as they can be very creative, wholehearted, focused and committed. As the modern world is so busy and complicated, with a relentless stream of choices and decisions to be made, and multiple stimuli competing for attention, the skills that people with ADHD develop in order to cope can be very useful for wider society. However, employment has been challenging for Emma and has led repeatedly to breakdowns in her physical and mental health from a combination of ongoing difficulties in dealing with the 'nuts and bolts' of everyday life, and a tendency to become obsessively hyperfocused and unable to disengage from work projects. Having received proper support, she is hopeful that she will soon return to work – a prospect that excites her, and seemed unimaginable several years ago.

Emma feels that things might have been different had she been diagnosed with ADHD earlier. She thinks that had she received support at an earlier stage, she would have found it easier to learn the skills needed to manage her condition. She is concerned that children with ADHD today are still being missed – particularly those who were not disruptive at school, as she was not – and that opportunities are lost because of ignorance and inaccurate assumptions about people with ADHD.

Jason's story

Jason is 24 years old and lives with his partner in North East England. He was diagnosed with combined type ADHD around the same time he applied for university.

Because of his condition, Jason finds that he gets distracted from things quite easily. Growing up, he felt that he was always being kicked out or dropping out of things and that he could never finish a project. Daily annoyances have been a theme throughout his life, such as being late because of forgetting his keys and having to go back for them. These experiences damaged Jason's self-esteem, and he felt frustrated that he could not function in the way that other people did.

Diagnosis made a big difference in boosting Jason's confidence and giving him insight into the causes of the problems he experiences, but the support that followed has been inadequate. After the diagnosis, Jason was attending an ADHD clinic and started to take medication, which initially had a positive impact on his speech (which had previously been difficult for others to follow on occasion) and his sleeping patterns, but he found that the positive effects began to wear off over time. The clinic Jason attended had no occupational therapist to help him with practical coping mechanisms so when the effects of his medication were subsiding the clinic could not be of any further help to Jason, and he was discharged.

Jason experienced challenges throughout his education – he had to resit his GCSEs, and although his mother persuaded him to go to sixth form he later dropped out. He was eventually able to apply to university, and was determined to do well to prove to himself that he could break the cycle of not finishing projects, but did not receive the support he needed to cope with the workload. After starting in September, he only received his Disability Student Allowance in March, by which point he was inundated with work that he could not complete. It was agreed that Jason would resit the year, and although more support was put in place it still was not enough – he was given a mentor, but the mentor did not know how to assist someone with ADHD, and Jason found staff at the disability department were unhelpful too, so he had to resit the year again. He has still not been able to complete the first year and is worried he will soon be kicked out of university, so he is looking for work.

Jason feels lucky that he has a partner and friends who are very supportive of him. Growing up, his mother was sometimes irritated when Jason was late or forgot to do something, but the ADHD diagnosis has helped her to understand Jason's behaviour and she is now another important source of support.

Jenny's story

Jenny is 36 years old and lives in London, with her two children. She is not currently in paid employment, but volunteers at her local Citizens Advice

during school hours. She was diagnosed with combined type ADHD at the age of 31, following her son's diagnosis with the condition.

As a child, Jenny found it difficult to be in a noisy, busy classroom and was unable to concentrate. She felt alienated by her teachers, who frequently told her off, which led to her skipping school. This created a vicious cycle, as the more she skipped school, the further behind she got, which made her want to miss more school. Her problems at school also led to conflict with her family, who wanted her to do well in her education. As a result, Jenny left home at 16 and although she started college, she dropped out within a few months.

Before diagnosis and treatment, Jenny experienced great difficulty sleeping, acted aggressively and cried impulsively. She believes that her condition played a part in prolonging an abusive relationship she experienced in early adulthood. When Jenny thinks back to her life before diagnosis, the clearest feeling she recalls is rejection.

Jenny's 17-year-old son has also been diagnosed with ADHD. She first began to think she might have ADHD after her son was diagnosed and she recognised some of the symptoms in herself. Having been previously diagnosed with depression, the GP and Access Team were reluctant to consider the idea that Jenny might have ADHD. She contacted her adult ADHD clinic directly and staff helped her get an appointment. Despite the stress and frustration involved in the process of getting a diagnosis, she feels that the diagnosis has helped her to better understand the challenges she has faced in life.

Jenny previously worked in a bar. Her boss was an old friend and was supportive, and Jenny enjoyed interacting with customers. She is unable to do paid work at the moment as she is focusing on her family, but she started to volunteer at her local Citizens Advice five years ago. She started her training for Citizens Advice before diagnosis and was initially struggling with being organised, focusing and communicating effectively with people – all essential requirements of the job. But medication has enabled her to be very successful and she is now a supervisor. Her own supervisor has also been very helpful in making appropriate adjustments for Jenny, such as providing her with her own room to write up her reports and adjusting her schedule so she can write up all her reports in one go, rather than throughout the day. Volunteering has been a wonderful experience – it has made Jenny feel a valued part of a team, intelligent and capable, and has given her a sense of purpose.

Jenny is concerned that her son is already suffering as a result of the condition. Despite Jenny giving his school information about how to manage her son's behaviour, he was repeatedly given fixed term exclusions, which seriously disrupted her son's education and their family

life. He started college but later dropped out, and Jenny expects he will soon start claiming Employment and Support Allowance. She is worried that not being in work and being away from his peers will make him feel low. She feels strongly that the government has a lot of work to do to ensure that people with ADHD and mental health problems receive better support.

Harry's story

Harry is 47 years old and lives in East of England with his partner and two young children. He is currently in full-time employment and has been working as a data analyst at the same company for the last ten years.

Harry was diagnosed with ADHD at 43 years old and remembers life before diagnosis as largely confusing and disappointing. Like many of those with ADHD, he knew something was not quite right; he knew he was perfectly adept but found himself struggling to achieve what others seemed to achieve so easily. Before his diagnosis, Harry worked as a temp in many different roles, most of which he believes were insufficiently challenging. He believes that before he knew he had ADHD, his lack of confidence and organisation contributed to the stagnation of his career. Even in his current workplace, Harry believes that lasting impacts of ADHD have halted the advancement of his career – he finds it difficult to comprehend a future beyond the 'here and now' and to understand the 'rules' of career progression. This has contributed towards the sense of disappointment Harry feels, as he believes he is not fulfilling his true potential. Fortunately, Harry's manager knows about his ADHD and offers support where possible, but Harry does not trust anyone else in the company enough to inform them about his condition.

Although his formal diagnosis is that he primarily has inattentive type ADHD, Harry believes he also has a tendency to act impulsively, pointing to his snap decision to uproot his life by moving from New Zealand to the UK as evidence of this. He is now in a long-term relationship, but previously had trouble finding, and holding down, a relationship. His impulsivity makes him susceptible to making unwise comments in inappropriate situations; Harry openly admits that previous partners found his behaviour 'annoying'. He believes that his inability to focus on important conversations also affected his relationships with friends and romantic partners. Again, Harry refers to an inability to understand the 'rules' or norms of relationships.

Harry sought diagnosis after the birth of his first child. He had expected that this event would enable him to focus and finally begin to see the future beyond the immediate here and now, but disappointingly for Harry this did not happen. After reading about the condition, Harry

completed a quick online test for ADHD, which suggested to him that ADHD might be the cause of his problem, and he subsequently visited his GP. His GP was very helpful in helping get Harry a referral to the Maudsley Hospital in South London, where he was diagnosed.

Harry's experience of diagnosis was mixed, and he likens it to the stages of grieving; while initially feeling angry and sad about a 'life lost' because of missed diagnosis, Harry eventually felt relief and a sense of validation. Although he was diagnosed at the Maudsley, he was referred back to GP for treatment, who put Harry on a course of cognitive behaviour therapy for low mood with a non-ADHD specialist, which did not get at the core of the problem. He was later referred to an adult ADHD clinic where he was prescribed medication.

Since his diagnosis, and subsequent prescription of medication, Harry finds it much easier to choose where his focus should be. It has also helped him and his partner understand why he is sometimes forgetful, inattentive and clumsy. The medication Harry takes has particularly helped his concentration at work, but only in the short term – he still feels unable to comprehend the future fully. Harry believes that therapy might help now alongside the medication, but it is unavailable to him through the NHS. He is considering going private to access therapy now that his children are out of nursery and the family has more disposable income.

7 CONCLUSIONS AND RECOMMENDATIONS

People with ADHD can be creative, energetic and dynamic. The traits associated with the condition can enable someone to draw links between supposedly disconnected ideas, dedicate themselves to a project 100 per cent, and be willing to try new things and break from tradition. But as things stand, too many people with the condition are going through life without receiving the diagnosis or support they need be happy and fulfilled, and to make the most of their talents. Many people with ADHD suffer immensely in all areas of their lives, including education, work and relationships. In addition to losing out on a personal level, this report has shown that the challenges they face have serious implications for other people in their social networks, along with wider society and the public purse. The evidence base is small thus far, but early estimates suggest that the costs of ADHD for the economy run into billions of pounds.

Reducing the socioeconomic burden of ADHD will be a complex task. It has only recently been recognised that the condition persists into adulthood, and researchers are early in the process of identifying how the costs of the condition might be reduced. Although the evidence base is small, it is highly plausible that the costs of ADHD are lowest for those diagnosed in childhood, higher for those diagnosed later in life as adults, and highest for those who never receive a diagnosis. If this is true, then there is an urgent need for early identification and intervention of ADHD. Further research is needed to strengthen the case for the significant levels of public investment this would require.

However, for moral as well as economic reasons, policy-makers and practitioners cannot wait for further evidence to be gathered – action must be taken now, and the green paper provides an important opportunity for the government to lead the charge.[88] It is clear that too many people with ADHD are suffering greatly as a result of the condition. It is critical that policy-makers recognise this, and that costs are experienced by not only individuals but the whole of society, and to devise a convincing and transformative strategy to ensure that people with ADHD are left behind no longer, using the green paper as a spring board. This will be an issue for not just the NHS, but all public services that have a role to play in helping people with ADHD to manage the effects of their condition, harness the elements that might be helpful and ultimately succeed in life. And none of this can be done without better understanding and awareness of the condition – not just among teachers, parents and healthcare professionals, but the general public too. Recognising where things are going wrong and leading change will

be an incredible challenge, but this research shows that it is one which we cannot shrink from.

Below we outline a series of recommendations for policy, practice and research.

Recommendations for research

The government should work with people with ADHD and the media to develop an awareness-raising campaign, aiming to make ADHD visible to a wider audience and promote better public understanding of the condition

It is likely that the socioeconomic burden of ADHD could be lessened if those with the condition were identified at an earlier age and given appropriate support. However, efforts to facilitate early diagnosis are hampered by poor understanding and awareness of the condition, which make parents, teachers, GPs, adults with the condition and others less likely to recognise the signs of ADHD and to work together to ensure that people receive the support they need.

ADHD is one of the most common disorders of childhood and adolescence, yet it is almost invisible in print and broadcast media. Presentations of ADHD in the media often revolve around the question of whether or not it exists, or whether it is being over-diagnosed, and provide few illustrations of what ADHD looks like and how it affects people – with Rory Bremner's documentary on *Horizon* a notable exception.

The government should work with media organisations, supporting them to fulfil their responsible reporting duties by giving the condition greater prominence by creating authentic, accurate output on the subject. This should involve working with people with ADHD themselves to ensure that content is accurate and conveys the diverse range of ways in which ADHD can manifest and affect people's lives. The government could draw on lessons learned from working with employers on the Disability Confident campaign to identify how best they are placed to support the media in developing the campaign.

Mental Health First Aid should develop its government-sponsored schools programme to include advice on ADHD

In 2017 the government announced that every secondary school would receive mental health first aid training, provided by MHFA, later extending this pledge to primary schools in the 2017 Conservative manifesto and children's mental health green paper.[89] Mental health first aid training equips people with the skills to spot the signs of mental health

symptoms, offer initial help and signpost the person to support. Over £200,000 will be spent providing mental health first aid training to teachers in 2017/18.[90]

In keeping with other mental health first aid training courses provided by MHFA and others, the existing programme for schools focuses on depression and anxiety, suicide and psychosis, self-harm and eating disorders,[91] and lacks a specific focus on ADHD. This is likely because these problems are considered more severe than ADHD – the same rationale explaining why some CAMHS do not provide services to children with ADHD. Yet our research suggests that ADHD can have a profound impact on children's wellbeing, educational outcomes and long-term success in life, and that early intervention could potentially make a significant difference. Furthermore, ADHD is one of the most common disorders of childhood and adolescence, the signs often first present in the classroom, and teachers are normally the first port of call for concerned parents. It seems a missed opportunity for the MHFA programme for schools not to include ADHD. Teachers trained in mental health first aid could pay particular attention to pupils at risk of being excluded or moved into alternative provision, triggering a health assessment for possible ADHD where they believe this might be the root cause of the problem.

As recognised in the green paper, more needs to be done to ensure that MHFA-trained teachers are able to refresh their knowledge.[92] The government should fund refresher training and incorporate an ADHD component for those teachers who have already attended a MHFA training programme in which ADHD was not a specific focus.

Initial teacher training providers should clearly focus on supporting children with ADHD in their programmes, in meeting the new requirement for SEND training to form a core part of all ITT courses from 2018

Aside from helping to identify children with undiagnosed ADHD and helping those experiencing clear challenges through mental health first aid training, teachers have a role to play in supporting children with ADHD to achieve their potential in education. A good education puts children with ADHD in a better position to succeed in later life, preventing the cycle of failure that so many of our research participants discussed from developing.

The new core content framework for ITT, which will be effective from later in 2018, stipulates for the first time that supporting children with SEND must be a core part of all ITT courses.[93] It states that providers should ensure that trainees understand the principles of the SEND code of practice, are

confident working with the four broad areas of need it identifies, and are able to adapt teaching strategies to ensure that pupils with SEND can access and progress within the curriculum – including ADHD. The recent green paper suggests that the framework is beginning to influence ITT course content, but the framework does not stipulate which SEND should be included in courses.[94]

There is a strong case for including a clear focus on ADHD in the SEND component of ITT as it is so common among children and adolescents, and symptoms first become apparent in the classroom setting. Thus ITT represents an opportunity for all new teachers to be equipped with the knowledge of ADHD they need to help identify and support children with the condition, if there is a strong enough focus on it.

NHS England should work with CCGs to ensure that they prioritise data collection and use as part of a drive to improve their commissioning of health services for people with ADHD

The structure and quality of health services for people with ADHD vary across the country, creating a postcode lottery. For example, in some areas there are specialist ADHD clinics for adults with the condition and in others there are not, while children may be seen through CAMHS or paediatric services. Furthermore, people with ADHD report wide variation in the quality of services they receive, and in the quality of transition from child to adult services.

Part of the problem is a lack of data. Commissioners are often ill-equipped to understand demand for ADHD services in their area because they lack population data. Moreover, the different outcomes associated with different service delivery models are not well understood, so commissioners have insufficient knowledge of how best to structure services to enable people with ADHD to achieve the best outcomes possible.

More academic research is needed to enhance the evidence base around which service delivery models produce the best outcomes for people with ADHD – something we discuss below. But commissioners also have a role to play in focusing attention and resources on understanding demand for ADHD services in their area, and in measuring the quality of care associated with their services, in order to ensure they have the data they need to plan ADHD services effectively. NHS England should instruct and support commissioners to make these activities a priority.

Health professionals treating children and young people with ADHD should work with other professionals (such as the proposed

designated senior leads for mental health in schools) to create transition plans ahead of key changes in the individual's life

The challenges of transition periods was a recurring theme in our interviews with experts and people with ADHD. In particular, many people with ADHD are not properly supported to cope with the transition from child to adult psychiatric services, often seeing their support reduced in this process through a lack of adult services and waiting lists for those that do exist.

Demos supports the call of the campaign Born to Be ADHD for multi-disciplinary plans to be created to help children and young people through key transition points.[95] More specifically, ahead of the transition from child to adult psychiatric services, health professionals should create a transition plan, outlining how the process will work, which can be shared with the individual, so they are more prepared for the move and to ensure they have continued access to support. The plan should also outline how the health professionals involved will work with other services to help make the individual's wider transition to adult life as seamless as possible. For example, some of the people we spoke to experienced significant challenges for the first time when they went to university. Thus health professionals could outline in the plan how they will work with the university disability department to help ensure that individuals have the support they need before starting their studies (eg by providing the medical evidence needed to support their application for support, helping to outline what support they need, etc.). The new designated senior leads for mental health proposed in the green paper should also feed into transition plans, especially when a pupil moves from primary to secondary school, and from school to college or university.[96]

DWP work coaches and employers should signpost people with ADHD to Access to Work

Research suggests that the single biggest component of the economic burden of ADHD is reduced employment. People with ADHD often face challenges in finding, staying in and progressing in work, resulting in reduced wage income, less disposable income for the individual, and reduced tax returns to the state – along with higher welfare benefit costs.

Support is available to people with ADHD who are preparing to start employment or already in employment through Access to Work, a publicly funded employment support programme that provides grants to disabled people and those with long-term health conditions so they can pay for practical support. The scheme can be used by people with ADHD to help pay for support such as ADHD coaching (specialist support

which helps people with ADHD to develop strategies to manage their condition and succeed in life, including in employment).

Access to Work has been praised as a world class labour market intervention, and it has been suggested that the benefits of the scheme far outweigh the costs,[97] but research has consistently shown that awareness of Access to Work is low among those who could qualify for support, along with employers.[98] Mind has criticised the scheme for being particularly inaccessible to people with mental health conditions,[99] so people with ADHD are at risk of missing out on support – especially given poor public understanding of the condition. DWP work coaches and employers should signpost people with ADHD to Access to Work to ensure that they receive any support they are eligible for.

Recommendations for research

In chapter 2 we demonstrated that the evidence on the socioeconomic burden of ADHD suffers from a number of limitations. Below we make four recommendations for work that should be prioritised by researchers and research funders.

Explore the difference made by early access to diagnosis and treatment to the long-term outcomes and costs of people with ADHD

Our desk research and qualitative evidence suggest that early intervention in childhood is effective in helping children with ADHD to achieve better outcomes as adults, helping them to manage their condition and prevent problems from escalating. Yet access to formal diagnosis and treatment for children with ADHD is currently restricted.

Improving services so that all people with ADHD are able to get a diagnosis and treatment would require significant investment. There is a critical need for a full and robust evidence base demonstrating the long-term cost savings that would result from greater access to care, if policy-makers are to be persuaded to provide this investment. But as things stand the formal evidence base is lacking. Few studies aim to monetise the costs of ADHD. Even those that do tend to focus on the incremental costs involved in providing services to those who access care, rather than compare costs and outcomes for people with ADHD who receive diagnosis and treatment and those who do not. Research is needed that draws out the difference in costs and outcomes between people diagnosed and treated and people who do not receive diagnosis or treatment (or, more realistically from a research point of view, who only received this much later in life).

Compare outcomes for adults with ADHD treated in general psychiatric clinics with outcomes for those treated in adult ADHD clinics

Most children with ADHD continue to experience symptoms and impairment in adulthood, creating a need for adult psychiatric services capable of managing the condition (and diagnosing those whose ADHD is missed in childhood). Evidence so far suggests that the socioeconomic burden of the condition is greater in adulthood than childhood, owing to the significant impact of lack of employment. It is therefore vital for there to be an accurate understanding of the best ways of identifying and managing the condition in adults, if the costs associated with the condition are to be reduced.

At the moment, care for adults with ADHD is provided through general adult psychiatric services or specialist adult ADHD clinics depending on where in the country an individual lives. Two of the experts we spoke to made a strong case for establishing specialist adult ADHD clinics, arguing that as things stand staff in general psychiatric services do not have sufficient knowledge of ADHD to manage these cases. Support for adult ADHD clinics is also evident in the literature.[100] Yet we found little research evidence exploring which pathway produces better outcomes for adults with ADHD. Setting up a new adult ADHD clinic is challenging – it requires existing funds to be diverted or new funds to be identified, agreement on a service model that meets local or regional needs, and training of clinicians including psychiatrists, nurses and pharmacists.[101] If the early evidence around the value of specialist adult ADHD clinics is correct, the sector would benefit from fuller research demonstrating this, in order to justify and encourage more of them to be established because of the better outcomes and cost savings they could deliver.

Explore under-researched social and economic impacts of ADHD

It is frequently recognised in existing research on the socioeconomic burden of ADHD that some areas of impact have not been adequately explored. In particular, the costs of substance abuse, crime and traffic accidents are rarely accounted for in work that monetises the impact of ADHD, despite there being substantial evidence that people with ADHD have an increased likelihood of experiencing these problems. Unless the personal and social costs resulting from these problems are accounted for, the research community (and policy-makers by extension) are at risk of underestimating the scale of the burden associated with ADHD, thereby undermining the case for greater investment. It should therefore be a research priority for there to be a greater focus on exploring these specific impacts and costs. Furthermore, given the number of ways in which ADHD affects people's lives, there should be further work to

identify whether additional social and economic impacts of the condition are being missed.

Separate the impacts of ADHD from the impacts of other psychiatric conditions that frequently co-occur with ADHD

People with ADHD frequently suffer from psychiatric comorbidities, such as depression, anxiety, conduct disorder and substance abuse. In exploring the long-term impacts of ADHD, it is crucial to take comorbidities into account. If impacts that are primarily a result of other conditions are being attributed to ADHD then the socioeconomic burden of ADHD could be overestimated. Conversely, the burden of ADHD could be underestimated if the condition is ignored, with the significance of conditions that appear more severe on the surface (such as depression) being exaggerated.

The extent to which previous work on the impacts of ADHD controls for comorbidities, and how it does so, varies. As a result, some of the most frequently cited cost estimates of the disease have not been able to separate fully the effects of ADHD from the effects of other conditions. For example, Doshi et al used a systematic review of existing research to produce their cost estimates, but most of these studies did not control for comorbidities.[102] If we are to grasp the long-term impacts of ADHD fully, more work needs to be done to disentangle the effects of ADHD from the effects of other conditions – a complex but urgent task.

APPENDIX RAPID EVIDENCE ASSESSMENT – METHODOLOGY

Demos follows the government's Magenta Book guidance on conducting evidence assessments and systematic reviews.[103] This REA, therefore, follows the core principles of a systematic review, undertaking a structured and comprehensive search strategy, screening on relevance and quality grounds, and thorough data extraction of selected material. However, being an REA rather than a full systematic review, we take a light touch approach in the range of databases and sources searched, and the level of detail recorded by the data extraction process – in line with the guidance in the Magenta Book, so 'conclusions may be subject to revision if [a] more systematic and comprehensive review of the evidence is subsequently completed'.[104]

Search strategy

The REA aimed to review the current evidence base on the socioeconomic impact of diagnosed and undiagnosed ADHD. The review also included studies of the socioeconomic impact of other related conditions which are undiagnosed (see the section 'Inclusion and exclusion criteria' below).

To develop our search terms, Demos drew on an initial scoping review, which identified the potential lifetime costs of ADHD to the individual and society, and the condition's impact on specific outcome areas, including education, employment, health, relationships, substance abuse and criminality. The scoping review also identified related conditions to be included in the search for the impact of undiagnosed conditions, including anxiety, autism, depression, conduct disorder and obsessive compulsive disorder, along with SEN.

Demos researchers conducted an initial trial of search terms based on this scoping review to refine terms and test accuracy and relevance. This initial testing was also used to assess the relevance of four databases: PubMed, PyscINFO (EBSCO), NHS Economic Evaluation Database and Social Sciences Citation Index. Following several iterations of testing, a final set of search terms was established and these were applied to the identified databases on 6 September 2017. Two searches were run in each database, one looking for relevant literature on the socioeconomic impact of ADHD, the other looking for studies on the socioeconomic impact of undiagnosed conditions. Our search terms are set out in figures 1 and 2.

Figure 1 Search terms for socioeconomic impact of ADHD

(TI ('attention deficit hyperactivity disorder' OR 'ADHD' OR 'attention deficit disorder' OR 'ADD' OR 'hyperkinetic disorder')) AND
(TI ('cost-benefit' OR 'cost*' OR 'consequences' OR 'impact' OR 'burden' OR 'outcomes' OR 'quality of life')) AND
(TI/AB ('socioeconomic' OR 'economic' OR 'lifetime' OR 'society' OR 'education*' OR 'academic' OR 'school' OR 'detention' OR 'expulsion' OR 'employ*' OR 'work*' OR 'job' OR 'health' OR 'comorbid*' OR 'illness' OR 'healthcare' OR 'care' OR 'drug abuse' OR 'substance abuse' OR 'alcohol*' OR 'addict*' OR 'relations*' OR 'friend*' OR 'isolat*' OR 'marriage' OR 'divorce' OR 'criminal*' OR 'offend*' OR 'convict*'))
TI=Title; AB=Abstract

Figure 2 Search terms for socioeconomic impact of undiagnosed conditions related to ADHD

('anxiety' OR 'autism' OR 'depression' OR 'special educational needs' OR 'SEN' OR 'conduct disorder' OR 'obsessive compulsive disorder' OR 'OCD' OR 'attention deficit hyperactivity disorder' OR 'ADHD' OR 'attention deficit disorder' OR 'hyperkinetic disorder') AND
('undiagnosed' OR 'untreated' OR 'non-treatment') AND
('cost-benefit' OR 'cost*' OR 'consequences' OR 'impact' OR 'burden' OR 'outcomes' OR 'quality of life') AND
('socioeconomic' OR 'economic' OR 'lifetime' OR 'society' OR 'education*' OR 'academic' OR 'school' OR 'detention' OR 'expulsion' OR 'employ*' OR 'work*' OR 'job' OR 'health' OR 'comorbid*' OR 'illness' OR 'healthcare' OR 'care' OR 'drug abuse' OR 'substance abuse' OR 'alcohol*' OR 'addict*' OR 'relations*' OR 'friend*' OR 'isolat*' OR 'marriage' OR 'divorce' OR 'criminal*' OR 'offend*' OR 'convict*')
TI=Title; AB=Abstract

In addition to the search of databases, researchers also searched for 'grey literature' and any academic studies not included in the selected databases. This was done using Google Scholar on 6 September 2017, with the search terms listed in table 4.

Figure 3 Search terms for Google Scholar search

'attention deficit hyperactivity disorder' *OR* 'ADHD' cost*
'attention deficit hyperactivity disorder' *OR* 'ADHD' consequences
'attention deficit hyperactivity disorder' *OR* 'ADHD' impact
'attention deficit hyperactivity disorder' *OR* 'ADHD' burden
'attention deficit hyperactivity disorder' *OR* 'ADHD' undiagnosed
'attention deficit hyperactivity disorder' *OR* 'ADHD' lifetime
'attention deficit hyperactivity disorder' *OR* 'ADHD' academic
'attention deficit hyperactivity disorder' *OR* 'ADHD' crime
'attention deficit hyperactivity disorder' *OR* 'ADHD' employment

Inclusion and exclusion criteria

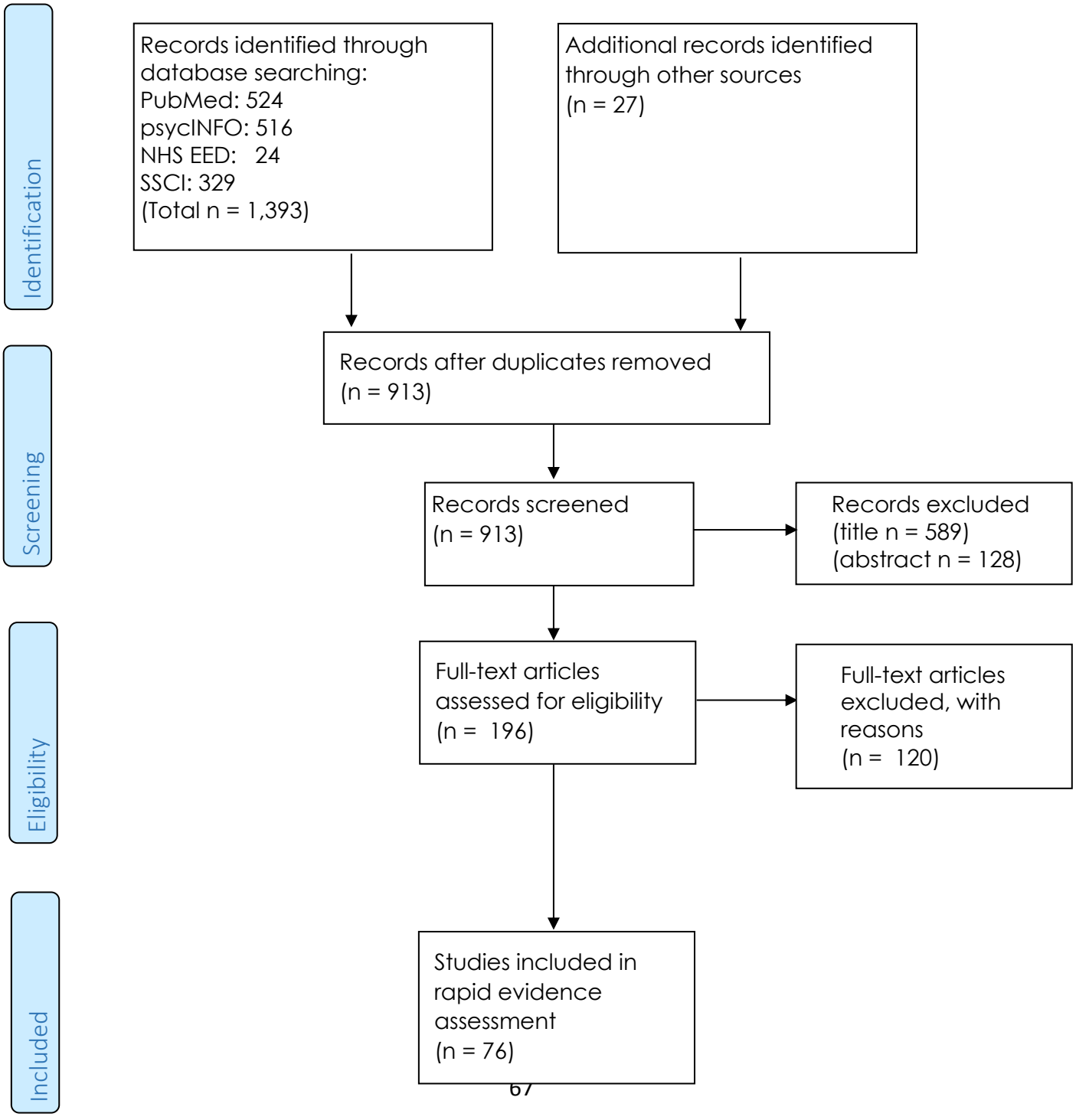
Any studies not in the English language were excluded, as were studies published before 2007 (although this cut off point was extended to 2004 for particularly relevant studies).

Quality criteria were applied on the basis of topic relevance and study design. The following studies were included:

- those related to the socioeconomic impact of diagnosed and undiagnosed ADHD
- meta-analyses and existing systematic reviews of relevant literature
- evaluations of interventions and initiatives relevant to this area which were sufficiently credible and relevant to the scope of research
- grey literature including policy reports and good practice reviews published by charities and other NGOs
- wider studies on the impact of other undiagnosed conditions

Figure 4 PRISMA 2009 flow diagram

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) is an evidence-based minimum set of items for reporting in systematic reviews and meta-analyses. The PRISMA 2009 flow diagram shown in figure 4 depicts the flow of information through the different phases of our REA.



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