ADHD: improving visibility in adults

An overview of the societal impact of attention-deficit hyperactivity disorder (ADHD) in adulthood, with consideration of opportunities to improve recognition and management
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This document has been developed by Shire to inform policy makers and other relevant stakeholders about the personal and societal impact of attention-deficit hyperactivity disorder (ADHD) in adulthood. Importantly, the document aims to raise awareness of potential opportunities to improve recognition and management of the disorder.

Chapter 1: Overview of adult ADHD

• ADHD can occur throughout the lifespan and often persists into adulthood\(^4\); in fact, ADHD affects about 1 in 30 adults worldwide.\(^4\)

• Adults with ADHD have symptoms of inattention and/or hyperactivity-impulsivity, which have a negative impact on social, academic and/or occupational aspects of their lives.\(^5\)
  – Symptoms can evolve over time; for example, physical signs of hyperactivity in childhood often become less obvious in adulthood, while restlessness, inattention and impulsivity may persist.\(^5\)
  – Many adults with ADHD also have other psychiatric comorbidities, such as mood, substance-use, behavioural and anxiety disorders.\(^4,6,7\)

• As a result of their symptoms, adults with ADHD face many challenges in everyday life at work and at home, which can include:
  – Difficulties in finding and maintaining stable employment\(^8-10\)
  – Difficulties with social interactions, family relationships and stigma\(^8-12\)
  – Risk-taking\(^9,10,13\) and criminal behaviours.\(^13-20\)

Chapter 2: Implications of adult ADHD for employment, healthcare costs and the criminal justice system

• Three studies are reviewed to provide further insight into the personal and societal burden of adult ADHD.

• Specifically, the studies indicated that:
  – Adults with ADHD are more likely to be out of work than their peers.\(^21\)
  – There are substantial healthcare costs associated with inadequately controlled adult ADHD, even before considering any indirect costs, such as lost work productivity.\(^22\)
  – Adult ADHD may be associated with involvement in crime.\(^16\)

Chapter 3: Improving the recognition and management of adult ADHD

• Based on the published literature, the following key areas are identified as providing potential opportunities to improve the recognition and management of adult ADHD:
  – Awareness of adult ADHD and information for affected adults
  – Transition from adolescent to adult services
  – Support for adults with ADHD in the workplace
  – Support for adults with ADHD in relation to social inclusion, family life and general lifestyle
  – Support for adults with ADHD in the criminal justice system
  – Further research required.

• Overall, the aim is to provide European, national and local stakeholders with a set of opportunities for priority actions to improve the quality of life of adults living with ADHD and to reduce the cost of this disorder for society and national welfare systems across Europe.
What is ADHD, and how can it affect adults?

ADHD is a neurodevelopmental disorder characterised by symptoms of inattention and/or hyperactivity-impulsivity, which can have a negative impact on social, academic and/or occupational aspects of an individual's life. While these symptoms start in childhood, they often persist into adulthood. However, symptoms may evolve over time; for example, physical signs of hyperactivity in childhood often become less obvious in adulthood, while restlessness, inattention and impulsivity may persist.

Adults with ADHD are often also living with other psychiatric comorbidities. An analysis of the World Health Organization World Mental Health Surveys (n=26,744) reported that 51.7% of adults with ADHD had a comorbid mood, anxiety, substance-use or behavioural disorder and that ~9% of adult patients with mood or anxiety disorders have ADHD. In a large Swedish study (n=17,899), symptoms of ADHD were associated with increased risks of symptoms of bipolar disorder, major depression, generalised anxiety disorder, obsessive-compulsive disorder and alcohol dependence. The incidence of various psychiatric disorders in individuals with ADHD symptoms was estimated to range from 0.6% for bipolar disorder to 13.3% for major depression. In addition, in a Spanish study (n=367), 66.2% of adults with ADHD had other psychiatric conditions at the time of ADHD diagnosis, with an overall mean number of 2.4 other psychiatric conditions; these included substance-use disorders (39.9%), anxiety disorders (23.3%), mood disorders (18.6%), personality disorders (14.4%), conduct disorders (7.8%) and eating disorders (4.7%). In terms of physical comorbidities, there is some evidence that childhood/adolescent ADHD may be associated with obesity and impaired physical health in adulthood, while asthma has been reported to be more common in adults with ADHD than in those without.

Examples of ADHD symptoms in adults may include:

**Inattention**
- Difficulty remaining focused during conversations and tendency to get distracted by unrelated thoughts
- Forgetfulness and difficulty in remembering to pay bills or keep appointments
- Disorganisation and tendency to miss deadlines
- Tendency to lose things like wallets or keys

**Hyperactivity-impulsivity**
- Feelings of restlessness
- Difficulty waiting in queues or being still (e.g. in meetings or restaurants)
- Tendency to interrupt or intrude on others, or take over what others are doing
- Excessive talking

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How common is adult ADHD?

While the validity of an ADHD diagnosis in adulthood has been much debated in the past, there has been growing recognition of adult ADHD in recent years, and examples of adult symptoms are now included in diagnostic criteria. In fact, research suggests that ADHD actually persists from childhood to adulthood in ~50–66% of cases, and affects about 1 in 30 adults worldwide.

Although ADHD is more commonly diagnosed in boys than girls, the ratio of boys to girls with ADHD appears to decrease with age (from around 2.4:1 in adolescence, to around 1.6:1 in adulthood). One explanation for why ADHD is less commonly diagnosed in girls, is that girls with ADHD often have inattentive symptoms, which could be more difficult to identify than the disruptive behaviours typically observed in boys. In adults, the distribution of ADHD symptoms appears to be more similar across genders, although the predominantly inattentive type of ADHD remains more common in women.

What is the potential impact of adult ADHD on daily life and wider society?

Some adults with ADHD report that they lead fulfilled lives and have a positive outlook on some aspects of the disorder. However, in general, research suggests that ADHD symptoms can lead to challenges in everyday life at work and at home, with broad implications at personal and societal levels.

In terms of the workplace, evidence suggests that ADHD leads to difficulties in finding stable employment. For example, two studies in Norway found that fewer adults with clinically diagnosed ADHD were in paid employment (22–24%) compared with control groups (72–79%). An analysis of data from Germany has suggested that the lower educational levels and reduced lifetime income associated with untreated ADHD results in reduced lifetime tax and social contributions, leading to long-term financial losses to society. The fiscal burden of untreated ADHD, based on 31,844 individuals born in 2010, was estimated at €2.5 billion in net tax revenue losses, compared with an equally sized, non-ADHD cohort.

Real-life successes and challenges:

diagnosis of ADHD in adulthood

The struggle to obtain a diagnosis was identified as a key challenge in a survey of 30 adults with ADHD in England, with some attributing this to poor awareness of adult ADHD among healthcare professionals. Other factors can complicate the diagnosis of adult ADHD, including the subtlety of symptoms compared with childhood ADHD and the frequent overlap of other behavioural or psychiatric problems. In addition, adults with ADHD may develop coping mechanisms that mask the true impact of the disorder; for example, they may choose an organised partner or work in a job beneath their potential.
ADHD can also affect many aspects of adults’ wellbeing and health, leading to problems with social inclusion, family life and general lifestyle. Some adults with ADHD have described how symptoms of irritability, inattention, impulsive talking and forgetfulness can lead to challenging social interactions; moreover, parental ADHD has been associated with family conflict, and there is a social stigma that can surround ADHD in adulthood. A survey in North America compared adults with ADHD (n=500) and adults without ADHD (n=501) and found that those with ADHD were less likely to strongly agree that they were popular among their co-workers, or report that they were completely satisfied with their social life, family life or relationships with partners/loved ones. The same survey also indicated that adults with ADHD often have a poor perception of their own health and fitness, and are more likely to smoke tobacco or use drugs recreationally than adults without ADHD; indeed, substance-use disorders are relatively common among adults with ADHD.

Some adults with ADHD have reported a change in their ability to assess risk, with participation in extreme activities and a tendency to drive aggressively and recklessly. For example, in a small comparative study, young adults with ADHD (n=105) experience more adverse driving outcomes e.g. speeding fines and licence suspensions, compared with a community control group (n=64). Overall, adult ADHD may be associated with some risk-taking behaviours and lifestyle choices that can have serious implications, although it should be noted that risky driving and risky sexual behaviour may in some cases be related to antisocial personality disorder or conduct disorder.

Beyond driving offences, broader criminality has been explored in adults with ADHD including two studies in Denmark. In a study of 206 individuals diagnosed with ADHD as children, 47% had a criminal conviction in adulthood, most commonly for theft; in another study of 155 adults with ADHD, 53% had been involved in property crime and 51% in violent crime. Similarly, in a study in Finland (n=122), adult ADHD was associated with an increased risk of being involved in economic or violent crime. Accordingly, ADHD is estimated to affect 26% of adult prison populations worldwide. However, evidence suggests that criminality may sometimes be due to co-occurring antisocial or substance-use disorders in adolescence, rather than a direct result of ADHD.

Summary

- ADHD is characterised by symptoms of inattention and/or hyperactivity-impulsivity, and many individuals also have other psychiatric comorbidities.

- In many cases, ADHD persists from childhood into adulthood, although symptoms may evolve over time.

- As well as impacting on the daily home and work life of the individual and their family, ADHD can also be associated with risk-taking or criminal behaviours and other far-reaching effects on wider society.
This chapter reviews three studies that evaluated the implications of adult ADHD for employment, healthcare costs and the criminal justice system, highlighting the importance of effective management of the disorder to reduce the personal and societal burden.\textsuperscript{16,21,22}

As with all research, it should be noted that results represent select patient populations and should be considered within the context of the study designs (please see source references for full details of potential limitations).

**Employment: study of 414 adults with ADHD in Norway\textsuperscript{21}**

This questionnaire-based study included 414 adults with ADHD and 357 control subjects from all regions of Norway.

Overall educational level was significantly lower in adults with ADHD than in the control group (p<0.001): junior high school was the highest educational level achieved by 29% of adults with ADHD versus 6% of controls, while a university-level education was achieved by 23% of adults with ADHD versus 59% of controls (Figure 1).

![Figure 1. Highest educational level achieved by adults with ADHD and control subjects\textsuperscript{21}](image)

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\textsuperscript{1}Mean age, 34.5 years; female, 47.8%
\textsuperscript{2}Mean age, 29.9 years; female, 58.5%
\textsuperscript{3}p<0.001 vs control subjects

Regarding employment, the ADHD and control groups differed significantly in the proportions of adults who reported being in work (24.3% versus 78.8%, respectively; p < 0.001) were receiving a disability pension (32.1% versus 2.2%; p < 0.001), were under vocational rehabilitation (20.6% versus 2.8%; p < 0.001), or were unemployed (4.8% versus 1.9%; p = 0.024) (Figure 2).

Of the 414 adults with ADHD, only 81 were diagnosed in childhood and only 75 actually received treatment in childhood. Treatment of ADHD in childhood was identified as a strong predictor of being in work as an adult, highlighting the possible importance of early diagnosis and access to treatment.

Healthcare costs: study of non-drug healthcare resource use in adults with ADHD in Scotland, Sweden and Denmark

This was a survey of 60 psychiatrists in Scotland, Sweden and Denmark to assess healthcare resource use based on the estimated average number of visits/consultations required for a typical adult with ADHD.

The survey found that many psychiatrists prescribed both pharmacotherapy and behavioural therapy to treat adult ADHD in Scotland (15/20, 75%), Sweden (19/20, 95%) and Denmark (10/20, 50%).

For Scotland and Sweden, results suggested that estimated costs were higher for patients who did not have an adequate response to medication (Figure 3), highlighting the importance of the diagnosis and effective management of ADHD in adults to reduce the economic burden.
Real-life successes and challenges: economic impact of ADHD in the workplace

A survey of 2,656 employees of a large manufacturing firm in the US provides some indication of the additional economic burden of ADHD in the workplace. ADHD was estimated to be present in 2% of the sample, and was associated with significant reductions in work performance and increases in sickness leave and the likelihood of workplace accidents/injuries. Overall, the human capital value of lost work performance associated with ADHD was estimated to be $4,336 per employee per year, although this did not capture all relevant costs, such as damage to equipment. It should also be noted that only a minority of employees with ADHD were receiving treatment for the disorder, and it is suggested that research into treatment cost-effectiveness in the workplace may be helpful.

Criminal justice system: study of 155 adults with ADHD in Denmark

This was a study of 155 adults (60% aged ≥25 years; female, 35%) referred to an adult ADHD unit in Central Denmark from 2010 to 2011.

Overall, 51% of these adults reported that they had been involved in violent crime and 53% that they had been involved in property crime, although these findings relied solely on self reporting and may not have reflected actual arrests or convictions. Driving licence suspension was reported by 16% of adults.

[Figure 3. Mean estimated annual non-drug healthcare costs for adults with ADHD in (a) Scotland and (b) Sweden, according to response to medication]

*Blood test, electrocardiograph, electroencephalography, allergy test, blood pressure, weight management
*Electrocardiograph, electroencephalography
*Excluding social workers/counsellors and neurologists

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Men with ADHD had a higher risk of involvement in violent crime or driving licence suspension than women with ADHD. Many of the adults also had substance-use disorders, mood disorders or personality disorders, but there was no apparent association between such co-occurring disorders and criminal behaviours within the group.

When combined with findings on risky sexual behaviour in the same group of adults, it is concluded that adults with ADHD may be impaired in terms of risk-taking behaviours. However, it is noted that this study only considered a relatively small population of adults with ADHD, and there was no control group for comparison.

**Summary**
- The presented data support the following conclusions:
  - Adults with ADHD are more likely to be out of work than their peers.\(^{21}\)
  - There are substantial healthcare costs associated with inadequately controlled adult ADHD, even before considering any indirect costs, such as lost work productivity, leading to a considerable overall societal burden.\(^{22}\)
  - Adult ADHD may be associated with involvement in crime.\(^{16}\)
- By highlighting the personal and societal burden, such studies provide a rationale for the improved recognition and management of adult ADHD.
Chapter 3: Improving the recognition and management of adult ADHD

Despite progress in the understanding of adult ADHD, much work remains to be done in order to achieve change: change in how adult ADHD is perceived and responded to, and change in how people with ADHD are empowered and supported to make the most of their potential and to lead fulfilled, complete and productive lives. Given the considerable societal burden of adult ADHD, it is important that policy makers at local, national and international levels collaborate and act on the following opportunities to improve the lives of people with ADHD, as well as the lives of their families and society as a whole.

Awareness of adult ADHD and information for affected individuals

While studies have confirmed that a large proportion of children and adolescents with ADHD continue to have ADHD as adults, there appears to be a continued lack of acceptance of adult ADHD, even within the clinical community in some European countries. The reality is that there is a lack of understanding of adult ADHD in the social environment, workplace and public institutions. Greater awareness is needed to ensure that adults are not simply given an ‘ADHD label’, but are met with a better understanding of their challenges and needs, and provided with appropriate support to take full control of their personal and professional lives.

Guidelines on ADHD, developed by the European Network Adult ADHD, UK National Institute for Health and Care Excellence and British Association for Psychopharmacology, provide valuable examples of how specific recommendations can be made for better management of ADHD in adult patients. By recognising the disorder and encouraging contact with local and national support groups, such guidelines represent an important step in helping to improve the lives of adults with ADHD.

Shire has identified the following areas for improvement:

- Addressing possible misperceptions that ADHD is a disorder that only occurs in children/adolescents by making existing data and evidence more widely available and including adult-specific aspects in all policy discussions about the disorder.

- Raising awareness of specific issues and costs associated with adult ADHD through broad educational approaches targeted at key stakeholder groups, such as social workers, healthcare professionals and civil society groups.

- Supporting adults with ADHD in explaining their disorder to peers and employers, potentially through the development of printed educational materials, or websites, that summarise key information.

Real-life successes and challenges: the European Network Adult ADHD (ENAA)

ENAA was founded in 2003 with the aims of increasing awareness that ADHD is a lifelong condition, improving the diagnostic assessment and treatment of adult ADHD, supporting international research into adult ADHD, improving access to services for adults with ADHD and establishing co-operation between professionals involved in child and adult ADHD. These aims are being achieved through initiatives that include publications, symposia, courses, educational materials and, notably, the development of the Diagnostic Interview for ADHD in Adults (DIVA). The organisation currently has 66 participants from 24 countries across Europe and beyond.
Transition from child to adult services

The consequences of non-treatment for the individual can lead to negative outcomes affecting education, employment prospects, relationships, quality of life and personal finances. Despite this, access to adult ADHD services and support is generally poor, resulting in frequent gaps in care during transition from child to adult services. Continuity of care into adulthood for patients with ADHD occurs less frequently than persistence rates of the condition would predict, leading to many patients being “lost in transition”.

An audit of transitional care for adolescents with ADHD in a North-West England district reported that in a sample of 104 eligible adolescents with ADHD, 73% were discharged or lost to follow-up over the period of transition to adult services. Similarly, results from the Irish TRACK study showed that in a sample of 20 adolescents with ADHD, none were successfully transitioned to adult healthcare services and almost half disengaged from services altogether. A prospective longitudinal study of 91 young people (aged 14–24 years) with ADHD found that only 9% had transitioned to adult services, although eight reported a need for more support.

Entering a new phase of life brings new challenges for people with ADHD, and there is a need to guide young adults and their families through this transition to prevent individuals falling through the cracks.

Shire has identified the following areas for improvement:

- Developing clear recommendations for protocols for adolescents with ADHD to transition into adult services that take into account both the individual and parent/carer or guardian perspectives and needs.
- Encouraging the sharing of protocols and their outcomes, so that local mental health services can consider the experiences of other centres as they develop their own protocols.
- Ensuring that adolescents with ADHD appreciate the importance of remaining engaged with specialist services and empowering them to seek appropriate support.

Case study 1: NICE clinical ADHD guideline – diagnosis and management of ADHD in children, young people and adults

In 2018, the UK National Institute for Health and Care Excellence (NICE) updated their guideline on the diagnosis and management of ADHD in children, young people and adults. One specific recommendation intends to ensure that people with ADHD do not fall ‘between the cracks’ when they transition from adolescence into adulthood and continue to have access to guidance, treatment and support.

The recommended transition process includes:

- A re-assessment at school-leaving age to establish the need for continuing treatment into adulthood. If treatment is required, arrangements should be made for a smooth transition to adult services with details of anticipated treatment and services required. Timing of arrangements may vary locally but should usually be completed by the time the patient is aged 18 years.
- A recommendation that “for young people aged 16 years and older, the care programme approach (CPA) should be used as an aid to transfer between services. The young person, and when appropriate the parent or carer, should be involved in the planning”.
- After transition to adult services, healthcare professionals should carry out a comprehensive assessment of the person with ADHD, including personal, educational, occupational and social functioning as well as assessment of any other conditions (e.g. drug misuse, personality disorders, emotional problems and learning difficulties).
Support for adults with ADHD in the workplace

Adults with ADHD have the same need and right to work as everyone else, but there are a number of barriers that may prevent them from finding and staying in work successfully. It is important to acknowledge that adults with ADHD may have difficulties in conventional workplace settings and this can have an impact on their occupational functioning.16

Greater understanding is needed not only about the possible limitations of ADHD but also on the skills and potential that adults with ADHD can bring to the workplace. In order to minimise job and workplace discrimination and maximise the employment and retention of adults with ADHD, it is imperative that, with the support of government, local strategic partnerships and employers develop tools for employers to better understand adult ADHD.

Shire has identified the following areas for improvement:

- Working with employment agencies to help them to support adults with ADHD in finding careers that meet their strengths and needs.
- Working with employers to support adults with ADHD in the workplace through better recognition of their needs and adjustments to working premises/practices.
- Highlighting any ‘best practice’ examples of how adjustments to working premises/practices have been successfully implemented with benefits to the employer as well as the individual with ADHD.
- Ensuring that mental disorders, including ADHD, are part of any initiative or action plan that is developed to improve occupational health and safety.

Support for adults with ADHD in relation to social inclusion, family life and general lifestyle

It is important to recognise that ADHD is not just a personal challenge, but also affects an individual’s social environment, with potential problems relating to social inclusion, family life, relationships and general lifestyle. ADHD in parents has been associated with family conflict and poor family cohesion.17 It is important to support people with ADHD and their families by providing structure for their daily living, enabling them to make informed, healthy decisions, and providing them with the right tools to improve personal skills.

Shire has identified the following areas for improvement:

- Identifying and developing guidance and tools for the social environment (family members, social services) to intervene when necessary.
- Providing adults with ADHD with social skills training and family therapy where available.
- Where needed, providing support for adults with ADHD to take control of their lives when confronted with impulsive/risky behaviour.
- Ensuring that mental conditions, including ADHD, are part of any initiative or action plan that is developed to address the issue of social inclusion.
Support for adults with ADHD in the criminal justice system

Although most people with ADHD do not commit crimes or spend time in prison, studies have indicated that, when combined with low socioeconomic standards, some personality traits of ADHD, like risk-taking and impulsive behaviour, can increase the probability of entering the criminal justice system. Indeed, the worldwide prevalence of ADHD in adult prison populations has been estimated at 26.2%.¹⁷

Greater understanding of ADHD within the criminal justice system – including among politicians, court officials, the police and the prison management service – is needed to better support adults with ADHD in this difficult environment and may bring benefits at both personal and societal levels. In the UK, this has been underlined by a consensus statement developed by the UK Adult ADHD Network and criminal justice agencies.⁹⁷

Shire has identified the following areas for improvement:

- Raising awareness and providing education on the issue of ADHD within the criminal justice system to combat stigmatisation and improve understanding of ADHD as a potential underlying contributor to the causes of certain criminal behaviours.

- Empowering corrections professionals/prison staff with the right tools to identify signs of mental health issues, such as ADHD, among inmates.

- Supporting the appropriate management of ADHD in adults within the criminal justice system, and upon release back into the community, with a view to reducing the risk of re-offending.
Further research required

In recent years, studies have been published that have improved understanding of the profound effect that ADHD can have on adults and their surroundings. In addition, initiatives such as the European Network Adult ADHD and the ADHD Alliance for Change (a European project led by a steering committee of independent experts in ADHD, initiated, developed and funded by Shire), have provided further insights into how the recognition and management of adult ADHD can be improved.

However, despite these efforts, existing knowledge gaps still need to be bridged in order to help identify the most effective policy solutions for addressing the personal and societal challenges of adult ADHD. Further research is needed to help improve understanding of adult ADHD and the potential impact it has at both personal and societal levels.

Shire has identified the following areas for improvement:

- Working with adults with ADHD to better understand the everyday challenges that result from the disorder and how these might be addressed.
- Increasing research on adult ADHD in Europe, particularly on associated costs and burden to society, to better understand the impact of and best policy responses to adult ADHD.
- Improving understanding of ADHD in the elderly, an area where little research has been published to date and where there may be specific needs.

Real-life successes and challenges:
research needs identified at a European Expert Roundtable

In November 2012, Shire convened a meeting of academics, patient organisations and other stakeholder groups in mental health and education to examine the impact, cost and long-term outcomes of ADHD in Europe. The group identified several research needs in ADHD, including studies of the relationship between social background and ADHD, and initiatives to improve understanding of how work environments could accommodate those affected by ADHD, rather than the other way around.
References


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