Chris Chandler

The Science of

A Guide for Parents and Professionals

WILEY-BLACKWELL

Table of Contents

Index

To Max and Guy

The Science of ADHD

A Guide for Parents and Professionals

Chris Chandler

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Boxes, Tables, and Figures

Boxes

Tables

Figures

6.4 The regions of the frontal cortex communicate with striatal regions, which go on to communicate with other regions of the basal ganglia and the thalamus

7.1 The neuron

7.2 The action potential

7.3 Dopamine and noradrenaline synthesis and metabolism

7.4 A normal unaffected dopaminergic synapse

7.5 The effects of amphetamine and methylphenidate on the neuron

Preface

Not another book on ADHD! This is perhaps the groan that will greet this publication. A quick look at Amazon.com indicates that this subject has been written about extensively. So – why another book?

The reasons are as follows:

In 1998 our first child was born. He was (and still is) a joy. However, after a couple of years we started to realize he was different. He had the energy and stamina of a superhero; he could walk for several miles by the time he was 3 (although running was his chosen form of movement). His activity was not a cause for concern, we would just accommodate his needs, and as new parents we considered this to be fine; we did not have a comparison. In fact we thought other children were inert and slightly boring! Excitement and activity were to be with us for sometime to come, shortly to be joined by stress and anxiety. But it was not just his zest for life and his activity that were noticeable; he was also starting to show signs of being impulsive and disorganized. He would react to others around him very quickly and often respond physically and sometimes aggressively. He would try to use physical force to get to his goal rather than thinking and problem solving. Although his behavior was not initially a problem in its own right (after all, boys will be boys), it was starting to become an issue not only with us as parents, but also with others who would occasionally care for him and eventually teach him. We became the parents the teachers always wanted to speak with after school.

In common with many others, but suffering in isolation – the loneliness that comes with differences can be acute – we realized that our son’s individuality, or, as they were to become, his difficulties, were preventing full participation and integration within the wider social world, and, more

worryingly, were severely restricting his education. To cut a long, and possibly familiar, story short, we went through the multiple processes of evaluation and diagnosis. Eventually, his consultant psychiatrist awarded him the diagnosis of ADHD that we had suspected now for some time. It may appear curious that I use the word *awarded* as it may imply a prize or goal. But it was an award, and a reward for all the hard work that went into his evaluation. He is now an expert at the psychometric tests. Along with diagnosis came treatment. We had tried a number of behavioral techniques with him, but after the diagnosis came methylphenidate (Ritalin). Methylphenidate is a notorious drug with a controversial history. Stories of addiction and worse were never far away. If the drug works, that's great, but *how does it work?* and *what does it do?* are important questions to resolve.

I am a psychobiologist by trade – that means I study the biological underpinnings of behavior. I am also a concerned parent, and as any anxious parent who has to make a decision about their child's health, I wanted to find out more about ADHD and its treatment. I thought I would get a good book that would explain it all to me – wrong! I was greeted with a lot of books, none of which had the answers I required. Many were books about the demise of a past society and the creation of a modern fast-paced society full of bad parents. On the back cover of Angela Southall's book in bold it states "This is not just another book on ADHD. This book tells the side of the story most of us are otherwise unlikely to hear." However, Southall puts forward a similar set of arguments about ADHD that a great majority of other anti-psychiatry books do, she just does it in one entertaining and intuitively appealing volume [1]. These books did tell me about the horrors of methylphenidate and that parents and society are ultimately to blame. Many of the books are

selective in their use of evidence – a criticism that the authors will no doubt direct at me.

As a result of my dissatisfaction with the available books, I went back to the original sources of information. This information is in the scientific and medical journals where new investigations on ADHD are published. This is not an exercise for the faint-hearted, As Ida Sue Baron points out, “the extensive literature regarding Attention-Deficit/Hyperactivity Disorder (ADHD) is often overwhelming, even to those most knowledgeable about this behavioural disorder” [2] (p. 1). Apart from the sheer volume of information that is available, anyone who has tried to read such papers will immediately know that they are often difficult to comprehend and focus on the small details of ADHD. This dissatisfaction with the accessible knowledge regarding ADHD prompted me to write this book. My intention is to inform parents, students, academics, clinicians, educators, and most importantly those diagnosed with ADHD with a clear account of this complex disorder and its treatment and dispel some of the erroneous assumptions that can be prevalent (e.g. [3–5]).

Like all people, I come with my own ideas and views on ADHD. As a psychobiologist, I approach the study and discussion of ADHD from a neuroscientific position: that is, a brain perspective or the medical model. Having admitted to a bias towards the medical model, I also have a view on the rapidly changing world around me, and I share the sympathies of those individuals who suggest these changes in our lifestyle have an impact. I do not subscribe to the notion that our environments and our biology are separate: nature and nurture cannot be untangled so simplistically (if they can at all!).

The simplistic notion that the world is too busy and there is an over-stimulation of the senses to which we react is an attractive hypothesis. We can all feel the bombardment of

our senses and the stress that it can produce in western society (and beyond). But do these changes cause ADHD? Even if they do, why is it that most children (or adults) can manage within this changing society? Ultimately, why do some individuals get ADHD and others do not? Is there a common cause of ADHD? Is there a common change in the brain? Is there hope? And is there a cure?

The questions are endless, though many can attempt to be answered. But for every question answered, many questions still remain and even more are created in the fine detail of ADHD research. The pursuit of knowledge and understanding is therefore endless, and this is exemplified in the case of ADHD. Finally, the complexities of the brain are still as yet to be unraveled. It is surprising given the brain's complexity that some people, many of whom are non-experts, will pass comment/judgment on the brain's output (behavior). As Lyall Watson said, "If the brain were so simple we could understand it, we would be so simple we couldn't."

I hope that this book explains some of the science behind ADHD, as well as its limitations, and empowers people with the knowledge that will move them away from the bar-room debates and playground comments to a more educated and informed level.

Acknowledgments

At the top of the list of those I need to thank is my wife, Diane. She has supported me in this venture and has given me much cause for thought and reappraisal of my views on ADHD, this book, and life generally. Her love and kindness are always appreciated.

Next up are my lovely boys, Max and Guy, who have been such a joy and inspiration. Of all the people in my life it is these two who have had the biggest influence. And without Max I would not have attempted this book. Thanks, Max.

I would also like to thank Jo Lusher, Carl Bate, and Sean O'Brien for maintaining my sanity and keeping me firmly based in reality. Thanks to Lou for keeping the beer flowing. Cheers!

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I would like to thank numerous colleagues for the conversations we have had that have made a difference to my thinking during the writing of this book (although they may not know it!). Thanks are also due to those I have spoken to at conferences and meetings who have helped with my thoughts – too many to mention. Finally, I am grateful to all the authors who sent me copies of their work (again too many to mention). Without their help this would have been a far more difficult enterprise. It is their work that is inspiring and thought provoking.

1

What is ADHD?

Attention Deficit Hyperactivity Disorder (ADHD) is not one symptom or even two symptoms, as the name might suggest. ADHD is not just deficient attention or excessive activity; it is a cluster of behaviors that are, more often than not, seen together. Thus ADHD is a syndrome comprising of several, presumably connected, symptoms.

The main behaviors observed in an individual with ADHD are *impulsivity*, *inattention*, and *hyperactivity*. These three are the key characteristics of ADHD, but as we shall see when we look at diagnosis (see chapter 2), this triad of behaviors is not always its absolute defining characteristic. For example, ADHD can occur without the hyperactivity being present – so children do not have to be running around and bouncing off of the walls all the time in order to have the condition. Or ADHD can be primarily about impulsivity, which the title of the disorder does not allude to. Impulsivity may be one of the greatest handicaps in the range of behaviors seen in ADHD (see chapter 4). Furthermore, until recently ADHD has been seen exclusively as a childhood disorder – a disorder that the child may eventually grow out of over time. Over the last 15 to 20 years, however, research and clinical experience have been able to challenge this assumption by defining and identifying ADHD in adults.

One could be forgiven for thinking that ADHD is a recent phenomenon emerging during the past 20 to 30 years. Certainly there has been a dramatic increase in the diagnosis and treatment of ADHD, but is it a new disorder?

The answer is most certainly *no*. The impact of ADHD may be greater than at other points in time, but it is not new. Indeed, early reports in the medical literature providing accounts of individuals demonstrating the behaviors associated with what we now call ADHD can be found at the beginning of the twentieth century.

Throughout the last century, and especially in the last 30 years, there have been a number of differing perspectives on the cause of ADHD. These perspectives are wide-ranging, including societal causes (typified by such books as *The Ritalin Nation* by Richard DeGrandpre [6]), neurobiological causes (e.g. [7]), through to evolutionary/genetic theories that claim ADHD is a result of behaviors that were useful in our ancestry, but that may now have little relevance in a modern-day westernized world [8].

Most accounts of ADHD in the scientific literature begin with describing the disorder as a complex neurobehavioral problem with a genetic component. The weight of the evidence supports this supposition. However, science is not without bias itself. Some have argued that there is a bias towards funding research that is medically oriented. We must remember that science, like everything else, does not take place in a cultural vacuum. Why, then, does the science not reach the media, the education systems, and even the medical professions? In short, science can be more difficult to comprehend than other explanations, which lend themselves to our own inherent biases and opinions.

So what is ADHD? It is a neurobehavioral disorder of great complexity; it is a disorder with a genetic pedigree; it is a disorder in which environmental conditions can exacerbate or ameliorate the symptoms; it is a disorder which has considerable impact on the life’s of those diagnosed with it, but also those who live/work/study/interact with someone diagnosed with the disorder; it is a disorder which can in many cases be treated; it is a disorder that is most likely

going to persist into adulthood; it is a disorder which is often seen with other disorders; and it is a disorder that requires further research for a greater understanding.

What Does ADHD Look Like and Who Has It?

One might expect to gain the answer from a review of diagnosis. However, this question is different from the question of clinical diagnosis (see chapter 2). The diagnostic criteria of ADHD do not do justice to a description of ADHD and what it is like to live with the disorder. Diagnostic criteria can be dry lists that lack detailed descriptions. Furthermore, there is a tendency for the symptom lists to be presented to the lay reader without a context or explanation of the process involved in the assessment. ADHD can have positive and negative qualities – although its negative components are the ones that impact most on normal functioning and are the most prominent; after all, psychiatry is concerned with deviation from normality and therefore they receive the greatest amount of press.

Who has ADHD? Is there a particular type of person who has ADHD? Do they have a certain type of parent? Do they come from rural or urban environments?

Essentially anybody can have ADHD! ADHD has no prejudice; it does not discriminate. It transcends socio-economic groupings, cultural and racial groupings, although some distinct clusters appear in the literature (e.g. in one American study non-Hispanic white males were mainly identified with ADHD [9]). However, there is one group that ADHD tends to select above all others, and that is the male (this is certainly the case in early childhood).

A web-based search reveals a number of notable individuals with supposed ADHD; however, they are not

subject to the diagnostic rigor necessary for confirmation. An interesting and recent paper has used several biographies of Che Guevara to identify him as having had the disorder [10].

ADHD – Two Faces of the Same Coin

Two famous cases of ADHD, with different courses of the disorder and outcomes, can be found in Kurt Cobain and Michael Phelps.

Kurt Cobain, the creative backbone and front man of Nirvana, is a case of ADHD with comorbidities (more than just one co-occurring disorder). At 7 years of age, Cobain was prescribed Ritalin (methylphenidate) for ADHD, which he took for the comparatively short time of three months. As a child, he worshiped stuntman Evel Knievel (the excitement, risk, and danger are all seductive to those with ADHD). In third grade, Cobain dived from the deck of the family's house onto a bed of pillows and blankets below. He clearly had no fear and was happy to engage in high-risk behavior typical of ADHD. Despite his troubled childhood he became successful with the grunge band Nirvana. As is often the case within the music industry, the artists avail themselves of drugs. Cobain is known to have had serious drug problems. In one of the many books on Cobain's life and death, his widow, Courtney Love, blamed Ritalin (which she had also been prescribed) for Cobain's later addiction to heroin. Love is quoted as saying, "When you're a kid and you get this drug that makes you feel that [euphoric] feeling, where else are you going to turn when you're an adult?" [11] (p. 20). This quote and its context are interesting for a number of reasons:

1 Initial reading of it suggests that Ritalin (methylphenidate) was the cause of Cobain's troubles – does taking a powerful stimulant open the door to addiction? There is a body of scientific evidence that suggests this is not the case (see chapter 8).

2 There was little continuity of care in that as an adult he no longer received treatment for ADHD. Perhaps if he had been treated for ADHD as an adult he may not have descended into addiction. This is pure speculation; Cobain had other demons in his psyche such as depression and physical/psychosomatic pain.

3 Finally, the quote indicates a need to feel sensations. As a child Cobain would engage in sensation-seeking behavior, but as an adult those sensations could be found by altering his biochemistry with drugs. A characteristic of ADHD is the need to seek out new experiences [12].

Sadly Cobain killed himself at the age of 28. The role of ADHD in his fate is far from clear and the disorder does not appear to be documented in his later life.

Michael Phelps, the Olympic gold medal-winning swimmer of 2008, is a more jubilant case of ADHD. Phelps was diagnosed with ADHD at the age of 9 and prescribed methylphenidate. Phelps was also supported by his family, most notably his mother, Debbie. According to Debbie, "I was told by one of his teachers that he couldn't focus on anything."[1] She continues, he "never sat still, never closed his mouth, always asking questions, always jumping from one thing to another. But I just said, 'He's a boy.' "[2] This is a common assumption: the child is just being a boy. The question that is important in ADHD is at what point do these behaviors become problematic for the individual. ADHD behaviors can be considered to exist along a continuum, e.g. hyperactivity at one end, normal in the middle, and sedentary behavior at the other end. The experiences with school were also problematic, as Debbie recalls, "In

kindergarten I was told by his teacher, ‘Michael can’t sit still, Michael can’t be quiet, Michael can’t focus.’ ”[3] Debbie was not one to accept no for an answer: “I said, maybe he’s bored.” The teacher said that was impossible, “He’s not gifted,” came back the reply. “Your son will never be able to focus on anything.”[4] It is surprising, and disheartening, that some teachers have such a defeatist attitude – such attitudes to ADHD need to be addressed. Cases such as Michael Phelps may well help dispel some of the negative assumptions surrounding the disorder.

Debbie Phelps worked closely with the school to ensure he received the extra help he needed. “Whenever a teacher would say, ‘Michael can’t do this,’ I’d counter with, ‘Well, what are you doing to help him?’ ” she recalls.[5]

Examples of her input can be seen in the following extract:

> After Michael kept grabbing a classmate’s paper, Debbie suggested that he be seated at his own table. When he moaned about how much he hated reading, she started handing him the sports section of the paper or books about sports. Noticing that Michael’s attention strayed during math, she hired a tutor and encouraged him to use word problems tailored to Michael’s interests: “How long would it take to swim 500 meters if you swim three meters per second?”[6]

After two years of taking medication, Phelps told her he wanted to stop. He stopped and he did fine, possibly due to the regime of competitive swimming. Phelps’s busy schedule of practices and competitions imposed so much structure on his life that he was able to stay focused without medication.

Phelps also had strong support structures that allowed him to succeed in swimming; furthermore, giving up stimulant medication allowed him to compete without fear of drugs

testing being positive. Methylphenidate and amphetamine are prohibited substances in sport.

At the Beijing Olympics in 2008, Phelps won eight gold medals, breaking the 1972 record set by Mark Spitz. However, his ADHD can still become evident, as witnessed by his mother: “He still jumps from thing to thing. He’s talking to me and texting someone on his Blackberry and I’m like, ‘Stop it. It’s either me or this.’ ”[7] More recently he has been implicated, by the media, in recreational drug use, which is very common in ADHD (see chapter 8).

The Negative Impact of ADHD

The symptoms of ADHD are rarely placed in a positive framework (except when considering evolutionary accounts of the disorder – see chapter 5). Whilst the symptoms of ADHD in some cases and situations can be positive (e.g. Michael Phelps), on the whole they have a profound negative effect on the quality of life experienced by the person with the disorder. However, this negative impact is not restricted to the individual with ADHD; it can also extend to those they come into contact with, such as family members and colleagues and fellow students. For this reason the world of psychiatry refers to it as an externalizing disorder.

ADHD, as we shall see in future chapters, is not just one single entity, but rather is a term that encompasses many sub-syndromes with differing symptoms and prognoses. The symptoms of ADHD fall into three categories: (1) inattention, (2) hyperactivity, and (3) impulsivity (see Table 1.1).

Table 1.1 The three key symptoms of ADHD

Inattention	Hyperactivity	Impulsivity

Inattention	Hyperactivity	Impulsivity
Does not pay attention Avoids sustained effort Doesn’t seem to listen when spoken to Fails to finish tasks Can’t organize Loses things “Forgetful” Easily distracted	Fidgets Leaves seat in class Runs/climbs excessively Cannot play/work quietly Always “on the go” Talks excessively	Talks excessively Blurts out answers Cannot await turn Interrupts others Intrudes on others

What is ADHD Like?

To answer this we need to decide on the perspective: are we patients, parents, siblings, educators, or health professionals? For parents the main feature of ADHD might be the impulsivity and aggression; for the teacher the main feature might be the lack of attention and/or self-control; for the psychiatrist the main problems may the behavioral impact of the symptoms across several aspects of life; and, most importantly of all, for the person with ADHD the social implications, e.g. the feeling of isolation and peer rejection and the need to fit in, may be the most important.

Clearly there are different agendas for each perspective. The symptoms of ADHD impact on all those they come into contact with, and if the behaviors result in negative interactions, this will only continue to fuel the psychosocial problems the person with ADHD experiences. By minimizing the symptoms, the psychosocial aspects associated with ADHD may reduce. However, there is a time delay between symptoms management and a return of self-esteem – it may take a long period of time for self-esteem to return.

A recent article looking at the views held by adolescents of their own ADHD [13] saw them as “square pegs” being forced into “round holes” (society/school). This study demonstrated that those with ADHD viewed themselves as existing in an imbalanced state and that differences were

intensified through interactions with others. The authors argue that the mismatch between the *square peg* that is ADHD and the unmovable *round hole* of society intensifies the squareness of ADHD – the rounder the society, the squarer the ADHD, and then a vicious circle which leads to a feeling of a lack of control. Whilst the *square-peg–round-hole* view may fit well with some of the pop psychology views of ADHD in which society is "wrong," one has to remember that there is a great deal of suffering experienced by the *square pegs*. Furthermore, why are there *square pegs* when there are so many apparently *round pegs* that fit nicely into the *round-holed* world? The answer to this question may lie in evolutionary biology and genetics (see chapter 5).

To get a feel for life with ADHD, the following extracts from the UK's National Institute for Health and Clinical Excellence (NICE) guidelines that were published towards the end of 2008 are illuminating. These accounts provide a touching insight into those who experience ADHD and are full of often instantly recognizable comments – the *square pegs* theme continues. These accounts of ADHD are both depressing, because of the suffering and injustices that have been experienced, but also uplifting, as many have been able to triumph over the adversity of the disorder. For those who wish to see the full transcripts, go to pages 68–89 of the NICE guidelines.[8]

To further help identify key features of ADHD or points of interest, comments are made where necessary with reference to chapters or other sources that focus on a particular aspect of the disorder.

Adult male personal account

My mother comments that she immediately saw many differences between me as a baby and my three older

> sisters; however she ascribed this to me being a boy. As a baby I used to bite my mum so much that she had bruises all down her arm … .
>
> Starting at my first primary school was a mixed experience. I did not make friends easily and although I was fairly bright I did not apply myself to my work with any commitment or enthusiasm. The older I got the more trouble I got into: answering back to teachers, lying to other children and performing stupid pranks to try and gain credibility … .
>
> I was rude, lazy and aggressive and I lied constantly; as a result I was very lonely … .

In this account the social isolation and a lack of self-esteem as a result of ADHD are abundantly clear.

> When I was 7 years old and had only been in the new school for less then two terms, my parents took me to see an educational psychologist. I completed a few tests and had a short interview with him. He concluded that I had some obsessive tendencies, anxiety and esteem problems … .

Here is a clear case of the need for differential diagnosis (see chapter 2). The symptoms of ADHD appeared similar to other disorders that can actually look like ADHD or coexist with it.

> [The Educational Psychologist] recommended to my parents that I move to a smaller school with smaller classes. This meant going to a private school, where I was relatively happy for 2 years.

This is interesting, and I have a somewhat cynical perspective. The Educational Psychologist, whilst highly professional and governed by a professional body (the British Psychological Society), is often employed by the Local Education Authority (LEA); surely there is case for a conflict of interests in such a role. The Educational

Psychologist will know that there are few facilities suitable in UK state education, therefore the problem is shifted away from the LEA, and the financial implications associated with such a facility, and placed back onto the parents. Whilst I am entirely in agreement with the Educational Psychologist, one cannot escape the fact that the LEA will not be able to provide such a provision (at least not without a struggle). The only way forward is to seek statutory assessment with the intention of obtaining a Statement.[9]

> I enjoyed boarding and found myself able to build good relationships with other children. I also really enjoyed sport, and eventually captained the cricket and rugby teams. I still got into trouble a fair amount, but the headmaster was very patient and not punitive.

In this instance a skilled headteacher was able to modify the behavior without the constant need for punishments, etc., which are not very effective in the management of ADHD. The self-esteem of the child was increased, as he was able to play to his strengths in sports – similar to Michael Phelps.

> My fortunes changed when a new headmaster came to the school. He and I did not see eye to eye from the start. He was a military-styled bully who suspended me on the second day. … His punishments were severe and eventually he took away any self-respect I had left when he forced a confession out of me for something I hadn’t done.

The child with ADHD is assumed to be guilty because of his previous history – even a jury does not have access to the accused’s previous criminal history! It often appears to be the case that he or she who cries loudest is the victim. It is easy for children to identify a person to blame when there is a precedent set. Furthermore, this new headteacher was not skilled in the use of incentives and only issued punishments. The stark contrast between the two styles of