

Outside the Box

**Rethinking ADD/ADHD
in CHILDREN and ADULTS**

A PRACTICAL GUIDE

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Introduction

FOR DECADES, THE DISORDER CURRENTLY KNOWN as attention-deficit disorder (ADD) or attention-deficit/hyperactivity disorder (ADHD) has been stuck in a box of simplistic old assumptions on the basis of having been identified long ago as a problem of little boys who didn't listen, were hyperactive, and chronically misbehaved. Many of those assumptions were based on outdated understandings of the human brain. Much remains to be learned about this syndrome, but there is now enough scientific evidence to step outside that box to rethink old assumptions and to develop a more up-to-date, science-based understanding of this disorder, which significantly impairs and causes considerable suffering for about 8%–10% of children and at least 5% of adults.

Below are 20 assumptions about ADHD that need rethinking in light of recent research. Each is followed by a very brief statement of facts that challenge that assumption and are reasons why it should be reconsidered.

Assumption #1: ADHD is a simple problem of not listening and not staying focused on a task.

Facts: Research has demonstrated that ADHD is impairment of a complex syndrome of brain functions essential for self-management: the *executive functions*. These include motivation and prioritizing for tasks, focusing and shifting focus as needed, managing sleep and alertness, sustaining effort, modulating emotions, self-monitoring actions, regulating processing speed, and utilizing working memory to keep information in mind while attending to multiple tasks. ADHD-related

impairments are more like the difficulties encountered when carrying out the multiple functions involved in focusing on driving than they are like the act of focusing a camera to take a picture. (See Chapter 2.)

Assumption #2: ADHD is essentially just hyperactivity, impulsivity, and behavior problems.

Facts: Many individuals identified as having ADHD have never had any significant behavior problems and even those who had problems with hyperactive behavior in childhood usually have much less difficulty with behavior problems from adolescence on. The primary problems of ADHD are with *attention*, broadly conceived as the management system of the brain, its executive functions. The DSM-5 (American Psychiatric Association 2013) label for this disorder includes the term *hyperactivity* even for individuals who are not and never were hyperactive. This label perpetuates older views and widespread misunderstanding of the disorder. (See Chapter 2.)

Assumption #3: ADHD affects mostly males; girls and women rarely suffer from ADHD.

Facts: During childhood and adolescence, three boys are identified with ADHD for every one girl; however, the number of women diagnosed with ADHD in adulthood is almost equal to the number of men with that diagnosis. Reports from women seeking treatment for ADHD indicate that many of them have suffered for many years with undiagnosed ADHD prior to their seeking treatment for themselves. (See Chapter 3.)

Assumption #4: Everyone has ADHD sometimes.

Facts: All of the symptoms characteristic of ADHD are similar to problems that everyone has sometimes, but not everyone has the severity of impairment required for an ADHD diagnosis. For individuals diagnosed with ADHD, those problems must be significantly more persistent and more impairing than for most persons of similar age and must seriously interfere with many aspects of their daily life. (See Chapter 3.)

Assumption #5: ADHD always starts in childhood, never in adolescence or adulthood.

Facts: For decades, it has been assumed that ADHD always starts during childhood, but recent longitudinal studies of individuals carefully evaluated and found to not have ADHD during childhood showed that a significant percentage turned out to have developed ADHD impairments by midlife. This may be due to their having ADHD impairments that were not very noticeable until they met challenges for self-management that arise only in adulthood, or it may be delayed action of genes, or both. Usually, ADHD is inherited, but it is not always present in childhood. Recent genetic studies indicate that, in some cases, genetic influences impacting ADHD do not emerge and cause symptoms until adolescence or early adulthood. (See Chapter 3.)

Assumption #6: ADHD is simply a lack of “willpower”; they can do it when they want to.

Facts: Virtually everyone diagnosed with ADHD has a few activities or tasks for which they have no difficulty utilizing their executive functions, but these executive functions are significantly impaired for most other tasks they do. This happens because strong interest in or strong fear about a task changes their brain chemistry to overcome their usual problems with motivation. However, this change is not under voluntary control. (See Chapter 1.)

Assumption #7: ADHD is always outgrown or always continues for a lifetime.

Facts: Follow-up studies show that about 75% of individuals with ADHD in childhood continue to experience significant ADHD-related impairments into adulthood. However, about 25% no longer have significant impairment from ADHD during adulthood. For those whose ADHD-related impairments do not persist, there are some measurable differences in brain development relative to those who continue to experience impairment from ADHD. (See Chapter 3.)

Assumption #8: There is no scientific evidence for diagnosis of ADHD.

Facts: There is strong, objective, scientific evidence that ADHD is highly heritable, that individuals with ADHD experience delays of 2–3 years or more in development of specific areas of the brain that support executive functions, that ADHD is associated with unique weaknesses of connection and communication between regions of the brain, that it is associated with different patterns of cortical thinning, and that treatment with approved medications improves ADHD symptoms during the times the medication is active in about 70%–80% of those affected. (See Chapter 1.)

Assumption #9: Highly intelligent people never have ADHD; they're smart enough to work around it.

Facts: Many studies have demonstrated that some children and adults with high IQ have ADHD. Despite their intellectual strengths, they tend to have significant weaknesses in working memory, processing speed, motivation, and other aspects of ADHD that are independent of their other cognitive abilities and often interfere with their ability to deploy those strong abilities. (See Chapter 3.)

Assumption #10: ADHD is simply a motivational problem; it has nothing to do with emotions.

Facts: Research has revealed that emotions, mostly unconscious emotions, attached to the individual's personal store of unconscious memories and learning, are the primary basis on which each person's brain determines moment-by-moment motivation—what is, at that moment, interesting and important, or not, to that individual. Working memory problems of ADHD are associated with chronic problems in managing these emotion-based motivations and priorities for activities of daily life. (See Chapters 2 and 5.)

Assumption # 1 1: ADHD can be diagnosed objectively with neuropsychological or imaging tests.

Facts: Impairments of ADHD are demonstrated over time in many diverse activities of daily life. They cannot be assessed adequately by brain scans or neuropsychological tests done over a short time in an office. Adequate assessment requires an adequately trained specialist systematically gathering information from self-report and others about the person's life situation, health, education, and many aspects of daily functioning over time and in various settings, relative to others of comparable age. A normed rating scale should also be utilized. (See Chapter 8.)

Assumption #12: Treating ADHD with medications is more dangerous than not treating ADHD.

Facts: Medications most often used to treat ADHD are controlled by the government because if abused by taking excessive doses, they can become addictive. This causes some people to fear that even well-controlled dosing could cause addiction. Research has shown that a child with ADHD not treated with appropriate medication has double the risk of developing a substance use disorder at some time in comparison with a child who does not have ADHD. Those treated appropriately with medication for ADHD have no more risk of having a substance use disorder in adolescence than would someone without ADHD. (See Chapter 10.)

Assumption #13: ADHD is unrelated to other learning and psychiatric disorders.

Facts: Research has demonstrated that an adult with ADHD has six times the risk of having at least one additional learning or psychiatric problem that warrants diagnosis at some point in his or her life. This is because the executive function impairments of ADHD often underlie other disorders. Unfortunately, clinicians often diagnose and treat other disorders with which they are more familiar, such as anxiety, depression, dyslexia, mood disorders, or substance use disorders, but do not recognize an underlying ADHD that may require treatment to help the individual to attain adequate functioning. (See Chapter 7.)

Assumption #14: Most medical and mental health professionals are trained to diagnose and treat ADHD effectively.

Facts: Most medical and mental health professionals, including psychologists, psychiatrists, and other physicians, have had very little or no professional training in assessment or treatment of ADHD, especially in adolescents and adults. Some have developed proficiency by getting extra training for ADHD, but currently, this is the exception, not the rule. (See Chapter 8.)

Assumption #15: ADHD looks pretty much the same at every age level.

Facts: ADHD-related impairments are determined based on the level of development of executive functions commonly demonstrated by most individuals of similar age. Infrastructure of the brain that supports executive functions develops very slowly and is not fully matured until late teens or early 20s. A person with ADHD is one whose executive functions are significantly underdeveloped or inconsistent relative to those of most others of comparable age. (See Chapter 4.)

Assumption #16: Once adequate executive function has developed, it will persist.

Facts: Natural developments in midlife and beyond can impair executive functioning. Also, as one gets older, normal development includes some processes of decline. The aging process alone tends to produce some impairments of executive functioning in persons not experiencing disease processes such as dementia. For example, some women experience in menopause some executive function impairments as their estrogen levels diminish. Recent research has shown that treatment with ADHD medications may help those women. Also, both genders tend to experience some slowing of processing speed and diminution of working memory efficiency as an aspect of normal aging. Some older adults report that treatment with ADHD medication seems to alleviate these developmental impairments somewhat. (See Chapter 6.)

Assumption #17: Current DSM-5 diagnostic criteria are sufficient for recognizing ADHD.

Facts: Current DSM-5 diagnostic criteria for ADHD are based on research done with children 4–17 years old. Some additional examples of symptoms in adults have been added, but many researchers agree that although the current criteria pick up some impairments associated with ADHD in adults, they do not include many aspects of executive function impairments that are important aspects of the syndrome, particularly some that may not be noticeable until late adolescence or adulthood. (See p. xix.)

Assumption #18: ADHD is purely an American problem; it is not found elsewhere in the world.

Facts: When the same diagnostic criteria are utilized, ADHD is found in most developed and developing countries, especially where there are significant demands for literacy. Despite methodological differences and regional differences, a meta-analysis of 102 studies including 171,000 individuals found the prevalence of ADHD to be 5.29% among persons 18 years or younger from regions all over the world. (See p. xxii.)

Assumption #19: ADHD is really a problem only during school years; it does not have any significant lasting negative impact on an individual's adult life.

Facts: Long-term studies comparing sample groups of individuals with ADHD to matched groups without ADHD show that those with ADHD are less likely to complete high school, complete fewer years of post-high school education, are less likely to complete a college degree, are more likely to be employed in unskilled occupations, are more likely to have a substance use disorder, and are more likely to quit or be fired from a job. Some with ADHD are very successful in adult life, but for many, ADHD-related impairments bring many continuing difficulties. (See Chapter 3.)

Assumption #20: The importance of ADHD is exaggerated by the media.

Facts: Media reports rarely describe the complexity of ADHD and the multiple ways it impacts the lives of those millions of children and adults and their families who experience this disorder, which is highly prevalent in the United States and around the world. Population studies have shown that, as a group, those with ADHD tend to have not only many difficulties in education, employment, social interactions, and other activities of daily life but also increased risk of premature death, mostly due to accidents. One population study found that individuals with ADHD also have elevated risk for attempted suicide and completed suicide. (See Chapter 1.)

Goals of This Book

Outside the Box was not written solely to challenge mistaken assumptions about ADHD. It is also intended to provide updated, science-based answers to questions many people have about attention-deficit disorders. Some readers may wonder whether they may have ADHD and how to get an adequate diagnosis. Others know they have ADHD but have questions on whether it is safe to treat it with prescribed medications. Some are perplexed about why they or others they know are able to focus and work very well for certain specific tasks or activities but have serious ADHD problems when they try to focus on most other tasks they need to do. Others believe they have ADHD but sensibly wonder whether their chronic difficulties in school, work, or social relationships are actually being caused not by ADHD but by smoking too much marijuana, excessive use of alcohol, or unrecognized psychiatric problems. Still others struggle unsuccessfully in undergoing treatment for their recognized anxiety, depression, learning disorder, or substance use problems and reasonably question whether their unsuccessful treatment may be due to underlying ADHD problems that have never been recognized or even asked about.

For most people at this time, it is not easy to get adequate answers to questions like these. Media, the Internet, and countless books and magazine articles offer contradictory information, much of which is unscientific, outdated, and wrong. Many physicians, psychologists, and other mental health professionals are not yet well informed about current scientific understanding of this complex disorder, which affects millions of children, adolescents, and adults throughout the world and

can seriously disrupt learning, employment, family relationships, social interactions, health, safety, and self-esteem for decades or a lifetime.

This book offers science-based answers in plain, understandable language to a wide variety of questions about ADHD that are often raised not only by adolescents and adults in the general public but also by professionals in pediatrics, general medicine, psychiatry, psychology, nursing, education, and other related fields.

Unlike some books, this volume offers a science-based perspective that is not limited to the understanding of ADHD provided in the current psychiatric diagnostic manual, DSM-5. DSM-5 is a valuable source of information about ADHD, but its diagnostic criteria for adults are based on field research with children ages 4–17 years and not on field research with adults. DSM-5 criteria do not include symptoms of executive function impairment that are most highly predictive of ADHD in adults and that most effectively distinguish ADHD from other psychiatric disorders (Kessler et al. 2010). Rigid application of current DSM-5 criteria for ADHD does not adequately identify some adults significantly impaired by this syndrome.

The current name of this disorder is problematic. DSM-5 confusingly continues to use the term *attention-deficit/hyperactivity disorder* to identify persons with ADHD who do not have, and may never have had, any problems with hyperactivity. Although the older term *attention-deficit disorder* or the newer term *executive function deficit disorder* (EFDD) would seem preferable, in this book I use the current official DSM-5 term *attention-deficit/hyperactivity disorder* to refer to presentations of the disorder with or without hyperactivity or impulsivity. I also report and utilize scientific research findings that move beyond the constraints of the DSM-5 description of ADHD.

The book's table of contents lists the overall topic of each chapter and also highlights one or two of the puzzling questions many people have that are related to that topic. Each chapter includes broad information about its theme as well as answers to the specific topic question. The chapters also provide much additional information on other related questions about ADHD often raised by laypersons and professionals. Embedded throughout each chapter are brief citations to sources for the information provided; these sources can be consulted for additional, more technical information. The reference list at the end of the book provides more detail.

The subtitle *A Practical Guide* is intended to emphasize that this book is focused primarily not on details of academic arguments but on practical aspects of ADHD—how it varies from one person to another, how it changes over the person's life span, how treatments need to be ad-

justed to different individuals, and how it sometimes gets better and sometimes gets worse.

The book is based on current scientific research and also on the experience and perspective of a clinician who has invested most of his work over more than 35 years in studying this disorder not only by reading scientific studies and doing research but also through countless hours of listening to, talking with, and providing treatment for a wide variety of children, teenagers, and adults with ADHD and related problems.

It is important to note that there is much ongoing research on ADHD, some of which it is hoped will provide the basis for broader perspectives and continuing improvements in our understanding of ADHD and our ability to provide safe and effective treatment for those who experience it. This book might be regarded simply as a statement about the current picture of our developing understanding of these complexities of the mind.

However, there is yet another purpose to *Outside the Box*. In this book, I seek to highlight multiple perspectives on how ADHD affects both individuals who suffer directly from it and those who love and care for those children and adults who have ADHD.

Many people think of ADHD as a trivial problem of children or adults who are scatterbrained, often a bit disorganized, frequently late, and excessively forgetful. In contrast, some consider ADHD to be an extraordinary gift that endows the person with exceptional talent, creativity, and the ability to “think outside the box.” Still others are convinced that ADHD is simply annoying laziness or apparent lack of willpower because they have seen that individuals with ADHD tend to focus and perform quite well on a few tasks or activities in which they have strong personal interest, even though they consistently fail to mobilize that same level of focus and effort for many other activities that are important for others or themselves.

Yet for children and adults who are affected with ADHD-related impairments that warrant diagnosis, this disorder, when ignored or inadequately treated, is not trivial. It is chronically frustrating, embarrassing, and discouraging in multiple aspects of daily life. Although some people with this disorder have impressive gifts of talents and skills related to their ADHD and are quite successful, most of those individuals also are seriously burdened by the disorder. Because of the persistent inconsistency it creates, this impairment of the brain’s self-management system can destroy self-confidence and severely erode one’s hope for ever being adequate to meet reasonable expectations of family, teachers, employers, friends, or oneself.

One example is a 19-year-old young man who came with his parents to consult with me over the Christmas break of his first year of college. Let's call him Jake.

Case Example: A college student who thinks his life is hopeless

He was good-looking, friendly, and bright. He greeted me with a warm handshake and a winning smile. As the four of us sat together in my office, I asked Jake why he had come to see me. He said, "My parents want me to talk to you because I went off to college last fall determined to be, for once, a decent student. My parents and teachers always tell me that I'm pretty smart. I did really well on my SATs, but since junior high, I've never been a good student. I don't get much of my reading or homework done on time, sometimes not at all. Even when I know it's important to study more for a test or to get started early enough on a paper to do a good job, I plan to do it, but then I keep putting it off until it's way too late. That's why, despite my high SATs, I wasn't able to get into any school better than this pathetic little college I'm stuck in now."

"I had figured I would go there, work hard freshman year, and then transfer to a better college, the kind of school most of my friends are in. I didn't party much, but I also didn't get much work done. Last week, my first semester grades were posted. I got a B in one course where I had a really interesting professor, but the other four courses were all Fs. My plan to transfer to a better school, the kind of school I should be in, is now down the toilet. My parents say they're willing to pay for one more semester to see if I can do better, but I don't see how it's ever going to get any better. If I go back in 2 weeks for spring semester to try again, it will probably be the same old thing I've been doing since junior high. I've been thinking a lot this week about how my situation is totally hopeless."

I spoke privately with Jake and asked him what he had in mind when he told us that he saw his situation as totally hopeless. He fell silent for couple of minutes, and then his eyes filled up. "When I saw those grades, it finally hit me that I really am going no place. I've been given so much, and I've passed by so many opportunities! It's too late now. Last week while we were visiting at my grandparents' house, I went into their medicine cabinet and grabbed a bunch of pills. Then I got a bottle of vodka. I took them to my room and hid them. Two nights ago, it was about 2 A.M. and I was alone thinking about how hopeless my life is. I took out the pills and laid them out in six rows. There were 180 of them. Then I took out the vodka. I was going to start drinking the vodka and then take every one of those pills. I wanted my life to be over because I just can't get myself to do what I need to do. I'm a loser!"

I asked Jake how he decided not to kill himself that night. He explained that he had gotten into thinking about how deeply that would hurt his parents for the rest of their lives. And he remembered that they had made this appointment for him to see me to try to figure out a way things might get better. He said he was not sure that anything would

ever work for him, but he had decided to check out this consultation and maybe give one more approach a try, even though he continued to have serious doubts about whether it would actually work.

Not every person with ADHD feels so profoundly hopeless as Jake did that evening, but many struggle often with persistent feelings of frustration, helplessness, and shame that result from their experiences with inadequately understood and inadequately treated ADHD. Over the past 20 years, there has been increasing talk about ADHD among professionals in medicine, mental health, and education, as well as in the media throughout the world. Much of this talk has been argument about whether this disorder is being overdiagnosed and whether increasing use of medications to treat ADHD in children and adults is a safe and useful benefit or a risky mistake. Unfortunately, many of these polemical discussions have not been adequately informed by relevant scientific facts or adequate understanding of ADHD. More importantly, these discussions tend to completely overlook or ignore the frustration and pain that those affected with untreated or inadequately treated ADHD are forced to live with.

Scientific research about ADHD and the workings of the human brain has generated substantial changes in our understanding of ADHD and related disorders. In this book, I build on updated, science-based information to describe in very practical terms how ADHD can be recognized at various ages, how it differs from more typical brain development, how it can significantly impair those affected, and how it can be safely and, in most cases, effectively treated in children and adults. Equally necessary is an empathic understanding of the impact of ADHD on individuals and family members who are affected.

I emphasize in this book the importance of empathic understanding of ADHD and using this perspective to explain this syndrome to patients and their families in understandable language. I also offer detailed, practical strategies for providing empathic, science-based treatment for children and adults with ADHD and their families.

In 2014, psychologist Stephen Hinshaw and economist Richard Scheffler published *The ADHD Explosion*, a book that describes various scientific, economic, and cultural reasons for the escalating rate of youths and adults being diagnosed with ADHD in the United States and internationally. They estimated that, despite considerable stigma and social controversy, lifetime rate of diagnosis for youths with ADHD may rise over the next 5 years from the current estimated U.S. level of 11% to as high as 13%. Their review concluded that

ADHD is here to stay and so is medication. ADHD is now an established part of child, adolescent and adult mental health with more than suffi-

cient evidence for its largely biological underpinnings and major associated impairments.... Stimulants work far too well for individuals with ADHD...for this diagnosis and such medications to quickly leave the scene. (Hinshaw and Scheffler 2014, p. 161)

Some epidemiologists and other researchers have questioned the accuracy of estimates of ADHD prevalence such as those cited by Hinshaw and Scheffler. Careful research suggests that reports of explosive increases in the prevalence of ADHD in the United States and in other countries throughout the world have been somewhat exaggerated because they are based on counting cases without adequate attention to the difference between those who have simply reported having symptoms of ADHD and those whose symptoms have been carefully assessed clinically and found actually to meet levels of impairment required for legitimate diagnosis (McKeown et al. 2015; Polanczyk et al. 2014). However, even if prevalence of ADHD is not increasing “explosively,” there is reason to believe that the number of individuals who have ADHD is large, and the number seeking treatment is likely to become larger as the disorder is more adequately understood and as more adequate resources for assessment and treatment become available.

Following their review of the rapid growth in the diagnosis of ADHD, Hinshaw and Scheffler (2014) lamented that most of the individuals currently being diagnosed with ADHD receive seriously inadequate assessments by clinicians who have had little training in assessment and treatment of ADHD. They urged “that ADHD be diagnosed carefully by professionals who know their business” and “that ADHD be treated by clinicians (and paraprofessionals) who are versed in evidence-based interventions” (p. 166).

At present, most medical, mental health, and educational professionals receive little or no instruction during their professional education to help them learn to recognize and treat ADHD in children or adults. More adequate and updated education about ADHD is desperately needed for these professionals. Improved understanding of this disorder is also needed in the general public so that parents of children with ADHD and those adolescents and adults affected will have ready access to updated, scientifically based information to counter widespread prejudices and misunderstandings.

This book is intended to provide understandable, science-based, practical guidance for explaining and treating ADHD. It is intended for the wide variety of clinicians involved in assessing or planning and monitoring treatment of children and adults with this disorder: pediatricians; primary care physicians caring for children, adolescents, and adults; psychologists; psychiatrists; neurologists; physician assistants;

advanced practice nurses; and clinical social workers. It could also be helpful to educators in primary, secondary, and postsecondary settings; disability service providers; and human resource specialists, as well as to adolescents and adults who are seeking more information about ADHD assessment and treatment for themselves or for family or friends.

In this book, ADHD is understood not only in the limited terms of DSM-5. It incorporates the DSM-5 ADHD diagnostic criteria as a useful tool for clinical practice, but it also draws on a wider range of scientific research and perspectives not yet incorporated into DSM-5. Prior to publication of DSM-5, two of the researchers involved in revising the section on ADHD offered a symposium at an annual meeting of the American Psychiatric Association to describe to researchers and clinicians the progress of their committee. After discussion involving many questions from various researchers asking “Why are you not including this or changing that?” the chairman made an important point. He said, “You need to keep in mind that DSM does not lead the field; it follows it.” This book includes some cutting-edge research and clinical strategies that gradually will be tested and improved on by subsequent research.

Since publication of DSM-5 in 2013, several respected researchers have published criticisms and suggestions for how diagnostic criteria for ADHD could be improved in the next version (Barkley 2015; Fayyad and Kessler 2015). In the meantime, clinicians need to assess and treat patients using not only the guidance of DSM-5 but also their clinical judgment supported by the best they can glean from scientific research and from more experienced clinicians. The authors of DSM-5 itself note, “Diagnostic criteria are offered as guidelines for making diagnoses, and their use should be informed by clinical judgment” (American Psychiatric Association 2013, p. 21). This book is one resource to support that clinical work while we continue to look for greater understanding and more effective methods of treatment for children and adults with ADHD.