CHAPTER 1

Introduction

Over the past 20 years, a relatively small but increasing body of scientific literature has begun to emerge on the nature of attention-deficit/hyperactivity disorder (ADHD) as it appears in adults who are self-referred to clinics (see Goldstein & Ellison, 2002; Spencer, 2004). While one might view this rather limited body of literature as being of little consequence, given the thousands of studies on ADHD in children in comparison, there is reason to suspect that adults with ADHD will not manifest identical problems to those seen in children having ADHD. The results of numerous longitudinal studies following ADHD (hyperactive) children to adulthood also suggest that they are not identical to self-referred adults diagnosed with ADHD. While it is clear that both groups experience the same disorder (O'Donnell, McCann, & Pluth, 2001; Wilens, Faraone, & Biederman, 2004), differences in comorbidity and other associated conditions and risks may differ significantly. That is one of the major topics of this book. It compares the results of an extensive evaluation of clinic-referred adults with ADHD, employing both a clinical and a community control group, to the results of the Milwaukee longitudinal study of hyperactive (ADHD combined type) children followed to adulthood (mean age 27 years), also involving a community control group, on many of the same measures. To our knowledge, this is the first and only such study or book to do so, giving a unique glimpse at the similarities and differences between these two populations of adults with ADHD.

Popular books on the subject of adults with ADHD abound, based largely on clinic-referred adults (Hallowell & Ratey, 1994; Kelly & Ramundo, 1992; Murphy & LeVert, 1995; Nadeau, 1995; Solden, 1995; L. Weiss, 1992), and a few clinical textbooks for professionals have also emerged (Gordon & McClure, 1996; Goldstein & Ellison, 2002; Nadeau, 1995; Wender, 1995; Weiss, Hechtman, & Weiss, 1999). But for all their good intentions, much of what is contained is most of these books is based solely on clinical experience

with self-referred adults, often seen in specialty practices and garnered without the benefit of scientific methods. Many of the assertions, especially those made in the popular trade books, about the nature of clinic-referred adults diagnosed with ADHD have not been put to the empirical test of controlled scientific research. For instance, some authors claim that adults with ADHD are more intelligent, more creative, more "lateral" in their thinking, more optimistic, more entrepreneurial, and better able to handle crises than those without the disorder. Similar advocates of adult ADHD have gone so far as to assert that the disorder conveys some positive benefit. To our knowledge, none of these claims have any scientific support at this time. Most, in fact, are refuted in this book. The information obtained from such clinical cases is also fraught with various confounding variables, not the least of which are referral bias and the effects of comorbid psychiatric disorders frequently associated with ADHD. Useful as clinical cases may be initially, when a vacuum exists in scientific information about a disorder, such case reports still remain, for better or worse, purely anecdotal. More scientifically oriented studies of samples of clinic-referred adults with ADHD have been published in the past 15 years, however. Also, many longitudinal studies of children with ADHD/hyperactivity have now followed them into adulthood, reporting their findings during this same period. The results of both types of research underscore both the legitimacy and the specificity of this diagnosis in adults while providing no support for the view that ADHD produces positive benefits in adults with the disorder (Spencer, 2004; Wilens et al., 2004). This is not to say that adults with ADHD do not have positive attributes; they certainly do. Rather, such attributes likely have nothing to do with their disorder. Nearly everyone possesses a profile of hundreds of psychological traits, including both numerous strengths and many weaknesses relative to the norm. Greater care must be taken in not attributing these strengths (or all weaknesses) to the presence of ADHD in an adult.

The overarching aim of this book is to report the results of two of the largest and most comprehensive studies of adults with ADHD conducted to date, juxtaposing the results for clinic-referred adults with the disorder against those for children with the disorder who have reached young adulthood. As noted above, one of these studies compared large samples of clinic-referred adults diagnosed with ADHD to both a large control group of adults having other disorders seen at the same clinic and to a large community control group. This project is referred to here as the UMASS Study, named for the University of Massachusetts Medical School where it was conducted. We here integrate those results with the small but growing literature on ADHD in adults and formulate what we believe are the clinical implications of those findings and the relevant literature for the diagnosis and management of adults with ADHD. The major purposes of that research project were to:

- Conduct a comprehensive study of the symptom presentation of ADHD in the adult stage of life as it occurs among clinic-referred adults so as to determine which symptoms were most likely to differentiate this population from clinic-referred adults without ADHD and community control adults.
- Examine the frequency of symptoms of ADHD from DSM-IV-TR (*Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, text revision; American Psychiatric Association, 2000) across groups to determine the relative utility or predictive accuracy of these symptoms for adults with ADHD, since they were originally and exclusively developed in the study of children with the disorder (Lahey et al., 1994).
- Evaluate a large pool of new and potentially useful symptoms reflecting the adult stage of the disorder apart from those presented in the DSM-IV-TR.
- Reduce this pool of items to a limited set having the greatest utility for distinguishing adults with ADHD from a control group of other clinic-referred adults having other disorders (mostly anxiety and depression) and from a general community control group.
- Determine the necessity or diagnostic utility of specifying an age of onset of symptoms producing impairment by 7 years, as set forth in the DSM-IV-TR, and determining if another age of onset would be more useful for diagnosis.
- Better understand the other psychiatric disorders and psychological maladjustment most likely to be associated with ADHD in adults (comorbidity) as compared with these two control groups.
- Examine the specific impairments that ADHD is likely to produce across the major life activities characteristic of adult adaptive functioning, with specific attention to education, occupational and social functioning, marital adjustment, financial functioning, driving, criminal activity and drug use and abuse, and current health lifestyles.
- Assess the general cognitive and neuropsychological deficits that may be specifically associated with ADHD in adults relative to that functioning evident in the two control groups noted above, with specific attention given to the executive functions of sustained attention, behavioral inhibition, working memory, and problem solving.
- Analyze the extent to which women with ADHD may differ from men with the disorder apart from those more general sex differences that arise in the general adult population.
- Evaluate the risk of psychological maladjustment in the offspring of these adults with ADHD relative to that in the two control groups noted above.
- Formulate research and clinical recommendations from these findings that may serve to guide future studies of adults with ADHD as well as to improve their clinical assessment and management.

This book also reports the results of a second substantial study: the adult follow-up of one of the larger longitudinal studies of hyperactive (ADHD combined type) children followed into adulthood, known as the Milwaukee Study, so named for the city where it was conducted. The major purposes of that research project at this follow-up point were very similar to those of the UMASS Study described above. Specifically those purposes were:

- To conduct a comprehensive study of the symptom presentation of ADHD in the adult stage of life as it occurs among adults who, as children, were clinic-referred, rigorously diagnosed with the disorder, and thereafter followed; as above, the aim was to determine which symptoms were most likely to differentiate this population from community control adults. In doing so, we further subdivided these ADHD subjects into those who continued to meet criteria for the disorder as adults and those who no longer did so.
- To examine the frequency of symptoms of ADHD from DSM-IV-TR across the ADHD and control groups to determine the relative utility or predictive accuracy of these symptoms. The current DSM-IV-TR symptoms for ADHD were originally and exclusively developed on and for children with the disorder (Lahey et al., 1994); therefore, their utility for identifying adults with ADHD remains unproven.
- As in the UMASS Study, we evaluated the same large pool of new and potentially useful symptoms reflecting the adult stage of the disorder for their utility in identifying adults with ADHD—in this case, those who had grown up with the disorder diagnosed in childhood. Similarly, we reduced this pool of items to a limited set having the greatest utility for distinguishing adults with ADHD from our control groups in that study.
- Again, to determine the necessity or diagnostic utility of specifying an age of onset of symptoms producing impairment by 7 years, as set forth in the DSM-IV-TR, and whether another age of onset would be more useful for diagnosis. Given that all of the children with ADHD in the Milwaukee Study were required to have an onset of their symptoms prior to 6 years of age to enter the study, it is important to evaluate the accuracy of their own recall of symptom onset if the DSM-IV-TR age-of-onset criterion is to be extended to adult clinical diagnosis.
- To further understand the other psychiatric disorders and psychological maladjustments most likely to be associated with ADHD in children growing up with the disorder who continue to have it in adulthood as compared with the two control groups (children with ADHD who no longer qualify for the diagnosis as adults and community control children followed to adulthood).
- To examine, as above, the specific impairments that ADHD is likely to produce across the major life activities characteristic of adult adaptive functioning, with specific attention to education, occupational and social functioning,

marital adjustment, financial functioning, driving, criminal activity, drug use and abuse, and current health lifestyles. The Milwaukee Study, in fact, not only took a more detailed health history of its participants than did the UMASS Study but also conducted various blood and urine analyses to further document current health status, making it the first study of which we are aware to examine this topic in adults who grew up with ADHD. From these results, one can begin to obtain some idea of the future medical risks that may be associated with the disorder and take a first glimpse of the impact that ADHD may have on life expectancy.

- To assess the general cognitive and neuropsychological deficits that may be specifically associated with ADHD in adults who grew up with the disorder relative to the functioning evident in the two control groups noted above, with specific attention to the executive functions of sustained attention, behavioral inhibition, working memory, and problem solving.
- Last, as above, to formulate research and clinical recommendations from these findings that may serve to guide future studies of children growing up with ADHD as well as to improve their clinical assessment and management as adults.

Unlike the UMASS Study, the Milwaukee Study did not contain a sufficiently large sample of females in either the hyperactive (n = 20) or control group (n = 5) to permit reliable conclusions to be reached on sex differences that may be specific to the former group. Therefore, while some comparisons of males and females in this study are reported herein, specifically within the hyperactive groups who do and do not have ADHD at follow-up, we urge caution in placing much confidence in those findings until they can be replicated by much larger studies. We also did not examine the psychiatric status or psychological adjustment of the offspring of our hyperactive and control groups at this outcome. Only half (48%) of the hyperactive group had children, many of whom were too young to reliably document psychiatric status by current measures, while most of the control group (87%) had not yet had children. We hope to continue to track the existence and whereabouts of these offspring for evaluation in a later follow-up of these samples.

There are numerous reasons why clinic-referred adults with ADHD would differ from children growing up with the disorder, despite having the disorder in common. An obvious one is that not all of the children diagnosed in childhood with ADHD (then called hyperactivity or hyperactive child syndrome) would be expected to qualify for the clinical diagnosis as adults. As a group, then, one might expect the children with ADHD to be functioning better in various domains of major life activities than would the clinic-referred adults, all of whom currently have the disorder. For this reason, we will break out those hyperactive children in the Milwaukee Study who have ADHD at the adult follow-up from those who no longer qualify for the disorder so as to permit a more direct com-

parison of the former group to the clinic-referred adults with ADHD in the UMASS Study. Of course it is also possible that the children growing up with the disorder may have a worse condition or greater impairments, given that they likely had an earlier onset of their disorder or were brought into clinics for treatment much earlier than most clinic-referred adults. An earlier age of onset or earlier age of referral for a mental disorder may indicate greater severity. That is, it is possible that the children growing up with ADHD may have worse outcomes than clinic-referred adults being newly diagnosed with the disorder. Another reason this may be the case is that self-referred adults may, by this fact, be more concerned about their current adjustment and have greater psychological awareness of the condition and impairments that led them to seek treatment. As we shall see, most children growing up with ADHD are not seeking current treatment and may be less likely to recognize or accept that they even have a disorder once they leave their parents' home. It was, after all, their parents (and often teachers) who referred them for treatment as children, not themselves. For these and other reasons, it would seem to be extremely informative to contrast the nature of ADHD and its comorbid disorders and impairments as seen in clinic-referred adults with the same sort of information obtained from those who grew up with ADHD, having been diagnosed in childhood. This is why we have chosen to combine both of these large research projects into a single book, offering for the first time an opportunity to compare directly these two groups of adults.

We do not address the etiologies of ADHD in this book. These have been extensively researched in children with ADHD; that literature is reviewed elsewhere (Nigg, 2006). Genetic contributions are the most prominent domain of etiology in this disorder, followed in importance by acquired injuries or adverse developmental influences of varying sorts on the developing brain. We see little reason why these same etiologies would not apply to adults, with the possible exception that acquired injuries to the nervous system may account for an increasing number of cases of ADHD across development, thereby representing a somewhat greater proportion of the adult ADHD than the child ADHD population. This would result from the greater time frame over which such etiologies, such as accidental injuries or poisonings known to exist in child ADHD, have an opportunity to operate on adults. We also do not evaluate the standard available treatments for ADHD in adults, as these have been addressed elsewhere (Barkley, 2006). The medication treatments effective for child ADHD have been found to be just as applicable to the adult stage of the disorder. Counseling, workplace accommodations, cognitive-behavioral therapy, and other psychological therapies have some utility as well and are addressed in the text by Barkley (2006). What we do strive to address here are the clinical implications for diagnosis and management that arise from the numerous results of the two large projects reported here, some of which point to a need for additional treatment

approaches in dealing with the various adaptive living impairments we have identified.

We are most grateful to the National Institute of Mental Health (NIMH) for its generous support of these two projects. The UMASS Study involved the better part of 4 years of research (2000–2003), while the Milwaukee Study has been going on since its inception in 1977–1980, with the most recent follow-up conducted from 1999 to 2003. Add to this the more than 2 years it has taken to enter and clean data and analyze all of the results of these two large projects—as well as to prepare this book—and you have some idea of the time and effort we have dedicated to it. We are most grateful for the NIMH and university support we have received along the way.

We could have chosen to present these findings in numerous smaller articles focused on highly specific topics or sections of our database published in various scientific journals. We elected not to do so for several reasons. Not the least of these is that such piecemeal publication, driven by space shortages in journals, would necessitate scattering these findings in small portions across as many as 20 different journals. That would make it very difficult for anyone, including ourselves, to appreciate the larger picture that these results paint for our scientific and clinical understanding of ADHD as it presents in adults. This is especially so for juxtaposing the results for clinic-referred adults against those of individuals who have grown up with the disorder. It would also have made it inconvenient for scientific and clinical colleagues as well as interested students to find those various articles so as to possess the totality of our results and gain this larger, multifaceted perspective. It would, moreover, have taken at least 5 more years to prepare, submit, revise, resubmit, and eventually publish the numerous papers that could have been derived from these two large projects, ensuring that our findings would grow progressively more dated (if not stale) over this period. This drawn-out process would surely have made our results of far less assistance to the field than this current comprehensive presentation of our findings. Finally, publication in journals would have been exceptionally limiting with regard to deriving the numerous clinical implications that arise from such a project; to appreciate them fully requires the perspective of the totality of the results of both projects and the relevant literature. For these and other reasons we have opted to publish these projects in book form. We are most grateful to The Guilford Press for allowing us to do so.

In bypassing the more traditional route of journal publications of our findings, however, we recognize that we have also bypassed a critical stage in the publication of scientific findings—the stage involving the peer review process. Clinical books written on ADHD adults do not need to undergo such peer review process, although one wishes at times that they would do so. But scientific studies, their methods, analyses, and findings demand such review to provide

some assurance of their integrity. In an effort to at least partially address this issue, we will make the entire database from these two projects (in SPSS format) available to any practicing scientist who purchases this book in order to allow those interested to confirm our findings or to conduct further analyses of the data from these publicly funded projects. We extend this courtesy to fellow scientists only because of the necessary expertise required to understand these methods, procedures, analyses, results, and so on. To obtain the datasets, such currently practicing scientists should contact the first author at *russellbarkley@earthlink.net*, providing a cover letter explaining their scientific background, the purpose of the request, and the proposed plan for use of the databases. In making the data available, we recognize that others may wish to pursue additional analyses and even publications from those analyses beyond those we have presented here. If so, we require that permission to do so be obtained in writing in advance of such analyses and publication from the first author (*russellbarkley@earthlink.net*) and that the source of the databases (this textbook) be fully acknowledged in any such publications. For further information on making such requests, contact the first author (R. A. B.), who is the final arbiter for the release of these databases to others.

While we report the results of these original research projects, we strive to do so in a manner that is more easily read and digested than is typical of the format of most scientific journals. So that the flow of the text and the story we wish to tell is not unnecessarily impeded by methodology, measures, and statistics, we will follow a somewhat different format from that used in journal publication. Nearly all of the results are presented in tables and supplemented in some cases with figures, so that they may be readily visible and appreciated. For our scientific colleagues, we provide, beneath each table in a footnote format, the statistical methods used to derive those tabled results. This should allow the clinical or general readers to bypass such information ordinarily provided in the text in pursuing the more clinically informative story line we wish to retain in the text. For similar reasons, we provide descriptions of the measures that we collected in this project in gray-shaded sidebars, such that the scientific reader interested in those details about the particular measures under discussion may have that information available. We believe that this does not detract from the reasoning and general flow of the ideas we present for our clinical readers. We hope that this approach to formatting of this book and specifically our methods, findings, and conclusions will prove satisfactory to the diverse audiences we are striving to reach (scientists, clinicians, students, and the educated general audience).

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