

## PREFACE

*“What has made all the difference for me is learning what other parents know and knowing that I am not alone. It’s too hard to try to do this all on your own.”*

*“In my opinion, the only way to make things change is to become more involved and not just trust everything the professionals tell you.”*

*“Trust the voice inside that is uncomfortable facing the daily challenges of ADHD and take it on, full force. The rewards are tremendous.”*

This book is for those who want to become experts in obtaining the best possible care for a child with attention-deficit/hyperactivity disorder (ADHD). Although I use the term *parent* throughout, I hope you’ll know I’m speaking to you too, if you are an adult who finds yourself to be the primary caregiver of, and responsible for getting help for, a child with ADHD—whether you’re a grandparent, a foster parent, an aunt, an older sibling, or anyone else.

### **Why Is This Book Needed?**

In my view, ADHD is a chronic problem usually covering all of a child’s growing-up years (not to mention his or her adulthood in most instances). As a result, you, like your affected youngster, are going to be dealing with the consequences of his or her ADHD for a long time, and if you are to succeed over the long haul, you will *need* to become an effective advocate for your child. In effect, then, this book is an advanced course in dealing with your child’s ADHD, and it is intended to complement (rather than replace) the various comprehensive handbooks for ADHD (such as Russell Barkley’s *Taking Charge of ADHD*). You can use this book alongside such other more basic books, just when you are learning more about ADHD and its management itself, or you can use it later, when you have run into the inevitable brick walls in finding the best treatment, creating the best learning environment, and/or constructing the most helpful overall program for your child.

As one parent put it, “It would have been a tremendous asset to us if someone had written a resource book pooling parents’ suggestions and ideas, thereby giving us

different avenues of approach to the question ‘OK, now that someone suspects our child has ADHD, whom should we see? What do we do first?’ ” This sentiment is in fact echoed by many parents who have a child with ADHD, because tackling all of the challenges is so much more complex than just dispensing a pill or taking your child to the doctor or a therapist on a regular basis. The harsh realities of managing a chronic condition such as ADHD stretch most parents and families well beyond what they would have initially anticipated, as obstacle after obstacle arises to thwart their attempts to “fix” the problem. I go into these inevitable obstacles in more depth in Chapter 1. For now, the fact that they are equal-opportunity hurdles means that *we all need help*. I say “we,” because I also have a youngster with ADHD, as well as four other children. My son with ADHD is now in his young adult years, so I can say “I’ve been there.” But as you will learn throughout this book, I am still “there”: The challenges I face have changed greatly since he was a youngster, but they don’t necessarily go away.

### **What Is at Stake?**

I often ask experienced parents who have a youngster with ADHD, particularly those who have become passionate advocates for improving the system for all children with ADHD, “Looking back now, how many years did you lose while learning how to make things work for your child?” Almost invariably, the answer is *between four and seven years*. Think of it: four or more years of your child’s development (and your daily struggles) lost trying to “get it right” before you finally learn how to get your child the best care possible!

But don’t despair if you’ve been slugging it out in the trenches for several years already and feel like you’ve been running in place (or even backward). As a parent or caregiver of a youngster with ADHD, you can use this book at any point along the way in the ADHD diagnosis, treatment, and long-term care of your child. Even if you’ve been struggling for years with your child/adolescent with ADHD, it is important to realize that it’s not too late. You and your child can benefit at any point along the way by applying the concepts and principles in this book. Your child continues to develop, and you can have an impact at any point in working to improve the care and assistance that he or she receives in school, medical, and home settings. What’s at stake at this point and as you look forward? Your child’s current happiness and chances for future success, your family’s tranquility, and possibly even some increased measure of sanity for you!

### **Who Needs This Book?**

Well, just about anyone who wants to get the most out of a child’s school, healthcare, and other supportive resources, as well as any parent or caretaker who wishes to learn how to make those resources become available by learning to work

the ropes of the system and negotiate what is needed for the child, the family, and themselves. Perhaps your child has just been diagnosed and treatment only started recently. Or perhaps you have reached a later point, when you realize there's no easy way out and there are no magic bullets—that the relief of getting a correct diagnosis is not the end but the beginning of your work on your child's behalf. Or maybe you're a parent who has been out there for some time—and you've become completely frustrated and need some help in negotiating the system. Or perhaps you're simply the parent who wants the best information available: You already know how to be assertive but appreciate having lots of practical resources gathered together in one book. Regardless of where you are on this personal pilgrimage, my goal in this book is to help you become savvy in all the areas in which you need to advocate for your child: getting your money's worth from the insurance system; getting the most out of overworked, underfunded educational systems; making effective use of fleeting time with doctors and therapists; turning the teacher into an ally; and refitting household systems so that a child's ADHD doesn't excessively affect siblings and other family members.

Not all parents need the same amount of help to become savvy in all areas, however. Therefore, this book offers a range of approaches for getting what your child needs under varying circumstances, from collaborative approaches to establish an alliance with school or medical professionals at the start, to more assertive and creative approaches that may be necessary when the system isn't working as it should.

Throughout this book, I attempt to help you stay in touch with the reality that resources may be limited, helping professionals may be overwhelmed, and you may not get everything that you want or need. But by becoming experts in the system, as parents, we will stand the best chance of getting what our children need.

## **How Should I Use the Book?**

Because my goal is to help you become an effective case manager for your child with ADHD, throughout this book you will find general tips on clear, assertive, and productive communication with mental healthcare, education, and other providers, as well as problem-solving tips from those expert parents who have gone through the process of managing their child's ADHD care. Practical tools, such as model dialogues, sample letters (to school boards, from lawyers, etc.), medication logs and other recording devices, and assertiveness and other exercises, are included in this book.

Practicality, problem solving, and putting wisdom to work are the book's repeated focus. In each chapter you will find discussions of at least three or four challenges or things to do that you couldn't or didn't do before, along with tips on how best to overcome these obstacles. If you're wrestling with any of the following questions, you'll find carefully considered answers not only from my professional experi-

ence but also from parents whose combined expertise adds up to a mountain of inventive ideas.

- What do I do when behavior therapies that sound great on paper or in the therapist’s office don’t work at home?
- How do I deal with an imperious doctor?
- How do I get the doctor, therapist, and teacher to collaborate with me in my child’s care?
- How can I get the best medical care for my child when my insurance won’t cover it?
- How can I tell when a second or third opinion is warranted?
- How do I exercise my child’s legal rights when things are going haywire at school?
- How do I make my child feel “normal” when outsiders are labeling him?
- What’s the best way to erase stigma and enlighten others when they are blaming me or my child for ADHD?
- How do I hold my family and my household—and myself—together while we’re expending so much time and effort on managing ADHD?

Many parents who’ve preceded you have struggled to find answers to the same questions, and wherever possible, I tell you what they came up with—as well as their thoughts and emotions along the way—in their own words. In fact, in the preparation of this book, over eighty parents have offered specific suggestions and advice concerning the most important things they learned in working with their children and with the system, knowing that this information would reach you throughout these pages. Please note that I have protected their identities by changing various specific details—name, age, gender, and so forth. In some instances I have also edited their quotes for clarity, but the language and advice is theirs. I am most grateful to these parents, as well as to CHADD, the organization that put me in touch with these parents. CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder), the leading parent self-help organization devoted to helping others tackle the problems of raising a child with ADHD, has greatly facilitated our shared effort through their marvelous president, Evelyn Greene, who contacted and encouraged members to contribute their advice.

Through these parents’ voices, and with my own experience as a parent of a child with ADHD and as a physician, I help you systematically identify, organize, and tackle the problems you have encountered and are likely still to encounter in managing your child’s ADHD. Chapter by chapter, I systematically take you through a planning/problem-solving process, helping you prioritize the various challenges you are facing, then offer guidance on how to put your plans into place. While many parts of the book are couched in these parents’ own words, I bear full responsibility for the final words in my role as the book’s author.

This book is divided into two parts. Part I provides general information on advocacy for ADHD. With the fundamental tools, skills, and information in this section, anyone can become an effective case manager for a child with ADHD. Part II

addresses each setting in which we as parents need to advocate for our children—healthcare, education, home, and the outside world—and tells you what you should expect and how to get it when it is not happening. Straightforward factual information on ADHD is delivered in a concise fashion and limited largely to what is needed in getting the best care possible for your child. Discussion of the nature of ADHD, its course, and the range of severity is succinct and includes liberal references to other sources. So if you've already digested the factual information in the comprehensive handbooks, you won't have to sift through it again. But if not, you'll find enough such information in the following pages to let you determine whether there are areas you want to investigate more fully elsewhere.

As a physician and child psychiatrist, I have had over twenty years' experience in diagnosing and treating ADHD. I have also had the privilege of working for ten years at the National Institute of Mental Health (NIMH), where I had oversight for the nation's ADHD research programs, as well as all other areas of federally funded research on treatments of childhood mental health problems. I have since directed the Center for the Advancement of Children's Mental Health at Columbia University. Yet despite all this "professional" experience, I have been awed by the extraordinary and often superior help that I and other parents have received through the process of parents sharing their insights and accumulated wisdom. In making this wisdom more widely available by writing this book, I believe, trust, and hope that I will do parents and families a greater service than I have ever been able to do in working with families one by one in my clinical practice. In fact, from here on out, I will make it required reading!

"I beat my head against the wall for the first few years, trying to make things work," recalled one mother of a boy with ADHD. "It was a difficult time for me. So one of the reasons I got so involved is to help other parents learn what I learned. They shouldn't have to make the same mistakes I made or lose the same time I lost."

Amen.