5

Talking to Parents about What to Expect

An evaluation of a child or adolescent for ADHD is a complex, multistep process that should produce a wealth of data on which to base a diagnosis, especially when done in a mental health setting. Following the principles and steps laid out in Chapters 2 and 3 and using the rating scales and other forms in Appendix A, you should be able to ascertain whether the individual youth has ADHD and any comorbid conditions. Your diagnosis is intended to lead directly to appropriate interventions that will help the child or teen function as effectively as possible from now on. But before you can recommend (and implement, if you will be the treating clinician) treatment, you need to talk to the patient's parents (and, in some cases, to the patient as well). Parents will be most likely to follow through on your proposed plan if they understand how and why your diagnosis was made, what the diagnosis means for their child now and in the future, and where the family will go from here.

This is the focus of the feedback conference, to which most parents will bring a variety of emotional reactions and questions. I introduced the goals of the feedback conference in Chapter 3. In this chapter, I help you prepare to respond to parental reactions and to answer their questions fully and compassionately. The chapter will also help you explain what the family can expect for this child and how parents can play a significant positive role in ensuring a healthy future for their growing child.

EXPLAINING THE DIAGNOSIS

The feedback conference should usually begin with a discussion with the parents of the findings you collected during the evaluation and what they signify for this child. Some clinicians wonder whether the child should be part of this discussion. My own experience is that this is not a good idea to begin with, as there are comments and critical points you may need to make candidly about the child or teen that the patient's presence will inhibit. Moreover, most children are not going to comprehend well the adult-level discussion you wish to have about the various findings and how they led to the diagnosis, and you don't want to have to substantially lower the level of the discussion here just for the child's or teen's sake. Also, parents need to be able to ask candid questions that they would be reluctant to raise if the child or teen were present.

In my experience, a separate brief discussion can be held with a teen or preteen (10–12 or older) who is of reasonable intellectual level and has shown some concern about their own adjustment, signaling awareness of problems and possibly openness to information about ADHD. Even then, however, my own experience is that most children and youth

do not see themselves as having the problems or, at least, the degree of problems that have been portrayed by parents and teachers during the evaluation. Many are not yet open to the idea that they have significant problems, much less a disorder. They did not call you for this evaluation, and they are usually not ready to accept and change their behavior. So, if you think it necessary, discuss ADHD in simplified terms with the preteen or teen in a separate meeting and let the parents have your full attention for this initial feedback conference.

Clinical Tips

- ✓ If you are not going to have a separate meeting with the patient, counsel the parents to be ready to educate the child about ADHD when the child indicates some openness to such information.
- ✓ Parents will recognize this "open window of opportunity to teach" when the child (1) asks questions about why they are struggling to succeed in certain activities, make friends, or get reasonable grades at school or (2) is lamenting yet another day in which something distressing and demoralizing has happened to them, such as receiving a time-out at school, criticism, or rejection by schoolmates or neighborhood peers.
- ✓ I advise parents to have some books or even videos about ADHD aimed at their child's age level available in the house to supplement their own explanation of ADHD to their child (you can find these at *www.addwarehouse.com* or any major Internet bookseller).
- ✓ Parents know the child far better than the clinician, of course, and thus are better prepared to know when the child will be open to such information about the disorder and will usually be more sensitive to the child's feelings during that discussion. To help the parents with this, I explain to them that I use the individual-differences perspective on human deficits:
  - Suggest that parents explain to the child that every single person has a profile of strengths and weaknesses, aptitudes and deficits. Recommend that they choose some of their own (weak vision, baldness, lack of athletic ability, poor art ability or mechanical reasoning, etc.) to disclose to their child, explaining that one simply accepts them, finds ways to compensate for them, and then gets on with trying to adapt to and succeed at life.
  - The next step is to note the child's own strengths and aptitudes.
  - Then parents follow this with mention of the child's ADHD-related deficits.
  - Finally, they can discuss ways that someone with those deficits can compensate for them or treat them, just as wearing glasses or contact lenses can correct for visual deficits. I find that this helps children see that they are just like all other people in having some deficits that they have to accept and deal with and be open to owning the disorder as nothing to be ashamed of.
  - Parents can now suggest that the child look at the books on ADHD they have obtained or watch a video.
  - Also, have parents Google ADHD success stories so their child can see all the celebrities who have succeeded despite ADHD (Michael Phelps, Adam Levine, Justin Timberlake, Paris Hilton, Howie Mandel, Bubba Watson, Ty Pennington, Simone Biles, etc.). A recent documentary titled *The Disruptors* (Soechtig, 2021) is

entirely about children with ADHD, their families, and the successes and struggles they have all had. It includes comments from many of the celebrities named above. Recommend that parents and older children or teens watch it together.

- The education of the child about their ADHD is not done in one single sitting but occurs over multiple occasions as those windows of opportunity to explain ADHD arise, as noted above. Should the child have many questions that parents do not feel confident answering, suggest that they all meet with you for a further opportunity to have the child's questions answered.

The parent feedback conference will certainly include discussion of relevant findings regarding the various concerns the parents brought up during their initial interview (school functioning, peer rejection, home conflicts, etc.). A primary focus of this meeting is, however, to explain to them whether the child has met the diagnostic criteria for ADHD (and any other disorders) as set forth in the most recent version of DSM (currently DSM-5). In many cases, especially if you operate within a specialty clinic for ADHD, the child will meet such criteria.

Because parents vary in their readiness and willingness to accept a diagnosis, I find it helpful to go through each criterion and explain how the information collected about the child fulfilled it. It is important for parents to buy in to the diagnosis if they are to support any treatment the child ends up receiving.

Developmental Inappropriateness

1. Explain how many symptoms of **inattention** were endorsed as occurring often or more frequently (at least six out of nine) from the parent interview, the teacher interview (if one was done), or the teacher rating scale of ADHD that was completed. Assuming you used a parent rating scale of ADHD symptoms, as recommended here, you can also present the information on the percentile rank of the child's symptoms relative to those of other children of the same age and sex to provide further evidence of the inappropriateness of the child's symptoms compared with those of peers.

Clinical Tips

- ✓ Typically, I look for symptoms to be at least at the 93rd percentile to be clinically significant (1.5 *SD*s above the normal mean) and refer to those between the 84th and 93rd percentile as marginally significant.
- ✓ Note any disparities between the two parents from their interview, but qualify this by explaining that disparities are common, depending on who spends more time with the child, especially engaging in schoolwork, chores, or other situations requiring self-regulation. So long as at least one parent reported sufficiently high symptoms and the reports of the other were also elevated, even if not to the same degree, there is little to make of such differences. But if one parent reported incredibly low symptoms and those reported by the other were in the clinical range, take time to explore this difference further with the parents to identify its reasons. Sometimes one parent, more often the father, denies any problems with the child, sometimes claiming to have been this

way as a child and having turned out just fine. (Given the genetics of ADHD, the father may well have had it as a child, and the relevant issue here is not how fine this adult turned out, which is arguable in some cases, but whether life could have been better had the parent's own struggles in school or with peers been identified and treated.)

- ✓ If scales were collected from more than one teacher, present an average across the scales if they are relatively consistent with each other. If they are grossly inconsistent between teachers, explain why that might be the case and whether it influenced your decision making about the diagnosis. For example, if the art, music, or gym teacher reported a low level of symptoms, this makes perfect sense, given the higher level of activity in those classes, how much more fun and rewarding they may be to the child, and that they involve far fewer demands for sustained self-regulation. In contrast, the English or math teacher may have reported a significant amount, enough to place the child at an extreme level (the 93rd percentile) compared with other children of the same age and sex. This, too, makes sense given the far greater demands such classes place on sustained self-regulation and that they involve more seatwork, mental concentration, and less reinforcing activities to the child.
- ✓ Give an example of one or more symptoms endorsed by both parents and teachers if you think that is helpful.

2. Explain how many symptoms of **hyperactive–impulsive behavior** were endorsed for this child, just as you did for the inattention symptoms, again highlighting both parent and teacher reports. Once more, six of nine symptoms are required for the cutoff to be met on this symptom list. Some children qualify on both symptom lists, but that is not necessary for the diagnosis, so long as six of nine are present on *either* list.

Note that if a female child meets criteria for fewer than six symptoms on either list (say, five or four) but was rated by parents and teachers on the ADHD rating scale as being in the clinical range (> 93rd percentile), the criteria for developmental inappropriateness have been met. The reason is that the symptom thresholds on these DSM lists were based more on males than females, and thus they may be slightly biased against diagnosing girls.

Clinical Tip

- ✓ Remember, the rating scales offer a far more accurate picture of developmental inappropriateness for females than does DSM in such cases. Even in males, the scales offer a finer grained numerical estimate of developmental deviance than the more crude, and global, symptom count from DSM that is used across so many different ages across childhood and into adolescence.

Duration

Discuss whether the child has met the criterion for the **duration** of symptoms, which is at least 6 months. This is usually readily drawn from the parent reports about the age of onset of the child's behavioral difficulties.

Clinical Tip

✓ The duration criterion is easily met for children 4 or 5 years of age and older but could be harder to establish for a preschool child, as some ADHD-like behaviors are more normative until around 3–4 years of age. With these young children, look for additional evidence of disorder by identifying any impairment from such behaviors (see the subsection on impairment later in this chapter), such as a preschooler being asked not to return to their day care or preschool setting because of persistently disruptive behavior.

Age of Onset

Did the child show any symptoms that caused concern or impairment by age 12? If so, their inclusion in the DSM criteria means that you should mention it to parents, but I prefer not to place any emphasis on this criterion if all others were met. One would never abstain from giving a diagnosis just because the age-of-onset criterion had not been met by age 12.

Clinical Tips

✓ The fact that this information usually comes from the parent interview can limit both its reliability and its validity. As noted in Chapter 3, parents (and patients) can be off by as much as 2–5 years (later) in reporting onset from what it likely was in reality, so even a reported onset up to age 15–16 is likely sufficient to meet this requirement.

✓ When parents doubt the diagnosis, claiming that the child was "just fine" until after age 12, when problems became evident and now meet the criteria, stress that onset means onset of *symptoms,* not of *impairment*. A child of high intelligence may have shown symptoms of ADHD well before age 12, before it adversely affected their educational functioning, which might not be until middle or high school.

Situational Pervasiveness

Discuss how you determined that the child's symptoms were evident in more than one setting or major life activity, typically construed as home, community, school, or peer functioning. Usually this will be by parent report from the interview, but it may also be evident in the teacher ratings.

Impairment

Besides degree of symptoms, the most important criterion to establish that a mental disorder exists is **impairment** as a consequence of those symptoms. Explain to parents why you believe their child's impairments are in fact caused by the symptoms identified. The term refers to ineffective functioning in a major life activity that is sufficient to have led to adverse consequences for the child (peer rejection, frequent family conflicts,

inadequate self-care and adaptive functioning for age, risk-taking behavior that has led to frequent accidents and injuries, day care or teacher complaints about behavior or academic performance, school discipline or dismissal, etc.). Impairment must be evident in one or more major life activities, typically construed as home, community, school, or peer functioning.

Clinical Tips

- ✓ It is incredibly rare for this criterion not to be met, given that it is most often the reason that the child has been referred for this evaluation in the first place. But be alert for the possibility that the parents have sought an evaluation because their child is not keeping up with the other students in a high-achieving school or other setting, not that the child is demonstrating impairment when compared with the typical population. In some instances, high-resource families who emphasize education and have intelligent children may construe grades that are lower than they expect, despite being satisfactory, as a sign of a disorder when that is not the case. The goal is to help parents understand that the problem they are observing is a mismatch between child characteristics and the school (or other setting) in which the child is enrolled, not a consequence of a neurodevelopmental disorder. Having a candid discussion about the difference and the likely need for these parents to lower their expectations for this child to more appropriate levels is a good place to start. In some cases, it may be warranted to recommend that the child be placed in a different school with more typical peers if the demands of the initial school are simply too great for this child's level of intellectual ability or academic achievement skills.
- ✓ Also, be aware that a problem of parental denial of disorder can arise when parents are under coercion to seek the evaluation of the child, as in a court-ordered examination or one strongly encouraged by school personnel. This can make it far harder to establish that all DSM criteria have been met due to parental refusal to disclose the true state of their child's problems, perhaps for fear that the child may be removed from their custody or that it will lead to one parent gaining sole custody in a custody dispute. In those cases, information from others, especially teachers, is vital to reaching a diagnosis.
- ✓ There may arise cases in which the child or teen falls just a symptom or two shy of the requisite six symptoms on either list and may score in the marginally significant range of symptoms on the parent and teacher rating scales (86th to 93rd percentile), yet there is clear evidence of harm or impairment occurring for this child. In such cases, you can tell parents that this is an instance of marginal, mild, or borderline ADHD, and that you believe the diagnosis is still appropriate and that interventions are warranted. Explain that ADHD is a spectrum representing a more extreme end of a normal continuum and not a category. Thus marginal cases will exist in which children are suffering impairment. After all, it is the relief of suffering (reduction of harm or impairment) that is our overriding goal in this enterprise, so it is appropriate to diagnose and treat marginal cases when impairment is evident despite not all DSM criteria having been satisfied.

ADHD Presentations

As I noted earlier, ADHD is really a single, albeit heterogeneous, disorder comprising two highly related dimensions of symptoms that can vary separately over time in their relative levels of severity and can change in that relative nature with development. You should acknowledge the type of presentation that the evaluation has established as present at this time but also explain that this could change in a week, month, year, or longer to a different presentation, yet still represent the same disorder.

Clinical Tip

✓ Stress to parents that one dimension of symptoms may be more prominent in their child for the time being, and likely more impairing than the other, but that the level of severity is not fixed and is highly likely to change over time. *What is more important is that the existence of ADHD has been established.* I find it important to make parents aware of this potential fluctuation in the two symptom dimensions so that they are not misled by inaccurate information in the trade or mainstream media that claims otherwise (that there are different types of ADHD) and that is out of date.

Other Disorders

1. Briefly explain to parents that an important element in reaching a diagnosis of ADHD or any other disorder is **differential diagnosis**—the need to weight various types of information in determining that the diagnosed disorder is the one that best explains the child's symptoms. Share with parents that you considered whether other neurodevelopmental or psychiatric disorders that nearly always produce inattention were ruled out in this case and why, so parents can appreciate the care that was taken in reaching the final determination of ADHD as the most likely disorder involved in this case.

Clinical Tip

✓ *ADHD inattentive presentation (or ADD) versus CDHS (or SCT).* As discussed in Chapter 4, there is a second attention deficit that is being increasingly studied at this time. Although it is not an official disorder in the DSM, it nonetheless is gaining substantial evidence that it exists, is distinct from ADHD, may overlap with it, and produces its own forms of risks and impairments in contrast to ADHD. Originally called *sluggish cognitive tempo* (SCT), the condition has been renamed *cognitive disengagement hypoactivity syndrome* (CDHS) by a work group of SCT investigators in November 2021 (Becker et al., 2021) to give it a less offensive and more accurate name, representing its cognitive and motor symptom dimensions (I am on that work group).

So, which one is it, ADHD or CDHS? One simple way of determining this is to establish that the child has six or more symptoms of inattention but three and usually fewer symptoms of hyperactivity/impulsivity (HI). That is likely to be a case of CDHS, as CDHS does not involve problems with inhibition and self-regulation like those inherent

in ADHD. So, if the child was ever considered impulsive and poorly self-regulated, it's ADHD. If there has never been a whiff of impulsivity during development as a persistent problem and the child is more often viewed as passive, hypoactive, or overly inhibited, it is most likely CDHS.

This is where your use of a CDHS or SCT rating scale can come in handy in showing just how much CDHS is present and that it is the more impressive problem in the child than the inattention documented on the DSM symptom review. Now, if the child had six or more inattention symptoms and four or five HI ones, then for the time being the diagnosis should be ADHD of the inattentive presentation, as there is clear evidence here of a self-regulation disorder even if it falls somewhat below the official symptom threshold for HI symptoms. If the child has the ADHD inattentive presentation, you don't need to explain here what CDHS is to the parents. The child just has a milder version of the combined presentation. But if the child's problems are more consistent with CDHS, the child has high ratings on the CDHS/SCT scale, and there is no history of disinhibition and generally poor self-control, then it is CDHS and not ADHD that should be diagnosed unofficially, and the parents should be told about this new attention disorder. Yes, for the sake of billing insurance and clinical records, some official diagnosis must be given—that is, ADHD inattentive presentation—but make it clear to parents that this diagnosis is purely for administrative purposes and not the "real" diagnosis in this instance; that is CDHS.

2. Explain any conclusions you have reached about comorbidities. See Chapter 4 for information about diagnosing comorbid disorders that you can pass on to parents at your discretion.

EXPLAINING CURRENT AND FUTURE RISKS DURING THE FEEDBACK CONFERENCE

At this point, parents are likely to want to know what the prognosis is for their child and what they can do to reduce the child's impairments and boost the chance of a happy, healthy future. Statistics regarding life outcomes, persistence of ADHD into adulthood, and health risks that you can share are provided elsewhere in this book (Appendix A, Handouts 3–14) and in the following pages. What is important to stress to parents right now is that there are effective treatments and that they can reduce impairments considerably, if not erase ADHD symptoms entirely.

As discussed in Chapter 2, if left untreated, ADHD poses considerable risks for other problems to arise both now and in the future. It is just as important to explain these to parents as to explain the basis on which you made a diagnosis of ADHD (and any other disorders). Not explaining these risks—and what parents can do now to minimize them—would be tantamount to diagnosing a child with diabetes without discussing what the future risks are if the diabetes is not managed (vision and other eye problems, including eventual blindness; heart and circulatory problems; risk for infection and even gangrene and, should that happen, the risk for amputation of digits and limbs, etc.). Not only does explaining the risks associated with untreated ADHD ensure that parents perceive the

gravitas of the present situation, but it can offset any misperceptions relayed through the media that ADHD is either a gift or "superpower" or just a trivial disorder of attention (and possibly forgetfulness and organization), as if being "a ditzy child" were its *sine qua non*. So, take time in the feedback conference to discuss potential risks if treatment is not undertaken.

Clinical Tips

- ✓ As commendable as it is to treat a child to reduce current adverse consequences, we also need to treat (as with diabetes) to prevent possible future secondary harms from an unmanaged disorder. The diagram showing potential impairments and harms associated with ADHD provided in Chapter 2 (Figure 2.1) is also provided as Handout 13 in Appendix A. It can be copied and given to the parents as part of this discussion.
- ✓ Parents may very well feel overwhelmed by the myriad risks associated with ADHD, so be sure to explain that not all children with ADHD will experience all these risks or to the same degree. Indeed, most will not experience most of these risks. The risks are based on studies of large samples of children and adolescents with ADHD that show that they have a higher likelihood of experiencing them than do other children, even if a majority of them do not fall prey to that type of harm or risk. The risks are averages, not guarantees of every outcome. Providing this perspective can mitigate the possibility of demoralization and dysphoria in parents. Risks represent an increased probability of such an outcome, not a guarantee.
- ✓ The opposite, failing to discuss such risks or minimizing them too greatly, can be just as problematic. Parents could end up having a Pollyanna-ish view that ADHD is no big deal and nothing that a little more sleep, less caffeine and screen time, and more fish oil supplements can't address. Clearly, therefore, you need to walk a fine line in this discussion, neither over-pathologizing ADHD and its risks nor understating those risks. The goal is for parents to take ADHD and the need to treat it seriously without feeling utterly overwhelmed emotionally and helpless in the face of the tsunami of potential harms. It may help to give examples of the harms ADHD can do in various domains of life; see the box "A Sampling of Higher Risks Associated with ADHD" on page 88.
- ✓ Perhaps the best way to walk that fine line effectively is to repeatedly emphasize what research has shown. *Virtually every major type of risk studied to date—from accidental injuries to teen pregnancies to risk of suicide to car accidents, crime, substance use, and abuse—has been shown to be reduced to typical or near typical levels by treatment, and in particular the ADHD medications.* So, get out Figure 2.1, briefly note each major category of risk, and let parents see the specific ones in each category, using your clinical judgment to emphasize some more than others based on what you have learned in the evaluation while being sure to at least mention all of them. (See Table 5.1 for comparative lists of risks associated, respectively, with inattention, HI, and emotional regulation deficits.) Then state that evidence to date shows that treatment can greatly reduce such future risks while also addressing the current ADHD symptoms and extant impairments. For more details on each domain of heightened risk that you can refer to in talking to parents, see Handouts 8, 13, and 14 in Appendix A.

✓ Wrap up this discussion by instilling hope in parents that, although ADHD is a serious condition, they have chosen to do the right thing by pursuing the evaluation and being open to the various treatments you will shortly discuss with them. Also note that ADHD is among the most responsive disorders to existing treatments, especially medications, with more cases responding to a greater extent to available treatments than in nearly any other serious psychiatric or neurodevelopmental disorder. To make this point concrete for parents, consider giving them this example: There are meta-analyses that show that antidepressants and antianxiety drugs improve symptoms by about one-third of a standard deviation, known as an effect size. ADHD medications change ADHD symptoms from .68 to 1.4 standard deviations and thus are two to three times more effective than these other widely dispensed medicines.

A Sampling of Higher Risks Associated with ADHD

A wealth of data is available on the possible negative consequences throughout life for those with ADHD who do not receive treatment. These include (even with treatment) a higher risk of mortality, as detailed in the following:

- Children with ADHD are nearly twice as likely to die in childhood.
- Adults with ADHD are 3 to nearly 5 times more likely to die by midlife compared with people without ADHD.
- During any 4-year period, adults with ADHD in the United States are almost twice as likely to die as adults without ADHD.

The negative consequences also include a decreased life expectancy of up to almost 10 years. These risks are very difficult for parents to consider, and it may be suitable to point this out only to those stuck in denial and resistance to treatment. But the following examples of risks (not all-inclusive) can drive the point home that mitigating risks by managing ADHD through effective treatments is paramount.

- The risk of injury is higher for those with ADHD across the spectrum of specific injuries, from fractures and sprains to bruises, burns, and more.
- Motor development is delayed in those with ADHD (e.g., developmental coordination disorder in 30–50% or higher, a 5-year lag in development of movement skills and agility compared with their peers into adolescence, and reduced physical fitness, strength, and stamina as measured on physical fitness tests).
- Those with ADHD have a greater risk for language disorders: expressive language deficits in 10–54%, pragmatic deficits in 60%.
- Academic impairments are comparatively high in those with ADHD: poor school performance in 90% or more of those with ADHD, a 10- to 15-point deficit in academic achievement, and learning disabilities in 24–70%.
- Positive adjustment in adolescence is lower for those with ADHD in both girls (20–65%) and boys (10–86%). The reason is that ADHD management continues into adolescence in only 25–30% of cases, and even fewer into early adulthood (5–15%).

TABLE 5.1. Increased Risks Linked to Different Symptom Lists

Inattention	Hyperactivity/impulsivity	Emotional self-regulation deficits
Poor attention to traffic density and speed while crossing streets when vehicles are present	Emotional impulsiveness and poor emotional self-regulation	Social rejection
Greater risk for children in pedestrian–auto and cyclist–auto accidents in traffic settings	Development of oppositional defiant disorder (ODD)	Interpersonal hostility and marital dissatisfaction
Greater crash risks when driving a vehicle (made worse by in-vehicle distractions, such as smartphones)	Peer relationship problems and peer rejection	Intimate partner violence
Accelerated use of nicotine products following experimentation (perhaps due to self-medication—nicotine has beneficial effects on attention)	Likelihood of experimenting with drugs or other substances	Greater number of job dismissals
Poor follow-through on chore performances and completion of other tasks in the home and community settings	Excessive speeding when driving a vehicle	Greater parenting stress and family conflict in families with children with ADHD
Poorer work performance as teens and adults in employment settings	Risky sexual behavior and risk-taking behavior more generally	Greater parenting stress in parents who have ADHD
Inattention to the comments and needs of others in social interactions	Suicide attempts	Greater risk for impulse buying, excessive debt, and poorer credit ratings by young adulthood
Reduced self-monitoring in social situations	Accidental injuries	Road rage, or the aggressive use of a motor vehicle against another driver
	Reactive aggression when provoked or frustrated	Driving while intoxicated
	Worsening of inattention symptoms by adolescence	Risk for vehicular crashes
	Greater risk for adverse health outcomes, earlier mortality, and shorter life expectancy	

Clinical Tip

✓ In discussing these various risks based on specific symptom domains, be sure to consider each child's symptom profile so as to increase or decrease the weighting you might give to some of these risks in your discussion of them, thus tailoring or individualizing the material for each case.

ADHD-Increased Risks in Various Life Domains

ADHD is among the most impairing disorders clinicians manage on an outpatient basis, being rivaled or exceeded, depending on severity, mainly by the other neurodevelopmental disorders: autism spectrum disorder (ASD), bipolar disorder (BPD), and intellectual disability (ID). This was made evident to me from the results of the nationally representative sample of children in the United States I used to norm the Barkley Functional Impairment Scale—Children and Adolescents (Barkley, 2012). Parents reported whether or not their children had been diagnosed with any other psychiatric or developmental disorders. We used those reports to cluster children by diagnosis and compare them with

ADHD cases that were defined as ADHD in two ways: (1) as parent-reported diagnosis and (2) as determined more rigorously by our research criteria that required the child to be rated by parents on the DSM symptoms as placing at or above the 93rd percentile (+1.5 *SD*s) and to be impaired in at least one major life activity. Because ADHD overlaps with many of these disorders and often worsens their impairment, as discussed in Chapter 4, its influence on the ratings of 15 different home, school, and community settings was removed statistically in the comparisons. *The end result was that ADHD produced larger degrees of impairment (as measured by effect sizes) on both the Home–Leisure factor and the School–Work factor than all 14 other disorders,* though ASD, BPD, and ODD were only somewhat less so and closer to ADHD in this regard. This effect of ADHD on impairment was especially strong if it was defined by the research criteria, under which it nearly doubled the level of impairment of those other disorders (ASD, BPD, ODD) in these factor scores.

Clinical Tips

- ✓ You might want to show parents Figure 5.1, which was drawn from a random representative sampling of the U.S. population in 2012. The data used to create the graphs come from a study comparing ADHD cases with a large community control group (Barkley, 2012).

  You can also explain to parents that, by adulthood, the number of domains previously or currently adversely influenced by ADHD has grown to such an extent that, on average, adults with ADHD place above the 93rd percentile (+1.5 *SD*s) in 5 or more of 15 domains we surveyed in their *current* functioning. The number of domains in which they may have been impaired at some time across their lifespan is considerably higher.
- ✓ For any parents who question how a "simple problem with paying attention or being too active" could cause so much harm, you can give them a simple overview of the extended-phenotype theory and my EF-SR theory of ADHD (see Chapter 1).

As noted earlier in the chapter, nothing is to be gained by overwhelming parents with the negative implications of their child's having ADHD. But knowing how broadly and deeply their child's life into adulthood can be affected by ADHD can provide great incentive to follow and support treatment recommendations. Where it seems wise, you can offer the following details:

- *Family relationships.* Because it interferes with compliance with house rules and parental dictates, ADHD can increase parent–child conflict, which can lap over into sibling conflicts. This strife is bidirectional and often worse when the child also has ODD or a parent has ADHD (as in 25–35% of cases), and the strife frequently increases during adolescence. These parent–teen conflicts may be related to specific topics, such as curfew, school performance, choice of clothing and music, disruptive behaviors within the family, sibling conflict, use of the family car, money, affiliation with certain friends, and even drug use. Obviously, such problems affect parents' ability to guide their children and keep them safe.

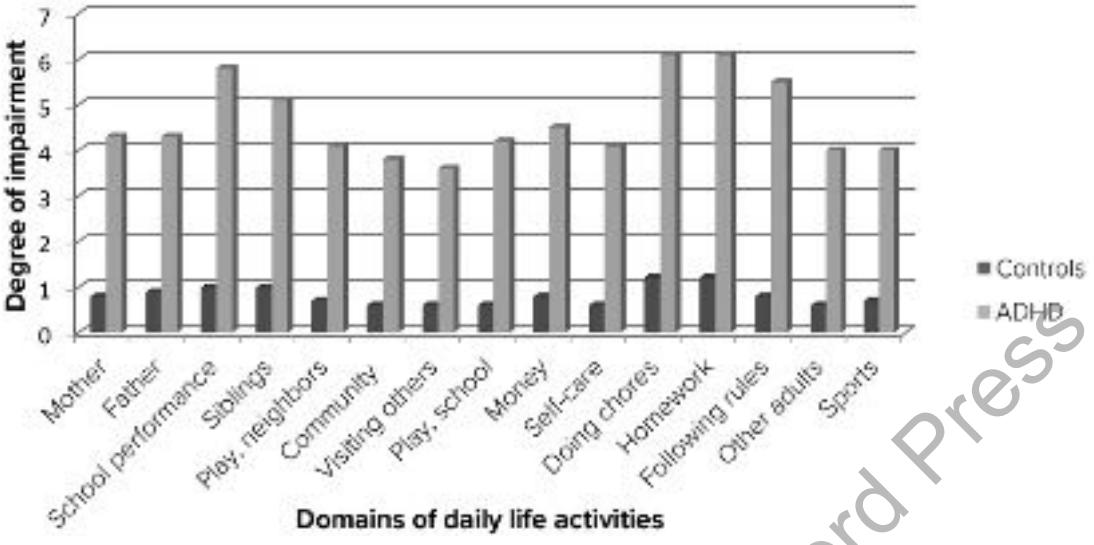

FIGURE 5.1. Comparisons of ADHD and typical children in a national U.S. sample concerning parents' ratings of impairment in 15 different domains of daily life activities. Data used to construct the graph are from Barkley (2012).

- *Peer relationships.* People with ADHD are much more likely to experience peer relationship difficulties, with up to 50% having no close friends by the end of second grade. That figure rises to 70% if they also have ODD/CD. The problems with peers persist to varying degrees into adulthood. More specifically, those with ADHD are more likely to be rejected and less likely to be accepted by the broader peer group, less likely to have mutual friendships, and more likely to have friendships that are more negative in quality and less stable over time. They are more likely to bully or to be victimized themselves and are more likely to have interactional problems on social media as well as in person.

- *Education.* Parents are probably well aware of impairments in this domain of their child's life. They have been discussed in Chapter 2, and treatment of them is discussed in Chapters 6 and 8.

- *Dating and sexual relationships.* Teens and adults with ADHD report poor-quality dating relationships 4–5 times more often than their typical peers, and adults who grew up with ADHD are less likely to marry and more likely to marry at a later age. Once married or cohabiting, they report higher levels of marital dissatisfaction, a greater likelihood of having extramarital affairs, and greater risk for marital separation. Over a 30-year follow-up, adults with ADHD have a 2.5 times higher divorce rate by midlife than people without ADHD (31 vs. 12%). Older adults with ADHD (ages 60–94) were also more likely to be divorced or to have never married, but also to have fewer family members in their social network and to experience emotional loneliness. Also troubling are findings of greater verbal aggression and more intimate partner violence in male adults with ADHD. As noted elsewhere, those with ADHD are likely to have sex at an earlier age and to experience more teenage pregnancies—but it is worth pointing out that a recent study showed that medication reduces the risk for early pregnancy by 30% or more.

• *Occupational functioning.* At least as adolescents, those with ADHD seem to be no different from normal adolescents in their functioning in their jobs. But consider that most jobs taken by adolescents are unskilled or only semiskilled and are usually part-time and typically of limited duration (summer months). Once they enter adulthood and take on full-time jobs that require full-time labor and mature EF-SR abilities, independence of supervision, acceptance of responsibility, and periodic training in new knowledge or skills, their EF-SR deficits handicap them on the job. Their occupational status by adulthood often ranks significantly lower than that of control groups, even into their 40s. They are viewed by employers as performing significantly worse in their jobs and consequently are more likely to be fired than typical adults.

• Adults with ADHD also have twice the risk for workplace accidental injury, higher rates of absenteeism due to sickness, use of more sick days, and more unexcused absences from work and are more likely to be on unemployment benefits, disability, or social assistance.

• They may also show up to a 33% reduction in earnings and a 15% greater likelihood of being on unemployment support or other forms of social assistance. More young adults with ADHD were also still residing with parents or had returned to do so after failed gambits at independence. They were also receiving greater financial support from parents into their late 20s or 30s.

• *Financial problems.* Given the poor impulse control and self-regulation deficits associated with the disorder, problems with handling money would be anticipated in adults with ADHD. Research shows that fewer young adults with ADHD had ever had a credit card or a savings account. More reported having trouble saving money to pay their monthly bills. Their average savings were lower, and they owed significantly more money to other private individuals than typical peers. At our age-27 follow-up, the same individuals reported more trouble managing their money, buying on impulse, missing rent payments, having utilities turned off for nonpayment, having a vehicle repossessed, declaring bankruptcy, and not saving for retirement than did children in the control group by adulthood.

• *Driving risks.* Driving is a domain that can markedly increase morbidity and mortality for teens and adults with ADHD, as well as for others they encounter. Specifically, teens and adults with ADHD are more likely to have driven an automobile before being licensed and to have more speeding tickets and accidents (scrapes and crashes), though not all studies show this. They are likely to be more impulsive, risk taking, and distracted in behind-the-wheel driving observations taken in natural settings. They display greater levels of road rage, are more likely to have had their licenses suspended or revoked, and are not likely to view their driving performance as being that much different from other typical drivers, even though it is significantly worse.

HELPING PARENTS COPE WITH THE DIAGNOSIS OF ADHD

Having their child evaluated is a big step for parents, who have invested a good deal of mental, physical, and emotional energy into trying to do right by their child. This sets the context for how they may receive the diagnosis that their child has ADHD.

Clinical Tips

- ✓ First, take a moment after explaining how you reached the diagnosis, its causes, and its risks, and ask how they feel hearing all of this. Just as many people say, upon first hearing that they have cancer or some other serious diagnosis, that they were numb and stopped listening so as to just process this change in their circumstance, many parents experience a moment of shock and disbelief when they are told their child has ADHD or some other neurodevelopmental disorder. You may have just told them their child is not who they thought they were, thus forcing a sizable reframing of their perspective about their child.
- ✓ Do *not* minimize this moment. Parents who have already done a lot of reading and research about their child's likely problems and treatment may be well past this moment of shock and realization and instead feel vindicated that their concerns are supported by an official diagnosis, but others may find the moment of diagnosis heartbreaking.
- ✓ From the several thousand parents I have counseled personally about ADHD, as well as the thousands of others I have heard from at my public speeches, I have come to realize that parents' emotional reactions to information about ADHD vary widely yet are an important part of their adjustment to their child's diagnosis. They also influence the quality of the investment they are able to make in helping and advocating for their child. So take time after rendering the diagnosis in the feedback conference to get some idea of where the parents are emotionally and in their reaction to that disclosure before barreling on into a treatment plan.
- ✓ As clinicians well know, parents frequently experience a grief reaction when told that their child has a chronic medical, developmental, or psychiatric disorder. While the stages of grieving are not as fixed in nature and sequence as was once believed, the phases of grieving may still occur even if their existence and order are not guaranteed.

Denial or Relief?

Some parents may initially engage in *denial* of the label or diagnosis or the largely neurological basis of it. They hold desperately to their original view that nothing is so wrong that it cannot be righted by some diet, form of counseling, cutting down on screen time, or simple behavior management methods. This reaction is likely to occur when the parents did not suspect that much was wrong with their child in the first place. Typically, it is a relative, a day care worker, a preschool teacher, or even the parent of a playmate who broaches the possibility that a problem exists. Until then, they didn't see this problem coming at them or their child. When parents are the last to know that their child has problems—in this case ADHD—it is natural for them to deny or minimize the extent of the problem until they can reevaluate the information they are receiving and come to see the problems of their child on their own.

Clinical Tip

✓ If you find parents resisting a diagnosis, the best way to erase their doubts is to do what I recommend first in the feedback conference—explain the basis for your rendering this diagnosis. The data don't lie. You covered that material in the hope of heading off parental denial that can result from a superficial explanation of the child's diagnosis. But should this denial persist through this feedback conference, encourage them to seek a second opinion from someone you trust who knows about ADHD.

Most parents willingly accept the information they receive about ADHD from a professional, especially after such a thorough evaluation and explanation of the findings. Some may even embrace its message as the answer they have desperately sought for so long. Finally, they have a name for their concerns about their child and can pursue ways to help. These families often have a welcomed sense of *relief* from the burden of uncertainty—and often alleviation of their guilt as well—guilt based on the possibility that they had caused this problem through inept child rearing. By explaining that ADHD has a biological basis, you allow them to let go of the sense that they personally created the problem.

Clinical Tip

✓ I encourage you to state this matter-of-factly: "You did not cause this condition in your child through the way you have raised them." For many parents that is the "get out of [guilt] jail free" card they may be open to hearing, with the sense of relief that it may bring to them.

Anger

For some parents, a diagnosis of ADHD evokes *anger* aimed at anyone who may have previously assured them that nothing was wrong, such as a well-meaning pediatrician; anger at those who blamed the problem on the parents' child-rearing methods or on family problems, such as their own parents, a relative, or even a pastor; and anger at the missed opportunities they would have had to improve their child's well-being had someone told them the truth earlier. Sometimes other people had been dismissive of the parent's concerns, reassuring them that nothing was wrong or that it was just a "phase" children may go through and that the parents should just hang in there, give more hugs, and all would be well. All too often, practitioners in my field, relatives, and the media chastise, shame, or otherwise "bash" parents in their quest to lay blame for the disorder. When the parents finally realize they are not at fault and that the disorder is "real," anger and resentment are not unreasonable reactions.

Grief

It is both natural and healthy for parents to manifest a mild *grief* reaction to the information about their child's ADHD. Almost all parents, when confronted with the news that their child is disabled in some way, will grieve for this loss of normalcy. Some parents

grieve over their child's future and attendant risks; others are reacting to the alterations that the family must make to accommodate ADHD.

Clinical Tips

- ✓ Tell parents that most parents you have counseled about ADHD had such a reaction to varying degrees, so that if they find themselves having those feelings, it is entirely normal and to be expected. They should not fight it or judge it as pathological. Explain to these parents that for most people this grieving will pass as they reframe their views of their child and the child's problems.
- ✓ I have been told by other parents, however, that they never fully resolve this grief. It's OK for you to tell parents this, too. Grieving can come and go. It's part of the normal human response of parents to dealing with a chronic condition in their child. Assure them that they will adapt to it and then for a time seem to put it behind them as they confront the day-to-day responsibilities of child rearing and work. But when the child has been doing particularly well for a long period and then has a regression or a significant crisis, the feelings of mild sorrow could return.
- ✓ If feelings of sorrow do return, reassure the parents that they can call you to talk about it, or send them to a parents' support group in your region where they can commiserate with other parents who have children with ADHD. They should be told that such commiseration can help tremendously. So suggest that they check out *www.chadd.org* for a local parent support group or supportive Internet chat rooms or blogs. If the grief reaction persists, consider offering them some short-term counseling with you or a more appropriate professional who is knowledgeable about ADHD or therapy with parents of children with disabilities.

Acceptance

I nearly always explain to parents as part of my commentary on grieving that it is a natural process that often leads to the desired outcome of dealing with information on ADHD: acceptance of their child for who they really are. *Acceptance leads to embracing the concept of their child as who the child rightly is* as opposed to what they had hoped their child would be when first learning they were expecting.

Clinical Tips

- ✓ Your job here is to encourage the parents to accept the child they have and love the one they are with and stop pining for the concept of that child they dreamed about while awaiting its delivery.
- ✓ I also tell parents that there is peace of mind at the end of this phase, as if a cloud has been lifted, allowing the parents to see their child's problems and their own reactions to these problems more realistically. From this new perspective, they can more clearly see that their child has a problem that the child did not ask for, cannot help having, and needs their help in dealing with, including protection from those who will not understand. The child needs the parents' advocacy to obtain the child's legal entitlements

among the community and school services. This change in perspective can be profound and moving, both to the parents experiencing it and to anyone who has the privilege to witness it as I have. Please browse the Internet or search for a video on YouTube called *Welcome to Holland,* bookmark it, and share it with parents. Be sure to find the ones that deal with ADHD, as there are many variations of it for various childhood disorders such as ASD and Down syndrome. It is a presentation designed to help parents confront and resolve their grief and anger and come to acceptance of having this particular and special child instead of the one they thought they would have.

- ✓ Further reassure parents that when they have reached this stage of acceptance, they may now thirst for knowledge about how best to help this child. Perhaps they are now motivated to enter a support group, counseling, or a formal child management training program that provides them with the skills and techniques that may help their child succeed. They may also find that they want to know about ways to modify the environment, not the child, in order to reduce the problems the child may experience in specific situations. Tell parents that the goal is to permit the child to succeed, given the symptoms and circumstances, and not to get rid of the ADHD.
- ✓ Help parents to learn that acceptance also means recognizing that some things simply cannot be modified to permit children with ADHD to succeed maximally or adapt as well as do children without ADHD. Failure to accept some limitations for their child can potentially instill intolerance, anger, and frustration in them, as well as put undue pressure on the child to conform to their own very unreasonable expectations.
- ✓ The bottom line is that parental acceptance of a child's ADHD and all it may entail will free them to fulfill the role so crucial to the child's progress. Counsel them that, more than other parents, these parents must actively support the child's self-esteem, perhaps via less traditional routes, and work to improve their competence in meeting the daily demands of life, whereas children without ADHD build their own paths through academic and social success.
- ✓ Note that they will need to exercise creativity to find successful outlets for their child, perhaps in organized sports, fine arts, hobbies, science, mechanical projects, or even in more nontraditional pursuits, such as music, drama and acting, photography, electronics and computers, cooking, and so forth.
- ✓ You can suggest that they Google ADHD success stories to see the myriad ways in which well-known people with ADHD have succeeded, often in surprising ways.
- ✓ Further, advise parents that once they have truly accepted their child's ADHD, they can look beyond the child's limitations and see—as no one else can—their unique strengths and talents.

WRAPPING UP THE FEEDBACK CONFERENCE

At this point, parents should understand that a diagnosis of ADHD does not sentence their child to a lesser life, that symptoms can be managed and impairments minimized with proper treatment, and that parents themselves have a lot of power to help their diagnosed child. Before launching into a treatment plan for this specific child, you might suggest that parents review my *12 Principles for Raising a Child with ADHD* (Barkley, 2021).