

Obstacles to Optimal Health Care

by Andrew Adesman, M.D.



IN RECENT YEARS, considerable advances have been made in the medical approach to evaluating, treating and managing attention-deficit/hyperactivity disorder (AD/HD) in children. Unfortunately, many roadblocks remain. Some of these obstacles are at the local practitioner level, whereas others are systemic—emanating from legislative, administrative and economic shortcomings of our country’s overall health care system. This article briefly highlights the most prominent constraints faced by families and health care providers alike.

Clinical

■ **Inconsistency in physicians’ clinical approach to diagnosis.** Although there has been an increased emphasis on behavioral and developmental disorders in the training of new pediatricians within the past 15 years, many practicing pediatricians are still uncomfortable diagnosing or treating children with AD/HD. Moreover, many pediatricians now assuming this responsibility do not consistently follow recommended guidelines for clinical diagnosis. In a recent survey of pediatricians to determine how they approach the diagnosis of AD/HD in their office, the majority of respondents indicated that they do *not* use the diagnostic criteria outlined in DSM-IV, the Diagnostic and Statistical Manual of Mental Disorders used by physicians to accurately assess a medical condition or illness.

More than one-third of the respondents indicated that they do not collect any data from the school or input from the child’s teacher, and 30 percent responded that they do not utilize AD/HD-specific rating scales to help quantify the magnitude of the

problem. To address some of these issues, the American Academy of Pediatrics (AAP) recently disseminated guidelines to pediatricians regarding the diagnosis and treatment of AD/HD. In addition, they have developed a set of rating scales and related support materials for pediatricians to more systematically assess and treat AD/HD.^{1, 2}

■ **Time constraints.** Due to insurance reimbursement challenges and busy physician schedules, it is difficult for many doctors to spend adequate time with families dealing with AD/HD. In the National Institute of Mental Health (NIMH) Multimodal Treatment Study of Children with AD/HD—MTA for short—children treated with stimulant medication as part of the study protocol had a significantly better outcome than those treated with medication by local physicians. Although some of this difference was likely due to the fact that the MTA-treated children received somewhat higher doses and were on medication for more hours each day, these children were also followed much more



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closely with mandated monthly teacher communication and monthly follow-up office visits. This led to more careful medication monitoring and adjustment as needed. Many physicians, and possibly families, are simply unable to commit this much time to medication management.

■ **Too much information, too little time.** Physicians are expected to be aware of major clinical advances in the disorders that they commonly treat. For a pediatrician, this would mean vigilant review of the medical literature on more than 20 common childhood conditions and disorders. This is impractical. In 2003 alone, there were several hundred new articles in medical journals focused solely on AD/HD. Even if a pediatrician religiously read every major pediatric journal each month, many important papers on AD/HD would still be “missed” because they are published in psychiatric journals, not pediatric ones. Physicians generally only review medical journals within their own specialty and do not have ready access to journals targeted to other medical specialties.

■ **Shortage of medical specialists.** Although pediatricians are expected to assume responsibility for the evaluation and management of children with AD/HD, families and pediatricians often seek the services of

medical sub-specialists when confronted with complex cases. Unfortunately, there is a severe shortage nationwide of pediatric neurologists, child psychiatrists and developmental pediatricians. Many communities do not have nearby specialists in these fields, and families have to travel many hours to access their services. Even in communities where these specialists do exist, there is often a three-to-six month wait before new patients can be evaluated.

■ **Insurance constraints, inadequate insurance and no insurance.** To adequately monitor treatment of children with AD/HD, physicians, families and teachers should routinely communicate with each other. However, most insurance plans fail to provide any payment to physicians for telephone time, resulting in a financial disincentive to physicians to speak at length by telephone with others who observe the child outside the home. This is unfortunate, as telephone consultation is often important in making certain clinical evaluations, coordinating care or providing case management. Health care providers should be compensated for this time. Also, more than 8 million children and adolescents in this country have no health insurance. And many doctors—because of inadequate payment—decline to serve youth covered by Medicaid programs, in which 17 million of our nation’s youth are enrolled.

Research

As noted earlier, the federal government, through NIMH, recently spearheaded a much-needed, major clinical trial to examine the relative efficacy of behavioral and pharmacological interventions. Although this study has contributed significantly to our understanding of treatment approaches for youth with the disorder, many important research questions remain, and new ones arise with the introduction of each new medication or newly proposed alternative treatment for AD/HD.

■ **Delays in independent comparative studies of new medications.** For a new medication to be approved by the Federal Drug Administration (FDA), it must be proven safe and effective compared to a placebo. This means new medications seeking FDA approval do not have to be proven to be equal to or superior to existing medication treatments. With each new medication, there is a significant delay from the time that it is introduced until the time that independent evaluations of the medication’s safety and efficacy are avail-

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able. It can easily take 18–24 months before results from independent studies by non-biased clinicians are available.

■ **Flawed research design.** There are many safe and effective medications available for the treatment of AD/HD, and there are some noteworthy differences among the various products. Consequently, some children will respond better to some medications than others. However, greater efforts need to be spent on independent, unbiased clinical research of new medications. There is a greater need for fair, objective comparative trials by investigators.

In an ideal world, adequate funding would be made available to compare new medications in a timely fashion, using well-designed methods. It would be wonderful if the FDA assumed a greater role in determining the relative merits of different treatments. In this manner, the FDA would not only be responsible for insuring the safety of a medication and its efficacy against a disease or disorder, they also would help evaluate how well a medication works compared to available medications.

Public Policy

■ **Lack of regulatory control for “natural” products.** Vitamins, minerals and dietary supplements are not regulated by the FDA. Thus, families with children with AD/HD are exposed to a myriad of “natural” alternative therapies for AD/HD. Although occasionally the government will investigate and challenge implied claims of safety and efficacy, this rarely happens. Unfortunately, the Internet is replete with many Web sites that tout “natural” remedies to treat AD/HD symptoms. More aggressive oversight by the FDA and the Federal Trade Commission is critical. Many have suggested that the FDA should have regulatory control over the manufacturing and marketing of dietary supplements and herbal remedies. This seems long overdue.

Since vitamins and minerals cannot be individually patented, there is less financial incentive to explore their clinical value. For example, there have been several recent research studies that suggest that zinc supplements may improve attention span and behavior in some children with AD/HD. Because zinc supplements cannot be patented, it is unlikely that pharmaceutical companies will invest in the needed clinical trials to determine if zinc is a safe and effective treatment.

■ **Limited funding to study alternative therapies and generic products.** Very little research is conducted on alternative therapies. Although the National Center for Complementary and Alternative Medicine (NCCAM) provides federal funding to evaluate complementary and alternative medicine interventions, very little money has been given to evaluate the range of alternative therapies that have been proposed for children with AD/HD. Alternative therapies should be held to the same burden of proof with respect to safety and efficacy as conventional therapies, and families must be cautious in evaluating all new, unproven treatments.

■ **Lack of mental health care parity.** When the Mental Health Parity Act of 1996 was enacted into law, significant advances were made toward providing families with equal coverage and reimbursement for “mental disorders” (as opposed to “medical conditions” such as heart disease or cancer).

Unfortunately, this law contains significant loopholes, and disparities in insurance coverage for medical versus mental disorders remain a problem. The federal government’s Congressional Budget Office estimated that parity for mental health would increase health care costs only one percent. Yet, despite this modest cost and despite widespread popular support, some politicians remain opposed to this expanded legislative entitlement. Politicians must recognize that

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the distinction between “medical” and mental” disorders is often arbitrary and indefensible. Children with AD/HD and other neurodevelopmental disorders should receive the same health care coverage as children with other chronic disabling “medical” conditions or disorders.

Conclusion

It is difficult to do justice to the full spectrum of problems and possible solutions to today’s health care obstacles in an article of this length. However, families and professionals concerned about AD/HD *can* make a difference through tireless advocacy efforts. Universal health care for children and parity for mental health coverage are long overdue and should be seen as essential by all. CHADD can help make this happen. Advocacy is one of CHADD’s major roles and, as part of its mission, CHADD encourages

families wishing to make their individual voices heard to contact their representatives in Congress and share their opinions. For more information on contacting Congress, visit CHADD’s Legislative Action Center at www.chadd.org. There is no time like the present to work for an improved health care environment for all.

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Andrew Adesman, M.D., is director of developmental and behavioral pediatrics at Schneider Children’s Hospital in New Hyde Park, N.Y. He is an associate professor of pediatrics at the Albert Einstein College of Medicine and serves on the national board of directors of CHADD.

References

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- 2 American Academy of Pediatrics, Committee on Quality Improvement and Subcommittee on Attention-Deficit/Hyperactivity Disorder. (2000). Clinical practice guideline: Diagnosis and evaluation of the child with attention-deficit/hyperactivity disorder. *Pediatrics*. 105(5): 1158–1170.