

A young girl with a joyful expression is peeking through a narrow opening in a vibrant blue fabric. She is wearing a light blue t-shirt. The background is a solid, deep blue color.

*Between the Devil
and the Deep Blue Sea*

Improving Advocacy for African American Children with AD/HD

by Faye A. Gary, Ed.D., R.N., FAAN, and Regina Bussing, M.D., M.S.H.S.

RECENT studies suggest that African American children are less likely than their Caucasian peers to receive evidence-based interventions for attention-deficit/hyperactivity disorder (AD/HD). Parents in the African American community appear to experience unique difficulties in the help-seeking process and face extra barriers as they advocate for their child. This article is based on the authors' clinical and research experiences; it reviews pivotal barriers in the help-seeking process. The accompanying sidebar offers parents and caregivers solutions for improving their self-advocacy efforts for African American children with AD/HD.



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What is “normal” child behavior?

The hallmark symptoms of AD/HD are impulsivity, hyperactivity and inattention. These behaviors can occur, to some extent and at some point in development, in all children. Academic underachievement and behavioral problems are also important indicators. The *Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV)* does not provide guidance on age and cultural variations in the expression of AD/HD. Historically, public school teachers have perceived African American children as more hyperactive and inattentive than their Caucasian peers; no doubt some of them might be. Cultural norms for what represents a normal child activity level and desirable exuberance vary considerably. Problems can arise when parents and authority figures differ on whether a child has AD/HD. Therefore, determining when AD/HD is clinically present in African American children requires knowledge of normal development, interviewing and rapport-building skills and high levels of cultural competence among clinicians.

Fear of educational marginalization

Many of the typical behaviors associated with AD/HD can lead to school suspensions, expulsions and

“special placements” in social adjustment classes. Such disciplinary interventions mobilize fears among African American parents that their child is being labeled mentally retarded or a slow learner or is otherwise seen as “defective.” African American parents, sensitized to the implications of educational failure, worry that receipt of school interventions may mean their child will not be able to realize future dreams and aspirations. As schools play an important role in a comprehensive treatment approach to AD/HD, school professionals need to understand and allay these parental fears to pave the way for cooperative relationships serving the child’s best interest.

Cultural disconnect

Help-seeking and advocacy behaviors are related to parents’ beliefs and knowledge about AD/HD. Research suggests that AD/HD has not become a significant part of the collective consciousness of African American social networks and that African American parents describe themselves as less aware of AD/HD and less knowledgeable about it than their Caucasian peers. Effective means to explain AD/HD symptoms vary significantly by culture and gender. When their health, belief and knowledge systems conflict with those of professionals designing and implementing AD/HD treatments, African American parents may perceive that providers are not interested or are culturally incompetent to address parental concerns sensitively. Professionals and parents need to be aware of this to avoid a cultural disconnect.



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Improving Advocacy for African American Children with AD/HD

THE FOLLOWING TIPS can be particularly helpful for African Americans who want to improve their advocacy for family members with AD/HD:

- **Learn where to go for help.** Find out from school officials how decisions are made, such as who serves as the point of contact, who has the authority to make decisions about the student, and the range of options and consequences of decisions for the child and the family.
- **Become well informed about AD/HD.** Multiple information sources are available to you. Make appointments to talk with education and health professionals. Look up information on the disorder at a public library with the help of a reference librarian. Join parent self-help groups. Be careful of Internet resources, because false claims and misinformation abound.
- **Write out ideas, questions and treatment preferences.** It helps to have written information before interviews and meetings so they can be discussed and integrated into plans proposed by education or health professionals.
- **Know the services available and your child’s rights.** By knowing which services are (or should be) available in the school system, you can help your child receive them. Remember those services are required to be provided in a confidential manner (no sharing with legal, health care or welfare system without parental permission).
- **Be an active player in the educational evaluation process.** Ask for written and oral/videotaped reports from your child’s evaluation. Take a trusted friend or family member to meetings to help advocate for you and your child’s interest.
- **Ask teachers for specific examples of desired behaviors and clear descriptions of undesired behaviors.** Knowing what teachers expect will help parents

reinforce these principles at home. Ask teachers to identify your child’s strengths and include these qualities in the action plan so that it does not solely focus on problem behaviors.

- **Participate in developing the treatment plan.** Don’t be afraid to voice concerns and preferences, including questions about medication side effects, and ask that expected benefits be clearly described. Ask for an explanation of the causes of your child’s condition and how treatment will be designed.
- **Keep records.** Maintain copies of all communications with providers, results of assessments, intervention plans and treatments (including treatment trials that did not work).
- **Make your pharmacist your partner.** Pharmacists can provide additional information about medication, benefits and side effects. Stop at the consultation window when filling a prescription and ask questions; pharmacists can also review with you the written information provided with prescriptions.
- **Learn about behavioral treatment options and how they may help your child.**
- **Get feedback and help from professionals.** Get assistance from guidance counselors or mental health professionals. Consider participating in community education groups.
- **Join community organizations.** Many groups, such as CHADD or your local mental health association, address child-related mental health issues. Consider joining the parent teacher association (PTA) or similar organizations that have policy-making authority over programs relevant to children with AD/HD. ■



Conference Notes
Regina Bussing, M.D., will be presenting findings from a cohort study of African American children with AD/HD during a research symposium at CHADD’s Annual Conference in Dallas, Texas, October 27–29, 2005. She will also be conducting a breakout session on “What ‘Dr. Mom’ Ordered: Self-care Strategies for AD/HD Symptoms” at the conference. For more information, visit www.chadd.org or call (800) 233-4050.



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Distrust of “helping systems”

African American parents view the two “helping systems” essential for child growth and development—education and health care—with a prejudiced eye. They want the best teachers and health professionals for their children, yet, they also remember that numerous generations of African American parents have had bad experiences and reasons to distrust these systems.

However, parents are legally constrained and have few choices but to place their children in public schools—a system in which they have little decision-making authority—or to seek mental health care for psychiatric problems, involving professionals that may be perceived as adversaries. One of the most feared threats among African American parents is the possibility that their child will be removed from their home by a government agency. This fear becomes even more potent when other conditions such as poverty, low health literacy and a lack of “systems savvy” are also realities in their life experiences. Without an acknowledgement of the historical roots and present remnants of distrust, relationships between African American parents and medical professionals can be impeded by

factors that are seldom acknowledged or addressed by either party.

Double stigma

Stigma associated with mental disorders is considered “the most formidable obstacle to future progress in the area of mental illness and health.” (*A Report of the Surgeon General*, DHHS, 1999). Stigma refers to a collection of negative attitudes, beliefs, thoughts and behaviors that influence the parents and/or the general public to fear, reject, avoid, be prejudiced and discriminate against people with mental disorders. From the other side of the discrimination paradigm, America’s history abounds with prejudice and discrimination against African Americans, American Indians and Alaskan Natives, Asian Americans and Pacific Islanders and Hispanic Americans. Unfortunately, prejudice and discrimination continue to exist and affect all aspects of the lives of many Americans. “Double stigma” refers to discrimination based on minority group status and the burden of having to live with a mental disorder. It is a formidable barrier for African American children and their parents who are in need of mental health services, but who are reluctant or refuse to seek help. ■

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