



CHADD and the National Resource Center on ADHD

Ask the Expert Chat Series

August 20, 2010 – African American Children with ADHD: Overcoming Stigmas and Barriers

Moderators – NRC Staff

Expert – Janice Cooper, PhD

Moderator 1: Welcome to today's Ask the Expert chat, "African American Children with ADHD: Overcoming Stigmas and Barriers." Our expert this afternoon is Janice Cooper.

Janice L. Cooper, PhD, directs the National Center for Children in Poverty (NCCP). She is a health services researcher who specializes in children's mental health. She received her PhD in Health Policy from Harvard University. Her research has focused on quality of care for children and youth with attention-deficit/hyperactivity disorder (ADHD), cultural and linguistic competence and mental health financing. Since 2005, she has led NCCP's work on Children's Mental Health. She was the lead author on Unclaimed Children Revisited. She also teaches Child Health Policy at the Mailman School of Public Health of Columbia University.

Dr. Cooper has served as an Associate for Abt Associates, Director of the Children's Mental Health Division in the State of Minnesota, Director of the New York State Coalition for School-Based Primary Care, and as Coordinator for the Christian Health Association of Liberia's AIDS and Family Life Education program. She is an appointee to the New York State Mental Health Services Council and a member of the Multicultural Advisory Committee of the New York State Office of Mental Health. She is also a former board member of the American College of Mental Health Administration (ACMHA).

Thank you Dr. Cooper for joining us! Are you ready to begin?

Janice Cooper: It is my pleasure. Yes ready to begin.

Barbara_D: Some African American parents are reluctant to seek evaluation for their children who may have ADHD/ LD stating they do not wish to label their child. They are fearful that the school system will expect less of their child's school performance. We encourage parents to have their children evaluated so they can enhance their school success and teach parents how to advocate for their child's educational support needs. What can we do to help improve this?

Janice Cooper: This is a real problem. It is one that can be taken care of as best as I can tell through education. The more families who have success stories with treatment, the better.

The concerns by parents about labeling are real and should not be dismissed out of hand. However, it's important for our community to recognize that contrary to popular myth, there is under-diagnosis according to many studies and if we cannot identify, it is difficult to treat; especially when payment for treatment requires funding. Schools and communities can initiate mental health awareness campaigns

FloridaAnne: As an attorney in Florida, I frequently have seen African American children with ADHD treated as children with disciplinary problems, not disabilities. Seldom are they afforded the manifestation of disability hearings in suspensions. Is this a national problem?

Janice Cooper: Yes. This is a national problem. When I worked as a state mental health director, it was common to see children of color access mental health services primarily through the justice system while children from majority communities accessed mental health through the social service sector.

As a practical matter, as a lawyer, you can begin to raise the issues of the role of the court in facilitating access outside of the judicial process and outside of the context of discipline. School wide strategies that begin to take a holistic approach to mental health can benefit these children.

Moderator 1: While we are waiting to learn more about communicating with the school, please see our [What We Know Sheet #4](#): Educational Rights for Children with ADHD in Public Schools found in the list at www.help4adhd.org/en/about/wwk.

AuntKaren: Why does it seem like more African American children are diagnosed than white children?

Janice Cooper: Thanks for that question. The research suggests that while parents and teachers may rate African American children at higher rates than White children, rates of diagnosis are lower and rates of treatment are lower. The evidence suggests that among the reasons for the lower rates of diagnosis and treatment include lack of parental knowledge and willingness to have a child assessed appropriately.

Cheraw: what do you view as the most difficult stigmas and barriers for African American children with ADHD to overcome?

Janice Cooper: That is a tough question. Initially there is the general reluctance in the African American community to really use psychotropic medications for children. Second, I would say our history with research and treatment including mental health treatment in the past has led to suspicions. And while children of African descent may be under-diagnosed, they are over identified in special education thus contributing to our community's suspicions. In addition, I would say that we have concerns about the labeling that an earlier participant identified.

Another barrier that is a real one is one of mental health literacy. Among many communities, not only African Americans, there is the lack of psycho-education -- what is disease/disorder is, how to address, it what are the culturally relevant approaches.

Finally, and you can see you have me going here, there are a range of systemic barriers that have to do with payment, access related to insurance and coverage, and general societal acceptance regarding mental health conditions on par with physical health conditions.

Moderator 1: To learn more about Managing Medication for Children with ADHD, please see our [What We Know Sheet #3](#).

Jolly: I wonder if there are behaviors or characteristics of African American children that look like ADHD but really are manifestations of something else that is cultural.

Janice Cooper: First let me say that I am not a clinician. One of my big issues is the importance of conducting a thorough assessment that is done by a provider who is trained in cultural competence. ADHD can be misdiagnosed not only from the perspective of behaviors that might reflect things going on in a family or community context, but also from the perspective of other disorders. A culturally appropriate assessment is key.

Finally, increasingly, researchers and scholars engaged in instrument development are getting better about culturally norming tools as well as adapting tools to ensure they are relevant from different cultural and language groups.

Lioness: What are the most common misdiagnoses made for black children who actually have ADHD? Are they different mistakes/misdiagnosis from those made for whites/Asians, etc.?

Janice Cooper: I am not sure that I know the answer to that question from the evidence. My best guess would be that there are probably a myriad of factors that go into making a wrong diagnosis. ADHD commonly co-occurs with other disorders so that might be a factor.

AuntKaren: How can I help my son without the school labeling him as being a troublemaker?

Moderator 1: While we are waiting, CHADD local groups provide support and networking with other individuals who understand the difficulties of parenting a child with ADHD. In addition to supplying each other with local resources and support, the meetings usually have a speaker who talks about current events or research in the ADHD community. Each local group is different, so use the CHADD website to find the group closest to you. To get started, visit [the CHADD chapter locator](#).

Janice Cooper: First I would say it depends on your school situation. Is there a clinician or school support personnel you can trust? Can you trust the teacher with the information in the sense that it is not used negatively against your son? Can someone in your school be a liaison with your clinician if you have one?

In many cases teachers can work with parents and the child's clinician to help develop a plan for helping your child stay on tasks, do what needs to be done and be successful. Local chapters of advocacy groups can often help pair you with a parent who has successfully navigated providing supports for their child.

I think the key is often finding that person in school who sees your child's strengths and can work with him to develop to his full potential.

Maureen: How should I make teachers accountable for expecting the same level of effort/achievement from their sons and daughters? My daughter goes to a predominately white school and I wonder if it's because of her ADHD or race that they expect less of her.

Janice Cooper: Probably both!! I would say that you need to hold the school and teacher accountable. From my vantage point it often means doing more work yourself. Make it clear to your child's teacher what your expectations for academic performance are.

The data is pretty clear that children with ADHD and co-existing conditions are often very smart. They can do well if supported. From an advocacy perspective I often promote the notion that communities can use data to hold systems accountable

Children with mental health disorders including ADHD can perform well academically, so asking for the data on how they perform relative to other children and requiring that schools have outcomes for them as comparable with other children...next question

Moderator 1: Do you Tweet? Follow the NRC on Twitter @help4adhd and receive daily tips on how to better manage ADHD, and be notified about future Ask the Expert chats!

Stephanie: What strategies do you suggest to raise awareness in the African American community? I was discussing ADHD with a church member last night, and he feels it's not real.

Janice Cooper: Bingo!! We need to start there. In the African American community, faith-based organizations are amplifiers of messages. We can use the church as a vehicle for education around mental health conditions.

I would suggest getting together parents for whom this is a real issue and organizing some small educational events at first. There is no cookie-cutter approach. To make it relevant it must resonate with the community in which you live.

Back to my data question - we have national prevalence data on ADHD, and you can use that. We know that ADHD is prevalent among children of African-descent in our systems of justice, and special education. Even if someone does not believe in ADHD, they probably believe that those children in those systems should not be there because of a behavioral manifestation of an illness or disorder.

I guess I cannot over emphasize education and different forms of education. Are there any local professionals that you can bring to a forum to help with public education, such as a local psychiatrist or

social worker or psychologist? Maybe there is a parent who has successfully managed her child's disorder.

Moderator 1: Please see www.help4adhd.org/en/about/myths for more information on the myths and misunderstanding surrounding ADHD. Also, national prevalence data can be found here: www.help4adhd.org/en/about/statistics.

PAMMO1949: My son has been diagnosed as ADHD since the age of 4. He has attended 10 schools (now in 10th grade). He has been suspended and expelled - but has superb testing scores. How can I get schools to understand that the ADHD comes with other negative behaviors which he is unable to control – anger, defiance, and lack of respect for adult authority?

Janice Cooper: I think this requires persistence which you clearly have. If you are able to develop allies in your son's school that can work with you this will be manageable. One thought is to recognize that while those are part of your son's disorders they can be managed and it takes creating the right environment for your child.

Having your son's teachers and the administrators in his school understand this would be helpful. Besides I doubt he is the only child in the school with ADHD, so look for allies among parents as well.

AuntKaren: What did you mean about cultural norming, earlier? How does someone go about doing that or making those instruments?

Janice Cooper: Many of the widely used instruments (such as the Connors and CBCL) were initially tested on predominantly white children. In some cases this is the same with our treatment modalities. So norming to a group involves testing the instrument with the group where there is a substantial number or all from that group to see if the instrument gives you the same or similar type of results.

I can't say that I can tell you how to develop an instrument. There is instrument development going on all the time. Some of what is being tested in developing instruments is to see how specific it is to the conditions it is trying to identify and how sensitive it is; meaning it is not giving us a bunch of false positive results.

Jean: My son's doctor directed me to research medications on my own and then to tell him which one to prescribe. He also would not refer me to a psychologist for counseling. What is the best way to find a physician familiar with this disability?

Janice Cooper: I am sorry. I cannot imagine if your child had heart disease your MD would give you a physician desk reference and tell you to find the med that fit the disorder. Such is our struggle with getting equality for mental health disorders. I think you need to find a pediatrician in your community who has a specialty in behavioral pediatrics. This means that they get extra training in behavioral development. Such a clinician is much more likely to be responsive to the needs of your child.

Moderator 1: The NRC has a page on our website devoted to [finding a health care professional with expertise in diagnosing and treating ADHD](#).

insideADHD_org: How can we promote cultural competence among health care providers when assessing/diagnosing/treating ADHD in this population?

Janice Cooper: Irrespective of the diagnosis, cultural competence is key to quality treatment. As a health care consumer you can ask your clinician about culture and the role it plays in his/her diagnosis. You can inform your clinician about the importance of cultural competence if you feel they do not get it.

I think it's important to start asking for both assessments and treatments that have been effective with children of color especially African American children.

Finally, from an advocacy perspective we need to be demanding data on the outcomes of treatment by race/ethnicity and making that data available publicly so that policy makers can start demanding more culturally competent care.

Jrothman: As an advocate I have found that in AA Faith Communities, mental illness is seen as almost a choice in that something you did brought it on. I have heard pastors comment that not everyone is crazy and that all you need to do is pray. What are the best ways to reach the AA population when this stigma exists?

Janice Cooper: As you are aware education is important. If you have individuals in your community that are respected and have raised children with the disorder that would like to share that experience, this is helpful. There are some communities where churches are taking on mental health awareness and stigma in a big way.

Every November, the Carter Center in Atlanta hosts the Rosalyn Carter MH Symposium and the faith community is well represented.

Moderator 1: Want to receive well-rounded comprehensive knowledge about ADHD? [Parent to Parent courses](#) offered in local communities and online, provide educational information and support for individuals and families dealing with ADHD and learning to navigate the challenges of ADHD across the lifespan. To learn more about our Parent to Parent classes visit this link.

Rone: if people are not talking about it within our community, how can we know if there are others in a similar situation?

Janice Cooper: I would ask the question if there are "safe" places for people to talk about it? It often only takes a couple of people providing an informal setting to share ideas before we begin to see the commonality among groups

Moderator 1: Missed part of the chat? Past chat transcripts are available to CHADD members as a benefit. To learn more about joining CHADD, visit: www.chadd.org/join.

AI_D: Is anger, defiance & lack of respect all part of ADHD?

Janice Cooper: I am not a clinician. These are manifestations of behaviors associated with many externalizing disorders of which ADHD is one.

Moderator 1: Being a CHADD member not only provides valuable members only benefits, such as Attention magazine, to you and your family; it also supports CHADD's work on behalf of individuals with ADHD at the local, state and national level. Join CHADD today: www.chadd.org/join.

Taieka: I am a parent w/ ADHD myself and my daughter (7yrs, 2nd grade) has ADHD. My daughter is also identified as gifted and talented and is instructed in a gifted and talented classroom. In addition I practice as a school psychologist within a different school district. My issue is that my daughter's school is not keeping up with the recommendations I provide and all the school keeps suggesting is that I put my daughter on medication and get her assessed for special education services. Due to my knowledge of ADHD due to my career and my own history of having it, I am doing all the work and providing the school w/ great RtI strategies, but I cannot sit in the classroom and monitor that the interventions are in place and are being implemented correctly. I keep hitting a brick wall with the school district and I'm becoming very frustrated. The school's treatment integrity is zero and I'm afraid that my daughter is suffering & will get left behind academically or be treated unfairly because she needs more supports to stay focused and on task. What options to do I have at this point?

Moderator 1: Thanks to everyone for all your questions! While we try to post as many specific questions as possible, we also try to post questions about different issues. We appreciate your patience and will continue trying to get through as many questions as possible in our time remaining

Janice Cooper: I am not sure if you have tried working with a local parent advocacy group that provides you with a parent expert or other to discuss different strategies of working with the schools. When I worked in state government, there were often groups that knew the schools and school administrators that could represent the parents. It is often difficult when the school leaves you no options other than a legal one.

Cris: Have there been any studies conducted on the success and challenges of homeschooling African American students with disabilities? Is this on the radar screen of researchers at all?

Janice Cooper: I am not sure. I have not seen any.

Moderator 1: Before our next question, you should know that the NRC produces a series of Information Sheets and all of these "[What We Know](#)" Sheets are found at www.help4ahdh.org, in the "[About ADHD](#)" section, including our [WWK #20A](#) and [#20B](#) on ADHD and Teens.

Margaret: How can we promote cultural competence among teachers and school staff? The reactions to my son's behavioral issues in school seem to be influenced by cultural issues as opposed to consideration for his diagnosed challenges.

Janice Cooper: This is not an easy task, obviously. Racial relations and racial awareness has historically been a difficult issue to address, and racial differences, especially with regard to strategies, are just beginning to gain a lot of ground especially in psychology and mental health.

Indeed, our evidence-based practices that are culturally relevant are still few compared to the myriad of treatments available. However, there is a quality reason as well as a fiscal reason, not to mention increased effectiveness reason, to advocate for culturally competent services. So practically, gaining the ear of someone in your child's school and educating them about the effectiveness and efficacy of certain strategies maybe the start.

Noelle: My son hasn't been diagnosed with ADHD (yet) but we have been seeing a psychologist and are working towards this. My family and friends all agree that he is just BAD and needs to be spanked. I find this hard to navigate and don't even like to discuss our issues with them. I feel isolated and alone as a parent. Do you have any suggestions on how I can rebuild relationships with them and not receive their opinions so freely?

Janice Cooper: This is a tough one and certainly worth discussing with your clinician and a parent group if you belong to one. The issue of discipline and corporal discipline is a difficult one in our community. I suggest that you find someone in your community that might be able to help you find the language to explain to family members about your son's diagnosis.

At a certain point, practically, you can also inform them that you did not solicit their opinions. Often times explaining what you know and how you wish to handle your situation can help those who wish to offer advice freely no matter how ill-informed.

ZDO: My son is 9. I sense he thinks there is something "wrong" with him because he has ADHD. How can I help him overcome that feeling?

Janice Cooper: I am not sure whether there are any groups in your community for children with ADHD. Sometimes being part of a group help children with ADHD build confidence about their diagnosis and what they and their family are doing to manage their disorder. It also helps put their disorder in perspective with the rest of their life.

Moderator 1: We have ten minutes left. Dr. Cooper will move through as many questions as possible. If we are unable to get to your question please contact one of our Health Information Specialists on ADHD by calling 1-800-233-4050 between 9 AM- 5PM EST or by clicking on the "Ask A Question" link on the top of our website: www.help4adhd.org.

Rone: What are some practical things parents can do to help turn our community (especially financially strapped school districts) away from the stigmas?

Janice Cooper: There are many mental health awareness strategies and I would suggests that you google mental health awareness day which was held last May and see what some of the low/no cost activities people engaged in and make it specific to ADHD.

ADHD is no different from many public health issues that need to be better understood. We have talked working with faith groups, working with legislators, they have children with ADHD too, working with influential community partners including getting corporate sponsors.

Professionals both in and out of mental health and education can also be good allies to getting rid of myths and highlighting the strengths of children with ADHD and how we can help them live productive lives.

insideADHD_org: Many inner-city schools lack adequate funding/staff/facilities. Many of these schools are egregious underperformers. For these children who must already face these barriers to education, do you have much optimism that things will change?

Janice Cooper: I think if we force systems to look at the data and make that data public we will do more to change the quality of the systems our children interact with than anything else. I have a lot of hope that if we push the education system to be inclusive of our kids when they demand improved outcomes we will get it. Whenever Sec. Duncan at DOE [Department of Education] or Sec. Sebelius at DHHS [Department of Health and Human Services] talks about outcomes we need to be asking them about performance and outcomes for these children.

Maureen: What assessments are geared towards assessing African American Girls? You mentioned "I think it's important to start asking for both assessments and treatments."

Janice Cooper: I think the question you ask your clinician is whether this tool has been shown to be as effective with African American girls. I am not an instrument expert, I am sorry.

Jazzdad: Where can I find more information and resources related to ADHD and African American children?

Janice Cooper: The National Resource Center is probably a place to start. There are a number of researchers that have worked in this area; Regina Bussing at the University of Florida is one that has focused a lot on parents of African-descent and has done some seminal work here.

Moderator 1: The [NRC library](#) is a great place to search and find publications on ADHD and African American issues.

And this will be our final question

Lioness: If you had something to say today to a parent whose child seems to have the symptoms of ADHD but is afraid to a) get him evaluated and b) agree to treatment because of all the reasons you have mentioned here, what would your final words be to leave them with?

Janice Cooper: I would say only you know how much you are struggling with your child and how much help your child needs. With any mental health disorder, and especially ADHD, there are treatments out there and we need to ameliorate the suffering our children experience. Proper treatment can do that.

I would also discuss how much improved functioning a child with a condition that is well-managed can experience and what joy can be brought back into your lives. Thanks for the question.

Moderator 1: Thank you Dr. Cooper for your knowledgeable insight. Your answers have helped us to better understand the obstacles that African American families with children who have ADHD face and how we can help overcome these stigmas and barriers. Thank you for helping us to understand this important topic.

If you have a question that was not answered today, please contact us online (National Resource Center's Web site at www.help4adhd.org) or by phone (800-233-4050) between 9AM and 5PM EST and one of our health information specialists will respond.

Janice Cooper: My pleasure!

Moderator 1: Please exit the chat room so that we may begin preparing the transcript of today's chat.

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The views expressed in this chat are those of the guest expert and do not necessarily reflect the official policy or position of CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder), the National Resource Center on ADHD, or the CDC.

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