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An American

Two Siblings Work to Fix a Broken System

by Bryan Goodman, MA

THERE WAS A HUSH THROUGHOUT THE ROOM as Karran Harper Royal told her family's story to a gathering of doctors in Atlanta. That response was typical for Royal, who is doing all she can to get the word out about attention-deficit/hyperactivity disorder. When she finishes speaking, people usually flock to her in droves, telling her how moved they were by her experience and how it has impacted them.

oyal has been working with CHADD for the last several years to get her message out about the importance of early diagnosis and treatment of AD/HD. Royal, who is African American, usually brings home the fact that, while her experience should have universal resonance, African Americans are a group of particular concern for her because of the evidence of undertreatment in that community. Royal is a tireless advocate, speaking at countless meetings before parents, adults, professionals, and even politicians.

"My whole life's work is to make sure people don't treat these black males as disposable human beings," she says. No doubt Royal's perceptions have been shaped by her own experiences with a brother who spent twelve years in prison due to what she believes are his various untreated disorders. In sharp contrast, her two sons, both of whom have AD/HD, were treated early and have overcome many of its barriers.

To understand the personal journey that turned Royal into an activist who served on CHADD's board of directors and enjoys a reputation of national renown in mental health circles, one has to first understand the story of Darran Harper, her older brother.

Falling through cracks

Forty-seven-year-old Harper, who was recently released from prison, is a living answer to the question of why no one ever

Darran Harper and Karran Harper Royal

heard about AD/HD and mental health disorders back in the 1960s and 70s. Like Harper, many people with unrecognized and untreated mental disorders fell through the cracks. Some flunked out of school and scraped by with menial jobs, while others faced barrier after barrier and ended up homeless, on welfare rolls, or in prison. Harper struggled with his challenges and eventually became an addict, a car thief, and a convicted felon.

"In high school, I knew I wasn't like other people," Harper explains. "I wasn't comprehending. I was

good with mechanical things, but in terms of reading and writing, I couldn't do it." Since he thought he was not academically inclined, he turned to auto mechanics, an area in which he showed a great deal of talent. But driven by symptoms of AD/HD and cooccurring disorders, Harper was not content only to repair cars. "I saw that I could make money [either] fixing them or taking them." He began using the money to feed his addiction to cocaine. Soon, he was no longer just addicted to drugs. He was also addicted to stealing. And his two habits were mutually reinforcing. "I would take ten to fifteen cars a day, cut'em up or sell'em whole."

On several occasions Harper's exploits brought him close to both death and prison. In his mind, they were one and the same. He remembers that one day at his mother's house, he decided to take a walk and ran across a 1988 Oldsmobile Delta. He couldn't resist his usual temptation—but little did he know the car's owner was watching with a shotgun in hand. "He shot me in my leg," says Harper. "I got away." An onlooker called police and soon the

Bryan Goodman, MA, is CHADD's director of communications and the executive editor of Attention magazine.

Family

shotgun-wielding man was testifying against Harper in court.

Another time Harper was driving to the movies with his girlfriend when he happened by a beautiful white Trans-Am that was for sale in all its glory. Shoe polish was visible on the windshield denoting the car's price. The next thing Harper knew he was parking the car at a nearby gas station. As he tried to scrub the polish off the windshield, two police cruisers drove by. Officers recognized the Trans-Am. A high-speed chase ensued, and the car was recovered. But thanks to his nimble feet, Harper eluded arrest that time.

A community underdiagnosed and undertreated

Harper had learned to beat a system that had for years failed him and others like him. Indeed, countless African Americans, particularly those of Harper's and Royal's generation, consistently go undiagnosed and untreated. There are multiple reasons for disparities in mental healthcare, including access to and affordability of services and stigma within a community that has been hard hit by racism, deception, and countless inequalities.

Research shows that while the prevalence rate of AD/HD is roughly the same for African Americans and Caucasians, African Americans are less likely to receive medical treatment for the disorder. Instead, African Americans are more likely to rely on prayer and trusted family members for help, rather than medical professionals.

For some African Americans, the mistrust for the medical community is driven by memories of the infamous Tuskegee Experiment. In a dark chapter of American history that lasted for forty years, the U.S. Public Health Services allowed over four hundred African-American men to die of syphilis without treatment or any explanation of the illness that plagued them. Many people in the community have also long been alarmed by the large number of African-American schoolchildren, mainly boys, who have been disproportionately identified as emotionally disturbed and/or mentally impaired and ushered into special education classes. Over the last several years anti-mental health groups have sought to leverage this mistrust in their favor, with varying degrees of success.

"Stigma against mental illness in the African-American community is pervasive," says Rahn K. Bailey, MD, chair of psychiatry at the historically black Meharry Medical College and a member of CHADD's professional advisory board. "It not only affects the person with AD/HD or mental illness, who will not seek treatment, it also affects his or her support system. That includes friends, family, you name it."

Heeding the warning signs

Harper bears out the statistics. His sister and her sons do not. While Harper was eventually arrested and sentenced to twelve years in prison for his crimes, his sister took action when she saw some of the same warning signs in her son Khristopher, now twenty-one



Making a Difference

CHADD sponsored a presentation on July 28 by Karran Harper Royal at the National Medical Association's annual convention in Atlanta. The NMA is a national organization representing doctors and patients of African descent. Royal spoke to a packed room of over sixty African-American psychiatrists about her brother's struggles, due in part to undiagnosed AD/HD, and the difference diagnosis and treatment of the disorder made for her two sons. Diane Buckingham, MD, chair of the NMA psychiatry section, emceed the event.

CHADD also hosted a community forum at an African-American church in the Atlanta area, attended by at least sixty people. CHADD planned four such community forums in an effort to reach underserved populations. Prior to the Atlanta forum, a similar event was held in Prince George's County, Maryland.

CHADD has forged strong relationships with leaders of the NMA. Both Buckingham and Rahn K. Bailey, MD, vice speaker of the NMA House of Delegates, serve on CHADD's professional advisory board. As an outgrowth of CHADD's work and relationship building, in 2005 the NMA passed a resolution acknowledging AD/HD and its impact on African-American children.

The Minority Health and Health Disparities Research and Education Act of 2000 describes disparities as differences in "the overall rate of disease [or disability] incidence, prevalence, morbidity, mortality or survival rates as compared



PhD, Christopher Griffith, MD, Angela Shannon, MD, Karran Harper Royal, Diane Buckingham, MD, and Clarke Ross, DPA.

Inset, presenters at the community forum on AD/HD in Prince George's County, Maryland. From left are Jacquelyn Duval-Harvey, PhD, CHADD coordinator Brenda Clark, Michelle Pittman, LICSW, LCSW-C, and Diona McLucas.

to the health status of the general population." In addition to its work with the NMA, CHADD co-chairs an advocacy coalition with the March of Dimes in an effort to convince Congress to appropriate \$5 million to address racial and health disparities in health outcomes for the special populations served by the Centers for Disease Control and Prevention. CHADD also works to alleviate disparities and educate the public about the disorder through its media relations campaigns and regular public-policy outreach.

years old, that her parents missed with her brother. "It fueled me to make sure Khristopher didn't end up like Darran," she says with a calm resolve. Later she would also seek an evaluation for her younger son Kendrick, now twelve years old, who has the inattentive form of the disorder.

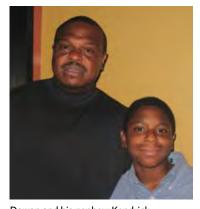
With AD/HD symptoms nearly identical to her brother's at an early age, Khristopher was bright but struggled with inattentiveness and hyperactivity in school and at home. His schoolwork and his self-esteem suffered as a result. Puzzled by her son's problems, Royal turned to the medical center at Tulane University, where she took her son for an evaluation.

Royal made sure her son followed a multimodal treatment regimen that the best scientific research showed to be effective. Treatment made a difference: Khristopher would go on to study at a prestigious school of music. "When I was younger, I didn't understand about this kind of stuff," she explains. "I thought at the time that there were normal people and mentally retarded people and nothing in between." That would soon change, as Royal joined CHADD, attended its conferences, and learned more about AD/HD. Soon, she

After a thorough examination, he was diagnosed with AD/HD.

But she still wanted nothing to do with her brother. Then

was an advocate with encyclopedic knowledge of the disorder.



Darran and his nephew Kendrick

her mother died as a result of complications from diabetes. As Royal was going through her mother's belongings, she came across some medical records showing that her mother had been hospitalized for depression. "The records showed that every time they treated her for depression, they got her diabetes and high blood pressure under control," she said.

Armed with more information about her family's medical history as well as the knowledge that she was her brother's only source of support, she began to correspond with him. The relationship was soon renewed. "I knew Mama was one of his main lifelines, and I felt

that everyone needs someone to connect to," she said.

Out of prison

Harper began reading the information his sister sent him about AD/HD, dyslexia, and other mental health and learning disorders. He had always suffered from severe inattentiveness and hyperactivity, and had difficulty reading.

Both Royal and Harper were surprised that the prison system offered no real mental healthcare. It also did nothing to connect prisoners to the services and supports they need to avoid reincarceration and be successful in the outside world. Harper says that he and other

How You Can Make a Difference

Ending healthcare disparities will take the efforts of people like you. So how do you get started?

CHADD is working with federal and state policymakers on a number of initiatives that will affect underserved populations, such as African Americans, Hispanics/Latinos, and people who lack the financial means to receive proper treatment. But we cannot truly make a difference if we don't have members. So make sure you're a member of CHADD. Follow closely the public policy section of the CHADD Web site and write letters to your officials about pressing issues.

Think about financially supporting CHADD's outreach to underserved populations. As with all nonprofits, the economy has impacted the organization's coffers, and CHADD may as a result be forced to scale back its efforts with underserved populations, potentially turning back the clock on many of the gains over the years. CHADD can only do what its budget allows. Donations specifically designated for outreach efforts will better enable CHADD to make a difference. Donations can be made through www.chadd.org, the CHADD Web site.

people with mental health problems are paraded in and out of prisons in a cyclical manner, like cattle. That's why studies show that jails and prisons, in the absence of appropriate treatment outlets, have become virtual warehouses for offenders with mental illnesses.

While the vast majority of people living with AD/HD and mental health disorders are not involved in criminal activity, many people in the criminal justice system do suffer from some form of mental illness. A study by the U.S. Department of Justice released in 2006 showed that fifty-six percent of state prisoners, forty-five percent of federal prisoners, and sixty-four percent of local jail inmates had mental health problems. In all three groups, the majority of prisoners received no treatment.

Even Harper still hasn't undergone an evaluation. Sure, he's out of prison, but he doesn't have a job and therefore has no health insurance. And in post-Katrina New Orleans, mental health services are hard to come by, especially for those with low incomes. Some facilities that served mainly low-income residents, like Charity Hospital, had to be closed after the flooding, and the remaining service providers are overtaxed and understaffed.

Harper now lives with his sister and her family and is trying earnestly and honestly to survive—hopefully even thrive—in a system that has repeatedly failed him. It's proving to be an uphill battle. But his spirits are high, and he is bolstered by his close relationship with his sister.

With no income and no means of transportation, he recently asked Royal if he could borrow her car to run an errand. After some deliberation, she gave him her keys. While he was gone, she wondered what she had done. Then she looked out of the window and saw him pulling up at the house in her car. While she feared the worst, her brother's errand turned out to be very routine.

Who knows if Karran Harper Royal will ever be able to change the world, but it's clear that her brother is trying his best to show the world that he's a changed man.