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THIS ARTICLE IS PART ONE IN A SERIES
PART TWO WILL FOCUS ON GUIDELINES AND STRATEGIES FOR DEALING WITH DENIAL

THE BIOLOGY OF DENIAL

Not Unwilling to See—Just Unable

by Gina Pera

DAVID'S WIFE ACKNOWLEDGES THAT SHE HAS AD/HD but fails to see how her behaviors adversely affect the kids and him, so she does nothing about it. "She read that changing her diet can help her symptoms, but she keeps forgetting what that diet is supposed to be," he says.

Merrie's husband refuses to consider the possibility that he and AD/HD have anything in common. But to her, his lifelong symptoms read like a textbook case. He is a highly intelligent man whose chronic misjudgments on the job and at home make his life—and his family's lives—unnecessarily hard and frustrating. "If an evaluation and treatment could make your life happier, why wouldn't you try it?" she asks. "It makes no sense to me, and it's extremely hurtful."

Collette's fiancé vehemently insists that he doesn't have AD/HD, three decades of classic symptoms to the contrary. "I am not your enemy and I am not telling you this to be mean," she says to him. "I'm trying to help you." Collette suspects he feels threatened. When he was a child, teachers labeled him everything from class clown to underperformer, and worse. As a teacher herself, she works with students who have AD/HD. "What if our own kids have troubles in school?" she asks him. "Are you saying that we won't get them help?" Sighing deeply, he replies that he knows his future kids will have the same troubles he's had, but he just doesn't want to talk about it now (translation: never).

To be sure, legions of adults with undiagnosed AD/HD do leap on the opportunity to pursue an evaluation once the facts are presented to them. They're bone tired of puzzling over why they struggle more than others who seem no smarter—and often less smart. Others view both the diagnosis and the possibility that they might have it with skepticism. For them, misperceptions about AD/HD and stigma issues, along with defenses built up around receiving lifelong criticism, might contribute to their so-called psychological, or defensive, denial.

Some adults, however, obliviously sail on, missing the connection between their dysfunctional behavior and dysfunctional work situations, relationships, and finances. They blame a bad economy, a pointy-headed boss, disharmonious feng shui, the children, or a "high-maintenance" partner—and sometimes the traffic cop. Echoing other leading AD/HD authorities,

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psychiatrists and researchers Margaret Weiss, Lily Hechtman, and Gabrielle Weiss offer this observation in their book *AD/HD in Adulthood: A Guide to Current Theory, Diagnosis, and Treatment* (JHU Press, 2001):

> Individuals with AD/HD are unaware of the behaviors that provoke negative reactions in others. They are aware, however, that others hover around them nagging. The connection between their behavior and this nagging response remains opaque. The white noise of nagging becomes an ever-more-distant hum, which the patients tune out; meanwhile, their families turn up the volume, becoming even more angry and controlling.

As a society, we've largely taken our cue from the psychoanalytic model and toss about the term *denial* with clinical confidence. It's common to hear someone with AD/HD described as being "in denial." And it's often said with smug superiority, implying that the problem is as plain as the nose on the denier's face—if only the denier would face what's in the mirror. Yet, what if steam has fogged the mirror? What if the mirror, along with the person's car keys, has been misplaced? What if it's a distorted funhouse mirror or car's side-view mirror, in which "objects may be closer than they appear?" In other words, denial sometimes springs not as much from a refusal to see—a willful action—as an inability to accurately perceive what sits before us.

For some people, the very symptoms that create so many problems for them also prevent them from connecting AD/HD symptoms to their personal struggles.

Doreen's teen son insists that his Dad has AD/HD, too, and she has to agree. "Our son won't accept that he has AD/HD, but he's failing in school," she says. "He asks why he should take medication if Dad won't. My husband 'copes' with his own AD/HD by drinking beer and riding herd on our son." Their fighting makes home a battle ground. And even though her husband accompanies Doreen to local CHADD lectures about AD/HD, it's solely to "support" their son. "You'd think he'd make the connection between the speaker's words and his behavior," she says, "but he doesn't."

With the help of the leading expert on denial in mental illness, clinical psychologist Xavier Amador, you'll soon be quite savvy about denial. Amador is currently an adjunct professor in clinical psychology at Columbia University, former director of research, education, and practice at the National Alliance on Mental Illness (NAMI), and a consultant to the National Institutes of Health. He has published more than a hundred peer-reviewed scientific papers and five books, and he served as a forensic expert in famous court cases, including that of Theodore Kaczynski (the "Unabomber"). Among Amador's books are *I'm Right, You're Wrong, Now What? Break the Impasse and Get What You Need* (Hyperion, 2008) and *I'm Not Sick, I Don't Need Help!* (Vida Publishers, 2000). To learn more about the nature of denial, especially as it relates to AD/HD, I interviewed Amador by telephone.

Anosognosia, the technical word for denial

People with AD/HD might not only deny they have it, they might also deny the presence of its symptoms. Here's the buzzword: *anosognosia* (pronounced ah-no'-sohg-no'-zee-ah). It's from the Greek words for disease (nosos) and knowledge (gnosis), and it literally means "to not know a disease." That is, people with anosognosia fail to realize they have a disease or disorder. Some kink or quirk in their brain wiring actually inhibits accurate self-observation, also called *insight,* which can vary over time for the same person.

For decades, neurologists used the term anosognosia to describe patients with brain tumors, Alzheimer's disease, or dementia—so-called brain pathologies. Thanks in large part to research by Amador and colleagues, we now know that low insight is highly associated with AD/HD, bipolar disorder, substance-use disorder, eating disorders, and other conditions that involve the brain's frontal lobes. (The frontal lobes, among other functions, integrate information.)

Back in the 1980s, though, as a young psychologist just beginning to study low insight in schizophrenia and bipolar disorder, he found only ten related studies. In 1990, he called the scientific community's attention to this fact by publishing a pivotal paper with three colleagues [Awareness of illness in schizophrenia, in *Schizophrenia Bulletin 17*(1): 113-21]. Today, more than two hundred studies have focused on insight and mental illness, with Amador contributing eighty peer-reviewed papers on the subject.

The first step in resolving most problems is getting people to realize there is a problem, he explains. You do that with your loved one's denial just as Amador did with the study of denial: by drawing his or her attention to the problem.

When Amador examined the scientific literature, he found that the mental health field had for decades relied primarily on psychoanalytic theories, not research, to explain denial. Fear of stigma created the denial, the theories maintained. Yet these theories had never actually been studied but simply accepted. That started changing when two of Amador's doctoral students based their thesis on research in this area. Their findings, confirmed in the twenty years since, included two key points:

- **Fear of stigma never entered the equation.**

The degree to which patients viewed their symptoms as potentially stigmatizing had little effect on how much insight they had into their illness.

- **Patients simply did not perceive their symptoms.**

"Everyone gets defensive occasionally and some of us are more denial-prone than others," Amador explains. "Everyday defensiveness, however, is not responsible for the gross deficits in insight that are so common in these patients," he says. "They honestly do not perceive the symptoms." The preponderance of studies on insight in mental illness focused on conditions such as schizophrenia, bipolar disorder, and anxiety, not AD/HD. Yet, in his years of clinical experience, Amador has also observed the same low insight in many other psychiatric patients. Consider anosognosia a "spectrum" disorder, with varying degrees of severity.

The person might not "see" the problems

This point is critical: What appears obvious to you or other observers might remain invisible or distorted to some people with AD/HD. Until you accept this possibility, you risk becoming even more angry or hurt at the person's "refusal" to acknowledge the obvious. Moreover, you risk being seen, in this person's eyes, as

unreasonable and unsympathetic—perhaps, in fact, as the enemy. To illustrate, let's focus on four common AD/HD traits:

1. Poor self-observation: After dating for six months, Pat asked her boyfriend, "Why do you lose your keys all the time?" He shot back, "Everybody loses their keys. You lose your keys, too." But whereas Pat might misplace her keys once a month, he lost his five times a week. He never noticed that, with him, it was a quantitative issue.

2. Difficulty linking cause and effect over time: Adults with AD/HD who don't make the "connection" between spending too much on eBay now and facing unmanageable debt five months from now won't be able to conceive that, in fact, *they* dented the family budget.

3. Poor working memory, distractibility: Mark can't understand how his wife can deny her dysfunctional actions. Their boys, age seven and nine, must constantly remind her of promises she's made. "I never said that," she'll often respond to them. The children are becoming understandably frustrated and even distrustful of their mother.

4. Confusing what you meant to do with what you did: Mark's wife also didn't remember setting her keys in the freezer when she came home frazzled on a hot day wanting some ice. Her mind might have been elsewhere, perhaps worried about what to make for supper or meeting that deadline at work. But even when Mark finds her keys in the freezer 24 hours later, she can't believe she left them there because, well, that's too darn weird.

Amador shares a remarkable clinical experience that explains how we don't simply *see* with our eyes what is happening; our brain also *interprets* what we see. After suffering a stroke, a patient's frontal-lobe condition left him unaware of his impaired ability to write. Asked by Amador to sketch a clock, the patient carefully did so and, upon questioning, pronounced himself pleased with the results. Then Amador drew the patient's attention to the numbers, which were, in fact, all jumbled outside of the circular clockface. Seeing this, the patient became agitated, pushed the paper away, and said, "That's not my drawing!"

"The truly striking part is that at first he perceived the clock looking as it should," Amador says. "But when I pointed to it and asked if the numbers were inside or outside the circle, he agreed they were outside." Growing more frustrated and angry at the disparity between what the patient thought he'd done and what the doctor showed he'd actually done, the patient said to Amador, "You've tricked me somehow."

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Psychiatrists and researchers observe that "Individuals with AD/HD are unaware of the behaviors that provoke negative reactions in others. They are aware, however, that others hover around them nagging. The connection between their behavior and this nagging response remains opaque."

Sound familiar? When confronted with the evidence of something that's broken or gone awry, has your loved one ever denied any involvement whatsoever or even pinned the blame on you or one of the children? Sure, it could be that the issue is protecting their hide or pride; many people with late-diagnosed AD/HD have learned to throw off constant blame out of self-protection. On the other hand, it's entirely possible that protests of innocence are sincere, even if based in misperception.

"People will come up with illogical and even bizarre explanations for symptoms and life circumstances stemming from their neurocognitive disorder," Amador says. (Further confusing their loved ones, pockets of awareness and unawareness often coexist.) The psychiatric lingo for this process is *confabulation*. And until you understand what's happening, it's easy to confuse it with lying.

If you've known anyone with early-stage dementia, you've probably seen confabulation in action. For example, an elderly lady with dementia parks her car and forgets where she parked it. Because she's never forgotten such a thing in her life, she's certain the car's been stolen. Why is this? Because only part of what we perceive comes directly through our senses—what we see, hear, and so on. The rest comes from our brain and how it interprets our perceptions and processes sensory signals. We know that conditions such as AD/HD can create difficulties with signal processing—that is, how brain chemicals transmit messages to and from within the brain.

"Our brains are built to create order, and even help construct our perceptions," Amador says. For example, his stroke patient certainly believed that he could draw a simple clock, and that belief superseded the physical evidence when it was shown to him. If you and your loved one have such different perceptions of reality, you might end up arguing about just who has the problem. When they feel cornered about "their problem," the only thing left for them is to say, "You have a problem, not me."

Now that you understand the brain-based denial of illness, what do you do with this knowledge? Consider making this your mantra: "The organ that's causing so many problems for my loved one with AD/HD is the same organ that he or she is using to evaluate these problems." Newly aware and grounded in this critical knowledge, you can start implementing practical strategies toward reaching through, around, over, or under your loved one's denial.

"It's not about *who* is to blame," reminds Amador. "It's about what is to blame. It's not you and it's not your loved one; it's the symptoms." Keeping this in mind can ease frustration and increase your ability to build trust.