Everything you thought you knew about ADHD is wrong

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Moving forward requires focus. <u>Mashable's Social Good Series</u> is dedicated to exploring pathways to a greater good, spotlighting issues that are essential to making the world a better place.

For decades, Attention Deficit Hyperactivity Disorder has been one of the most debated disorders, generating countless <u>books</u> and articles fretting over its <u>alleged over-diagnosis</u>. Yet even while people question its validity, ADHD also seems uniquely of our time, used now as a colloquialism to describe a digital age of technological distractions and low attention spans.

Despite being such an en-vogue disorder, though, ADHD remains one of the most misunderstood and stigmatized brain conditions of recent history.

NEXT STORY:

Whether it's outdated stereotypes of what it looks like, who it affects, widespread lack of clinical education on its overlooked symptoms, the demonization of its medications, or internalized shame in those with ADHD — everything you thought you knew about ADHD is wrong.

But that's not your fault, either.

Top medical professionals and advocates in the field are the first to admit there's a lot more research needed to fully understand ADHD. In a way, the disorder is undergoing something of a paradigm shift not unlike the one that <u>recategorized autism as a spectrum</u>.

"They're both going down the same pathway in terms of how people view the disorder," said Dr. Patricia Quinn, a <u>renowned pediatrician</u>, <u>author</u>, and founder of the National Center for Girls and Women with ADHD. "We've found that the disorder is much more complex than how we oversimplified it for so long."

Terry Matlen, one of the many top mental health professionals in the field with ADHD herself, personally understands the importance of demystifying it and the consequences of its stigmas.

"The biggest problem we face is ignorance and stigma. The contentiousness around ADHD is simply rooted in ignorance."

"People with ADHD, especially those who've lived with it undiagnosed, suffer a lot of losses in their lives, a lot of defeats," said Matlen, who is a practicing psychotherapist for ADHD patients and the author of <u>Survival</u> <u>Tips for Women with AD/HD</u>. Research suggests that untreated ADHD often leads to higher risk of divorce, joblessness, incarceration, depression, substance abuse, suicide, and accidental death. "People blame themselves, wondering, 'What's wrong with me? I must be dumb. I'm never going to make it.' That's when you see a lot of broken spirits. Very capable people suffer a lifetime of sadness and not living up to their potential — all because of improperly treated ADHD."

For Michelle Price, a board member of the adult ADHD advocacy group, it's something she only narrowly escaped after finally getting a diagnosis late in life.

"The issues impact us most when we don't know what ADHD is, what's really going on," said Price, who was identified as a gifted child but later struggled in professional structures. "It's a horrible thing to have and not know you have it. It's debilitating."

If you ask Dr. Edward Hallowell, a leading psychiatrist who treats ADHD patients and co-authored the book *Driven to Distraction and Delivered From Distraction*, "The biggest problem we face is ignorance and stigma. The contentiousness around ADHD is simply rooted in ignorance."

We fundamentally misunderstand what ADHD is or looks like.

ADHD is a brain disorder, with scans of people with ADHD indicating notable <u>structural and chemical differences</u>. Advocates use the term neurodiverse to identify people with ADHD and other conditions, including autism.

A deficiency in neurotransmitters affects chemicals like dopamine, impairing the brain's reward and pleasure centers and impacting executive functioning, impulsivity, attention, organization, hyperactivity, emotional regulation, and a "short-circuiting" of information and communication.

But that doesn't capture what living with ADHD actually means.

When we say everything commonly known about ADHD is wrong, we mean literally *everything* — including the very label.

"The misunderstandings of ADHD begin with the term Attention Deficit Hyperactivity Disorder. It's a horrible term," said Hallowell. "We don't have a deficiency of attention, but an abundance of it." Hallowell even likens ADHD to having, "an amazingly powerful Ferrari engine of a brain with bicycle brakes. So your challenge is to control it."

Aside from attention, ADHD commonly leads to a variety of issues with self-regulation, like mood and emotion. But the <u>American Psychiatric Association's (APA) definition</u>, which health professionals use to diagnose patients, doesn't address those symptoms whatsoever.

"If you treat patients for their symptoms rather than for a flawed label, you find that the biggest impairment to people's lives with ADHD tends to be impulsivity," said Quinn.

Aside from an overemphasis on "attention" and "deficit," the "hyperactivity" part is equally misleading. Quinn, Matlen, and Hallowell said that it tends to be the least bothersome symptom for patients — especially for <u>girls</u>, <u>women</u>, and <u>adults</u> who were under-diagnosed because they didn't display visible signs of hyperactivity.

"The changes we're seeing right now is a correction to the myth that ADHD was merely an academic disorder that affected hyperactive young boys," she said. "We need to shift our understanding of it as a chronic disorder that usually persists into adulthood and affects people in the workplace, in relationships, in so many serious ways throughout their lives."

It was <u>only in 2000</u> that the APA's mental disorder manual officially recognized <u>three different subtypes of ADHD</u> with unique symptoms. Although that added much-needed nuance to capture the diversity of ways ADHD manifests, these additions still omitted a <u>bevy of overlooked symptoms often more prominent in women and girls</u>.

Take hyperfocus, a common ADHD trait, for example. People can become so engrossed in an activity that interests them (like playing video games) for so many hours that they lose <u>all sense of time</u>. But because it isn't included in the diagnosis manual and doesn't fit the "attention deficit" stereotype, clinicians wrongfully use it to disqualify patients from an ADHD diagnosis.

For Price, learning that folks with ADHD have an interest-based nervous system was essential to understanding everything the diagnosis manual leaves out. Combined with impulsivity, interest-driven nervous systems can lead to issues like emotional hyperarousal, making those with ADHD prone to sudden explosions of everything from anger to sadness to joy.

Another related feature of ADHD overlooked by the diagnosis manual is Rejection Sensitive Dysphoria (RSD) where, as Price described it, "rejection becomes so debilitating you literally feel like you've been punched in the gut."

Hallowell even coined his own companion term: a phenomenon he calls "recognition sensitive euphoria." In the same way that mild or merely perceived criticism and rejection can cause a person with ADHD to wilt, the smallest forms of encouragement and recognition do wonders to motivate them.

Another under-researched symptom, Matlen said, is sensitivities to sound, touch, light, smell, or taste, with a higher tendency to be overwhelmed by sensory stimulation.

ADHD is a legitimate condition, and not a product of "stupidity," "laziness," or "bad parenting."

One widespread misconception that even clinicians still get wrong is that ADHD is *not* considered a behavioral disorder, despite the diagnosis currently relying on identifying symptoms through behavioral patterns. ADHD also isn't a personality disorder, mental illness, or character flaw, though it does carry many of the same stigmas.

"A huge part of the stigma comes from how ADHD is an invisible disorder," said Matlen. "You can't see what I struggle with everyday so it isn't real."

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Often, people with ADHD learn to hide, manage, or internalize their symptoms so it's hard for others to pick up on their neurological difficulties — especially for those who aren't super visibly hyperactive (like women and girls).

"The lay public still thinks that ADHD is an excuse or that people use it as a cop-out for bad behavior if they're not performing, not fulfilling job obligations, deadlines, or obligations at home," said Quinn.

This misperception isn't helped by how people view <u>ADHD accommodations like extra time on tests</u> as an unfair advantage, with reports claiming <u>rich parents seek false diagnoses</u> to <u>help their kids cheat</u>. It feeds into the myth that kids with ADHD are a result of bad parenting with disruptive behavior that'd be quelled through discipline. But actually, evidence suggests that punitive parenting can make the symptoms of ADHD worse.

Ultimately, these stereotypes stem from the wrongheaded belief that people with ADHD can control their disability.

"The perception is that we're just lazy and, well, if you only tried harder, if you had more willpower, you could do these basic tasks," Matlen said.

In reality, people with ADHD need to expend more mental energy than the average person to accomplish tasks like meeting deadlines or even responding to emails. So they're actually trying harder than neurotypical people (meaning those who don't have developmental disorders).

A related myth is that people with ADHD are "stupid" or have a low IQ, so high-achieving people can't have it. There's no shortage of ambitious, successful people diagnosed with ADHD. But the general public doubts the legitimacy or seriousness of their disorder more, precisely because of their achievements.

"The difficulties of ADHD are often incongruent with a person's abilities," said Matlen. "People think, 'You're a capable person, you've got two college degrees, how come you can't remember to sign your daughter's school field trip papers?"

These misconceptions have lasting, damaging effects on self-confidence. Because symptoms like forgetfulness, disorganization, inattentiveness, mood swings, and impulsivity are viewed as deliberate misbehaviors or flaws, kids (<u>particularly girls</u>) with ADHD blame themselves for their neurological difficulties, <u>internalize that guilt and shame</u>, and carry it into adulthood.

"The real disability is believing you're less than, believing you can't measure up," said Hallowell.

No, not everyone has ADHD. But circumstances can either exacerbate or help hide the symptoms of ADHD.

With little understanding of the complexities of ADHD, the same folks who minimize its seriousness and question its existence also tend to claim things like, "Everyone has a little ADHD nowadays!"

Many people occasionally experience some ADHD-like symptoms. But for those who actually have it, it's a chronic neurological inability with the potential to cause longterm impediments to a successful, fulfilling life.

This fallacy also feeds into the notion that ADHD is caused by or is an invention of the modern world. While the term ADHD is relatively new, symptoms of the disorder, <u>categorized under different names</u>, <u>are centuries old</u>. Yet some point to rising rates of people diagnosed with ADHD to imply it's a manufactured fad, without <u>understanding the reason behind that increase</u>.

"ADHD is not caused by the world today. The world today has just created a situation where people with ADHD cannot cope."

"ADHD is not caused by the world today. The world today has just created a situation where people with ADHD cannot cope," said Quinn. It's true that technology has led to a modern life with more distraction,

information, demands for multi-tasking, and higher academic and professional pressures than ever before. "If we didn't have a world like this, maybe their symptoms wouldn't show as much, but the person would still have ADHD."

This is also why people like Price (the advocacy group board member) and other high-functioning adults (particularly women) don't get diagnosed until later in life, if at all: Their symptoms don't visibly disrupt theirs or others' lives enough, until a change in lifestyle gives them more responsibilities that trigger the ADHD or make it more apparent.

The reason Price made it as far in life as she did without crashing and burning, she said, was because she figured out workarounds. That is, until she quit her corporate job one day on an impulse to build her own career path more catered to her strengths.

"I could figure things out, as long as I had structure," she said about the difficulties she encountered after trying to do it all on her own. "But I could not understand why some things were so easy to do, and other things I just wouldn't do at all."

In the end, her decision worked out though. Her personally-tailored career path led her to be part of an ad campaign for a book on ADHD, which helped her realize why she was struggling in ways others didn't, often silently and without anyone noticing.

That's common for adults with undiagnosed ADHD, Malten said. They find strategies, jobs, environments, the right partners, and create circumstances to help mask their ADHD. But there's usually an eventual breakdown, typically brought on by significant changes to lifestyle demands.

"We see that a lot around early marriages or after children come into the picture, when now you're responsible for other human beings," said Matlen.

This is especially true for mothers made responsible for child-rearing and household duties. They not only need to cope with their own (often undiagnosed) ADHD, but commonly their kids who inherit it. Chemical changes from aging can cause ADHD symptoms to worsen, too. <u>Estrogen plays a big role in how ADHD</u> symptoms manifest in women and girls, so menopause can increase ADHD's mood swings and forgetfulness.

ADHD medications are not a "smart" drug people take to "cheat."

ADHD medicine is central to the many stigmas and myths around the disorder.

Big pharma's <u>marketing pushes around the stimulant medicines used for ADHD</u> should definitely be cause for concern and further investigation. Medical professionals also do not deny that stimulants can be addicting when misused, like anti-depressants and many other drugs for chronic illnesses and disorders.

However, stimulant medication used to treat ADHD are uniquely demonized. Parents giving their kids the medication needed to level out the neurological playing field are commonly accused of "drugging up their kids" for a disorder they do not believe is legitimate.

"There was a time when stimulants were abused and used as diet pills and doctors were handing them out like M&M's. And of course amphetamine is speed, and speed can kill when abused," said Hallowell, referring to one of the most common stimulants used for ADHD.

But neither doctors nor people with ADHD are at all advocating for unchecked use of stimulants. Actually, the recreational abuse of prescribed amphetamines by people who don't have ADHD hurts those who do have it by creating more stigma and even shortages.

Counter to the popular myth that taking prescribed ADHD medication raises the risk of substance abuse in patients, research <u>suggests it has the exact opposite effect</u>. It can actually decrease the chances of people with untreated ADHD turning to drugs and alcohol to self-medicate. Far from pill-popping addicts, they often even struggle to remember to take their medication.

Also, the popular notion of parents and doctors pushing pills on kids is the opposite of the reality seen by every medical professional we spoke to. Parents and adults are extremely hesitant to try stimulants, in part because of stigma and myths about addiction.

The best clinicians also know that successful ADHD treatment and management requires multiple management methods. Stimulants shouldn't be a replacement for therapy. Doctors also recommend alternative and supplementary coping strategies, like meditation and regular exercise.

"Those are all helpful, but none are as helpful as stimulant medication," said Matlen. She equates not giving someone with ADHD the stimulants they need to asking someone who's near-sighted to not wear glasses. "I've seen the downfall of those who listen to media panic and don't get the medication they need. I see their worlds fall apart."

All the clinicians agreed about the effectiveness of stimulants, while still stressing that effective treatment first and foremost requires working with what a patient is comfortable with.

"People ask me, 'Do you believe in Ritalin or Adderall?' The answer is that it's not a religious principle, not a matter of belief. It's a medication. So if it's helpful and doesn't cause side effects — great, use it. If it's not helpful or causing side effects, then don't use it. Medication is a trial, not surgery or something irreversible," said Hallowell.

He never pushes a patient to use stimulants, but he does present them with the facts that dispel common myths. More often than not, that's enough for them to decide to at least try medication.

Diagnosing ADHD is a difficult issue, but not for the reasons you think.

While a lot of the moral panic around increased ADHD diagnoses are unfounded, there's no denying the legitimate difficulties of getting an ADHD diagnosis right.

"ADHD has a high percentage of what we call comorbidities, which means coexisting conditions," said Matlen. People with ADHD often have at least one or two other conditions, like depression, anxiety, OCD, learning disabilities, bipolar disorder, or substance abuse. "It takes a really good clinician to be able to figure out, alright, is this other disorder traveling with the ADHD and needs to be treated separately? Or is it caused by the ADHD?"

As Quinn explained, "You have to be very careful that you're not missing the comorbidities and treating them appropriately. But if you happen upon the comorbidity first, like bipolar disorder, you can't only focus on that and potentially miss the ADHD as well."

An added complication is that ADHD symptoms — like inattentiveness, distractibility, impulsivity, mood swings, lack of motivation — can easily mirror other medical conditions and mental health concerns. Determining whether ADHD is an overlapping versus misdiagnosis of those other conditions is difficult.

Years ago, pediatrician Dr. Nicole Brown from the Strong Children Wellness Center in the Bronx published important findings showing a significant connection between youths diagnosed with ADHD and childhood trauma. Children dealing with higher levels of poverty, divorce, violence, and substance abuse were three times as likely to be prescribed ADHD medication, and symptoms of chronic or post-traumatic stress – like disassociation, hypervigilance, behavioral issues, impulsivity — can be mistaken for ADHD.

"I always think of ADHD as a diagnosis of exclusion," Brown said. "You need to ask other questions to make sure it's not something else that looks like ADHD that you might be missing."

But Brown's findings don't necessarily mean that the kids with traumatic stress disorders didn't also have ADHD. In fact, research into the relationship between childhood trauma and ADHD is a growing area of study.

As Quinn explained, brain scan research shows how early childhood trauma can indeed change the structure of one's brain, in similar ways to the structural differences of the ADHD brain. Brown's findings also align with two important factors:

- ADHD is genetic, so kids with ADHD are likely to grow up with parents who have (often untreated)
 ADHD.
- Adults with untreated ADHD show higher rates of divorce, violence, substance abuse, and difficulty holding down a job that could very well lead to poverty.

<u>Theories posited by Dr. Gabor Maté</u>, while not yet accepted by the mainstream medical community, suggest that early childhood trauma can potentially bring out ADHD in kids genetically predisposed to it. Matlen's not alone in the opinion that, "There's a grain of truth, if not more, in the theory that we need to look more deeply into."

What happens is the adult or parent has to become an advocate for themselves.

Price personally sees a very close connection between trauma and untreated ADHD in the Black community.

While data from 1998-1999 showed <u>African American children were being diagnosed with ADHD</u> at two-thirds the rate of white children, <u>data from 2016-2018 reveals a shift</u>, with slightly <u>more African American children being diagnosed</u> with ADHD than white children.

"As a Black woman, it's important to me that people understand more about ADHD because I see so many things in our community that are clearly related to ADHD," said Price, who has four generations of ADHD in her family. "In our community, one of the biggest issues is not wanting to address mental health issues, especially one as invisible as ADHD."

Accurate diagnosis and effective treatment for a complex disorder like ADHD requires thorough, longterm observation of a patient's bigger picture: family and relationship history, life circumstances, workplace and schooling background, and awareness of the full spectrum of symptoms. The tests used to diagnose ADHD are flawed, with Brown suggesting adding a <u>test for childhood trauma</u> to all assessments. A proper ADHD diagnosis cannot be made by general practitioners doing hasty 20-minute evaluations, which is unfortunately common, ADHD experts noted.

"Many if not most clinicians aren't educated in the accurate information on ADHD," said Matlen. "So what happens is the adult or parent has to become an advocate for themselves. And it's such a struggle, having to fight so hard in every arena to be understood and not seen as less than anybody else."

Despite stigma, ADHD can be a gift.

The stigma around ADHD is so pervasive and damaging that medical professionals like Hallowell and Malten hesitate to even call it a disorder or disability.

So Hallowell characterizes it as a "brain trait with positive and negative effects." He even has his own acronym to avoid the pitfalls of the ADHD label. "I renamed it VAST: Variable Attention Stimulus Trait. Because people with ADHD are all drawn to high stimulation situations and their attention varies according to how stimulating the situation is."

What Hallowell hopes his patients understand is that, yes, living with ADHD can be hard. But the brain trait can also influence resilient, resourceful, curious, creative, intuitive, innovative, outside-the-box thinkers who are at the top of their field and represented across all areas of interest.

What hinders people with ADHD most is a world that's ill-prepared to help their best qualities flourish, both in school and the workplace.

"What you want to learn is how to maximize the blessing and minimize the curse."

"We need senior people to understand how to be conversant in the language of neurodiversity, because you are skipping over people in your organization who deserve better. You're not using everybody's strength," said Price. "They're missing out. And neurotypicals need to recognize how they're making it very hard for us at work."

People with ADHD can and often do excel, but they're typically forced to figure out how to on their own.

"It's a blessing and a curse, having this condition. What you want to learn is how to maximize the blessing and minimize the curse," said Hallowell.

There are a few key parts to that, Hallowell and Hatlent believe, including:

- A support system to provide encouragement and affirmation
- Identifying your talents and a job that caters to them
- Positive, stable emotional connections, especially with partners who complement your ADHD
- A creative outlet, even if it's just a hobby

Ultimately, the more we demystify ADHD, the more we can recognize how it contributes to society.

As Price put it, "People with ADHD can take on the world. We've just been waiting for everybody else to catch up."