

LOOKING AT ADHD:
A personal exploration of Attention Deficit/Hyperactivity Disorder

by

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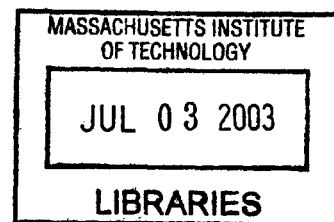
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ABSTRACT

“Attention Deficit/Hyperactivity Disorder,” or ADHD, is the most commonly diagnosed mental disorder in children. According to the National Institute of Mental Health (NIMH), it affects 3 to 5 percent of all children, as many as 2 million children in the United States alone. A report issued by the American Medical Association in 1998 calls ADHD “one of the best-researched disorders in medicine.” However, the condition is very little understood outside the circle of those who research it or work with people who have it. In the media, and among those without direct experience of it, the idea of a disability involving trouble paying attention can inspire confusion, skepticism, and even downright contempt.

I was diagnosed with ADHD as an adult. What I’ve experienced in my own life doesn’t seem to bear much relation to the “attention deficit disorder” that most people talk about. There is a gap between what scientists mean by ADHD and what the term evokes for most people, and as a medical condition it remains much more controversial than, say, cancer or diabetes. One hundred years after doctors began observing this condition, scientists still find it necessary to defend its existence and declare its validity.

I’ve set out to explore why such confusion exists around ADHD, and why it remains so controversial.

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“So there’s a name for what I am! I thought to myself with relief and mounting excitement. There’s a term for it, a diagnosis, an actual condition, when all along I’d thought I was just slightly daft.” – Edward Hallowell, in Driven to Distraction

“Attention Deficit/Hyperactivity Disorder” was just an obscure term to me when it entered my life about seven years ago, in the form of a dog-eared paperback book. While browsing, I found something called Driven to Distraction: Recognizing and Coping with Attention Deficit Disorder, by doctors Edward Hallowell and John Ratey. I knew that it had something to do with children and “special needs,” but I had never really understood what it meant, so I picked up the book and started flipping through it.

Before I knew it I was sitting on the floor poring through it avidly. The pages were full of stories: Jim, who had wonderful ideas at work but couldn’t manage to write them up; Penny, who daydreamed through the fifth grade and forgot her homework; kids who couldn’t sit still, and adults who either couldn’t concentrate or couldn’t be pried away from something once they got started. I stared and kept turning the pages, mesmerized. Completely out of the blue, I had found a book where every character was singing my song.

It was downright eerie, the way the book drew a connection between things that had dominated my life but seemed to be completely unrelated to each other: being restless; being forgetful; blurting things out in conversation; fighting uphill battles to get focused; throwing myself into projects with passionate intensity but quickly losing track; always missing cues and feeling out of the loop; never quite getting it together.

I learned that there were other people whose lives were strangely like mine, and that their experiences were due to a brain-based condition involving impulsivity, inattention, and hyperactivity. The authors of the book were two doctors who not only treated people with this condition, but also had it themselves, and they described case

after case in rich detail. Sitting on the floor of the bookstore, I experienced a blinding “A-ha!” moment in which a lifetime of idiosyncratic experiences fell into place, within a new frame that seemed to tie everything together.

Despite my unfamiliarity with it, “Attention Deficit/Hyperactivity Disorder” (or ADHD) is not a rare and unusual thing. It’s the most commonly diagnosed mental disorder in children, and the National Institute of Mental Health (NIMH) estimates that it affects 3 to 5 percent of all children, as many as 2 million children in the United States alone. A fact booklet released by NIMH in 1996 proclaims that “on the average, at least one child in every classroom in the United States needs help for the disorder.” Once considered a childhood problem outgrown by adulthood, there is a growing perception of it as a lifelong condition, one less obvious in adults but still present nonetheless.

ADHD is also not a new idea. Doctors and scientists have labeled and studied it in one form or another for over a hundred years. A report issued by the American Medical Association in 1998 states that “ADHD is one of the best-researched disorders in medicine, and the overall data on its validity are far more compelling than for most mental disorders and even for many medical conditions.” And yet the condition is very little understood outside the circle of those who research it or those who work with patients.

After reading Driven to Distraction, I saw a doctor and was diagnosed as having ADHD. As an adult, for the first time I began learning about the condition and how to cope with it using medication, coaching, cognitive and behavioral strategies, and a whole lot of learning and re-learning. I’ve also learned, however, that the thing that I’ve experienced in my own life doesn’t seem to bear much relation to the idea of “attention

deficit disorder” that most people talk about. There is a gap between what scientists mean by ADHD and what the term evokes for most people, and as a medical condition it remains much more controversial than, say, cancer or diabetes. In the media, and among people without direct experience of it, the idea of a disability involving trouble paying attention can inspire confusion, skepticism, and even downright contempt.

When “attention deficit disorder” comes up in general conversation, it’s not unusual to hear comments like “oh yeah, if it even exists.” Others mention it with suspicion, as an example of over-medicalization of normal, everyday behaviors. It comes up in criticisms of the modern education system: people say that the natural rambunctiousness of children is now considered a “disability.” Some see it as something dreamed up by pharmaceutical companies in order to create a market for their medications. Some even use the phrase to typify modern society: you can find “attention deficit disorder” used as a shorthand for a lifestyle of information overload, led by people with pagers and cell phones and a hundred cable channels, and by easily-bored children with dozens of toys and an overflowing schedule of activities.

I’m not the only one troubled by this perception gap. In January 2002, a group of scientists released an “International Consensus Statement on ADHD” in the journal Clinical Child and Family Psychology Review. That statement, signed by 70 scientists internationally, declares that ADHD is a valid disorder with a serious impact on the lives of those it afflicts:

“We... are deeply concerned about the periodic inaccurate portrayal of attention deficit hyperactivity disorder (ADHD) in media reports. This is a disorder with which we are all very familiar and toward which many of us have dedicated scientific studies if not entire careers. We fear that inaccurate stories rendering ADHD as myth, fraud, or benign condition may cause thousands of sufferers not to seek treatment for their disorder. It also leaves the public with a general sense that this disorder is not valid or real or consists of a rather trivial affliction....To

publish stories that ADHD is a fictitious disorder or merely a conflict between today's Huckleberry Finns and their caregivers is tantamount to declaring the earth flat, the laws of gravity debatable, and the periodic table in chemistry a fraud."

One hundred years after doctors began observing this condition, these scientists still find it necessary to defend the existence of ADHD and declare its validity as a medical condition.

I've set out to explore why such confusion exists around ADHD, and why it remains so controversial.

What is an "attention deficit"?

The name "Attention Deficit/Hyperactivity Disorder" is unfortunate, because it simply sounds like a label for people who don't pay attention very well. It shares this problem with conditions like Chronic Fatigue Syndrome (CFS): the name doesn't tell you what the condition is or what causes it; it's just a name for something that doctors have observed and are trying to make sense of. The names don't express the way these conditions go far beyond the normal human experience of "fatigue" (CFS) or getting focused (ADHD): they're much more complex and debilitating than they sound.

ADHD is characterized by inattention, impulsivity, and hyperactivity, but these are just surface symptoms whose underlying causes are still being researched. Someone who is having trouble paying attention may or may not actually have ADHD: being very tired or being under a lot of stress, for instance, can temporarily cause similar problems. While everyone has trouble with these things from time to time, most people can overcome those problems by taking a break or trying harder. People with ADHD, however, don't just have these symptoms; they have chronic difficulties with them, from a very early age, in a way that seriously interferes with their ability to function in a variety of situations, across their whole life history. Doctors aren't claiming that "not

paying attention” is a disorder; they’re saying that there is a disorder (or perhaps more than one) which can cause problems paying attention.

The fact remains, however, that the very idea of an “attention deficit disorder” just doesn’t make sense to many people. The complexity of the underlying neurological processes that govern attention, learning, and memory are hard to communicate, and definitions of the condition that are based solely on the symptoms can sound implausible. It’s very hard to understand persistent problems with attention and focused thinking that can’t be overcome just by “putting your mind to it,” unless you’ve experienced it directly.

When I was about three years old, my parents brought me to my pediatrician to have my hearing tested. They were concerned because they would call me and I wouldn’t come, or they’d tell me things and I would just continue doing whatever I was doing, oblivious

“We didn’t want to cause trouble. We didn’t start our days with a plan to drive everyone crazy. ... We did these things because we had [ADHD]. But, unfortunately, most of us didn’t know that.”
– Kate Kelly and Peggy Ramundo, in *You Mean I’m Not Lazy, Stupid, or Crazy?!?*

to what they were saying. When they’d yell louder or physically interrupt what I was doing, I’d look up and seem angry and surprised.

The doctor tested my hearing and found nothing wrong. After talking with me for a while, he concluded to my parents that I could hear fine, but that I only heard what I wanted to hear.

In some ways my doctor was right, of course; I only heard things that got my attention. If I was focused on something, I could hear it fine; if something was loud or startling enough to grab my attention, I could shift my focus to it long enough to hear and

understand. But I wasn't making conscious choices about what to hear and what not to hear: most things just never registered with me at all. The fifth time my parents said something, by which point their voices were loud and angry and right next to me, was the first time I was really hearing them. (The idea that I was perfectly capable of hearing them, but just willfully choosing not to, led to my being treated with anger and accusations of stubbornness by parents and teachers for years to come. This is very common for children with ADHD.)

“Attention” is a funny thing. Even Professor Susumu Tonegawa, Director of the Picower Center for Learning and Memory at the Massachusetts Institute of Technology, says attention is difficult to define. He prefers to describe it by saying what it does: it affects the way we acquire information. Suppose, he says, a lecturer is speaking to a class. If you ‘attend’ to the lecturer, then some of the information he’s putting out will stick better in your brain. Attention is a mechanism that helps people take in information from the outside world, and fix it in the brain.

Behavioral scientist B.F. Skinner described attention as a “relationship between something in the environment... and the behavior of the individual.” Again, in this view, attention is something that focuses the brain on a particular thing in the environment, so that information coming in is better perceived, responded to, and remembered.

If attention is what allows people to perceive, learn and remember things, then it's easy to see why problems with attention lead to problems with anything that requires learning and memory.

When I was in the first grade, the teacher asked us to hand in an assignment. This was the first moment that I had heard anything about it. I raised my hand and told her

quite sincerely that she had never told us to do anything like that. The rest of the class let me know that I was crazy – they had all known about the assignment and had theirs ready to hand in. The teacher knew from my look of panic and utter bewilderment that I wasn't just pretending ignorance in order to get out of my work. She mentioned the episode to my parents, but no one seemed to know what to make of it.

To remember an assignment, a child must be paying attention to the teacher when she is giving the instructions, not fully absorbed in looking at a book on her desk. The child must also maintain attention on the teacher long enough to hear all the instructions and assimilate them. She may hear the first part of a sentence, but halfway through she is suddenly thinking of something else, or drawn to a butterfly outside the window. If the full sentence isn't heard and understood as a whole, then the initial pieces that were heard just fade away without the context needed to understand them, and they're gone like so much background noise. At the end of the day, ask the child what went on at school, and she'll remember the butterfly, but she'll have no memory of being given an assignment.

This kind of situation was to become terrifyingly familiar to me. Demands would regularly jump out of nowhere – assignments that I didn't remember being told about, instructions that I had failed to follow through on, angry reminders of things that I had no memory of having been told in the first place. I did learn very quickly, however, that this was my problem – my memory of events almost never matched that of other people, and they were in charge or outnumbered me. I learned to just keep quiet when slips occurred, cover my confusion, and try harder. I grew to hate the phrase “in one ear and out the other,” because I was lectured with it so often, but it's actually a fairly accurate description of what can happen. If information doesn't register, it won't be remembered.

Attention isn't the only thing that seems to work differently in people with ADHD. One of the most well-known traits of ADHD is hyperactivity. The stereotype is of someone who can't sit still – they're restless, rambunctious, always dashing off to something new. Not only do hyperactive people seem compelled to keep moving, they often actively crave and seek out high-energy activities. As adults they may participate in extreme sports, ride motorcycles, jump out of airplanes, anything that provides that burst of adrenaline. (Adrenaline and excitement have a focusing effect. Some hyperactive people feel much more alive and fully present during these risky, highly-charged activities than they do in the fog of their normal existence.)

Running wild, particularly as children, is so characteristic of ADHD that when trying to diagnose it, doctors will often ask someone about their childhood accidents: how many bones did they break? How often were they in the emergency room? Not everyone with ADHD is hyperactive, and often this component fades by adulthood, but it's an indication of possible ADHD when combined with a history of attention problems.

When I was a child, I ran away. I don't mean that I did it once; I mean that it was a personality trait. My mother would get together with other mothers, who would let their kids out to play in the backyard while they talked; they'd tell her, "Oh, just let them play, I'm sure they'll be fine, you're just being overprotective." The next thing you know, I'd be off running down the street. I wasn't particularly running away from anything, I was just completely absorbed in exploring wherever I was, focused on seeing what I could see and oblivious to property lines, distance, and time.

I was so hyperactive, from such an early age, that when I was around two my mother took me to a doctor to find out if there was something wrong with me. She says that when they came to call her in, I had already climbed halfway up the curtains in the waiting room. The doctor decided that yes, I was clearly much more hyperactive than a normal two-year-old (which should inspire serious sympathy for my parents from anyone who has known a normal two-year-old). He gave my mother some kind of sedative medication to give to me. When she tried it on me once, however, I acted drugged and slept all day, which scared her so much that she never used it again. My parents decided they didn't want to give me any more medication; they'd just have to deal with me and see if I outgrew it. (Luckily, I was their first child, so to some extent they just assumed that all children were like this.)

A third trait of ADHD is impulsivity. This is related to hyperactivity – one way to think of impulsivity is as a diminished barrier between thought and action.

As a child, I usually became aware of having done something by the reactions of the people around me; I hadn't been aware of thinking about doing it, I had already just done it, without the intermediate step of consciously considering it.

In grade school I would just jump up from my desk and wander around the room, picking things up and looking at them. I might remember a book we had read, and the next thing you know I'm standing in front of the classroom bookshelf paging through it, while the teacher is yelling at me because she was in the middle of giving us a math lesson that I had simply tuned out of.

People with ADHD often leap before they look, speak before they think, and jump into things full throttle with guns blazing. They can often be annoying in social interactions, talking a mile a minute (one of my childhood nicknames was “motor-mouth”) and overriding other people in their eagerness or their desperation to finish what they say while they can still think it, before they forget it and it’s lost. Through years of negative social feedback, and perhaps because my adult brain is easier to control than my childhood brain was, I’m better now at riding herd on myself than I used to be. I consciously developed a habit of squelching my initial reactions to anything, forcing a filter of “is this appropriate?” before saying anything. When I get enthusiastic or comfortable enough, though, it all goes completely out the window and I start jumping all over the place again.

There’s another characteristic of ADHD that relates to attention, and it’s something particularly strange when you consider the other problems people with ADHD tend to face. This is the phenomenon of “hyperfocus,” or very sustained focus on something. Some people describe it as “flow,” a Zen-like state of complete attention on some activity, and looking up hours later having had no sense of time passing.

People with ADHD, who sometimes can’t sit still or pay attention long enough to hear a single sentence, at other times can get so involved in something that you’d have to hit them over the head with a truck to pull them away from it. When they’re absorbed in something, talk to them and they won’t hear, mealtimes and appointments will come and go and they won’t notice, and other goals and promises will be completely forgotten. Forcefully pull them away, and they’ll be furious.

It seems strange that people with attention deficits could hyperfocus, but some scientists think that both problems could come from the same thing: difficulties in controlling where attention is focused. If someone lacks conscious control over their attention, then they can neither keep their attention from wandering, nor pull it away once it becomes fixated on something.

Things that can pull someone into hyperfocus are those that are interesting, absorbing, and highly motivating – things that tend to “get your attention”. This is true for everyone, but people with ADHD seem less able to resist the things that pull their attention. Once lost in something, their awareness is completely focused on it.

This can lead to serious problems for people with ADHD. It triggers accusations of laziness, irresponsibility, and lack of willpower – if a child can spend hours poring over a comic book, why can't they pay attention in class? If they can spend all their free time drawing elaborate fantasy worlds for their action figures, then why do they act so restless and miserable after ten minutes of sitting at a table trying to do their homework? What makes it worse is that the things that focus one's attention tend to be fun and interesting, and the things that shut it down are those that are boring, un motivating, things that we don't particularly want to do. Again, this is true for everyone, but most people seem to be able to make a conscious decision to focus on something they don't really find interesting, something much more difficult for someone with ADHD. A child isn't choosing to be this way – he literally can't focus on his homework the way he can on his comic books, and sitting there shackled to a chair staring at incomprehensible homework is excruciating. Hyperfocus provides an experience of being clear, focused, and highly functioning that stands in sharp contrast to the rest of the experiences of someone with

ADHD. No wonder a child will toss their homework in frustration and crave getting lost in a video game (an extremely common habit in people with ADHD), but no wonder this leads to these children being seen as lacking discipline and moral character, constantly choosing to do what they like and avoiding what they don't.

While not a symptom, one common consequence of having ADHD is problems in socialization. People with ADHD often have problems socially, being perceived as eccentric, overbearing, or not quite all there. Some run roughshod conversationally over other people, speaking a mile a minute or interrupting often. Others space out, don't hear what people are saying, or forget what was said. Someone may say something that reminds them of something else, and they either jump in with their own story, or space out in that direction, rather than paying attention to the person speaking. This can cause problems with forming friendships and long-term relationships.

Some researchers see these social problems as a result of ADHD symptoms: problems with attention can interfere with hearing subtext and learning to read social cues. Hyperactivity and impulsivity make it harder to restrain one's own behavior and interact smoothly with others. Dr. Michele Novotni, a psychologist who works with children and adults with ADHD, describes them as expressing a common theme of frustration when they miss cues, misunderstand people, and can't make themselves understood. They feel like they're standing in the middle of a sea of radio waves, with no receiver. She has written a book called What does everybody else know that I don't?, which attempts to explicitly spell out these rules of conversation, body language, and relating to others that people with ADHD are missing.

Novotni says that “subtext is something most people learn about growing up.... Children learn social skills, like subtext-reading, from examples. As they watch and hear older people in conversation, paying attention to the details of pace, inflection, body language, etc., they learn to understand a full range of meaning. However, as you know, this is not always the case for those with AD/HD. It’s tough to pay attention to those details, and so subtext can remain a mystery. Unless you work at learning and deciphering it, you probably won’t just pick it up.”

I have extensive experience with the typical problems of ADHD: inattention, impulsiveness, hyperactivity, and many of the corresponding problems with learning and socialization. But I’m not necessarily typical – for one thing, a lot of ADHD people seem to be much more hyperactive than I am as an adult, while other people may not be hyperactive at all. Some people are more “spacey” – zoning out rather than acting up. Others create very rigid structures and habits that allow them to function – rather than being wild rebels, they can be among the most strict and orderly people you know. Some scientists speculate that there are “sub-types” of ADHD – variations of the same underlying cause.

I’m also not typical because I’m female. Among people diagnosed with ADHD, males outnumber females 3:1. Many scientists speculate, however, that as many girls as boys have ADHD, but they’re less likely to be diagnosed. ADHD may look different in girls, who are more likely to be withdrawn than to be hyperactive and rebellious. Girls may also learn better how to behave socially, and cause fewer problems that get them noticed as troublemakers and eventually diagnosed.

There's another way in which I'm very unrepresentative of ADHD: I don't seem to have any other neurological conditions. There are high rates of "co-morbidity" of ADHD and certain other conditions. ("Co-morbidity" means medical problems that appear together.) For instance, dyslexia and other learning disabilities are quite common in people with ADHD, and as many as 70% of children with tic disorders and Tourette's syndrome also have ADHD. Co-morbid conditions can make it more difficult to diagnose exactly what the causes are of various learning and behavioral problems, particularly in children. The high co-morbidity of a number of these conditions, however, also raises the interesting question of whether they might have similar or related causes. (For instance, genes that seem to be connected to autism are near or closely related to genes that seem to be connected to ADHD, but the research identifying these gene areas is still preliminary.)

There is really no one description or type that fits everyone with ADHD. The same underlying condition can look very different in different people, and there may be a number of different causes and conditions that can result in what is currently a single umbrella label. My experiences provide one data point, but there is a large body of research, case studies, and clinical work that doctors and researchers have developed over the years since the condition was first identified.

A brief history

The history of what we now call ADHD began over a hundred years ago with George Still, a British doctor who worked with children. He observed that some of the children in his care shared a similar cluster of symptoms and behaviors, and that these behaviors seemed to be persistent and chronic in these children rather than just something

that happened from time to time. He found it interesting enough that he gave a series of lectures on it to the Royal College of Physicians in 1902.

He described these children as being “often aggressive, defiant, and resistant to discipline,” “excessively emotional or ‘passionate,’” and having “little ‘inhibitory volition.’” They were “overactive” and didn’t pay attention. They tended to get into accidents and injure themselves or others. This might describe all children, of course, but in this case the behavior was “unnatural relative to the behavior of normal children at a given age,” and in these children couldn’t be explained by bad home life or poor child rearing. He described it as a “defect in moral control,” and speculated that it might result from either a “decreased threshold of inhibition of responding to stimuli” or a disconnect between intellect and “will.” He believed that the cause was biological, due either to injury or inherited problems.

According to Dr. Russell Barkley, an ADHD doctor and researcher and author of a definitive ADHD diagnostic manual, the next major event in the history of ADHD was the encephalitis epidemic of 1917-1918. This epidemic left a number of children with symptoms and behaviors similar to those that Still had observed: they were “impaired in attention, regulation of activity, and impulse control... They also showed impairments in other cognitive abilities (including memory), and were often noted to be socially disruptive.” Doctors began to refer to this condition as “postencephalitic behavior disorder,” and described it as a result of damage to the central nervous system.

Over the next few decades, this cluster of behavioral and cognitive problems were observed in children in other cases of damage to the brain and nervous system, resulting from causes like infections, epilepsy, lead poisoning, and injury. A variety of names

arose to describe these conditions, including “organic drivenness” and “restlessness syndrome” were used.

In the majority of these cases, doctors saw biological damage of one form or another behind the symptoms. One particular kind of damage was particularly interesting: it had been observed for years that when monkeys had their brain’s frontal lobes damaged in experiments, the monkeys showed “excessive restlessness, poor ability to sustain interest in activities, aimless wandering, and excessive appetite, among other behavioral changes.” It seemed plausible that the similar restless, inattentive behavioral problems that had been seen in certain children might have been caused by damage to their frontal lobes.

Eventually it became a widespread belief that cognitive and behavioral problems with hyperactivity and inattentiveness could be explained by brain damage. In many of these children there was a clear illness or injury, and the problems only appeared afterwards. The fact that certain kinds of damage were known to cause these problems led scientists to reason in the opposite direction: in children who had these problems but had no known injury or damage, it was assumed that damage must have happened at some point in the past, such as being deprived of oxygen during birth. The cases where a person showed hyperactive and inattentive symptoms without any known illness or injury became known as “minimal brain damage” or “minimal brain dysfunction (MBD).”

This history of cognitive and behavioral problems, so far, groups together what scientists today would consider quite a variety of different conditions, including ADHD, oppositional behavior, dyslexia, lead poisoning, fetal alcohol syndrome, mental retardation, Tourette’s syndrome, and various forms of physical brain damage, among

others. Common symptoms like hyperactivity might have a variety of causes, but children with these symptoms were classified together and studied as one group because it wasn't clear what those causes were. It's only in the past few decades that scientists began to separate out ADHD as a separate condition with its own distinct characteristics and mechanisms. Even now, there is much discussion of "sub-types" of ADHD (Ratey proposes 13 sub-types for clinical use in working with patients), and some scientists believe that the umbrella term "Attention Deficit/Hyperactivity Disorder" itself masks several different conditions that can look similar.

This growing understanding of a variety of separate causes and mechanisms for the generally similar symptoms happened as scientists learned more about the brain, thinking, and behavior. Eventually, the idea of "minimal brain dysfunction" began to seem too broad, applying to too many things. At one point, in 1966, the National Institute of Neurological Diseases and Blindness listed 99 possible symptoms for MBD. Some scientists were also starting to question the fact that the model of MBD so strongly assumed that brain damage was the cause without any history of its having taken place.

At around the same time, starting in the 1950's and 1960's, there was a large research effort into hyperactivity in particular. (In his diagnostic manual, relating this history, Barkley calls the period 1960 to 1969 "The Golden Age of Hyperactivity.") The term "hyperactive child syndrome" was introduced, and in 1968 the second edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-II) defined "Hyperkinetic Reaction of Childhood disorder." An early researcher defined hyperactivity as follows: "The hyperactive child is one who carries out activities at a higher than normal rate of speed than the average child, or who is constantly in motion, or both." According to one

theory, this was caused by a problem in the thalamus, which filters sensory stimulation reaching the brain. Children with hyperactivity seemed to have a lower stimulation threshold, allowing a flood of input to reach the brain. This could mean that hyperactive people react more strongly than other people to less noticeable things in the environment. (“Hey, look at this! Hey, look at that! Hey, what’s over there? I have to do it NOW!”) Or rather, to flip it around, according to this idea the system that scans the environment and grabs the brain’s attention for anything important is at a higher setpoint in hyperactive people, repeatedly setting off the alarm bells and pulling the brain away from whatever it was doing to focus on the new input (“This just in! There’s a loud noise over there!”).

While hyperactivity captured scientist’s attention for a long time, eventually the ideas of attention and impulsivity came to the foreground in trying to understand these thinking process and behaviors. In 1972, Dr. Virginia Douglas proposed that “deficits in sustained attention and impulse control were more likely to account for the difficulties seen in these children than was hyperactivity.” Her team “repeatedly demonstrated that hyperactive children had their greatest difficulties on tasks assessing vigilance or sustained attention.” Eventually, the idea of problems with sustained attention and impulse control became so central to the definition of this condition that it became possible to think of hyperactivity as just one symptom of it. The third edition of the Diagnostic and Statistical Manual (DSM-III), in 1980, listed two subtypes of attention deficit disorder: with and without hyperactivity.

Beginning in the 1980’s, some researchers have also explored the issue of wide variability in attention. People with ADHD can focus both very well and very poorly;

their attention and performance can vary enormously depending on the situation and what their motivations are. More recently, some scientists have proposed that ADHD comes from something in the reward and motivational systems in the brain. For instance, some studies have suggested “decreased activation of brain reward centers” as a possible cause of ADHD, something which affects the way people learn information and habits, particularly through reinforcement. This is a newer model, however, and research is still going on to figure out whether it might explain ADHD.

It’s only in the past 10-20 years that researchers have had tools at their disposal to study some of the underlying biological, neurological, and genetic mechanisms that could explain what has been observed in people’s thinking and behavior all these years. Magnetic resonance imaging (MRI) is one tool that researchers can use to look inside the brain. Some scientists challenge its usefulness in figuring out exactly what’s going on in the brain, because there’s still so much we don’t know about how the brain works, and the data from these scans is very hard to interpret. However, a number of studies seem at least to indicate differences in the brains of people with ADHD, such as reduced white matter in basal ganglia structures, and differences in functional MRI scans. A lot more research is needed to figure out what differences exist, what causes them, how widely they occur, and what they might mean for people with those differences.

Another interesting approach scientists are taking is to look at glucose metabolism in the brain. Because the brain uses glucose for energy, some scientists look at how much glucose is used by various parts of the brain while subjects do a specific task, in order to understand which parts of the brain might be active during those tasks. In 1990, in a widely-cited study, Dr. Alan Zametkin and his team at the National Institute of Mental

Health studied cerebral glucose metabolism in adults with ADHD symptoms who had never been treated with stimulant medication, and compared them to the brains of adults with no such symptoms. They found that overall glucose metabolism in the brain was 8.1 percent lower in the hyperactive group than in the non-hyperactive group, and that the hyperactive group had “significantly reduced” glucose metabolism in certain specific brain regions. They concluded that “Glucose metabolism, both global and regional, was reduced in adults who had been hyperactive since childhood. The largest reductions were in the premotor cortex and the superior prefrontal cortex – areas earlier shown to be involved in the control of attention and motor activity.” In other words, according to this study, hyperactive adults may have lower activity in parts of the frontal cortex, the part of the brain that controls attention and physical movement.

In addition to tools looking at the activity of the brain, other researchers have been looking into possible genetic components to ADHD. As far back as 1902, doctors noticed that symptoms of ADHD seemed to cluster in families, so it’s plausible that there might be some genetic aspect. With the cracking of the human genome, researchers can analyze the genes of larger numbers of people with and without ADHD and look for correlations. While nothing has been proven, researchers have identified a certain area of the gene that shows promise as a possible site related to ADHD. Interestingly, more than one study has found possible overlap of this gene area and the gene area for autism.

Tools such as MRI scans of the brain and genetic studies are still too unwieldy to allow us to really see what’s going on in the brain or what might be happening in the case of ADHD to lead to the thinking and behavior patterns, but just the indications they give us

of the general areas of difference in ADHD people can help indicate where to look further.

Testing the brain

One of the methods used to try to understand ADHD is cognitive testing. In these tests, people are asked to perform certain tasks that involve attention, perception, learning, memory, and other cognitive abilities.

One cognitive test that works quite well at zeroing in on the problems present in people with ADHD is the “continuous performance test.” In the early 1970’s, Dr. Virginia Douglas and her team at McGill University were studying hyperactive children. They were trying to understand the causes and mechanisms underlying hyperactivity, and to learn whether there might be multiple things being classified under the larger umbrella of hyperactivity. They performed a wide range of cognitive tests to tease out how their brains might be working, and how the hyperactivity came to be.

What they found, over and over again, was that “hyperactive children had their greatest difficulties on tasks assessing vigilance or sustained attention such as the continuous-performance test.” This and other findings were a major factor in developing the model of ADHD as based upon impulsivity and attention problems, rather than simply hyperactivity. According to Dr. Russell Barkley’s ADHD: A Handbook for Diagnosis and Treatment, the continuous-performance test was so useful in identifying problems with sustained attention that it became a standard diagnostic tool for ADHD and the most widely-used laboratory measure to find problems with sustained attention.

I decided to undergo some of these tests to see what they might demonstrate. For the continuous performance test, the doctor sat me down at a desk with a laptop computer sitting on top of it. When she started the testing run, a single letter of the alphabet appeared on the screen. She told me that my task was to hit the space bar whenever capital 'A' appeared. Then she walked out of the room and shut the door, leaving me alone with the screen.

B. I did nothing, and just waited. After a pause, the B was replaced by a G. I did nothing. P. B. T. B. B. B. G. B. Sigh. A – oh good! I hit the space bar. B. B. B. Yawn. A – hit the bar! B. G. T. Q. R. B. C. B. B. B. A. Got it. Q. T. A. (yup) A. (got it again) B. Q. S. (gee, a new letter).

If this is boring you now, imagine how I felt doing this at the tail end of a long afternoon. Soon I had to fight very hard just to keep paying attention to the letters, remaining vigilant for that 'A' and the opportunity it provided to actually do something. Just trying to force myself to watch didn't do much good after the first minute or so. At first my mind wandered, speculating about patterns in the order of the letters, whether the timing mattered, whether I was being measured on my reflexes by how quickly I hit the bar after the 'A' appeared, trying to be as fast as possible. Then I tried digging my nails into my palms with both hands – that often seems to sharpen my awareness a bit and make me more conscious and alert in the present moment. Even that palled after a while – the test seemed to go on forever. I found that I was repeating little instructions to myself over and over, like "Hit space when you see the 'A,' hit space when you see the 'A'...". (If I keep instructions cycling like that then I can often keep them in my mind and keep remembering what I'm supposed to do, rather than zoning out.) After what felt

like at least an hour of this, the letters disappeared and the screen suddenly refreshed to the instructions page, leaving me blinking in a stupor. (By this time I had been grunting the instructions to myself half out loud through gritted teeth, and periodically slapping myself in the face to make myself keep paying attention. I will do this. Look for the A, look for the A.)

The doctor laughed when she saw my face and apologized for the excruciating nature of the test. She even seemed relieved – apparently teenagers and adults are quite often really and truly angry at her after they sit through this ordeal. She often finds younger children hiding under the desk, having found it so pointless and stultifying that they've completely given up. (I think they have the right idea.)

The continuous performance test seems to be one of the particularly good indicators of ADHD. It's good at being very difficult for people who have trouble paying attention and staying focused, particularly in really boring and unmotivating tasks. What's interesting is that performance on tasks can vary enormously in people with ADHD, depending on the circumstances: sometimes someone with ADHD can perform horribly, completing tasks in a slow and scattered way, or not completing the task at all, and yet in different circumstances they can perform as well as or even better than a control group.

When studying hyperactive children using the continuous-performance test, Douglas observed an “extreme degree of variability demonstrated during task performances by these children – a characteristic that was later advanced as one of the defining features of the disorder.” She and her team found that hyperactive children showed “normal or near-normal levels of sustained attention under conditions of

continuous and immediate reinforcement, but that their performance deteriorated dramatically when partial reinforcement was introduced, particularly at schedules below 50% reinforcement.”

In a description aimed at helping doctors to diagnose children with ADHD, Dr. Russell Barkley describes them as showing:

“excessive variability of task or work performance over time. The standard deviation of performance on multi-trial tasks is considerably larger than that seen in normal children. Both the number of problems or items completed and their accuracy of performance change substantially from moment to moment, trial to trial, or day to day in same setting. Teachers often report much greater variability in homework and test grades, as well as in-class performance, than is seen in normal children. An inspection of the teacher’s grade book for an ADHD child is often revealing of this pattern of performance. Similarly, parents may find that their children perform certain chores swiftly and accurately on some occasions, but sloppily if at all on other days.”

This inconsistency has been observed again and again as an identifying characteristic of ADHD. It’s also something that causes some of the biggest problems for people with ADHD – if someone can’t do something, they can often get sympathy, but if someone can do something sometimes, then the rest of the time they’re seen as lazy and stubborn. Barkley continues:

“As some have noted, the fact that these children have done their work well on a few occasions will be held against them for the rest of their academic careers. They are seen as capable but merely lazy. Yet this excessive variability may in fact be a hallmark of this disorder relative to other behavioral disorders, and that it may even be diagnostic of it.”

The Problem of Diagnosis

I was walking down the street one sunny afternoon, when I was stopped by a cheerful young woman with a pen and clipboard. She asked me to take a survey. The survey page had just three questions: “Do you ever feel unhappy or dissatisfied with your life?... Is there anything not completely working in your current relationships?... Do you ever feel like something’s missing from your life, and you want more?”

After the questions there was an explanation that the survey would determine if you were a good candidate for the religious group running the survey. If you answered yes to any of the questions, then their solutions were an ideal fit for what you needed.

The group had a reputation as a local cult, so as soon as I recognized the name I declined quickly and walked on. But the “survey” stuck with me – I found it intriguing that it used the language and appearance of a scientific diagnostic tool, and yet the tool itself was useless. The questions identified things that were part of the human condition, that would apply to anyone at least some of the time. It was no good at classifying anything – it simply swept everyone into one box.

Critics of the ADHD diagnosis accuse doctors of doing something similar: making a list of everyday characteristics that could apply to anyone, and calling them a “disorder.”

ADHD, like other psychiatric conditions including depression and schizophrenia, currently has no laboratory test that can easily identify it. Diagnosis relies

“No valid, independent, consistent test [is] available ...ADHD was voted into existence by the American Psychiatric Association.”

*- “Dr.” Mary Ann Block,
www.blockcenter.com
[From website selling ‘natural products’ for medical conditions.]*

upon the judgment of a trained clinician, who observes a person and conducts extensive interviews regarding their medical history, education, social interactions, and day-to-day functioning. The clinician refers to a list of diagnostic criteria that embodies the current scientific consensus on the behaviors and symptoms of ADHD.¹

These criteria can sound vague, subjective, and non-scientific to someone not trained in their use. What’s worse, they sound like they could apply to almost anyone at

¹ See Appendix A: DSM-IV Diagnostic Criteria for ADHD.

least some of the time. Here's an example of one of the criteria: "is often forgetful in daily activities." That doesn't seem like much of a distinguishing characteristic, and it's not clear how to measure it objectively ("I'm 5.75 forgetful!").

I asked a psychiatrist who treats people with ADHD about the checklist issue, and she became very passionate about the way the diagnostic criteria are misunderstood and misused by untrained people. She told me that the diagnostic criteria aren't simply a checklist, they're a summary of symptoms that persistently and extraordinarily dominate the life of someone who has ADHD. To receive a positive diagnosis, someone must have these characteristics not just in a general, everyday way, but they should appear constantly, consistently, in multiple settings (both school and home, for instance), over the person's whole history. Even more importantly, the symptoms must be much worse than in an average person of the same age and cognitive level.

For example, one of the diagnostic signs of hyperactivity is: "often fidgets with hands or feet or squirms in seat." It's easy for me to imagine this symptom matching any given five-year-old, and it doesn't surprise me that there are people who read this checklist and become concerned that doctors are medicalizing normal behavior. A diagnosis of ADHD, however, requires much more than simply matching one of these descriptions. According to the way the diagnostic criteria are meant to be used, a five-year-old who fidgets and squirms isn't considered hyperactive unless he does so excessively, for at least six months in a row, much more than would a typical five-year-old. The hyperactivity needs to be much worse than usual for that age group, and it has to be significantly impairing the child's ability to function at home and in school. Even then, this alone isn't sufficient for an ADHD diagnosis; it has to appear along with other

symptoms of impulsivity and attention problems, and the child must meet certain other conditions as well. The diagnostic criteria for ADHD don't just list a bunch of common traits; they encapsulate a cluster of symptoms that form a particular pattern, one recognizable to those who diagnose it. As the catchphrase goes, "I know it when I see it."

This category of conditions, which lack diagnostic laboratory tests and clear biological mechanisms, whose diagnosis is subjectively defined, raise a number of issues regarding what constitutes a "real medical condition." Many people question the use of diagnoses in such cases, and consider the conditions so described to be illusory, purely in the heads of those making the diagnosis.

"Here's something that's partly genetic, that's recurrent, that causes pain, that does damage, that has chemical changes, some lasting... it looks a lot like anything we call an illness. Any reasonable scientist would believe that something would have to be found [to explain what's going on.]"
- Peter Kramer, author of Listening to Prozac, speaking about depression and medical models of mental illness

Peter Kramer, psychiatrist and author of Listening to Prozac, says that after his book's publication he was surprised at the number of people who used it to challenge the medical model of depression. At a recent talk, he explained that he wrote the book to explore issues of medication and self raised by the borderline-normal area of the spectrum of depression, but not to argue against a medical model for depression entirely. Based on his experience as a doctor, he completely supports a medical model of mental illnesses like depression and schizophrenia, and during the talk he tried to explain the reasons for using diagnostic criteria even though they're currently subjectively defined: "The operational criteria were developed to capture something people see," he said.

Doctors develop criteria in an attempt to capture a condition sufficiently enough that it can be recognized and dealt with in patients, and treatments developed. When doctors are convinced enough that there is something real that people are suffering from, then it's worthwhile to attempt to describe and deal with it, even before complete scientific understanding of it is achieved.

For similar reasons, the diagnostic criteria for ADHD were developed to capture the essence of something that has been observed for over a hundred years, for which most scientists believe an explanation does exist. There are real and effective treatments that have been shown to help people who have the cluster of symptoms associated with ADHD. The diagnostic criteria are a tool that help those people to be found and treated.

Despite its value, of course,

diagnosis that uses checklists and case histories and trained judgment is subjective, hard to define and teach, and leads to diagnostic variation from

"There is nothing objective about the ADHD or any psychiatric diagnosis...All is ...in the eye of the beholder/beholders, be they teachers, parent, GPs, pediatricians."

*- Fred A. Baughman Jr., MD,
www.addfraud.com*

one doctor to another. As anthropologist T.M. Luhrmann documents in Of Two Minds, her analysis of American psychiatry, even doctors can find this kind of diagnosis troubling. Psychiatrists-in-training often spend at least a year working with patients before they feel comfortable recognizing specific conditions based upon the diagnostic criteria. She relates:

"Because none of the psychiatric categories (at least, none of the ones that count as truly psychiatric) can be diagnosed by a test or a telltale symptom, most of the diagnoses are presented as a checklist of criteria, in which the patient has to have some but not all of the items on the list to qualify for the diagnosis. [...] To new psychiatrists, fresh from treating cardiovascular disorders and lung cancer, diagnoses for which you need five of nine symptoms seem strange, despite the fact that certain medical diseases, such as lupus, are also diagnosed by checklist.

These diagnoses become particularly suspect when the criteria include items such as 'feelings of detachment or estrangement from others' or 'feelings of worthlessness or guilt.' These complaints do not seem like 'real' diseases; they do not feel 'organic.' They suggest that a committee sat down one afternoon and voted on what 'depression' should include. Which, of course, some committee did."

The subjectiveness of the criteria sows doubt about the validity of the condition, particularly among people without direct experience of it. It's also open to abuse, particularly when non-psychiatrists, pediatricians, and even teachers or parents try to make the call using those criteria without the associated training and experience of working with people with ADHD.

Lawrence Diller, a doctor in California who treats children with ADHD, raises this concern in his book Running on Ritalin. He states that in 1998, almost five million people in the United States were prescribed Ritalin. He believes that ADHD is a real condition which severely impairs some children, but he also believes that more and more parents are pushing for the label where it doesn't apply. He has seen parents looking for ADHD to explain very mild problems, or problems caused by other things like boredom, neglect, or bad parenting. He suspects that the enormous rise in ADHD diagnoses and Ritalin prescriptions may be due to social and cultural factors, like parents and teachers looking for quick fixes.

While individuals may be attempting to gain entrance through the diagnostic doorway, there are other forces attempting to push the door open wider to let them in. Robert Whitaker, author of Mad in America, has given a lot of scrutiny to pharmaceutical companies, and the way they further their interests by sponsoring drug studies, spinning the results favorably, and use public relations campaigns to promote their messages about the characteristics, diagnosis, and treatment of various conditions. Some conditions, like

ADHD, seem to exist along a spectrum: some people have severe impairment, while in others it's barely visible. There are large grey areas where the condition shades through various degrees of affecting someone's life, without a clear boundary between "disabled" and "normal." In spectrum conditions like these, says Whitaker, it's in a pharmaceutical company's best interests to push the definitional boundary as far as possible, in order to include as many people as possible. Even if a condition is real and significant, there are powerful forces in the media and the economy which will push the envelope until there are probably many more people falling under the diagnostic umbrella than may be justified.

Pharmaceutical
companies today certainly
seem to be trying to expand the

*"If you took this quiz, Zoloft is probably right for you."
- news parody, TheOnion.com, May 14, 2003
"Pfizer Launches 'Zoloft for everything' Ad Campaign"*

diagnostic doorways, particularly with direct-to-consumer advertising. ("Ask your doctor about the purple pill!") If an individual can be convinced that a diagnosis applies to them, then they are more likely to see their doctor and press for a diagnosis, and thus to get a prescription.

Joseph Dumit, a professor of science and technology studies at the Massachusetts Institute of Technology, has studied this phenomenon. He collects examples of direct-to-consumer advertisements which appeal directly to individuals to consider whether they or a loved one has a particular condition. These often depict symptoms from a list of diagnostic criteria, but the criteria are taken out of their medical context and shown to people without a full understanding of how to apply them.

A particularly egregious example that Dumit cites is the website for Prozac (www.prozac.com), which offers a 'depression screening tool' that asks visitors to look at a list of statements and answer how often these apply to them. The statements include things like: "I am more irritable than usual" and "I get tired for no reason." As in the case of ADHD, the full cluster of these symptoms could, in the judgment of a trained doctor and along with the full context of a case history, indicate clinical depression; yet as a set of questions they could apply to almost anyone. Like the religious group's "survey," they don't really distinguish anything, they simply create a box into which the vast majority will fall.

In fact, it seems that whatever the visitor to the web site answers, the quiz results suggest possible depression. If the answers score is above a certain (rather low) threshold, the visitor is told "consider printing the results of your test to show it to your doctor. Ask him or her to evaluate you for depression." If the score is not above the threshold, the visitor is still told:

Even if you did not score 50 points or higher, and if you suspect you are depressed or suffering from a mental illness, you may still want to consider printing the results of your test and showing it to your doctor or qualified mental health care professional. Despite lower scores on this questionnaire, it is possible that you are depressed or suffering from another mental illness and you may benefit from a treatment program.

The site does display a warning that "the diagnosis and treatment of depression and other psychiatric disorders can be performed only by a doctor or qualified mental health professional." And it's certainly true that people who seek out a website about depression may be having problems and may be helped by being encouraged to visit a doctor. But it's hard to escape the impression that this and similar advertising is pushing the envelope of diagnosis, by appropriating diagnostic criteria to create scientific-

sounding marketing tools, and by encouraging people without training in recognizing and diagnosing particular medical conditions to believe they can do so simply by looking at the checklists.

It's easy to see why there are concerns about conditions like ADHD, in which the diagnosis is subjective and open to abuse, and which both individuals and powerful parties have reason to promote.

The Issue of Medication

“Being a parent, any foreign substance like a drug scares the hell out of me. Taking it as an adult, I wouldn't see an issue. But something with my baby girl, no. Even though I've read about it and I understand what it's supposed to do and Doctor Baker has gone through what the benefits are and he's described basically no side effects – still, to me, it's somewhat of an unknown, and maybe it's just my ignorance but it's somewhat terrifying for me.”

– father quoted on PBS Misunderstood Minds website

One of the most controversial aspects of ADHD is the issue of medication. The preferred treatment for ADHD in children and adults is stimulant medication, usually methylphenidate, known to most people in the brand-name form of Ritalin. While the ideas about ADHD have evolved over the decades, with changes in the proposed model, causes, and mechanisms, on one thing the literature has been remarkably unified: for people with ADHD, stimulant medication seems to be enormously effective at combating impulsivity and hyperactivity, and in helping them pay attention and focus.

In Barkley's textbook on diagnosis and treatment, he describes the “significant increase in research on the effects, often dramatic, of stimulants on hyperactive children,” using “much more rigorous scientific methodology in drug studies” during the 1970's. By 1976 there were over 120 studies published on the topic, and interest continues to

increase, “making this treatment approach the most well-studied therapy in child psychiatry.”

In 2002, the United States Committee on Government Reform held a hearing on the topic: “ADHD: Are Children Being Overmedicated?”. Dr. David Fassler testified on behalf of the American Academy of Child and Adolescent Psychiatry (AACAP) and the American Psychiatric Association (APA): “There are more than 200 studies showing that the stimulant Ritalin (generic name: methylphenidate) works effectively for children with ADHD. Stimulants have been used in the treatment of ADHD for more than 90 years.”

Decades of observation have convinced scientists of the benefits of stimulants for treating ADHD. What remains less clear, even today, is exactly why the stimulants work, and how they affect the brain; these questions are closely connected to and buried among the general questions about what causes ADHD and how it operates.

During the Congressional hearing, Fassler explained it this way: “Adults feel more focused and alert after a cup of coffee in the morning. This is basically how Ritalin, and newer stimulants such as Adderall and Concerta, work for children with ADHD. Ritalin and other stimulants increase the alertness of the brain and nervous system, stimulating it to produce more dopamine and norepinephrine. The medication increases the child’s attention and reduces excess fidgetiness and hyperactivity, allowing him to focus on his work. Children with ADHD who take Ritalin make fewer errors on a variety of tasks than untreated children do. They are less impulsive and more attentive, both in the classroom and in social situations.”

When I was first diagnosed with ADHD, as an adult, my doctor explained it to me in terms of the “executive function” that we looked at earlier. He said that the brain’s frontal cortex is where the executive function takes place, and that in people with ADHD it is understimulated or underfunctioning in some way. With stimulation, the brain can actually perform the executive functions better: it can more consciously choose to pay attention, choose what to pay attention to, and focus for far longer than usual. For someone with ADHD, a stimulant generally has the paradoxical effect of calming them down. Someone who is usually restless, hyperactive, and unable to sit and focus on any one thing can actually do so much more easily when taking Ritalin. My doctor theorized that many of the typical behaviors of people with ADHD, like physical restlessness and risk-taking, are actually methods of trying to stimulate their brains and help themselves to function better.

This made sense to me; I already knew that under certain conditions, like drinking lots of caffeine and being under a high-pressure deadline, I could achieve a rare state of deep focus. I could then work in a state of flow, looking up only hours later. This usually left me drained and haggard, but the amount of work I accomplished during that time made it worthwhile. (Of course, I had to be really careful that what I got lost in was productive work, not a video game or a book, because the flow would be just as powerful.)

I now understand that flow state to be the experience of being truly focused and involved in what I’m working on, rather than being scattered among many things and flitting from one thing to the next without being aware of it. At the time, I only knew that it was a rare and precious state that I was never able to bring about through sheer force of

will (not for lack of trying, believe me); I could only set up the appropriate conditions and hope that something kicked me over the edge. Appropriate conditions often involved high pressure deadlines, enough time to build up my focus and not be interrupted, a quiet place to work, and large amounts of caffeine.

So this medication, Ritalin, would apparently act in the same way as caffeine and high-pressure situations.

I was very uncomfortable with the idea of taking medication because I really hated the idea of altering my mind, “drugging” myself, changing how I think and who I am, becoming a different person. I was also really unhappy with the idea that there was something wrong with me, that my entire way of thinking and perceiving the world was subject to some kind of fuzzily-defined brain damage.

In a way, it felt to me like taking medication would mean choosing to label myself as being defective, and brain-damaged. It would also mean changing myself in order to submit to some definition of “normal” that didn’t include me the way I was. But my doctor told me that Ritalin only lasts in the body for around 3-4 hours, and then it’s gone, with no lasting effects. I could try it once without causing any permanent changes; if I didn’t like what it did, I’d be back to myself after just a few hours.

In the end, the temporary nature of the change was the only thing that convinced me to try it. And I went from an anti-medication skeptic to a believer in the space of about an hour.

That first day, I took 10mg of Ritalin at breakfast, and then walked to the subway with a friend. We boarded a train, and each of us began reading a book. He said something to me, and I looked up from what I was reading, listened to what he said,

understood it and responded to it, and then looked back to the book and continued reading where I had left off, absorbed again. Then I practically jumped up and started yelling to the other subway passengers, because never in my life had I been able to do that before. Normally, if I was absorbed in what I was reading, by the time I switched my attention to my friend I would have missed what he'd said and have asked him to repeat it; and once interrupted, I would have struggled for a while to remember where I was reading and recapture the context of the book, and to focus enough to continue reading once again. This is just part of daily life for me; until that day it had never really been highlighted that this might not be the way things worked. I explained to my friend what had happened, and when he expressed surprise that this was unusual for me, I responded, "you mean it's like this for everyone else ALL THE TIME?!" That's when I started to get really, really angry.

I didn't feel high, and I didn't feel "drugged." Mostly, I felt clear, and thoughtful, and focused. If anything, I actually felt more like myself, like waking up rested and alert after a good night's sleep. I recognized my state of mind as being very much like being focused on a particularly fascinating project that I really wanted to do, in a very quiet place, first thing in the morning, after a whole lot of caffeine; but this time, I had the very bizarre (to me) sensation of feeling this way in a noisy subway doing nothing particularly interesting.

After that, I was completely converted to the medical model of ADHD. I started to take a prescribed dose of Ritalin each morning before work, and the difference in my performance and experience of work was like night and day. Ritalin wasn't guaranteed to put me into a flow state automatically; I had to combine it with the good habits one

otherwise uses to focus and be productive: being well-rested, exercising, organizing my work, setting aside my most productive morning hours, and trying really hard. It's just that this time, these things actually worked; although the Ritalin wouldn't make me productive all on its own, it seemed to be enough when combined with all the other right things to give me that last push over the line into focused work.

If stimulants have been so well-studied, and are so effective at treating ADHD, then why do they still

cause so much controversy?

For one thing, the general public still

"That sounds like me in grade school. I didn't take Ritalin. I became a congressman."

– Dan Burton, R-Ind, in

"ADHD: Are Children Being Overmedicated?"

House Government Reform Committee,

September 2002

has trouble understanding what ADHD is. As with many psychiatric conditions, not having a clear and understandable definition of the causes and mechanisms leads to skepticism that what doctors and researchers describe really exists. As Fassler pointed out during the ADHD hearing, "To the extent one believes that such conditions are rare or do not exist in children, any amount of prescribing of psychotropic agents is likely to be viewed as 'over-prescribing.'"

For another thing, the idea of medication itself can be a problem, particularly in the United States. Dr. Edward Hallowell, co-author of Driven to Distraction and founder of the Hallowell Center for Cognitive and Emotional Health, often confronts this issue. In his book Worry, he says: "Sometimes people talk about medication as if it were a political or religious tenet, instead of a medical tool. People sometimes ask me if I am in

favor of or opposed to medication, as if medication were a candidate up for election. My answer is that I am neither in favor of nor opposed. Instead, I emphatically endorse the proper use of medication. I am a radical moderate; I believe radically in preserving a balanced perspective. Medications should be used when they are indicated, and they should not be used when they are not indicated. It is that simple.”

A more serious concern for many people is whether taking stimulants leads to drug abuse, particularly in children. This concern is made stronger by the fact that many people with ADHD self-medicate using cocaine, which seems to have similar effects, and other illegal stimulants. Researchers have taken these concerns seriously, and a number of studies have looked into the risks and followed the histories of people taking stimulant medication. In a review of ADHD issues published in the *New England Journal of Medicine* in 1999, Dr. Alan Zametkin at the National Institutes of Health concludes: “Parents of school-age and teenage children must be reassured that, when used orally and in commonly prescribed dosages, stimulants do not lead to drug abuse or drug dependence. In fact, a recent follow-up study supports the concept that stimulant treatment prevents later substance abuse.”

Another reaction to the large rise in Ritalin prescriptions is the charge that parents are pushing for Ritalin for their children in order to increase their performance in school. Because stimulants have a focusing effect on almost anyone, it is argued, anyone can take Ritalin and get a boost in productivity. What’s to stop some kind of “brain inflation,” where children take stimulants in order to compete in school, get into better colleges, and thrive in their careers?

This fear seems quite reasonable to me. There have been widespread reports, for instance, of trading in Ritalin among college students in order to do well on exams. The advertisements for stimulant medication aimed at the parents of ADHD children can also contribute to the perception that stimulants will help their child perform better in school, without getting into the details. I can easily believe that the number of parents taking their children to doctors looking for an ADHD diagnosis and medication largely exceeds the number of children who are truly suffering from serious ADHD impairment.

In the long run, however, the real risk of parents pushing performance seems to be the dilution of the ADHD diagnosis and the wasting of time and money, because while stimulants do help everyone somewhat, they don't seem to help people without ADHD do all that much better than they would normally do anyway.

According to one neuropsychologist who treats children and adults with ADHD in academic situations, stimulants do help everyone to some extent, but they have a much stronger effect on people with ADHD. To someone who doesn't really need it, Ritalin may help them concentrate better in class or while studying for a test; but to someone severely impaired, Ritalin can mean the difference between being able to study well for a test and being unable to even sit through the test at all. Stimulants can allow someone with ADHD to take part in class and hear what is being said, even to finish their homework for the first time. The boost provided by stimulants has the most effect where they counteract serious impairments and allow someone to function more normally. If someone doesn't really need the stimulants to function, then it won't really have much effect on their performance.

In a review spanning decades of studies on the effect of stimulant medication on children with ADHD, a team of researchers at the University of California, Irvine, put together a list of what those studies indicate can and can't be expected from treating children with stimulant medication. They found that things that are likely to improve include overactivity, attention span, impulsivity and self-control, compliance, aggression, social interactions, and academic productivity and accuracy.

However, the list of things that are not yet shown to improve with stimulants includes larger performance areas like reading skills, learning, and overall academic achievement. While these are still being investigated, it doesn't seem likely that taking stimulant medication will turn a normal child into an academic superachiever; the effects are more constrained to the ability to pay more attention and focus better in specific situations.

Disability or Difference?

"Imagine that you're trying to get across the MIT campus. Everyone else has a bicycle. But you're walking," the doctor says, looking at me intently. She's trying to explain to me why accommodations are justified for people with ADHD. She tells me that I can do the same things as most people, but that it can be twice as difficult or take twice as long. "The playing field will never be level for you."

This doesn't satisfy me. It's a question that I return to again and again: am I "disabled," or just different? Do I actually have an illness? Or am I just someone with particular ways of thinking, someone that needs the right environment to thrive?

Some doctors have no doubt that there's something wrong in the brain in people with ADHD. The "International Consensus Statement" says outright: "ADHD is not a benign disorder. For those it afflicts, ADHD can cause devastating problems." Children with

the condition are more likely to drop out of school, to be labeled troublemakers, to have trouble holding down jobs or forming lasting relationships. Rates of drug abuse and other risky behavior are higher than in the general population.

There are others, particularly authors of books for people with ADHD, who portray it as a condition that gives people a unique and valuable way of experiencing the world. People with ADHD can be spontaneous and creative, energetic, pursuing ideas in unusual directions, making interesting and unforeseen connections. People with ADHD, they say, have trouble with certain things, but the flip side of the condition is a set of particular talents. In some situations they struggle and flounder, but in others they thrive.

Thom Hartmann is an author with a particularly seductive view along these lines. He envisions people with ADHD as “Hunters in a Farmer’s World.” He looks at typical characteristics of ADHD, and sees them as traits that would benefit a hunter in a pre-agricultural civilization:

- “- They constantly monitor their environment...
 - They can totally throw themselves into the hunt; time is elastic...
 - They’re flexible, capable of changing strategy on a moment’s notice...
 - They can throw an incredible burst of energy into the hunt...
 - They love the hunt, but are easily bored with mundane tasks...
 - They’ll face danger that ‘normal’ individuals would avoid...
- ... If you compare the list of classic [ADHD] symptoms, and the list of the characteristics of a good hunter, you’ll see that they match almost perfectly. In other words, an individual with the [ADHD] collection of characteristics would make an extraordinarily good hunter.”

The things that “Hunters” lack, like patience, consistency, and long-term planning, are those that work better for a “Farmer” who has to stay in one place and labor steadily to plant and harvest crops.

Hartmann suggests that ADHD traits could have provided an evolutionary advantage in finding food and surviving threats throughout much of human history in hunter-gatherer environments. If ADHD is an inherited condition (or if it has at least some inherited components), then it wouldn't be surprising to find it in many people today. Hartmann compares it to other genetic conditions like sickle-cell anemia and Tay-Sachs disease, which have probably survived because they may provide certain evolutionary advantages (rendering people less susceptible to malaria and tuberculosis, respectively.)

Trait as it appears in the "Disorder" view	How it appears in the "Hunter" view: they're...
Distractible	Constantly monitoring their environment
Attention span is short, but can become intensely focused for long periods of time.	Able to throw themselves into the chase on a moment's notice.
Poor planner: disorganized and impulsive (makes snap decisions).	Flexible; ready to change strategy quickly.
Distorted sense of time: unaware of how long it will take to do something.	Tireless: capable of sustained drives, but only when "hot on the trail" of some goal.
Selection of Thom Hartmann's reframing of ADHD characteristics as assets. (From Thom Hartmann, <u>Attention Deficit Disorder: A Different Perception</u> , p.55.)	

Hartmann isn't a medical doctor, and his Hunter/Farmer model isn't proposed as a scientific hypothesis. Rather, he's presenting a way of thinking in which ADHD isn't a "disease" or disability; it's a set of traits that are advantages in the right environment. He talks about careers in which "Hunters" tend to thrive, like becoming salespeople, entrepreneurs, and freelancers rather than forcing themselves to maintain boring jobs and strict office hours.

I like the idea that ADHD gives me advantages to offset the problems. I like to see my restless scanning and fast, jumpy reactions as being the lightning reflexes of a Hunter.

Never mind that I would never last a week in the wild (the hunting I do is pretty much restricted to finding my dinner in a grocery store). According to this view, I'm not "disabled": my mind and senses are just finely tuned to thrive in a different environment from the agricultural, industrial, 21st-century world into which I've been born. I don't know if I buy it, but I often find it fascinating to look at the world through that lens. I try it on, and allow it to transform my problems (restlessness, frustration, sensory hypersensitivity, random thought processes...) into signs of special talent (expanded awareness, single-minded focus, ability to form larger patterns).

I've watched myself react strongly and immediately to sudden events. I've seen a friend, who many suspect to have ADHD, streak across a room and jump into position to catch a falling child, in the time it took for a chair that was starting to tip to fall all the way. In a crowd of my friends, if there's a sudden loud noise, immediately the same certain heads will be swiveled and eyes fixed in that direction, while the others have slower and more mixed reactions. Sometimes in a boring meeting, I wait for sudden noises and then pretend I'm watching the Discovery Channel: find the herd members with ADHD! See their heads turn as they track the wild car alarm!

Is it fair to say that I overreact to sensory stimuli? Maybe most people just under-react. What looks "normal" and "abnormal" can depend a lot on your perspective.

For instance, there's someone on the Internet who got fed up with the "arrogant, insulting, and just plain wrong" descriptions of autism that he was reading. In response, he created the website "Institute for the Study of the Neurologically Typical."² Here are some excerpts:

² isnt.autistics.org

“Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behavior.”

The author of the site reverses the viewpoint: from his perspective, the “neurotypical” are the weird ones. He concludes: “I and my experience of life is not inferior, and may be superior, to the NT experience of life.” For many whose brains seem to work differently from that of the average person, it can be frustrating to be treated like their way is wrong. As someone once complained to me after first seeing a doctor for ADHD, “why is it that *I’m* the one that has to change?!”

Sometimes it isn’t necessary to decide if ADHD is a “disability,” if the environment is flexible enough to accommodate a variety of learning styles.

I have a friend who teaches in the 6th grade, and I asked her how ADHD is handled in her classroom. She says that in her class, any diagnosis of ADHD is something handled between the child, the parents, their pediatrician, and the school nurse; she doesn’t come into the picture. As far as she’s concerned, if a child takes medication and is brought to the point where they aren’t having problems in class, then there’s no need to approach her about accommodations and special help. If a child can participate at the general level of functioning in the classroom, then labeling isn’t even an issue.

She has a few students, for instance, who like to stand during reading class, and she allows them to do this if they’re not disrupting the class. As the teacher, she develops

a feel for which students tend to need a break more often, or who could be chosen to run errands because they're antsy, or who works better when work is broken down into smaller steps for them. Not only are labels unnecessary in her classroom, but she even dislikes the idea of some of the kids having certain labels. She fears that a label may cause children to grow into defining themselves by their label, and limiting themselves. The way this teacher deals with her classroom allows for a variety of learning styles and needs, although she notes that this wouldn't necessarily work for children with severe difficulties, or in an environment that was chaotic and disruptive like some school systems.

According to the National Institutes of Health, treatment of ADHD isn't as simple as taking Ritalin: "Although the drugs help people pay better attention and complete their work, they can't increase knowledge or improve academic skills. The drugs alone can't help people feel better about themselves or cope with problems. These require other kinds of treatment and support." People coping with ADHD often learn and perform much better in flexible environments that allow them to work at their own pace, take breaks, and get extra help where needed. One way for people to gain the accommodation they need is to describe ADHD as a disability, and to ask for the flexibility and support that will allow them to perform on a somewhat more even playing field.

Whether or not others choose to consider ADHD a disability, however, I have certainly come to see ADHD as a "difference." Having ADHD enormously affects the way someone learns and experiences the world, and these differences can color that person's personality, way of thinking, and way of relating to other people in every area of their lives, for all of their lives. My hope is that as we learn more about the brain and how it affects the person, this knowledge will spread further to parents, teachers, and the general public. Deeper and more widespread understanding of the experiences and challenges faced by people with ADHD will help those whose lives are affected by it be better understood and better able to find a way to function in the world

Appendix A: DSM-IV Diagnostic Criteria for ADHD

In the United States, psychiatrists are guided by the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), which lists the criteria for diagnosing ADHD as follows:

A. Either 1 or 2:

1. Six or more of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

- a. Often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- b. Often has difficulty sustaining attention in tasks or play activities
- c. Often does not seem to listen when spoken to directly
- d. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)
- e. Often has difficulty organizing tasks and activities
- f. Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as homework)
- g. Often loses things necessary for tasks or activities (toys, school assignments, pencils, books, or tools)
- h. Is often easily distracted by extraneous stimuli
- i. Is often forgetful in daily activities

2. Six or more of the following symptoms of hyperactivity-impulsivity have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

- a. Often fidgets with hands or feet or squirms in seat
- b. Often leaves seat in classroom or in other situations in which remaining seated is expected
- c. Often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- d. Often has difficulty playing or engaging in leisure activities quietly
- e. Is often "on the go" or often acts as if "driven by a motor"
- f. Often talks excessively

Impulsivity

- g. Often blurts out answers before questions have been completed
- h. Often has difficulty awaiting turn
- i. Often interrupts or intrudes on others (such as butting into conversations or games)

B. Some hyperactive, impulsive, or inattentive symptoms that caused impairment were present before age 7 years

C. Some impairment from the symptoms is present in two or more settings (such as in school or work and at home)

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning

E. The symptoms do not occur exclusively during the course of a pervasive developmental disorder, schizophrenia, or another psychotic disorder and are not better accounted for by another mental disorder (such as a mood, anxiety, dissociative, or personality disorder)

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