THE MYTH OF AUTISM

How a Misunderstood Epidemic is Destroying Our Children

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Glossary
Although the focus of this book is the autism illness, a lot of the information, studies, and conclusions can be applied to how we understand and approach ADHD variant, CFS, and CFIDS in children and adults (and to many other nonspecific psychiatric and learning labels applied to many “special needs” children today).
When I graduated from UCLA Medical School as a pediatrician in 1972, I was told if I had even one autistic child in my practice it would be unusual. Today most of my practice (250–300 active patients at any time) is composed of children and young adults diagnosed on the autistic spectrum, something we were never prepared for in medical school. General pediatrician practices now have between six and twelve children on the spectrum or with significant learning difficulties. I have heard from parents that their pediatricians were as unprepared as I was for this onslaught. So how is it that in thirty years the rate of “autism” in American children has gone from nonexistent to affecting nearly 1 percent of the total population or even higher?

To understand this change, let me give you some history. After I failed handwriting in the third grade my teacher joked that I should become a doctor. Growing up, I enjoyed math and science, liked working with people and children, and did not envision myself in a lab with test tubes, so medicine, and in particular pediatrics, became my goal. I was extremely thankful to be accepted into UCLA Medical School, and I remain thankful for the wonderful training, for my internship and residency in pediatrics spent between Los Angeles County–University of Southern California Medical Center, and for my rotations through Children’s Hospital of Los Angeles. What I learned within these institutions gave me an excellent background in infectious disease, immunology, allergies, and more. The professors and the medical system to
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which I was exposed formed a dynamic, exciting system. There was still the expectation that a physician would use a combination of clinical skills and emerging technologies to help advance their understanding and take their research to new levels. Medicine was viewed as a frontier that needed to be consistently explored. This expectation was quickly dropped when it came to researching the causes of a rising disease called autism.

I entered private practice in Tarzana, California, with optimism and excitement. I built the third largest practice in the San Fernando Valley in Los Angeles. On a busy day, I could see up to fifty-two children. I would never let a sick child wait for an appointment if it were at all possible. I was taught preventive medicine in medical school; I was a good pediatrician if few children needed admittance to the hospital. The United States has evolved rapidly to a system where hospitals encourage admissions, however. Our collective “health” now boils down to dollars and cents.

Back then, for example, the standard practice was to postpone immunization for a child if he or she had a cold or a fever; parents would bring the child back for the shots once he or she was healthy. Economics now dictates that we limit visits. The more we bill at one time the better, so let’s shoot them up with everything we can give them while they are here in the office, all in the name of efficiency.

What new vaccines are being added to the roster of necessary childhood vaccinations, and why? How many readers are aware that the fairly recent decision by the Academy of Pediatrics in the 1991 to give a Hepatitis B vaccine in the newborn nursery [1] (the most dangerous adjustment time in a baby’s life) was not made on the rational basis of medical efficacy but, in large part, due to the sticky issue of political correctness? It would not be PC to point out the limited number of cases where a child might be returning to a high-risk home, so let’s vaccinate all the infants. (For the record, I never have given that shot in the nursery, and many pediatricians now have no problem if parents elect to defer that vaccination until later.)

In the early eighties I met the woman who would become my wife. Around fifteen months after we met, Elyse developed a mysterious illness that at that time had no name—she was suffering sudden severe headaches, overwhelming fatigue, constant short-term memory issues and often periods of severe brain fog, fibromyalgia muscle and
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joint symptoms, fevers, and swollen glands. She visited various doctors all around the country, but she remained miserable and undiagnosed. Her blood work came back positive for an astounding number of viruses—almost every virus she was tested for excluding HIV. While she tested positive for Epstein-Barr, CMV (cytomegalovirus), HHV6, rubeola, and rubella, to name a few, it was rapidly obvious that while some of these titers might represent a potential virus to target, others were just false activation from a dysfunctional or misdirected (perhaps an unidentified virus or retrovirus) immune system. With these test results in hand, it seemed logical to suspect that some of these viruses (not as a new acute infection, but with the new concept of reactivation) were causing an impairment of her immune system or that somehow her immune system was making mistakes. Healthy patients do not run around with three or four active viruses in their bodies, or even multiple elevated titers—although some of the medical profession didn’t see any significance to the results of these blood tests, whether true viruses or just false titers, there was no direct evidence as far as they were concerned that this was causing harm (retrospectively this was a very large mistake).

She was sick and scared. As a physician I felt helpless, and we turned to prescription-grade vitamins and amino acids, thinking maybe they would help address any imbalances in her system. She took sixty-eight supplements a day, leaving little room for all the liquid she needed to swallow them. It was years before she would have a diagnosis. It is both sad and ironic that some of the same treatments tried on her then and others we never would have allowed (because they were potentially harmful) are being used on children today with about the same success rate of close to nothing. Of more concern is preliminary evidence (with formal study being planned) from NeuroSPECT testing showing potential increased stress to children’s brains when they undergo some of the more untested treatment ideas (including chelation, hyperbaric oxygen, and megasupplements).

We were married, and her symptoms continued. One night at dinner my son, around four years old at the time, said, “Dad, why are you sending Mom all over the country? Why don’t you just fix her?” This began my journey into the complex workings of the immune system and how it controls the body and our brains.
In the early eighties, I was starting to see a shift in the concerns of the patients in my practice. Children were tired. Moms started complaining they couldn’t keep up or that they were feeling “spacey” or “zoney.” This was troubling, since early in my career I could safely joke that if a mother checked the fine print on her child’s birth certificate, she was not allowed to get sick until the child was at least eighteen years old. I had to stop saying that, since mothers were among the first being hit by what was facetiously named the “Yuppie Flu.” Running viral blood titers (measurement of specific viral antibodies in their bloodstream/serum) on these patients was eye opening. We were taught in medical school you were only supposed to have one active virus at time, and “old” titers were suppose to be present but at low numbers. These patients were presenting with multiple viruses evident. A theory evolved that the immune system was so dysfunctional, it mistakenly thought it was fighting many viruses. How could so many moms and children be walking around and functioning with obvious evidence for some type of a severe autoimmune or viral disorder going on? After a few years, I attended the First International Congress on Chronic Fatigue in 1990 hosted by the late Dr. Jay Goldstein, who was beginning to define this new illness that had been given an official (but deliberately demeaning) name by the Center for Disease Control two years earlier in 1988. Dr. Goldstein and other clinicians were using the term post-
viral fatigue syndrome/chronic fatigue syndrome (the British still use the term M.E.—myalgic encephalomyelitis). The CDC made the official criteria/definition in 1988. Several years later, I had the honor of cohosting, and our journey toward understanding began in earnest. At these conferences I met many great doctors, including Dr. Nancy Klimas, who would finally offer some answers. Dr. Klimas sat my wife down and explained the immune system to her. She explained how it worked and, if you pushed the wrong buttons, how it didn’t.

Those sixty-eight amino acids my wife was taking were from a company that at the time was producing amino acids of pharmaceutical grade (which in theory could be absorbed safely by the body). Since amino acids are the basic building blocks of proteins and other biomolecules, and play a role in energy pathways, it was a good premise: the company would take a patient’s blood specimen, analyze it, and then decide what mixture of supplements (proportion of amino acids and some vitamins) you needed to take to help the body get back to normal. In medical school, and in an internship residency, I was fortunate to study under Dr. Ben Kagan (Cedars-Sinai Hospital–UCLA). Several years, before he passed away, I got the courage to ask him about supplements. I was particularly interested in lysine, a key essential amino acid, for its known ability to fight viruses—and I thought the strange viruses in my wife’s blood might be cured with the proper amino acid treatments. “What do you think about amino acid supplements?” Ben looked at me, and he said, “You know, Michael, we tried to do that, help fight disease, help make a child healthier with amino acid supplements, but the first problem was that you have to have the proper ratio of arginine [the other key amino acid tied with the immune system, but a problem since it could strengthen, feed herpes-related viruses] to lysine. But way more important, we couldn’t get it past the liver.” I was told that this research had already been done in Boston back in the 1930s, and it had also been unsuccessful because they could not get the amino acids through the liver. Because the amino acids could not be absorbed, it was impossible to strengthen the right pathways in the body through supplementation. The medical community acknowledged that the concept had potential, but it seemed impractical. Dr. Kagan told me that most OTC (over-the-counter) products would not work because they could never be absorbed by the human body or pass the blood–brain barrier. Our bodies are designed to protect us from foreign substances—that’s why the acid in our stomachs is so strong and
why we have a liver, other filtering devices, and protective cells.

Back at my practice, investigating if this avenue of therapy could really help, I was doing a lot of amino acid profiles. This test measured serum amino acid levels, in the belief that the “pattern” was predictive of the type of disease and some of the dysfunctions that were occurring, and in theory a guide on how to try to help change that by supporting the body in a very directed nutritional manner. I was noticing a similar pattern in both the children and adults I was testing. By this time, I had begun to treat some of the parents of the children in my practice who were complaining of this generalized, nonspecific illness.

My practice began to grow, but instead of seeing newborns for wellness checkups I was seeing chronic fatigue patients and children with CFS and children with mixed attention deficit and hyperactivity disorder (ADHD) and quiet attention deficit disorder (ADD) that we had never been taught about in medical school (because these categories had not existed at that time). One of my colleagues whose practice had yet to see a similar increase in these types of complaints joked that it must only be happening on my side of the street. How I wish that statement had been true.

While I was working with these amino acid profiles, using the company’s research and testing, looking at applications of their recommendations in products, the company sent me files of a group of families from West Los Angeles who had children with autism. Their head researcher had noted an early similarity in their testing and that of adults with chronic fatigue syndrome. They wanted me to run additional amino-acid profiles, viral titers, and also candida (a form of yeast) titers on these children. At that time, you were considered a borderline quack if you even said the word candida. If I said I believed yeast caused the dysfunction in these children or adults, researchers I respect and count on would never speak with me again, because I would be a fool. If I qualify my discussion, note that work on adults has confirmed that when the immune system is stressed, what we call “delayed hypersensitivity” is off or dysfunctional. In turn, at that point, anyone, a child or adult, is prone to a potential yeast or fungal overgrowth. Unless critically ill, this overgrowth will be appropriately restricted to the GI tract (sometimes vaginal area in a woman), sometimes the skin externally, but will not be found in a patient’s blood, their brain, or any other primary internal organ. In that way, yeast or candida can be a symptom—evidence of the stress
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on the body—but not the reason or cause. When I ran these tests, I made an interesting discovery. I noticed that the results of the amino acid profiles for the children with autism were similar to the results of these adults and other children whom I was seeing and treating in my practice for these generalized symptoms of Chronic Fatigue Syndrome. When one realizes that a previously high-functioning, Type-A, college-trained “yuppie” does not know why they went to the kitchen or drove to the end of the block, cannot remember the right word to say, and becomes overwhelmed in loud places and prone to panic attack and anxiety attacks, one gains a tremendous insight as to what is really happening to these children, how bad they must feel, how terrified they must be at times, when we are completely misinterpreting them. I ran immune panels, viral titers, ANAs (antinuclear antibodies), and did NeuroSPECTs (brain single photon emission tomography—an imaging technique showing blood flow in the brain using a low-dose radiologic isotope, with the rationale that blood flow correlates directly and objectively to brain function). There was an overlap of patterns of multiple viral titer elevations to Epstein-Barr, CMV (cytomegalovirus) and HHV6 (human herpes virus 6), and low NK cells (frequently below 4 or 5 percent—a key marker for immune dysfunction in children and adults). On NeuroSPECT the “autistic” children’s brains showed abnormalities nearly identical to those of the adults and older children in my practice—that is, a temporal lobe hypoprofusion affecting their function and specifically areas of memory, social skills, auditory processing, and language—all the deficits we mistakenly blame on autism. The results floored me. “What does autism have to do with the immune system?” I wondered. I, like everybody else at that time, had not even begun to consider the fact that autism might be associated with illness. At that time, autism was considered to be a mysterious disorder with no known cause. Since patients seemed “psychotic,” and it was an era of psychiatry deeply set in Freudian theories, (“refrigerator parenting” was thought to be a key reason for this psychological disorder), autism was defined as a form of childhood schizophrenia. The key point is when Dr. Kanner himself was asked what separated a child with this new idea of autism from classic childhood schizophrenia, Dr. Kanner’s response was “The child with autism was never affectionate.” Based on that statement alone, 99.9 percent of the children today would not have “autism,” and the medical world would really have to be trying to figure out what was happening to these children. Without the myth
of autism we would be figuring out how a disease process could strike
down and destroy a potentially normal child—not children mysteri-
ously miswired, congenitally beyond hope of a true recovery (the basis
for the concepts we call “autism”).

When Elyse realized these children had similar viral titers and im-
mune markers as she had, she looked at me almost in tears and said,
“If these children feel even one-tenth as bad as I did, you have to do
something!” As an adult, although she hadn’t understood what was hap-
pening to her body, she had at least known she wasn’t normal. But
these were children. “Mike,” she implored, “they don’t know what ‘well’
feels like. They have no basis for comparison. They may not know their
brains don’t work. They believe this is all there is. There can’t be much
quality of life.” She wanted me to take action.

But where to begin?

After approximately seven years of research and eighteen months of
my treating Elyse with very primitive immune modulators and whatev-
er else I could get my hands on to improve her immune system. (With
the knowledge that there was no conclusive evidence that these agents
were helpful, I would meticulously avoid any agent that we knew in
theory could be potentially harmful to a normal, physiologic brain or
body. I follow this strict policy to this day, and it has served me well.)
My wife returned to function and, as she puts it, “the world.” It is hard
to believe looking back just how dysfunctional she was. Elyse has a
very high IQ and graduated from college at nineteen years of age; she
was not used to forgetting why she walked into the kitchen or where
she left her keys, not experiencing “forgetfulness” (as can happen to
anyone) but periods of brain fog, making it impossible to think. Short-
term memory loss was a constant issue. One day she told me she felt
as if a switch in her body had been turned on, and she felt well and
continued to do better. Elyse jokes that she doesn’t remember getting
married; the countless vacations we took with the children (two girls
from my previous marriage, and a boy from her previous marriage) are
hard for her to recall. Thank goodness for pictures! It is a travesty that
the expanding idea of “autism spectrum disorder” has become a waste-
basket diagnosis and an excuse for the medical community to abandon
research, treatments, and hope for so many ill patients. At my first talk at
the Autism Society of America my wife elbowed me and asked, “Where
are the doctors?” While I was a medical doctor and keynote speaker,
most of the other speakers were PhDs, and the audience mostly parents.
While I was presenting NeuroSPECT scans of the brain, actual pictures of what was going on in the brain of sick children, and offering a medical reason for the dysfunction—a possible disease process, not a developmental disorder—it didn’t seem to matter beyond the walls of the conference! If the medical profession does not address this as a problem to be solved, how will parents and thousands of affected children ever hope for an answer? Children are showing classic symptoms of viral disorders, true encephalopathies, yet these symptoms are ignored because these children are labeled autistic. It is beyond rational.

As a physician, I understand that the previous ideas of developmental learning difficulties (i.e., autism, ADHD, childhood dementias), which were once under the guidance and the control of psychiatry, should be no longer viable. Pediatricians and parents are being faced with a rapidly enlarging medical epidemic. The starting point of research, the starting focus needs to be that of figuring out a true medical epidemic, not of disproving a nonobjective, psychiatry-based “label.” Without this change in focus, years more will be wasted and millions of dollars will continue to be misdirected to nonproductive ends.

So where did it all begin?
In Dr. Leo Kanner’s now classic 1943 research paper he outlined the behavior pattern, present from early in life, that he named “early infantile autism.” Prior to this, there were, in the literature, occasional accounts of individual children whose behavior fit the picture Kanner later described. Kanner described only the autistic children referred to his clinic and, later on, those attending a particular special school (Kanner, 1955). He made no estimates of the numbers in the general population, but he thought that this syndrome was rare.

Later, Kanner and Eisenberg (1956) discussed Kanner’s original conception of autism and the five features he considered to be diagnostic. These were a profound lack of affective contact with other people; an anxiously obsessive desire for the preservation of sameness in the
child’s routines and environment; a fascination for objects, which are handled with skill in fine motor movements (an area of actual weakness in many of the children being diagnosed today); mutism or a kind of language that does not seem intended for interpersonal communication; and good cognitive potential shown in feats of memory or skills on performance tests, especially the Séguin form board. Kanner also emphasized onset from birth or before 30 months.

In the same paper, Kanner and Eisenberg modified the diagnostic criteria by selecting two as essential.

These were:

1. A profound lack of affective contact; and
2. Repetitive, ritualistic behavior, which must be of an elaborate kind.

They considered that, if these two features were present, the rest of the typical clinical picture would also be found.

Rates of autism in 1956: 1 child in 10,000.
Rates of Autism in 2011: 1 child in 110, 1 child in 91, with much higher numbers being quoted routinely.

So, how can so many children now have such a previously rare disorder? How can a rare, almost unheard-of “severe mental dysfunction” become something every pediatrician is seeing, something every parent is concerned about? How can we now have this rare misfortune threaten to overwhelm our school and social systems while destroying families across this country and around the world?

To understand this, one needs to go back to the beginning. Per above, Kanner (1943) described a disorder according to its “behavioral” features. Needless to say, “behavioral” dysfunction can be caused by many factors, not just the idea of a developmental or psychiatric dysfunction.

Think of it: a general idea noting patterns of behavior held to be true over decades, with only a “behavioral” pattern for diagnosis, not one objective or consistent physiologic dysfunction or finding required to prove or disprove this “disorder/diagnosis” (but somehow all these children have it for life). Health professionals have no idea what causes this disorder. Explanations have ranged from childhood schizophrenia to bad parenting to something biologic, all with the underlying concept that “something” must have happened developmentally. Somehow (mechanism unknown) the brain was miswired; these children were not
okay, could not be okay (but with no idea of what was happening, or why or how it happened).

If one goes back and reviews the literature of the 1940s and 1950s, there was no support for or even a discussion of a genetic linkage. I have proposed there is no more evidence of a genetic connection than the now fully disputed, insulting idea of a "refrigerator mom."

In the world I trained in, a rapid increase affected children all showing a similar pattern of behavior should have created appropriate questions and initiated scientific, medical investigations. What’s going on? Why are we suddenly seeing so many dysfunctional children? Maybe something is wrong here? Maybe this is not autism? The initial diagnosis has just kept expanding and modifying, and all the new children were just put into a variation of the old basket. Instead of expanding the alphabet soup of autism (PDD, Asperger’s, autistic spectrum, LKS [Landau-Kleffner Syndrome], etc.), or likewise ADD (from a hyper, usually intelligent child, we evolved new labels for the different children appearing as mixed ADHD, quiet ADHD, ADD without hyperactivity, and many more) perhaps experts could have said maybe this is not just something we can label autism; maybe this is not the ADHD we were trained to treat. Maybe we have another problem (with some “autistic” or ADHD-like symptoms) occurring. Maybe we need to ask the critical questions: Do these children even fit this label? How many parents (often against their own belief) presently are being told their children have this strange disorder called “autism” (or are on the spectrum) and they must learn to live with it, accept it? How many parents think their children even come close to meeting Kanner’s main criteria: “a profound lack of affective contact and elaborate repetitive, ritualistic behavior?” Kanner made a very important distinction, one that perhaps we should all be applying now. He separated a child with this new idea of autism from the child with childhood schizophrenia. Remember that it was all a psychiatric disease; Dr. Kanner’s statement was that a child with autism was “never affectionate.” Now if all we did was apply that one
criteria (as we’ve applied the ritualistic behavior criteria exclusively today), 99.99 percent of these children would be classified with an illness, and not as having autism, and that would certainly become a pathway to more a desirable outcome than what we have now.

The precedent is that there has never been an epidemic of any type of genetic or developmental disorder. There are no exceptions. And yet, the vast majority of the researchers in this country, and throughout the world, are still studying these children as if they had some undefined, unknown “developmental” disorder. Instead of focusing on what can be understood only as a disease (not developmental) process, the system continues to fund researchers trying to figure out and understand “autism” (as a developmental disorder), and an ever-expanding list of connected physical problems.

This is why so little progress has occurred in spite of millions of dollars being spent. Researchers are being funded to study what the vast majority of the children appearing today cannot have. If this process continues, everyone will lose (except the researchers and universities receiving mass amounts of funding as well as the industry of alternative therapists helping to try and treat these “special-needs” children).

It is blatantly obvious that 99.99 percent of affected children do not come close to meeting Kanner’s definition of autism. The overwhelming majority of children being diagnosed as “autistic” do not have autism (as the term is understood or used), but rather are exhibiting symptoms of a disease state, a CNS (central nervous system) dysfunction. Unlike a developmental disorder, this disease is treatable if we act quickly enough. How many of the the existing autism groups are questioning present funding, present efforts? How many are going before Congress protesting that we have a large group of children that if helped, if treated, might grow up to be productive citizens, might pay taxes (rather than requiring more and more social services) one day? Why not?

That is “the myth of autism.” Children are being labeled with a disorder they do not really have. Parents are being told there is little hope, when there should be a lot of reasons for hope. As long as we continue to label so many children and families with this undefined, unexplained disorder, few physicians, parents, or politicians expect these children could ever recover or regain regular function. In the myth of autism, many dangerous or partially successful therapies abound, with some success (often with large risks) being better than nothing.
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What bothers me is the autistic child who spends the day at a special school with five to ten other children and copies their bad behaviors rather than learning from a normal child.

What if physicians and therapists expected a child to recover and focused on finding answers to fix this now, for this generation of children, rather than accepting any degree of minute improvement as wonderful? What if we could bring the children and parents of this generation back to the field of pediatrics that existed when I trained?

It has become obvious that neuroimmune and/or chronic viral connections are the only possible cause, the only proposed mechanisms that have no scientific contradictions and an ever-enlarging compendium of articles in support. While many will pose the question “Where are the controlled studies?” every medical fact and recent discovery helps substantiate the likelihood of an autoimmune, neuroimmune-related process.

We are presently at a crossroads. Are we going to continue to blindly follow old logic, old thinking with no consistent physiologic dysfunction measurable or documented, or can we unite behind scientifically sound data, more than reasonable medical probability and clinical logic, before we lose forever the chance to help this generation of children? There are excellent researchers, clinicians, and scientists ready to focus on solving this disease now, rather than study the myth, but this effort to fight a disease (NIDS, or whatever name is eventually used) remains buried under the wall of controlled misinformation. This is now obviously a medical crisis, a true medical epidemic that should no longer be under the supervision of psychiatry, but should be relocated to the realm of pediatric infectious disease, pediatric immunology, and a medically focused pediatric neurology.

Unless we all step up now to change this, to demand clinical science and logic, not mythology, the system could easily take another ten to fifteen years (or longer) to come around to the right answers. How many are ready to step up and say, “Enough is enough”? How many millions of dollars have been spent (particularly in the last six to seven years) with no answers and without any new hope?

The NIDS effort was formed to help look at this crisis appropriately, scientifically, logically, and medically. Many parents are working hard to help make a real future for their children.

At an NIH-sponsored conference many years ago (1996), presenting my preliminary NeuroSPECT work with Dr. Ismael Mena and Dr.
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Bruce Miller, before a room full of high-level researchers, including many Nobel laureates, I expressed cautiously (expecting resistance to this idea) that if this process hits you as an adult, you get CFS or the new idea of adult ADHD. If it hits you as a teenager or older child, you get ADD/ADHD variants or CFS/CFIDS. But if this process hit you as a young child, with an immature brain an immature immune system, you get autism/PDD. They did not laugh (or ban me from future conferences), and, two years later, at the next conference many were coming up to express their agreement. As that was 1998, it remains a sad mystery to me today why more money and more resources have not been allocated to a medical investigation of “autism.”

It is my fervent hope that in the near future the existence of an immune dysfunctional/dysregulatory state will be commonly accepted, whether the patient exhibits fatigue or not. Perhaps we will come to recognize that an immune dysregulatory state is a generalized condition that may include many interrelated phenomena, such as CFS/CFIDS, atypical and/or typical rheumatoid disease, most if not nearly all of autism, and parts of ADHD, as well as other learning disabilities. It seems probable that this disease has an element of genetic predisposition (confirmed in emerging epidemiologic studies). In following a number of families in my practice, I have found that not all members of the same family become ill. Often one child and/or one parent alone is affected. This likely implies a lack of ongoing contagion, if any, associated with this syndrome, suggesting genetic predisposition with probable multiple triggering agents or events. These can include viruses, a combination of stresses, or various traumas, setting off a state in the body in which the immune system, the CNS, or both do not come back to a normal functioning level. As supported by many peer-reviewed papers, once in motion this is controlled by the innate immune system, not the initiating stress or stressed (or any kind of a simple genetic) chromosomal defect.

The social-educational-economic implications of all of this are terrifying. We are running out of money and bankrupting educational systems to deal with the epidemic of special-needs children. I try to be respectful to teachers, who are on the front lines, being asked to do their best to educate a growing number of children who are “space cadets.” With all the studies on all the possible reasons for this, how many have thought of looking at the bigger picture? These children are all points on a bell curve. Rather than just exhibiting multiple variants
of learning difficulties, put under different labels, these children really are ill and have part of their brains not working. How much more successful would these teachers be, how much could we begin to dream of lowering education costs, at minimum being far more effective for all students, if we recognized that, as physicians and parents, we have an obligation to send children to school alert and healthy? Whatever the combination of factors, once in motion, there is likely a medically definable problem that can be treated. We must stop assuming these children’s function is carved in stone, determined in some mysterious way genetically, developmentally.

I continue to believe awareness and recognition of the true medical crisis being discussed in this book will mean parents and children receive more help, but help focused and dedicated in the right direction. For, if helped, with children’s body and brains made healthy, the system will not only smile at its success but also save hundreds of millions (at this point likely hundreds of billions) of dollars in now unneeded expenses.
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Incidence of "Autism" Compared With Genetic Conditions

Cumulative Growth Rates (Age 3 - 22)
How Can This Be Anything But an Illness?

Unlike Down syndrome, fragile X, and other common childhood disorders that have a genetic link, can be evident at birth, and whose rates have remained stable in the last fifty years, autism rates are increasing rapidly across the globe, affecting childhood populations in numbers similar to those of the Spanish flu and the bubonic plague. This disease affects children after they are born. It is acquired, like other illnesses. Based on early clinical work and reports, linked by the emerging NeuroSPECT (the use of a low-dose radioisotope and imaging to measure blood flow, which defines function in areas of the brain), myself and a few other physicians coined the term NIDS (Neuro Immune Dysfunction Syndromes) as a way to try to create a medical umbrella over the previously developmental categories of ADHD, autism, and other now likely immune-mediated (a CNS system-, neuroimmune-created dysfunction in key areas of the brain) learning or cognitive disorders. The NIDS hypothesis was first discussed in early 2000, and found wide agreement with no scientific debate or dispute by researchers and pharmaceutical representatives who read it. It just made sense.

Under the umbrella of NIDS, the multiple secondary metabolic, physiologic, and immune markers that are abnormal in these children make sense. The “new” family constellation presenting to many physicians begins to make sense. Representing nothing I was ever taught about in medical school, internship, or residency, there was now a newly emerging family constellation of a mother or father with CFS/CFIDS
or “other” immune mediated disorder, an older child (or two) with an ADHD variant (or other learning disorder), and a younger child (or two) with autism or PDD. This pattern is impossible for a developmental or genetic disorder. It is the logical result of an immune connection with NIDS.

Let’s go back to the symptoms and forget the label. If we remove the “diagnosis” of autism and simply look at the symptoms, we see a variety of common factors. Typical medical histories include immune-related issues of eczema, hives, or other allergic issues, along with recurrent ear infections, frequent sore throats, and flulike illnesses.

Confusing for many parents and health professionals is the fact that many "normal" children will typically also experience recurrent infections, recurrent ear infections, a stressed delivery, and recurrent allergies and not fall into this complex disorder (NIDS). The logic is simple when one understands that most normal children in the past were not born under already stressed circumstances (many adults and children now have activated immune systems compared to the normal baselines of two or three decades ago), and then depending upon the combination and number of stressors, while most of them will manage to recover and come back to an acceptable baseline; an enlarging group of infants and children are being pushed over the edge into this complex neuroimmune, then complex viral dysfunctional state. It is interesting that as with a "normal" child, some of these children, probably dependent upon their allergy responses, have a history of recurrent congestion and then recurrent infections, while some (usually those without the congestion issues or in whom the "triggers" for congestion have been removed) will generally seem to stay healthy and not present with recurrent ear, sinus, or chest infections. My overwhelming experience for years with a large "normal" pediatric practice (in which some children were prone to allergies) was in how to keep a child clear, and how to avoid recurrent congestion/infections.
Common symptoms of neurological dysfunction (rather than a psychologically based disorder) include trouble concentrating that can be described as “spacey” or “zoney;” a sensory, auditory, or vestibular processing difficulty; “executive dysfunction;” sleep difficulties or an abnormal sleep cycle; and fine or gross motor abnormalities. As noted elsewhere, these findings, particularly the fine and gross motor issues, become markers for the likelihood of a virus occurring. If one goes back to the autism literature of the 1940s and 1950s, there is no mention of fine or gross motor issues.

The presence of the above symptoms should demand a medical focus and a medical evaluation. We can no longer continue to ignore or discredit it. If we remove the label called autism and again focus on the patient, the child, we can begin to deal with symptoms that without the hysteria, without the misconceptions of “autism,” would be regarded as medical crisis.

How We Got Here

Unfortunately, without the tools or the technology to accurately investigate the human brain, the label of autism evolved from the observation of a set of symptoms in a dysfunctional child. In its most severe form (“classic autism”), effective speech was absent, and clinicians often saw symptoms of repetitive, highly unusual aggressive and sometimes self-injurious behavior. Those afflicted had extremely abnormal ways of relating to people, objects, or events. Parents noticed that something was “not right,” often within the first three to six months of life. These children typically did not smile and often resisted affection.

Most researchers and clinicians did not look for medical answers to autism (likewise ADD/ADHD and most childhood learning or psychological disorders) because they believed it was a disorder that was medically untreatable. Without the technology to understand these children, pediatricians and pediatric psychologists accepted the concepts of poor parenting or childhood psychosis/schizophrenia and classified autism as a psychological and/or developmental disorder. Psychologists and psychiatrists typically delivered treatment.

In accordance with this premise, recent discussions have focused on the difference between “congenital autism” (including “classic” Kanner autism) and another form related to neurologic and medical disorders such as tuberous sclerosis, phenylketonuria, congenital rubella,
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and Down syndrome. However, a third form has emerged that is being referred to as “acquired or regressive autism” (perhaps the largest subgroup of these children). For purposes of this book, acquired autism is a condition in which the child develops normally for the first twelve to eighteen months of life and then regresses into the increasingly wide spectrum of autistic disorders.

These children challenge the previous belief that 70 to 80 percent of autistic children are mentally challenged. They crawl, sit up, walk, and usually attain normal motor milestones on schedule. Until the age of symptom onset, they are affectionate (which rules out Dr. Kanner’s definition) and appear to have above-average intelligence. Children with acquired autism may begin to develop some speech but then, without warning, cease to progress and begin to regress. Suddenly, these children become withdrawn. They vacillate between being quiet and hyperactive. Often self-stimulatory behaviors (e.g., arm flapping, rocking, spinning, or head banging) may develop. Over time, some manifest symptoms that are both similar to and atypical of those of children previously diagnosed as having congenital autism. I propose that many of these children with acquired autism fall into this medical category of NIDS. (Neuroimmune Dysfunction Syndromes), and need to be viewed as suffering from an autoimmune medical illness that is potentially treatable.

Understanding, Insight Emerges

To understand how we got here, one has to understand the history. In the early 1970s the human brain was still mainly a black box. There were sophisticated, indirect studies to determine areas of anatomical functions, but the objective data was still essentially nonexistent. We had CAT scans (computed axial tomography) and MRI (magnetic resonance imaging) capable of illustrating damage, tumors, possible AV (arteriovenous) malformations—essentially what we think of as “structural.” There was very little understanding as to the cause of any brain dysfunction. In fact, in the field of psychiatry, it was generally accepted there was no real objective data, and a whole system of labels and the classification of mental dysfunctions evolved based on symptoms—no one imagined that we’d eventually be able to “look” at how that brain was working or not working.
While specific knowledge was weak (opening up the door to a world classifying many of these disorders, condemning children to a presumed life-term dysfunction, with an absence of objective data), if something was going to go wrong there were only certain ways that could happen. These children started off with presumed normal brains and normal skulls anatomically; the possible causes of dysfunction are limited.

The possible mechanisms are:

1) a structural defect

2) a congenital/developmental malformation, a chromosome abnormality, an AV or vascular malformation, an injury, a neoplasm/tumor, or a primary metabolic process.

Over many years of study it has been found that none of these possible mechanisms (including any idea of simple genetic or chromosomal defect) is in effect in these children (or adults with these related disorders). The only possibility that remains is that the brain can become dysfunctional by infectious (viral, bacterial, other agents) and immunologic mechanisms. Herpes viruses in particular like to go to the temporal lobe of the brain and are known to cause seizures. Our knowledge of neuroimmune, ultimately complex viral interactions has blossomed because of the appearance of HIV. Short of the indefinable expansion of previous psychiatric-based disorders, one inevitably begins to focus on complex immune and viral mechanisms; that might be a far more reasonable and far more logical explanation than psychiatric/undetectable “developmental” disorders mysteriously present from birth.

The body has different “systems.” These include endocrine, immune, hematology, EENT (ear, eye, nose, throat), cardiovascular, pulmonary, GI (gastrointestinal), GU (genital-urinary), muscular-skeletal, and neurological. Within those systems, only certain disease mechanisms can occur. These are metabolic-toxic, genetic/developmental, infectious, immunologic, and tumor-trauma-insult. Looking at these systems, it is obvious by now, while there may be dysfunctions within different body system, the only systems key to the pathophysiology of all this dysfunction/illness are the immunologic and infectious systems. Unless nature and physiology have changed, it’s time to focus on reality, science, logic, and a cure.

While in an “ivory tower” medical school—UCLA—I was also thankful upon reflection that I was exposed to the early evolution and
understanding of what we called collagen-vascular disorders—things like lupus, scleroderma, and other disorders we now think of as autoimmune diseases. Since we had limited knowledge of our immune system and its complexities, retrospectively it is not a surprise that many markers were not consistently diagnostic or validated as causational. However with ANA and other markers (including abnormal changes in viral titers) we approached patients with an understanding that they could have a potentially serious medical illness.

When I graduated from medical school, the presence of an abnormal immunoglobulin IgM, particularly when elevated, was reason to work up someone for an occult lymphoma or other cancer. Now it is often ignored instead of at least being interpreted as an immune system deficiency. The cause may not be obvious, but giving these tests as a precaution is a far better, anticipatory, preventative approach than our present system.

When I graduated from medical school, if a young adult developed shingles, (chicken pox reactivation), you would work them up for likelihood of a serious illness, including an occult cancer or leukemia. The reason was that for a young adult to break out in shingles was considered a very serious sign of a stressed immune system. Children, teenagers, and many young adults have this happen now, and are not urgently investigated for a serious illness. Why?

In medical school there was no discussion of entities in adults of chronic fatigue syndrome, fibromyalgia or in children of mixed ADHD, quiet ADHD, or of an epidemic of “autism.” As discussed, the appearance of these entities makes sense when looked at together.

It is worth noting that classically autoimmune diseases are more common in women than men, and while “autism” is now in girls and
boys, the fact that it is more common in boys than girls may support discussions that boys, before their hormonal changes, may be more susceptible to immune dysfunctions/stress and were being honest when they said they didn’t feel good, couldn’t think straight, that their brains felt foggy—it turns out that in medical history the mysterious idea of chronic fatigue or CFIDS goes back to at least the 1500s. There have been epidemics throughout history (one documented by the father of English medicine Thomas Siddenhaum in the 1680s) of a mysterious ailment, fatigue, mental dysfunction with a flulike presentation—but unlike today, these presumed outbreaks were reported and then would disappear for long periods of time. Of course with no objective data, no ability to determine the cause of these epidemics, the result was hysteria rather than scientific investigation.

In 1934, Dr. Sandy Gilliam described an outbreak of an unusual fatiguing illness that was then termed “atypical poliomyelitis.” Two particular outbreaks that were investigated by Dr. D. A. Henderson at the CDC and Dr. Alexis Shelokov at the NIH led to the term “epidemic neuromyasthenia,” which has been the preferred term for outbreaks of fatigue since they reviewed this problem in the *New England Journal of Medicine* back in 1957.

The problem began somewhere in the late 1950s and early 1960s, accelerating dramatically by the 1970s and 1980s. Worldwide outbreaks of this strange phenomenon began to occur, but unlike in the past, they keep recurring, instead of stopping. One of the outbreaks in Japan, in 1984, was termed the “Low NK Syndrome.” Symptoms were a general dullness, with no identifiable bacterial or viral agent evident.

If one applies our emerging understanding of complex immunology and virology, it appears that a medically based epidemic may be occurring—and we have ignored this for at least twenty-eight years now.

As far back as an NIH-sponsored research conference in Boston in October 1998, it was acknowledged that some of these “psychosomatic” adults might really have something medically wrong with them. Some of them showed low NK cells, evidence of an immune stress that could lead to chronic viral activation, mitochondrial dysfunction, and unfortunately an increased risk for cancer. At that conference
was the recognition that some of these patients were found to have evidence of an “activated” HHV6. Twelve years later, these findings are still being challenged and investigated. Over the years it has remained easier for many in the NIH and our academic institutions to “debate” and challenge viral or immune findings (they are not the same, they are not consistent on everyone), rather than focus on explaining and understanding how they might really be playing a key role in the pathogenesis of these disorders. The reasons or explanations for this become harder and harder to understand or remotely justify at a time of crisis like this.

Although historically these outbreaks have led to an inquiry and investigation by the NIH’s National Institute of Allergy and Infectious Disease and the CDC’s Viral Exanthems and Herpesvirus Branch. But unfortunately, CFS/CFIDS was not classified as a possible infectious disease, and, sadly, high-powered experts concluded these symptoms were psychosomatic. I do not believe we would be missing the medical reality of this misnamed epidemic of “autism” today, if CDC experts, when called in to investigate this outbreak, had been constructive, leading the way on a progressive, logical course to understanding, prevention, and likely treatment. Instead, after first mistakenly dubbing it Epstein-Barr syndrome, due to elevated viral titers, many of the researchers went on personal vendettas, encouraging the press to use the term “Yuppie Flu,” and implying this was not a serious medical illness in these adults (mostly women). It is worth noting that CFS is no longer considered an infectious disease. While perhaps not an acute, fast-moving infectious disease like the flu, a cold, measles, or polio, there is no question that we are looking at a slow, but insidious immune/viral phenomenon we might have stopped or corrected by now if we had focused resources on understanding, getting answers.

One of the major reasons for the misdirection of the medical system can be traced back to the confusion over the patients presenting during the Lake Tahoe outbreak starting in August/September of 1984. As noted, high-level investigators/researchers disregarded the importance of elevated viral titers. By focusing on psychosomatic causes and ignoring the evidence of viruses and markers for probable immune dysfunction
in these adults, we veered off course more than twenty-six years ago.

Back in medical school, we were all taught that evidence for an acute viral infection meant what was called an IgG titer rose, changed fourfold (i.e. 1:20 becomes 1:80 (borderline), 1:40 became 1:160, 1:80 became 1:320, etc.). While not definitive, when symptoms of an illness were present and a viral titer changed fourfold or more, that was considered suggestive, very suspicious evidence for that virus. Even then, without a brain biopsy or a technique that evolved to what we call a positive PCR probe, the titers were suggestive, even convincing, but not definitive proof. (the brief appearance of any positive IgM titer was very suspicious, often felt to be hard evidence of an active virus—now even that is often ignored as a “false positive”). However, as noted, in 1984 for very complex reasons, when at first these adults and later children appeared with constantly high elevated titers, titers that in medical school we were taught were elevated, represented presumed evidence of that virus. Instead of what should have been that start of a medical investigation into why these adults had these acutely elevated Epstein–Barr or other viral titers but now on a chronic, long-term basis, mainstream researchers and “medicine” decided (and began to teach) that these titers meant nothing.

Now, instead of twenty-eight years devoted to understanding this new disease phenomenon, definitive protocols, and new medications to help, we first discredited adults by calling them all their complaints psychosomatic, and now we are somehow selling a completely illogical, unscientific idea that everything in these children is developmental. No. A recent article from Stanford University illustrates how extreme this has become. A Dr. Montoya and his associates argued that if we were taught that it was significant if viral titers went up fourfold, shouldn’t it be significant if with therapy the titers went down fourfold? He treated twelve adult, chronically ill CFS/CFIDS patients with elevated herpes-6 (HHV-6) and Epstein-Barr virus (EBV) titers. Each patient had to have four or more of the following neurocognitive symptoms (parents, think of your children): Impaired cognitive functioning, slowed processing speed, sleep disturbance, short-term memory deficit, fatigue, and symptoms consistent with depression. After 6 months with an agent called Valganciclovir™ (an antiherpes antiviral, but not safe for routine use), nine out of twelve (75 percent) of the patients experience near resolution of their symptoms, resumed daily home and/or work functions—something they had been unable to do for years.
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In a world that denies meaning to these titers in adults and children, the researchers showed a significant drop in both their EBV VCA IgG titers (1:2560 > 1:640) and their HHV-6 IgG titers (1:1280 > 1:320).

Key researchers I’ve been involved with, who are openly pleased with "The Dr. Montoya Article" acknowledged they could never have received funding or approval in the current research atmosphere. Only because he was so powerful, so "big," was he able to do it. After twenty-eight years of this, isn’t it time the prevailing attitudes changed?