The Alphabet Soup of Learning Disabilities:
How We Diagnose Children with ADHD and Autistic Spectrum Disorders

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Learning Disabilities are a confusing topic for many parents and teachers. The list of labels seems to be growing at an alarming rate. New diagnoses pop up and old labels get replaced sometimes at a tempo that outpaces the knowledge of professionals. Parents are equally confused about all of the D's? Diagnoses such as: LD, ADHD, ODD, PDD, OCD, NVLD, ASD, CAPD and others.

What is going on here? What do all of these labels mean? What are the important features of the most common learning difficulties? Are there really that many children with learning problems now? Or do we Americans just love to label everything so we are special and unique, including our children? Are the expectations and demands of our technologic society placing unrealistic demands on our children who are incapable of measuring up to these standards? Has this proliferation of labels gone too far? Who is assigning these labels? How are diagnoses made? These are some of the questions parents ponder when their child begins to struggle in school, or is diagnosed with a developmental disorder. Ideally a diagnosis should foster understanding and facilitate the use of strategies and tools to help a child. Instead, oftentimes there is confusion and a feeling of helplessness.

Is it just Alphabet Soup?

Before I can try to answer some of these questions, think for a moment about the act of labeling children and what this means for teachers, parents, and children. For example, it is a well know fact that a student's performance in the classroom is strongly influenced by the expectations and attitudes of his or her teachers. This is also true at home and in activities outside of the classroom. This had been demonstrated by numerous

experiments in clinical psychology and educational theory over the years. However, even without the research, we all instinctively know this is true from our own personal experiences. We can each recall those individuals and teachers who got our best or our worst performances in school and life.

A specific diagnostic label can be stigmatizing and encourage misleading assumptions about a child. Labeling a student may bias a teacher leading to self-fulfilling prophecies regarding a student's abilities. This may also create a difficult relationship with the parents from the start. The parent can be defensive about the child's abilities or problems, as they feel their child is being judged before even given an opportunity to perform in the classroom.

For children, having a "diagnosis" may cause them to feel they are somehow defective or disabled. This in turn can lead to problems with self-esteem and feelings of isolation. For many a label reinforces a negative self-image, and proves that they are not as smart or talented as others. Not surprisingly for many children when they hear the term "disability" or "disorder" they think of someone physically handicapped or in a wheelchair.

Where does the model of labels as deficits come from?

In their more traditional everyday use, labels emphasize weaknesses and deficits, often obscuring a more positive and optimistic view of a child. Some have blamed this bias on the insurance industry. To be reimbursed for diagnosing and treating a child in medicine or psychology a diagnostic code must be given. These are diagnoses predominantly based on a model of deficits. Identifying how a child differs from the norm is what determines a given diagnosis. What is "wrong" is catalogued in the Diagnostic and Statistical Manual (or DSM for short), among other diagnostic tools, which are used to determine the exact diagnostic label.

Public school systems utilize the same model of deficit based labels. To qualify for an IEP (Individualized Education Plan) or any special education services, students must have a diagnosis which satisfies different eligibility criteria. A child must have impairments significant enough to interfere with functioning to obtain special services. Eligibility criteria are designed to be stringent to prevent over utilization of special education funding. As such this model also does not emphasize strengths, unusual abilities, or the potentially positive aspects of a learning difference.

There still continues to be debate about some of the actual diagnoses. The question of what constitutes a learning disability continues to be debated in the special education literature. The most widely accepted definition is a child who shows a significant discrepancy between intelligence testing (I.Q.) and achievement test scores. Different school districts may vary in their precise definitions and terminology. However, it is the child who fails to learn or achieve, in spite of apparently normal intelligence that generally qualifies for a learning disability. Within the realm of learning disabilities there are numerous more specific labels such as: dyslexia, disorder of written expression,

dyscalcula, dysgraphia and others. Under ADA, (the Americans With Disabilities Act) guidelines other disorders traditionally viewed as behavioral will also qualify a child for special services under the category of Other Health Impaired, this includes ADHD, ODD, Autism and other labels. There are many excellent books written about the specifics of the Federal Laws enacted to protect and serve children who learn differently, as well as the obligations of teachers and administrators to ensure the student's needs are being addressed. The important point here is that all children who receive any type of special remedial services in the public education system must qualify based upon their specific diagnostic label. No diagnosis, no services.

What is in a label?

The most pervasive "D" is ADHD or Attention-Deficit Hyperactivity Disorder. Conservatively the prevalence of this diagnosis is anywhere from 4-12% of school aged children. Some investigators have suggested the incidence may even be as high as 20% of school- aged children. The population numbers approximately 1.5 million children. These numbers are constantly being revised. The condition is still thought to be more prevalent in boys, but it is also often overlooked or misdiagnosed in girls, as they less frequently present with hyperactivity or other obvious and externalizing symptoms. The prevalence is still about 3 to 1, boys to girls.

For teachers this is the most common learning disorder they will encounter in the classroom. For parents it is often one of the first diagnoses to be entertained when a child is struggling in school. The amount of information currently published on this topic is mind- boggling. Similarly the amount of research funding for ADHD and the use of medications for the disorder is astounding. As such you are bound to find confusing and conflicting information. I will try to provide clear, concise, and understandable background information about ADHD, the most common learning disorder of childhood. I will use the questions that follow as a guide:

1. How the diagnosis is made?
2. What is the history of the disorder?
3. What are the observable phenomena?
4. Where do we go from here?

How the diagnosis is made

To understand how a child is given the diagnosis of ADHD it is helpful to understand the terminology, which has gone through many changes over the years. The current terminology for ADHD comes from the so-called "bible" of psychiatric medicine called the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, or DSM-IV published in 1994.This manual includes the diagnostic criteria for most of the learning disabilities and psychiatric disorders seen in children. The psychiatric disorders are classified into two broad groups: either behavioral disorders or emotional disorders. In general, the only diagnoses, which do not appear in the DSM, are clarifications and refinements of a learning disability given by learning specialists, speech and

occupational therapists, educational psychologists and others. Also not included in the DSM are other medical diagnoses, which secondarily affect learning (syndromes, physical impairments etc.). The DSM, however, being "the bible", is very comprehensive. According to the generally accepted diagnostic criteria for ADHD, a child must have the following:

1. Fulfill the criteria as stipulated in the DSM (see below).
2. Information regarding the child's symptoms must be obtained from more than one setting (not just school).
3. Any coexisting condition which may be masquerading as ADHD or complicating the child's symptoms must be uncovered.

What are the exact criteria to diagnose ADHD?

A summary of the main criteria in the DSM- IV must include six or more symptoms from list 1or 2.

1. Inattention Symptoms

- Often fails to give lose attention to details
- Difficulty sustaining attention
- Often doesn't seem to listen when spoke to directly
- Often doesn't follow through
- Often has difficulty organizing
- Often avoids tasks requiring sustained attention
- Often loses things
- Is easily distracted
- Is often forgetful in daily activities

2. Hyperactivity-Impulsivity Symptoms Hyperactivity

- Fidgets
- Leaves seat
- Runs and climbs excessively
- Has difficulty with quiet leisure activities
- Is always on the go
- Talks incessantly

Impulsivity

- Blurts out answers
- Difficulty waiting for his/her turn
- Interrupts or intrudes upon others

In addition to the symptoms catalogued above, the following criteria must also be met:

1. Onset of symptoms is before the age of 7 years old
2. Problems due to these symptoms have lasted for more than 6 months.
3. Symptoms are true impairments affecting the child's ability to perform developmentally appropriate activities and not explained by another disorder (such as Autism, or another learning disability).

This last point may be worthy of further discussion. We are all familiar with the child diagnosed with multiple seemingly overlapping disorders. Some of this may be due to the professionals involved and their understanding of the child's symptoms. Especially with the diagnosis of ADHD there is a considerable amount of subjectivity involved when the diagnosis is predominantly based on descriptions of behavior. No matter how clear and precise these descriptions are they are still based on judgments about what teachers, parents and others observe. Also the symptoms of ADHD are present in all children and adults to some degree, what establishes the disorder is the persistent and severe pattern of the child's symptoms. It is possible for a child to have ADHD and another diagnosis. In fact, as we will see the majority of children with ADHD have "co morbid" conditions. This is the medical terminology for the coexistence of more than one learning or behavior problem at a time. The current professional view is that 15-20 % of children with ADHD have co morbid conditions.

What kinds of ADHD exist?

The current subtypes of ADHD are as follows:

1. ADHD, Predominantly Inattentive
2. ADHD, Predominantly Hyperactive-Impulsive
3. ADHD Combined Type
4. ADHD, NOS (not otherwise specified)

Depending on the symptoms noted above from lists one and two, the child will then be assigned a type of ADHD. Children who have symptoms of both inattention and hyperactivity or impulsivity will be given the diagnosis of ADHD Combined Type. Other than the labels listed above there are not valid uses of the diagnosis. For example, there are no such diagnoses as: atypical ADHD, mild ADHD, autistic ADHD, or other interesting combinations of terms you may have heard.

Exactly how is a diagnosis made?

The diagnosis can be made by a medical doctor, psychologist or learning specialist. However, only a medical doctor (M.D.) is qualified to treat the disorder with medication. The M.D. could be the child's Pediatrician, a Developmental Pediatrician, Neurologist, or Psychiatrist. All are trained to prescribe medication for ADHD, though different practitioners will have varying levels of expertise, qualifications, and experience treating the disorder.

Professionals will make the diagnosis of ADHD based on the presence of the symptoms listed in the DSM as reported by parents, teachers, and other care givers. The information is usually obtained by rating scales or questionnaires. Some professionals independently make their own observations of the child in natural settings but this is not always the case, and a diagnosis can be made without direct observation. Even with the use of other tools, which can aid in the diagnosis of ADHD the standard of care still utilizes questionnaires from teachers and parents. Computer based continuous performance tests where the child is presented with a target and must hit a computer key only when that target is visualized or heard, are helpful but not critical to make the diagnosis. Similarly brain scans of various kinds are still only being used as research tools. Careful analysis of school work including error patterns can be helpful but only with the behavioral descriptions. Ultimately, the diagnosis of ADHD rests on the eyes and ears of the observers.

In the past the diagnosis of ADHD was rather sloppily applied. Children were put on medication without complete evaluations. Teacher and or parents could get medical professionals to trial stimulant medication in children without a full assessment. Some teachers and parents over labeled hard to handle or active children with the disorder. Now however, there are more professional guidelines in the fields of Pediatrics, Child Psychiatry, and Child Neurology for the diagnosis of ADHD. Hopefully, this will limit continued misdiagnosis and over diagnosis of the disorder. At least it is a start in the right direction.

Some of the most commonly used teacher rating scales are the Connors Teacher and Parent Rating Scales, and more recently the Vanderbilt Rating Scales. There are others being used as well. There must be some type of structured observation of behavior by adults, to qualify for the diagnosis. It is not sufficient for a parent or teacher to make generalizations about a child's behavior. The questionnaires are designed to require an observer to give more thought and careful consideration to a particular student who is struggling. Some of the materials used in making a diagnosis are listed below. Keep in mind there is still variability in how different professionals make the diagnosis and the materials they use.

1. Teacher rating scales and questionnaires
2. Parent report and questionnaires
3. Psycho educational evaluations (may include a variety of different tests such as IQ)
4. Physician report (usually a Neurologist, Psychiatrist, or Pediatrician)
5. Computer based Continuous Performance Tests (TOVA, the Gordon. and others).
6. Samples of schoolwork.

This vital role of the teacher may explain the political fall out which occurred in October of 2000, when congressional hearings were held on the topic of teacher and school recommendations for stimulant medication. At that time various different experts testified before congress about ADHD, the use of medications, and the proper diagnosis

of the disorder. Prior to these hearings the Christian Science Monitor as well as other entities had been staunchly protesting against the use of medication to treat children diagnosed with ADHD. They also unfairly implicated teachers and entire school systems. They in fact go much further and question the entire validity of the diagnosis.

The overwhelming body of scientific research not only demonstrates ADHD does exist, new imaging techniques have actually been able to demonstrate how the brain of a child with ADHD differs from a control subject. One of the earliest and most widely known research studies was published in 1990, but since that time studies at the National Institute of Health, and elsewhere, have continued to refine the neurobiological basis of the disorder. If anything, research has become more specific in refining our knowledge about ADHD. Some of the basic neurobiological problems noted in children with ADHD are: differences in blood flow to certain regions of the brain, neurotransmitter dysfunction (dopamine and norepinephrine), and possible anatomic findings (smaller basal ganglia). The important feature here is not to learn neurology, but to accept the fact that children who are properly diagnosed have basic wiring differences that are affecting their behavior. To insinuate that a student can simply control him or herself, or turn misbehavior off or on, is to have a limited understanding about what constitutes ADHD. It is extremely typical for ADHD students to suffer from "performance inconsistency". This on again, off again phenomenon can be very frustrating for teachers and parents. However, to penalize a child for doing something well once, by insisting they should always be able to perform at that level is very unfair. Children with ADHD struggle in this area and quite often are victimized by their own successes. This is also true for children with a host of different learning disabilities.

Current Political Trends

Politics continue and always will. In 1999 the state of Colorado Board of Education passed a resolution, which asked school personnel to use academic solutions to resolve problems with behavior, attention and learning, instead of recommending psychotropic drugs. Similar resolutions have been passed in Connecticut, California, Texas and Georgia among other states. Obviously this reflects the much needed goal of using greater precision and restraint in making a diagnosis of ADHD, as well as considering all available options for treatment. This zeal for prescribing medication is not apparent among all teachers or school districts. Ultimately it is the medical professionals who prescribe medications, and it is their obligation to work with children and families to use medication appropriately. Although medications have clearly been over prescribed for ADHD, there are still children who greatly benefit from medication for their ADHD. The recently published and highly regarded MTA study demonstrated the clinical benefit of medication in treating children with ADHD. This study compared children who received counseling only, medication only, or medication and counseling. The group of children who did the best was those who received medication only. This study is ongoing and will continue to produce new data to help us in understanding what works best for children with ADHD.

Difference of opinion should and will always exist. Even though, the overwhelming body of scientific research today demonstrates the value of using medication in a child with ADHD this does not mean that every child will respond to medication. In some cases side effects interfere more with a student's functioning without enough improvement to merit the use of a drug. All of these are issues a good professional will work on and discuss with the family of a child with ADHD. The question of proper diagnosis will always exist, and professional organizations as well as parents and teachers have a role to play in monitoring how children are labeled.

ADHD A Different Perception

There are other authors and researchers that have advocated an entirely different view of ADHD. One of the more prominent is Thomm Hartman who in his book, ADD A Different Perception opened the door to debate about how we view ADHD globally. Perhaps ADHD is not itself a disorder, but a description of traits found among the earlier societies in the hunters and warriors. In his view, ADHD may in fact be a collection of skills and predilections that were advantageous at a different time in human history. With the advent of an agricultural society these traits are no longer advantageous. It is a different set of skills that makes you a good hunter vs. a good farmer. The ADHD traits, which served ancient hunter-gather societies, cannot serve the same purpose in modern agrarian societies. Numerous other authors in different fields ranging from psychology to cultural anthropology have since made this and similar arguments. These authors have speculated that ADHD is not so much a disorder as a human survival trait, which although it may not carry the same benefits in today's society it still has the potential to positively impact creativity, entrepreneurship, and ingenuity. This viewpoint may not be accepted in to the body of mainstream scientific literature, but it is thought provoking nonetheless.

The Soup can under pressure

We cannot ignore the fact that as school funding declines, and demands placed on teachers to prepare their students for standardized tests increases, that there is a diminished tolerance for children with learning differences. The traits seen in a child with ADHD or other "learning disorders" become an inconvenience in the classroom and disruptive of a tight schedule necessary to prepare children for standardized achievement tests. We must be as objective as possible in making or suggesting the diagnosis of ADHD. There is the real danger of implicating a disorder when it is the child's learning style and temperament, and a teachers teaching style that are at odds. We must resist the tendency to view every child who doesn't fit in as having a "disorder" or "diagnosis". There will always be those children who walk to the beat of a different drum.

The history of the Disorder

Over the years the diagnosis of ADHD has been refined. Experts in the field of ADHD cite literary references dating back to Shakespeare which describe characters with

features characteristic of ADHD (Fidgety Phil). In 1902 an English physician, George Still, made the first medical description of what we now call ADHD. Dr. Still's initial descriptions were followed years later by similar descriptions of children. In 1918 there was an Encephalitis epidemic in this country, after which the concept of the brain injured child syndrome developed. Numerous recovered children with various degrees of impairment were found to suffer from some of the now classic symptoms of ADHD. This is where the initial idea of "minimal brain" damage came from. The names continued to change over the years: minimal brain dysfunction 1950's, hyperkinetic disorder of childhood, ADD, and ultimately ADHD with different subtypes the term in use today.

What are the main symptoms of ADHD?

The hallmark symptoms are: inattention, impulsivity, and hyperactivity. Current research is beginning to suggest that the disorder has less to do with attention than it does with behavioral inhibition. This view is that ADHD is primarily a "developmental problem of self-control". Attention is not the problem per se, and may actually play a more minor role than previously thought, when the disorder was first named. We take for granted now that ADHD is not just a disorder where attention is lacking. Research has gone so far as to anatomically locate the main impairments of ADHD in the frontal lobes of the brain. This is the area where the "executive function" skills are located. The executive functions are those brain processes, which are the overall managers of all of our goal directed activities.

The Observable Phenomena

To this day controversy continues regarding the key features of ADHD. Along with refinement of the diagnosis into the different subtypes has come debate about the true nature of the disorder itself. One of the leading researchers in the field Dr. Russell A. Barkley has recently proposed that ADHD has less to do with attention and more to do with a "developmental problem of self-control". In fact deficits of attention may not even be universal in the disorder. What about that behaviorally disruptive impulsive child in the classroom, who can sit and attend when the activity has a high degree of interest for him or her (computer based learning game, hands on project etc)? Is attention really a key feature describing their disability? Parents would often wonder when their disruptive ADHD child can sit and hyper focus on a Gameboy or computer program for hours on end. According to Dr. Barkley "ADHD is a developmental disorder of behavioral inhibition that impairs the development of effective self regulation (executive functioning) and is not, as its name implies, chiefly a disorder of attention."

A paradigm shift may be underway here. In fact Dr. Barkley thinks those children who simply can't focus (ADHD Inattentive subtype) may comprise an entirely different disorder all together. Often these children have no behavioral difficulties and may be socially well integrated but "space out" for their academics and can't sustain their attention. Often they have little or nothing in common on the surface with their impulsive and hyperactive ADHD cousins. ADHD is not just a disorder of attention, and in spite of

the name other features of the disorder may drive the impairments from which a child suffers.

There is a well known Developmental Pediatrician who does not subscribe to the use of the label "ADHD", Dr. Mel Levine. He writes: "Sometimes it is difficult to decide whether a particular child's brain is "disabled" or "highly specialized"…It is only during childhood that a young person is expected to be reasonably adept at everything. That expectation may discriminate against children who have uneven abilities. Furthermore, it may sometimes cause variation to be confused with deviation. So it is that some of the children who suffer from significant neurodevelopmental dysfunctions may ultimately perform very well in life when they are permitted to practice their "specialties", to pursue the areas where their abilities best serve them. In the adult world such specialization is not only encouraged by the way jobs are organized, but is also highly desirable and likely to increase the chances for success." (Educational Care)

What about the other big "D"?

The Pervasive Developmental Disorders are another large heterogeneous group of learning and behavioral disorders that are increasing in number. Here terminology has become very confusing. There are many professionals using the specific diagnostic terms differently, as well as creating new categories of disorders that do not actually exist in the medical literature. As a group the Pervasive Developmental Disorders include the following:

1. PDD- NOS: Pervasive Developmental Disorder Not Otherwise Specified
2. Autistic Disorder
3. Aspergers Disorder
4. Rett's Disorder
5. Childhood Disintegrative Disorder

The last two disorders will not be discussed here. However all of the disorders share certain common features. All of the disorders describe individuals with significant impairments in:

Social interaction
Communication
Stereotyped or repetitive behaviors

Some confusion has arisen as professionals have used the term PDD as a diagnosis when it is not. PDD's are a category which includes the five disorders listed. Professionals have used the term PDD as shorthand for PDD-NOS, but the distinctions are important when trying to understand the differences between these overlapping disorders.

All of the PDD's are present by age three and share some features. All of the individuals in this group share difficulties in relating to others. There are significant differences

however in the degree and severity of impairment. The term itself describes a pervasive developmental disorder, as such this does not include individual unless their degree of impairment is both pervasive, throughout all areas of their lives and severe in how it impacts functioning and relationships. Once again as we noted in our discussion of ADHD the diagnosis is based upon descriptions of behavior (except in Retts syndrome where we have a genetic marker). For each diagnosis there is a description of qualifying criteria. We will look at each disorder, and then make some generalizations about the use of the labels.

There are a variety of standardized tests or screening tools professionals use to diagnose any of the PDD's. A complete assessment should include the following: complete medical evaluation by a Pediatrician or Neurologist, interviews with teachers and caregivers, direct observations of behavior, psychological and educational assessments, a thorough communication assessment by a speech and language pathologist, and the use of specific rating scales. The most well known behavior rating scales include: the CARS (Childhood Autism Rating Scale), GARS, and ADOS (Autism Diagnostic Observation Scales). Many of the "autistic" behaviors however, are noted through direct observation, preferably in a natural setting (home or the child's preschool). Intelligence testing, in the form of an IQ test, is not required to make the diagnosis of autism.

Autistic Disorder is also called early infantile autism or childhood autism is the classical picture of autism most of us are familiar with. The criteria for this diagnosis include the following:

1. Qualitative impairment in social interaction - This encompasses the lack of non-verbal communications; inability to develop peer relationships appropriate for one's age; a lack of spontaneous sharing with others; a lack of socio-emotional reciprocity.
2. Qualitative impairment communication - This encompasses a delay or complete lack of spoken language; difficulty sustaining a conversation; repetitive use of non-meaningful language (echolalia); limited imaginative skills.
3. Restrictied repetitive and stereotyped areas of interest and activity - preoccupations, inflexibility, obsessions with the parts of objects, and stereotypical motor mannerisms (flapping, twisting etc).

Individuals with Autism can have a range of intellectual abilities ranging from severe mental retardation to intellectually superior IQ. Because of the heterogeneity of children with autism the term autistic spectrum disorder has become common. This refers to the broad range of children with autistic like disorders ranging from PDD-NOS to Aspergers Disorder. It connotes the broad range of abilities and disabilities one can see amongst this population of individuals.

Autism is more common in boys than in girls, about four to one; however as with most developmental disabilities it is probably under diagnosed in girls. At the higher functioning end of the spectrum autism can be difficult to differentiate from Asperger's

Disorder, PDD-NOS, Non-Verbal Learning Disorder or Semantic and Pragmatic Speech Delay.

PDD-NOS has become an increasingly popular diagnostic label as it describes an individual with some of the more classical features of autism, but to a milder degree, and not all of the criteria. Some professionals have used other terms, such as atypical autism or simply PDD, to describe PDD-NOS, causing some confusion. Also young children without clear features of any one disorder, or who possess a rapidly evolving profile, are often placed in this category as professionals are reluctant to label them "autistic". To add to the confusion some school districts do not recognize PDD-NOS as a diagnostic category and lump these individuals under the category of Autism.

In truth PDD-NOS does differ from autism in being less severe in its presentation. However, individuals with PDD-NOS can still be significantly impacted and have limited intellectual capacity. The lines between autism and PDD-NOS are blurry, and a diagnosis may simply reflects the bias of the professional making that diagnosis. The important fact is that the interventions are similar regardless of the diagnostic label. For all of the PDD's intensive therapeutic interventions (speech, occupational, and physical therapy), structured educational programs, and different varieties of behavioral and emotional support are all necessary parts of a comprehensive program.

Summary

I hope this introduction to the alphabet soup of some of the more common developmental problems of childhood helps you to navigate your way to create the most successful therapeutic program for your child. It provides you with a glimpse of the depth and complexity in which I view your children and their struggles.