

Your Child's Assessment and Diagnosis

A Guide for Parents

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Parents first become aware of learning or developmental differences at a range of times. Some parents see something "different" in infancy when a baby seems unresponsive and uncommunicative. For another parent, the first sign of trouble may be when an 18-year-old who has always seemed endearingly disorganized comes home from college in the middle of their first semester because they can't handle the demands for independence. Many encounter the first warning signs somewhere in between: the five-year-old who can't sit still with the other kindergartners at story time; the seven-year-old struggling to learn to read; or the 13-year-old who is left behind socially in the maelstrom of middle school.

What all of these children have in common is that their development has, in some respect, diverged from that of peers. Or has it? Aren't there just some five-year-olds who are bursting with physical energy? Isn't it true that some babies are tentative and reticent? Does "failure" to assimilate to the social culture of middle school indicate that it is the *child* who has a problem? Is a child intense and mercurial, or anxious and depressed? So here is your first question: "*is there a problem at all?*" This question will divide couples and families for years. One parent may be convinced that there is a problem and accuse the other of being "in

denial." The partner may insist that there is not a problem, and call the other a "hysterical." How do we go answering this question?

A Pragmatic View of Diagnosis

Let's first spend a few moments with this basic question: "*is there a problem?*" Should you, as a parent, start down this road of assessment and diagnosis for your child? If you are struggling with this question, I suggest that one useful view may be a very pragmatic one: *is the way that my child is thinking/learning/behaving working for him or her?*

This question is deceptively simple. There are times when things are obviously not working the right way. A child may clearly not be making developmental progress; this is a child who is simply not mastering the skills that they need to at their stage of development (for instance, not speaking as a toddler, not relating to other kids in pre-school; or not reading as a elementary school student). In other cases, a child is suffering emotionally and there is an imperative to find out why. And in still other cases, it is others who are doing the suffering...these are cases of children who are acting out and hurting those around them, sometimes physically but also verbally and emotionally. These are all kids who clearly need evaluation to determine what the underlying problem is.

But what about more subtle cases? The child who is not obviously in deep pain, is not egregiously acting out, and is not grossly failing to meet milestones...how do

we decide what they need? In these cases, I think that it is very helpful to think about the concept of efficiency. Imagine a machine that makes ketchup. You put tomatoes in one end, and bottles of ketchup come out the other. You expect that, say, 10 tomatoes will make one bottle of ketchup. And then one day you observe that, wait a minute, you are pouring in dozens of tomatoes at one end, but only two or three bottles of ketchup are coming out the other!

I perceive many kids' processing problems as being like the faulty ketchup machine. These are kids who put in effort – academic effort, social effort, effort to control their own behavior and mood – and the payoff is meager. They are expending disproportionate effort for the results. They try hard in school, but their grades don't reflect it. They are kind and well meaning socially, but don't click with any of the other kids. They strive to be “good”, but their anger keeps getting the better of them. These kids, like the inefficient ketchup machine, are not “broken”...they are “working”, they are manufacturing “ketchup”...but at great cost. And for many of them, the ultimate result will be what it is for the inefficient machine – overheating and meltdown. When you see your child displaying this asymmetry between effort and outcome, then they need the adults in their life to take a closer look and to diagnose the problem.

Assessment: Who to see?

If you have decided to seek out professional help in determining whether there is a learning or developmental issue (and if so, what it is), then there are a range of options for you. The first question you will face is: “where should I take my child?” Assessment of learning and developmental functioning is carried out in a range of ways by members of a wide variety of professions. Pediatricians and family doctors monitor a child’s developmental milestones within the context of well-child visits. When development is disrupted dramatically they will often screen for an underlying medical cause and may refer to a medical specialist – such as a neurologist – for additional medical assessment. This type of screening may identify the rare major neurological anomaly, but it is important to understand that there are many neurologically-based processing problems which are not evident on medical evaluation. As dramatic and impressive as modern neuroimaging is, it is not yet used to diagnosis most neurodevelopmental disorders. A child with ADHD, or dyslexia, or Asperger’s Syndrome will likely have a normal neurological examination and a normal MRI. Therefore, a medical screening, whether by the primary care doctor or by a specialist, is what we would call “specific but not sensitive”. This means that, if something is found, it should

be taken very seriously...but the reverse is not necessarily true; the lack of a finding does not guarantee that all is well.

It is also important to recognize that the training for many, if not most, primary care physicians does not include substantial exposure to learning or developmental needs. Medical education, understandably, focuses on medical diagnosis and disorder. It is often the case, therefore, that more subtle developmental issues will not quickly be recognized by a child's primary care doctor. Moreover, from the primary care doctor's perspective, the patient with a true learning or developmental problem is a little but like a needle in a haystack! These professionals see so many families, and of these a very large proportion express some level of concern about their child's development...are they talking on time? Walking on time? Is it normal for them to take awhile to read or to connect with other kids? The vast majority of the time the child is ultimately fine. Picking out the one case of true developmental atypicality from among the pool of concerned parents is a monumental task for a pediatrician, regardless of their level of training. This is particularly the case given the very limited amount of time which medical systems and insurers commonly allot for well child visits!

So your child's primary care doctor is a good place to start, but it is also often a good idea to go on to look further. Another venue for seeking help is your local school. Neurodevelopmental disorders span the border between medicine and

education. Within the public school system there are generally special education professionals whose job it is to identify children with these challenges. School psychologists assess intellectual functioning (more on that later), and also often screen for emotional problems and various processing problems. Occupational therapists and physical therapists assess sensory and motor functioning. Speech pathologists look at speech and oral language. Special educators test academic skills. These professionals are immersed, day in and day out, in the school community and as such they often have a strong sense for children who are struggling. The opportunity to access these professionals in the public schools for assessment (and sometimes for treatment) represents an enormously positive and progressive attitude towards education. We, as a society, are saying that we are not going to let struggling children sink in a “survival of the fittest” atmosphere; rather, we are going to invest in identification of vulnerable children and support of their progress.

In my experience, however, parents often voice several concerns with school-based evaluations:

- First, these evaluations tend to be descriptive, but not diagnostic. What I mean by this is that the assessments are measurements to see whether a child has fallen behind in some way. They generally are limited, however, in the degree to which they identify underlying causes of lack of progress, and also in the degree to which they make prognoses about the future.

- Second, as noted above, the evaluations are often carried out by several different professionals working within their areas of expertise. The issue which this can create is one of integration – putting all of the pieces of the puzzle together into a cohesive picture of the child that can guide decision making.
- Finally, there is the touchy subject of money (you will find that this will come up again and again throughout this book). In theory, financial considerations are not supposed to play into school district’s decision to assess, or their interpretation of assessment results. They are mandated by the federal government to provide a “free and appropriate public education” to every child, no matter how costly it may be for a child with a disability. In practice, however, this is a heavily underfunded mandate. Typically, the federal government and the states underfund their contributions to these programs. As such, individual cities and towns are faced with explosive costs – particularly in the modern environment, where parents are increasingly aware of developmental syndromes, and where (often expensive) treatments proliferate. The point is that, when the institution responsible for performing an assessment is going to have to pay a large part of the bill for any problems it finds, there is a built in conflict of interest.

There is also the option of having a private evaluation. Depending on the type of concern you have, you could choose to see a wide variety of professionals. This includes all of the types of professionals mentioned above; many speech language pathologists, occupational therapists, and psychologists all practice outside of the schools as well.

There are also professionals such as myself who are called neuropsychologists. Neuropsychology is a specialized field within clinical psychology which deals with neurologically-based processing issues. It began with the study of adults with different neurological problems – veterans with brain injuries, for instance. In more recent years, child neuropsychologists have also become interested in studying and helping children who learn and develop differently. The neuropsychological evaluation is a detailed process which often brings subtle learning issues to light, and the knowledge that we now have about memory, organization, self-control, and a range of other areas is often very useful in helping parents and teachers to understand the problems and needs of children with learning and developmental issues.

In the spirit of full disclosure I should say that independent evaluation is the area in which I have built my career. In performing these evaluations I have the luxury of being able to make recommendations without financial considerations; I can

simply think about what is best for the child. On the other hand, having an evaluation done privately presents its own challenges. Often, aspects of developmental evaluations are classified by insurance companies as educational in nature, or otherwise as “not medically necessary,” potentially leaving you with the bill. Moreover, financial incentives may run the other way. If you are being seen in a for-profit, entrepreneurial health care setting, problems identified may lead to the provision of costly treatments by the same agency, and there may be an incentive to over-pathologize in order to drum up business.

At the end of the day, when you are deciding where an evaluation should be done and by whom, I think that there are several key considerations. Cost is an obvious one, as is the professional’s level of experience...how many evaluations do they perform per year? Are they exclusively in pediatrics, or are children the minority of their practice? It’s hard to overstate the value of experience in building a professional’s judgment.

You also must consider the person’s familiarity with the system with which you want them to interact. For instance, if your primary concerns about your child pertain to reading, and you want an evaluator to think about how to advise the school and even perhaps to come to the school to consult, then you may be frustrated going to a major medical center for the evaluation. The worlds of institutional health care and education are very different and don’t always mesh

well; for instance, I know many professionals who work in great hospitals who literally *can't* go to a patient's school to consult because there is no applicable medical billing code with which to bill for the time. Conversely, if your child has a neurological disorder and you hope to get help with issues such as walking and vision, a medical center may be just the place, whereas a community based practitioner may have limited resources to offer.

On the other hand, I think that the evaluator's professional and academic credentials are often overvalued. I've seen many people with impressive resumes and academic positions who are pretty poor as clinicians. Sometimes it is because they would rather be doing research than engaged in messy clinical work. Sometimes it is because their reputation is built around expertise in one particular condition, and they see everything through that lens (for instance, an expert in ADHD who sees every struggling child as having that diagnosis.) Regardless, don't be "wowed" just because someone has lots of letters after their name, or is on staff at an impressive hospital or university.

You shouldn't be shy about quizzing a professional who you are considering for the job of evaluating your child. You also should feel comfortable going around to meet several different people before you settle on one. If you are not comfortable with the person who is lined up to do the evaluation you should look elsewhere. One great question to ask a prospective evaluator is: "*why do you do this sort of*

work?” or “*what got you into this field?*” Some parents recently asked me this in an initial interview, and I think that they really got to know about who I am in a way that most other parents don’t. A professional’s response to that question tells you not only about their background, but also about their professional commitment, their emotional connection to the work, and their personality – all factors that will help you know if they are a good match for your child and their needs.

I mentioned, in the introduction, that this is a field in which it is critical that parents develop a strong understanding of their own child’s profile and needs. As you have likely discovered, this is an ongoing process. So another important question to ask is: *will the evaluator be available and responsive on an ongoing basis?* If you go into a radiology clinic for an x-ray, it is unlikely that you are going to need to have an ongoing dialogue with the doctor in the months and years to come. You will get your result and be on your way. Not so with developmental or neuropsychological assessment. As your child grows older, you may very well see behaviors or encounter learning challenges which you will want to bring back to the evaluator. You will wonder whether a particular issue is connected to the diagnosis that they gave you, or whether it is something different? Is a new observation something you should be concerned about, or does it seem to be as expected? Moreover, as you try different approaches to helping your child, you may want to go back to the evaluator to get some insight into whether the

interventions are working. For all of these reasons, it is crucial that you work with someone who will be responsive to you in the long term. Are they readily reachable by phone? Do they welcome email from clients? How long does it take to get an appointment to consult with them in an urgent situation?

There is a very specific question which few parents ask when they take their child to an evaluator: *how long does it take to get a written report of the evaluation results and recommendations?* This may seem like a very mundane issue, but it's not. The written report is likely to be much more important to you than you realize at the outset. For instance, if you are hoping to share the results of the evaluation with your child's school and perhaps to amend their programming, it is almost certain that you will need the full report in order to initiate any action. Yet many evaluators get into the bad habit of falling behind in their writing, and as a result families have to wait for months – sometimes many months – until they get a written document. Imagine being told by a clinician that your child critically needs certain services, but that you need to wait to get their written recommendation for those services to be put in place. Now imagine that you wait three or four – or eleven or twelve – months, and no report is forthcoming. It's a position which families too often find themselves in and it hamstringing them as they go about trying to get their child's needs met. So it is very important to understand a particular evaluator's turn-around time before you commit to working with them.

Finally, as noted above, one key consideration that parents often don't think about is the financial structure of the system in which an evaluation is being performed...public school, private clinic, teaching hospital, etc. In every case, there are financial incentives in play. We don't like to think of our doctors and our schools as taking money into account, particularly when it comes to our children, but it is inescapable and therefore must be understood. Is there a bias to do less? To do more? To exaggerate problems? To minimize them? My point here is not that doctors and school administrators are dishonest or only out for their own gain. Few people go into education or child development to get rich (and any who do are quickly disappointed.) The vast majority of the professionals you encounter in these professions are good people who care deeply about kids. My point is that every single one of us operates within an economic structure, and understanding that structure will help you to be a better consumer of the information that comes out of it.

What is done in an assessment?

First, it is important to make a distinction between “testing” and the broader concept of assessment. Tests are tools which we use to understand the way someone thinks, feels, or behaves. They are only one component of the assessment – more on that later. For now, let's talk about the different kinds of tests.

Questionnaires

Parents hate filling out questionnaires. I know this because I ask them to do it all the time. These are generally checklists which ask you to rate how often a behavior or problem occurs, or how much of a problem something is for your child. I think that the key reason that people often feel anxious about filling these out is that they sense that their subjective perceptions and judgments are being calcified into numbers that will be interpreted as objective. This sense is absolutely right. Once we convert something into a number it somehow seems much more real. If you come into my office and tell me that your kid seems really anxious, then OK, that is your perception. If you fill out a questionnaire asking questions about anxiety and check off every symptom, and I come back to you and say that your report of your child's worrying is at the 98th percentile...whoa, that suddenly seems so much more real and scientific! Of course, I have not really done anything new...I have not even given you an independent opinion about your child's anxiety. All I have done is converted your own report into a numeric form.

Questionnaires are useful as yardsticks. They allow us to compare your perceptions of your child's emotional state, or behaviors, or organizational skills, to those of other parents of same age children. Talk to any parent of an eight year old boy on the street, and they will tell you that their kid sometimes disobeys, seems inattentive, has tantrums, etc. What you want to know is, does your experience diverge from that baseline? This is the question that the questionnaire

can help to answer. It is important to remember, however, that it does not tell you “why”, only “how much”. It is a yardstick, not an x-ray.

Performance Based Tests

This is any test for which we bring the child into the office and actually measure something that they do. A simple example would be a measure of reading speed; we can ask a child to read out loud and time them. Then, we can compare their time to data from a large sample of other children of the same age reading the same passage to see how they compare.

One obvious question is: why use performance based tests at all? Why bring a child into the office to test reading speed? Couldn't we just observe a class at school and note who seems to be the slowest reader? The answer is that most behaviors, such as a child's performance in a reading class, are “overdetermined.” This means that, in any given situation, you are using multiple psychological functions. At this moment, you are reading this page. To do this successfully, you need to use your vision to see the letters, your language skills to understand the words, your working (short term) memory to integrate these words with those earlier in the chapter, and your long term memory to integrate this material with what you already think and know. You have to be able to sustain attention, even if there is something else going on wherever you are. You need to be in a calm enough emotional state to settle down and read. When you look at it this way, a

“reading problem” is a very general term. There are so many different things that can go wrong and lead to reading difficulty. Any one of the links in the chain can be weak...each link must be assessed.

Here is another example. Imagine that you go out to your car in the morning, and it won't start. If you want to do something about it, you have to understand why it won't turn over. So you need to look under the hood – you need to look at each potential culprit, one at a time, to see who isn't doing their job...is it the spark plugs? The battery? It's only after eliminating different possibilities that you will have some sense of what to do to make the car run.

Performance based testing is like looking under the hood of the car. You look at each link in the chain, one at a time, to see which are contributing to the problem. Take another example...a child in the middle school years who has a really hard time with written composition. There are at least three things going on when a child sits down to write: 1) they need to use their language skills to formulate their thoughts; 2) they need to use their organizational skills (often referred to as a component of “executive functioning”) to plan and organize their output; and 3) they need motor skills to produce legible handwriting.

So when a child has a problem with writing, how do we differentiate these components? Well, we would want to administer a motor test that has minimal

organizational and linguistic demands. And we would want to administer a language test with minimal motor demands. And a visually-based test of organization that does not have language demands. By doing this again and again, over the course of a whole battery of tests, we can begin to pick up on the “thread” that runs through the child’s difficulties – language, organization, motor skills, etc. What is the factor that pops up again and again, consistently acting as a troublemaker regardless of which other skills are paired with it in a task?

There are many different kinds of performance based tests:

- Tests of memory, assessing all kinds of approaches to learning...visual memory, verbal memory, rote memorization, contextual learning, incidental learning, etc.
- Tests of visual-spatial perception and processing.
- Tests of all different aspects of language...verbal expression, language comprehension, articulation, etc.
- Tests of motor skills...hand-eye coordination, fine motor speed, etc.
- Tests of organization, attention, inhibition, and abstract thinking (sometimes referred to in aggregate as “executive functions”).
- Tests of emotional functioning – depression, anxiety, anger, aggressiveness – as well as broader tests of personality.
- Tests of academic skills.

Of all of the performance-based tests, the one which is best known and which has the most cultural and emotional baggage tied to it is the IQ test. This is a type of test which creates more anxiety and more misunderstanding than any other. For this reason, the topic of IQ testing deserves some special consideration here.

IQ Tests

There are few other areas of psychology which lead to more misperceptions and misunderstandings than IQ testing. Let me begin by offering my personal definition of what an IQ test measures: it measures a diverse group of skills considered to be pre-requisite for learning, particularly in a traditional classroom setting. I know that sounds a little abstract and nebulous, so I'm going to make an analogy to try to make it clearer.

Imagine that we wanted to be able to assess athletic ability in children. We wanted to identify which kids were really ready to take off in sports, and also which ones should get remedial help. We would begin by realizing that "athleticism" is a pretty broad concept, and involves lots of different skills. We could make a list of the skills that go into being a good athlete: speed, endurance, eye-hand coordination, strength, etc. Next, we would create objective tests for each of those skills...maybe someone's time on the hundred yard dash for speed, the amount they are able to hoist in a deadlift for strength, etc. Once we had created this series of "subtests" we would take them on the road, measuring the performance of lots

of different kids at different ages to see what is normal. Then, once we had that data (our “norms”), we would be ready to go to work. We could apply our series of tests to a particular child, assessing their performance on each one. We could assign a specific value to their performance on each subtest...speed at the 45th percentile, strength at the 75th percentile, etc. Finally, if we wanted to, we could average the child’s performance on all of the subtests together into one big number...the Athleticism Quotient, or AQ. For the sake of simplicity, I might decide to use a scale wherein the average AQ is arbitrarily called 100, with lower scores representing poorer performance and higher scores better performance.

So what do you think of the AQ? Will it predict athleticism? I would think that it would do a reasonably good job of that. Kids who do the best on these tests will be the ones most likely to be the baseball and football stars of tomorrow. But there are a couple of finer points that should also be clear about the AQ:

- It is an average. Two kids may have the same AQ, but get there in totally different ways. For instance, one boy may have an AQ of 110 because his very high strength score more than balances out a weaker performance on a measure of speed. Another boy may also have an AQ of 110 but have a low score on the strength subtest which is obscured by very high scores on measures of eye-hand coordination and speed. Is this important? Are these two boys athletically the same, even with the same AQ? Of course not, and

we need to understand the fine grained composition of their profile, not just the aggregate number.

- It only pertains to skills within its scope. A high AQ may indicate strong athletic potential, but does it tell you who is going to be a good accountant? Who has the best social skills? Who will be a really creative artist? Needless to say, it will not. It measures only what it measures; it is not the whole person.
- It is not immutable. What if a kid has a low AQ? Does that mean they are hopeless as an athlete? If I see a kid with an AQ of 85, my first question will be “what is dragging it down?” Perhaps they did particularly poorly on the strength subtest. What is the proper response? Should we just put the kid on the bench and tell them not to try, or should we develop a remedial program of strength training to make them as strong as their bodies will permit?

The above points may seem obvious, but they are frequently confusing as applied to IQ tests. IQ is the same as AQ, except that we are trying to measure preparedness for academic success rather than athletic success. Instead of subtests assessing speed and strength, we have subtests assessing pattern recognition and vocabulary knowledge. And people make the above errors all the time...they view IQ as a holistic, universal quality, as indicating and predicting everything about a child, and as representing a core, immutable quantity. These misconceptions all

too often lead us to sell a child short, to expect too little because a low score on a test “tells us” that there is little potential. This is a point which we will return to when we begin to think about treatments.

Judging the validity of your child’s testing

As we start to think about what the IQ score means, we beginning to explore the issue of test validity. Is an IQ test valid? That question is asked all the time and there is not just one simple answer. We need to ask: *valid for what?* Is it a valid predictor of athletic skill? No, absolutely not. Is it a valid predictor of preparedness for learning in a typical elementary school classroom? Maybe...but you need to ask a few more questions about validity when we are confronted with your child’s test score. These questions apply not only to IQ testing, but to any performance based test.

- First, do we have a good sample? Remember, these tests are sampling behavior, not bodily tissue. If a child needs a blood test, we can hold him down while the nurse takes it from him, kicking and screaming. It will still be a good sample, whether he likes it or not. The same is not true of behavior. To have a good sample of behavior, we need to have a child who is cooperative and engaged. A child who does not want to participate, who is not trying hard, who is tired or sick...any of these factors will undermine the validity of the sample, and give you bad data. Similarly, we need to consider the environment. On several occasions construction crews have

decided to demolish structures outside of the office where I work. Clearly, I am not going to be able to get a good sample of thinking and behavior from a child who is distracted by a jackhammer outside of the window! This is an extreme example, but lesser versions happen all the time. In many hospitals the room dedicated to testing is small, windowless, and poorly ventilated. It may not lend itself to focused, sustained effort. So ask: *what was my child's state when taking this test? What were the environmental circumstances? Is this a valid sample of their behavior?*

- Second, what is the reference sample? As I described above, the process of testing involves comparing a child's performance to a normative group of peers. "Peers" is the sticky word here. Is it right to compare a child in the northwestern US to a child in the southeast, where the culture, language, and educational systems differ? Is it valid to compare a boy's performance on a math test to a girl's? What about race and ethnicity? Should we be comparing children to samples of other children from similar backgrounds, or to a more mixed sample? These sorts of questions have led to endless, heated, politically charged debates that stretch far beyond the scope of this book. The question for you is this: *who is my child being compared to in generating these test scores? Does this seem to be a fair comparison group?*
- Finally, we need to ask what precisely it is that is being tested. This may seem like an obvious one, but consider this example: I see many children in

my practice who struggle with writing at home and in school, oftentimes to an extreme degree. When tested, however, they may generate average scores on a writing test. What is going on here? Well, the problem is that we are not being precise enough in stating what is being tested. “Writing” is too broad of a term. Some writing tests focus on the motor aspect of writing, the ability to control the pencil. Others focus on writing speed, or on grammar and sentence structure. Others tap into a child’s ability to plan and formulate a response to an open ended question. So a child who has writing difficulties as a result of disorganization may do great on a “writing test” focusing on spelling and sentence construction. The question that you need to ask is: *what exactly was assessed here? What were the performance demands? And most critically: how do these performance demands mirror those of his day to day life?* A child in middle school is being asked to produce large writing samples in response to open ended questions. There is a huge organizational demand. A writing test which only looks at grammar and spelling is not a valid or helpful writing test for this child.

Labeling and Diagnosis

I began this chapter by talking about situations in which parents are asking whether there is a problem. Various assessment techniques in various settings can be used to answer this question. Now, let’s move on to situations in which we are

not asking “whether” there is a problem, but rather “what” is the problem? In other words, we are trying to come up with the right diagnosis.

One key point here is that, in most cases, diagnosis is integrative. There is not one single test or questionnaire for ADHD, or autism, or dyslexia. The diagnosis is the result of the synthesis of many different tests, the “configuration” which the data produces. I alluded to this above, when I wrote about the “thread” running through the body of data. Moreover, as I mentioned above, the test scores are only one piece of the evaluation. The data has to be looked at in combination with the child’s history and the examiner’s observations. Often, the numbers don’t tell the whole story. A child may perform poorly on testing, but interacting with them and reviewing their achievements it may become obvious that they are able to compensate for their challenges remarkably well. Another child may have relatively normal test scores, but their “minor” challenges may have a major impact that is only apparent when one puts the tests aside to listen to their story. These are all reasons why there is so often disagreement with respect to diagnosis, and why diagnostics in this field are probably as much of an art as a science.

It is also critical to understand that there are several very different kinds of diagnoses out there when it comes to learning and developmental disorders. I am going to call these “clinical” diagnoses and “relative” diagnoses. Let me explain how I define the two.

We need to remember that any problem that a child is having occurs within a particular environment...let's say, a 21st century mainstream American elementary school. It is extremely useful to ask yourself: *is this problem specific to this environment, or would it manifest itself in any time and place?*

Some of the children who come into my office are clearly displaying neurodevelopmental problems which would be disabling for them in any environment. They experience basic challenges in learning, in reasoning, in perceiving or remembering. These challenges make it extremely difficult for them to adapt. This is the case in the classroom, but it would equally well be the case in a dramatically different environment – say, for instance, if they were trying to learn how to work the land and to solve agricultural challenges on a farm 200 years ago. For these children, it makes sense to view the disability as being *absolute*; it is a clinical disability. Their brains are not fully carrying out the function they are intended to, in the same way that a diabetic's pancreas is not properly fulfilling its evolutionary function of producing insulin.

Contrast this scenario with a child whose problems in adaptation are very specific. Perhaps this is a child who is socially engaging and who seems bright when he has the chance to work with his hands or to perform on the sports field. In the 2nd grade classroom, however, he is having a horrible time making the connection

between the spoken word and those little squiggles on the page. Moreover, he wants to move! Sitting behind a desk for hours each day is torture for him, and his teacher sees the resulting fidgetiness as disruptive to the class. For this child, the disability may be viewed as *relative*. There is a mismatch between the demands of the particular environment and this child's innate temperament and processing style. The environment demands physical stillness and sustained auditory attention; it demands close discernment of speech sounds and fluent connection of those sounds with visual symbols. Think about how idiosyncratic these demands are! If this child lived in another time and place, indeed in most other times and places, would his difficulty in meeting these demands be so problematic? Probably not; in fact, these demands would probably not be made at all. He might be an energetic and attentive farmer, or an engaging and charismatic merchant. As a student in an early 21st century classroom, however, he is a square peg in a round hole.

So what should we think about the child with this sort of a "relative" disability? Should we ignore it or minimize it? No, the reality is that this child requires intensive intervention in order to succeed, as does the first child with the clinical disability. This child does live in a society in which certain demands are being made, and it will be devastating if he is unable to meet these demands. The point is that we need to be very careful about where we "locate" the disability. The disability is found in the interaction, the "fit", between this child and his

environment. We want to be very clear about this, because if we are not it will be too easy to locate the disability as solely within the child, and to send him (and you) the message that he is less capable than he really is, that there is an interior pathology or defect, and in so doing to impose false limitations.

Alphabet Soup

There is a well known parable with which many of you are probably familiar. It is about six blind men who are asked to determine what an elephant looked like by feeling different parts of the elephant's body. The blind man who feels a leg says the elephant is like a pillar; the one who feels the tail says the elephant is like a rope; the one who feels the trunk says the elephant is like a tree branch; the one who feels the ear says the elephant is like a fan; the one who feels the belly says the elephant is like a wall; and the one who feels the tusk says the elephant is like a solid pipe. The lesson, of course is that all of them are right. They were all interpreting the elephant differently because each one touched a different part of the elephant.

I often think of this parable when certain diagnostic questions are raised. The unfortunate truth is that the field of diagnosis for children with learning and developmental disorders is a mess. If you think about each disorder as an elephant, then the problem is that each one has many different blind men (i.e., professionals from different backgrounds) touching it and they are not talking to each other.

For instance, there is clearly a neurodevelopmental disorder characterized by social skills deficits, an inclination towards accumulation of verbal knowledge and verbal discourse, and often involving a limited range of interests and organizational difficulties. This entity has been studied from a behavioral perspective by professionals from a medical background for many years, beginning with Dr. Hans Asperger, and the disorder resulting from this body of work still bears his name (Asperger's Syndrome). Elsewhere, psychologists interested in learning disabilities have identified a very similar group of children and labeled them as having Nonverbal Learning Disabilities. And, a group of British speech-language pathologists became interested in a similar phenomenon, labeling it Semantic-Pragmatic Language Disorder. Finally, occupational therapists interested in sensory processing will often view these children as presenting with a Sensory Integration Disorder.

What is going on here? Do we have four different diagnoses...or just one, viewed from four different perspectives by professionals who are unwilling or unable to come together and develop an integrated, comprehensive system of neurodevelopmental diagnosis? This is a tremendously complicated question, and it is certainly not reasonable to expect that you as a parent will work out the problems of inter-disciplinary collaboration as part of caring for your child. What you are faced with, however, is the need to sort out an alphabet soup. If your child

is diagnosed with AS, NLD, SID, and S-PLD, what do you do? How do you think about the validity, not only of your child's testing, but of the resulting diagnoses?

What is a valid diagnosis?

In "The Development of Psychopathology" (Guilford Press, 2002) psychologist Bruce Pennington writes: "the basic goals of a nosology are to identify clusters of symptoms that reliably co-occur and identify groups of patients that are homogenous at the level of etiology, pathogenesis, or treatment." So what does this mean? Well, to understand it let's take a made up example of a diagnosis that would not be very useful or valid – Social Skills Disorder of Childhood (SSDC).

Let's say that I, as a psychologist, decide to "discover" and publicize SSDC. I could write a book about the "epidemic" of kids with poor social skills, and I could develop tests to reliably identify it – say, for instance, a parent questionnaire about your child's social behavior and a performance based test assessing their understanding and interpretation of social conventions and their ability to generate solutions to social problems. Now, imagine that your child came to see me for assessment and I gravely told you that he or she had SSDC. The question you will be facing is this: *is SSDC a valid diagnosis?*

My answer to the above question is “no”, and I think that most of you will agree with me. SSDC just seems like something made up, doesn’t it? (of course, it *is* something that I just made up, so that makes sense!) It is useful, however, to ask precisely what is wrong with SSDC because I think that you will find that many of these same problems characterize more respectable diagnostic formulations which you may encounter. Pennington’s definition of what makes for a valid diagnosis is a helpful guide in breaking this down.

First, SSDC will inevitably be comprised of a very heterogeneous group of kids. Put fifteen kids meeting criteria for this “diagnosis” in a room, and they will look very different from each other. Some will be bright, sweet, well meaning kids who are good at a lot of non-social things (like computers) but don’t seem to “get” other people. Others will be kids with entrenched behavioral problems who couldn’t care less about social conventions. Still others will be kids with severe neurological disorders whose difficulty assimilating to social situations is reflective of a general challenge in comprehension and adaptation.

Second, there is no clear causal pathway to SSDC. It is a location with many, many paths leading to it. In other words, being given this diagnosis does not really explain why your child has social skills problems. I don’t only mean this in a “big picture” sense, such as the question of whether the environment or genetics have caused this disorder. We really don’t know that for many of the disorders we see,

and in most cases the answer is a complex combination of the two. Rather, I mean that even though we have a label we still don't know *why* the child is struggling. It's a common misconception that naming a problem explains it, when in fact it easily leads us into circular reasoning ("why does he have such poor social skills? Because he has SSDC. How do we know he has SSDC? His horrible social skills!") So what I mean is that we don't know why this particular child has these difficulties...is it because he is anxious about social situations? Because he doesn't pick up on nonverbal cues? Because he doesn't have the language skills to converse effectively? This imaginary diagnosis doesn't answer these questions...and neither do many of the "real" diagnoses you may encounter.

A diagnosis needs to give us some insight into the causes of the problem; if it does not, then we have the third problem with SSDC: the diagnosis does not help us to determine what will be an effective intervention. At the end of the day, the reason we pursue a diagnosis is not as a matter of academic interest, but because we want insight as to what will make the child's problems better. Now, it is fair to say that we do not always need to understand the ultimate cause of a clinical problem in order to treat it effectively. My doctor has no idea what, in my genes or my environment, caused me to develop Type 1 diabetes in my mid-30's. Nonetheless, he is able to help me to manage it effectively...not because he understands the ultimate cause of the disorder, but because he understands the nuts and bolts of where things are breaking down. If you don't have that, it is going to be very hard

to put together an effective treatment. You need to ask: *does this diagnosis tell me about the inner workings of my child's problem?*

Should you share a diagnosis with your child?

Once you have a diagnosis that you feel is valid we will be talking in the coming chapters about what to do with it, in terms of treatment and advocacy. Now, however, you need to ask the above question, which is both common and exceedingly difficult. I have seen children who are absolutely liberated by the provision of a diagnosis. They have long felt that there is something “wrong” with them, and have felt deeply and painfully alone. To be told that their problems are real, and are known to science, that there are other people like them who have walked down the same path they are on, can be transformative. Indeed, for some children and adolescents the diagnosis is integrated into their identity in a positive way. Some adolescents and adults with Asperger’s Syndrome, for instance, playfully refer to themselves as “Aspies” and create a positive, cohesive culture around their diagnosis.

I often comment to parents that, in the world of children, there tend not to be shades of gray around learning. Few children have backgrounds in neuropsychology or special education. For kids, there is “smart” and there is “stupid”, and the child who struggles is apt to decide that he falls into the latter category. Even if a diagnostic label is not shared with a child, it is often

meaningful to talk with them about their own cognitive profile, to help them to see themselves through a more fine-grained (and forgiving) lens. Helping them to bring together two ideas that seemed to them to be mutually exclusive – for instance, “I am smart” and “I have a hard time with reading,” can be very therapeutic.

On the other hand, I have also seen children who are crushed by their diagnosis. These are often children who have entered into a depression as a result of chronic experiences of frustration and failure, and who have deeply entrenched beliefs about themselves as defective and incapable. One notorious trait of the depressed individual, whether they have a disability or not, is that it is very difficult to break into and modify these self-deprecatory beliefs. Many parents (and therapists) have had the frustrating experience of finding that any evidence introduced which contradicts these beliefs is distorted and discredited. You may tell your child that Dr. Moldover can tell that he is bright even though the way he learns has made it hard for him to read, but a child with depression can often find a way *not* to believe this good news (“Moldover works for my parents, he *has to* tell them I’m smart.”) Dislodging these beliefs is the arduous work of psychotherapy; we will talk more about depression and therapy in a later chapter.

This is also a time when it is important to think about your response to your child’s disability. We will deal with this in more depth later in the book; what I

want to note now, however, is that in conveying a diagnosis to your child it is going to be important for you to model a positive, accepting attitude towards the disability. It is very typical to struggle for a long time with the issues of guilt, anger, anxiety, and sadness which come with a diagnosis for your child. It's not fair (or realistic) to expect that you be completely at peace with the diagnosis before you present it to your child. If it's a very "hot" issue for you, however, something which you are experiencing a high level of grief or frustration over, it is probably not the right time to discuss it with them because they are likely to sense your feelings and to infer that, whatever you may say, the diagnosis is a catastrophic piece of information.

In sum, like so many of the questions we are facing in this book, there is no pat answer. Sharing a diagnosis, particularly with an adolescent, is often helpful and meaningful if done in a sensitive way (and with an awareness that many of these terms have taken on derogatory connotations in youth culture; many kids, for instance, use the word "dyslexic" to mean "stupid.") If, however, you are embroiled in your own struggle around acceptance of the diagnosis, it is probably not the right time to share it with your child. Moreover, if your child has already entered too far into the process of constructing their fortress of depression, then it will likely take more than a heart-to-heart talk to break through. The diagnosis may well be co-opted by the depressive process, and a formal therapeutic intervention may be called for.

Wrapping up the Evaluation

Parents often ask me what they should expect at the end of an evaluation. I have pretty strong feelings about this, mainly because I have seen so many families go through evaluations and not get what they should. So here is my take on what you should reasonably expect when you walk out the door after the assessment is complete, whether it is something you are pursuing in a school, a hospital, or a private office.

- First, you need to have the diagnosis. When I say this, I mean “diagnosis” in a broad sense. There are certainly many kids who don’t fit inside a neat “box,” whose profile is not summed up in a pithy label. Also, not all evaluators are licensed to diagnose. This mainly comes up in school-based evaluations, where an evaluator’s scope of practice often does not allow them to officially give a clinical diagnosis such as ADHD or autism. Broadly, however, you need to be told what is going on under the hood of the car.
- Second, you need to find out what the recommended interventions are. There are an enormous number of therapeutic, medical, and educational interventions out there (more about them in the next chapter). Some are valid, some are snake oil. Even the good ones don’t work for every kid.

Following the diagnosis, you need to have a game plan for your child because realistically, you can only pursue a tiny fraction of the many avenues that are probably going to be available to you.

- And finally, as you understand the diagnosis and prepare to take a course of action, you need to understand what the reasonable expectations are. An evaluator may not be able to tell you everything that you want to know about your child's future, but you should be able to take away some sense of an "aperture" of possibilities – the best that you can hope for and the risks that you need to worry about.

Ultimately, you should expect an explanation, an answer to the question that brought you in to begin with. This seems really obvious, but there are two problems with it that I have noticed. First, evaluators often don't volunteer to offer up a clear answer. Sometimes it's because they don't know, but often it's because it's hard to tell parents something hard, or to explain something complicated, or to take responsibility for advising a course of action that will be challenging. I clearly remember the way that my stomach used to tie into knots when I had to sit down to give parents a difficult diagnosis. Discomfort on the part of the clinician, however, should not be a barrier to your getting what you need out of the evaluation. When you feel that you are encountering vague answers you should feel empowered to press for specifics. If someone doesn't have an answer for you

then that's fair, but it is better for them to say that than to dance around it...it only takes three words to say "I don't know".

Second, parents sometimes lack a clear sense of why they are getting the evaluation to begin with. Sometimes, parents come into my office for the initial interview and when I ask them why they are there, they don't really have an answer. They are there because someone told them to come, or because they don't know what else to do. It's OK to come for those reasons, but before you walk in the door it's important to formulate a question to ask. It might be as broad as "is there something wrong with my kid?" or as specific as "what kind of dyslexia does my child have, and which reading program will work best for him?" Regardless, if you don't have the question then the evaluator probably won't have the answer!