

Questioning Conventional Wisdom

# Early Diagnosis: Boon or Bane?

Revolutionary Common Sense by Kathie Snow, [www.disabilityisnatural.com](http://www.disabilityisnatural.com)

The early diagnosis of children is so widely practiced that we seldom question its validity or helpfulness. The theory behind early diagnosis makes sense, on the surface: the earlier the diagnosis, the earlier the child can get help and services, and the earlier the disability/condition can be remediated or “fixed.” These are considered the benefits of early diagnosis, but there is also potential harm in early diagnosis.

In 2003, while presenting at an Early Intervention (EI)/Early Childhood Education (ECE) conference that included parents and professionals, I discussed this issue. At one point, I shared examples of what can happen when a child is diagnosed (and this applies primarily when the child has *not* been diagnosed at birth): parents often *see* the child differently and begin *treating* the child differently. I then noted that the *child is no different* before he was diagnosed than after, but once the diagnosis is issued, the child’s life is often turned topsy-turvy. He didn’t change, but his parents did! They see him differently and treat him differently, his daily life may change when he starts receiving therapy or other interventions, the way people talk *to* him and *about* him changes, and other shifts may occur.

At that point during my presentation, a woman in the audience piped up and exclaimed, “That’s altered parenting!” I had not heard that descriptor before, but as she explained what it meant to her, it seemed an accurate term for what I was describing.

The woman was a nurse who worked in hospital pediatric units for many years, but now worked within the EI system. She briefly described what she and others observed in hospitals: when a child was diagnosed with a life-threatening illness and/or if a child required numerous and lengthy hospital stays, the mother and father *altered their parenting styles*.

It was interesting to learn that this happens to “other” parents. At the time, I thought it was unique to parents of children with disabilities, regardless of the type or severity of the condition, because that’s what I was familiar with, based on my own personal experiences, as well as the experiences of hundreds of parents I’ve met over the years. Interestingly, the majority of children with disabilities, in general, *do not* have life-threatening illness, nor do they have numerous and lengthy hospital stays. Still, the two groups of parents share this Altered Parenting phenomena.

So let’s go back to what happens when a child is diagnosed “early.” (Again, this applies more to children who are diagnosed some time *after* birth, as opposed to at birth.) First, the parents have “seen” the child one way, from the time he was born. He is, to one degree or another, the “perfect child” they dreamed of. At some point, the parents may believe that the child does have some differences. And there are a variety of outcomes to parents noticing these differences. Some parents take them in stride, believing “that’s just the way he is,” and they make accommodations, help the child, and/or deal with these differences in a pretty casual way. (And this can be a very good thing!) In other cases, the differences create great tension, especially if the child is unable to communicate orally, and he attempts to communicate in the only ways available: through his body or behavior.

So at some point, the child is taken to a physician, and the diagnosis is delivered. At that moment in time, for many, many parents, the world changes. Everything they know, everything they hoped for, everything they believed about their child and their family’s future is shaken to the core. And from then on, *most see their children through the lens*

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*of the diagnosis.* They may already know something about the condition, or they may immediately try to learn everything they can about it. In either case, whatever they know or learn about the diagnosis is, in general, negative. And the negative perceptions that go with the diagnosis are often *transferred to the child.* Some parents find it difficult to continue loving the child the way they once did; love might be replaced with pity, distance, or revulsion. Sadness, anger, disappointment, and confusion are, unfortunately, considered “normal” parental reactions. Moreover, we, as parents, are *expected* to “grieve,” and if we don’t, we’re said to be “in denial.” (Gag!)

This, then, is the first negative outcome of early diagnosis: the wounding of a parent’s perception of the child. And while parents might be confused and hurting, in the long run, it’s the child who pays the price—which leads to other negative outcomes of early diagnosis and its accompanying Altered Parenting.

Mothers, fathers, and other family members may abandon their dreams for the child, which causes them to have low—or no—expectations for the child’s success. (This may be the worst thing we can do to a child.) The treatments, interventions, and services that are prescribed for the child profoundly change the lives of the child and her family. Therapies and interventions dictate the schedule of the child and at least one of the parents. The other children in the family may feel lost, be left to fend for themselves, and/or be forced to go without the parental attention they need. Unintentionally, the services and treatments designed to “help” the child create an Altered Family.

Furthermore, many of the treatments and services which are designed to help may actually be harmful to the child and his development. For example, how is it helpful to put a three-year-old child who has not yet acquired speech into a segregated special ed preschool class in which the other children are not yet speaking?

If we want a child to learn to speak, shouldn’t he be surrounded by children who speak?

A child with a physical disability may spend a great deal of time receiving physical therapy to enable him to walk. In the meantime, he may be treated like a baby (*and see himself as a baby*) because he “seems” like a baby: always being pushed in a stroller or carried. Instead, he *could* be exploring and learning from his environment, doing the things three-year-olds do, by using a power wheelchair.

As I’ve written in other articles, many parents of children with autism (and similar conditions) are learning that when we accept the conventional wisdom of putting a group of kids with autism together, they learn how to have more autism! *Shouldn’t we question these and other “helpful” interventions?*

Another negative outcome is a family’s dependence on the system and/or professionals. “Receiving services” becomes a way of life. Some parents and families are made to feel incompetent and believe they can’t cope *without* professional intervention. This trait may be passed on to the child, who will then become an adult who is dependent on the system. In other cases, parents willingly cede their power and authority to professionals. They *want* others to take control.

Regardless of how power is transferred to the system/professionals, the outcome is the same: emotional and financial dependency, which causes a family to lose its autonomy, privacy, dignity, and freedom. Social isolation and physical separation from the mainstream of a family’s community is the result.

The solutions, it seems to me, are simple. First, we can discard specific disability diagnoses, in favor of the generic “developmental delay” during the early years. Such a diagnosis would enable a child to get the services he may need. This would also prevent parents, professionals, and others from making judgments and presumptions about a child based on the known characteristics of a more specific diagnosis.

Furthermore, this could prevent the *misdiagnosis* of a child. There are many children who *are* misdiagnosed, and once the label is affixed, it’s almost

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impossible to get it changed! We don't need to rush to judgment.

Some may think that appropriate interventions could not be determined or prescribed if a specific diagnosis is not known. But I don't believe this is true. We simply need to look at what the child needs—what his personal, individual, unique needs are—to know what help or assistance is appropriate. Far too many treatments and interventions are prescribed *based solely on the diagnosis*, with little or no consideration to what the child's actual needs are!

Some enlightened professionals recommend not diagnosing a child with a specific condition until the child is eight or nine. I think that's probably a wise idea. Here's a scenario to consider. In many cases, once a child is diagnosed with autism, for example, people start treating him "like he has autism"—in their personal relationships with him, in the services he receives, in the environments he's "placed" in, and so on. The diagnosis, in many ways, can become a self-fulfilling prophecy. But what if the diagnosis was "developmental delay," and we simply provided the help the child needed? And, this help can be provided in the most natural ways possible, at home and in other natural environments, instead of making the child into a "patient/client" for the rest of his life.

In addition, if he doesn't have oral communication by the time he's two, we provide a communication device. If he needs behavior supports, we provide those, and so on. Then when he's eight or nine, if necessary, he can be evaluated for a diagnosis. I believe it's possible that because he's had effective communication (via the communication device) and has developed "age-appropriate" social skills *because* he's been able to effectively communicate, he may no longer exhibit all the characteristics of autism (or other condition), and he may end up with a "speech disorder" or other "less significant" diagnosis.

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However, we don't necessarily need to assign a specific diagnosis even at age eight or nine. We could use the generic "developmental disability" (DD). The federal DD definition essentially encompasses all the specific conditions we're familiar with (autism, cerebral palsy, and so on).

Can or will this happen? And what about all the children who have already been diagnosed? First, many physicians may be reluctant to use the "de-

velopmental delay" diagnosis. Many like to be precise, believing a specific diagnosis is crucially important, and many parents want that. (But what difference does it really make?) Parents, however, could say to a physician (or to educators or others), "We only want the 'developmental delay' diagnosis." If you're accused of being "in denial," you can either let the insult go, or you can explain why that diagnosis is the one you prefer. If your child has already been diagnosed, you can try to get the diagnosis changed.

In either case, you can, as a parent, *choose* to ignore the specific diagnosis and adopt the "developmental delay" in your head, and begin treating your child as a precious son or daughter who simply has some delays or differences, instead of treating him as a "child with autism" or any other diagnosis. Spend some time thinking about what this might mean to you, your family, and your child.

Some people think *I'm* in denial, that I'm not being "realistic." They're entitled to their opinion. What I know in my heart is that early diagnosis and the associated disability-specific treatments can be harmful. What evidence supports these assertions? The personal stories of adults with developmental disabilities—the true experts—who were robbed of their childhoods because of all the "help" and baggage that accompanied their early diagnoses.

The hearts of small children  
are delicate organs.  
A cruel beginning in this world  
can twist them into curious shapes.  
Carson McCullers