

2 - Early Diagnosis: Boon or Bane?

the label and from then on, *most see their children through the lens 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 label 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 others (children and adults) 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”

We don’t need to rush to judgment.

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 about in other articles, many parents of children with autism (and other 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 particular label.

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 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 labeling a child with a specific disability 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 we "place" him in, and so on. The diagnosis, in many ways, can become a self-fulfilling prophecy. But what if the label applied 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" condition.

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

However, we don't necessarily need to assign a specific label 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 labeled? First, many physicians may be reluctant to use the "developmental delay" diagnosis. Many like to be precise, believing a specific label

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, knowing you're not, 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 might 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, the labels we assign to children, 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" they received.

©2003-06 Kathie Snow. Permission is granted for non-commercial use of this article: you may photocopy to share with others as a handout. Please tell me how/when you use it: kathie@disabilityisnatural.com. Do not violate copyright laws: *request permission before reprinting in newsletters, web sites, list serves, etc.* To learn more new ways of thinking, to sign up for the free Disability is Natural E-Newsletter, to see products that promote positive images, or to learn about Kathie's *Disability is Natural* book and video, visit: