Negative Prognoses and the Disability Double Standard

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

You're the parent of a precious three-year-old daughter who does *not* have a disability. At the end of a routine medical check-up, the pediatrician solemnly announces, "Mrs. Brown, I'm sorry to tell you this—but I don't think your daughter will be college material, so I suggest you begin planning a different path for her..."

What if this happened to you? (Furthermore, what if someone told the doctor something similar about *his* child?) Most people say they'd think, "Who does this doctor think he is—trying to predict my child's future...putting limits on her potential...telling me not to dream big dreams for her! How does *he* know what's possible?"

Most people say they would also be appalled and angry, would not believe this "quack," would change doctors immediately, would tell others not to take their children to such a jerk, *and their righteous indignation would be justified!* Furthermore, they would be supported by many: grandparents and other relatives, parents who appreciate the warning, etc.

Now consider an alternate scenario. The parent of a three-year-old daughter who happens to have a disability diagnosis takes *her* precious child to the doctor. The physician tells the mother that her child is not college material, and tosses out a variety of other negative prognoses, such as the little girl will never be "normal;" she may never walk or talk or read or write (or whatever); she'll need to be in special classes in school; don't expect her to ever hold a job or be able to take care of herself...just don't expect too much, so you won't be too disappointed. In many cases, physicians deliver this doom and gloom when the child is a newborn baby!

But when parents of children with disabilities have the same feelings as the parent in the first example—when they're outraged by the doctor's "fortune-telling"—they're told they're "in denial;" they need to "be realistic;" they're still "grieving," etc. In other words, if they have the same reaction as other parents *they*—not the fortune-telling physicians—are considered wrong and inappropriate! Furthermore, family and friends may provide little or no support, and they may even be on the side of the doctor, telling the parents they should "listen to the experts" who "know best."

What a crock! Why is the doctor considered a "quack" when he delivers his misguided opinion about a child without a disability (based on whatever criteria he was using), yet he's perceived to have infinite wisdom and his opinion is valuable if the child has a disability?

How *does* he think he knows what's possible? Does he routinely treat adults with developmental disabilities? No—as a pediatrician, he sees only children. So how *does* he know what's possible? He doesn't! Most likely, he's guessing and/or regurgitating what he read in medical books years ago, and he's most likely imposing his own personal beliefs, values, and feelings—not facts—into the discussion.

When my son, Benjamin, was diagnosed with cerebral palsy at the age of four months, doctors said my son would probably never do this or that, they recommended therapies and interventions, and then added, "Take him home and do the best you can..." Other professionals spun a similarly gloomy picture. Initially, their words were shocking, and for a brief time I *did* believe them; I was surrounded by others (including parents of children with disabilities) who seemed to worship at the altar of professional expertise.

Within a short period of time, however, my natural skepticism, coupled with my irritation that others seemed to be trying to crush our hopes and dreams, kicked in. In some cases, we continued seeing certain doctors because they were the only specialists available, and I listened to *some* of their words, while ignoring others. I realized early on, after learning from adults with developmental disabilities, that certain parts of Benjamin's life would be more difficult (e.g., experiencing prejudice, discrimination, etc.), so why would I add to these difficulties by listening to naysayers—people who were supposed to be helping him? Thus, there were times when we

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changed doctors, therapists, and/or others, when their views and ours were too far apart to bridge. If people weren't going to be "on Benjamin's side," we didn't want them in his life!

We eliminated these negative influences in Benjamin's young life and held on to our hopes and dreams, despite warnings that we weren't being "realistic." At the time of this writing, Benjamin is in his last semester on the path to earning his Associate's Degree from community college—graduating with honors—before entering a four-year school for his Bachelor's degree (and beyond)! Would this have happened if we had believed the dire prognoses of the so-called experts?

Doctors, therapists, and/or other medical per-

sonnel aren't the only ones who may routinely peer into their crystal balls; teachers, school administrators, service providers, and even family members may also share their opinions about a

child's potential. And parents are expected to respect this "wisdom." But imagine the brouhaha if, for example, a fifth-grade teacher told a parent that her child would "never grow up to be anything." The parent would justifiably want the fifth-grade teacher's head on a platter! She would probably complain to the principal and, in the best-case scenario, the principal would issue a stern tongue-lashing to the teacher. But, again, parents of students with disabilities are supposed to be respectful of—and even grateful for—the professional expertise of educators!

Whether you're a physician, therapist, educator, grandparent, or have any other role, recognize your own limitations *and* responsibilities: you cannot predict a child's future based on the presence of a disability and you have no right to crush the hopes and dreams of parents. (Ditto to parents: we have no right to crush our children's hopes and dreams.)

Learn to say, "I don't know..." (see the "I Don't Know" article); keep your opinions to yourself recognizing that they are just opinions, not the truth with a capital T; and put yourself in the parents' shoes

(and, parents, put yourselves in your child's shoes). You may be thinking, "But I would want people to be brutally honest with me..." Think again: think longer and harder on the issue. What would happen to your child if you embraced the negative pronouncements of others, regardless of their so-called expertise? We're all too familiar with the "self-fulfilling prophecy:" a person will rise or fall based on our expectations. If we want children with disabilities to be successful, we must have high expectations for them. For too long, we've had low expectations and so have undereducated them, segregated them, tried to "fix them" via treatments and interventions, and worse-and the dismal outcomes when they reach adulthood (low self-esteem, massive unemployment, dependence on government systems, etc.) are clear evidence that our misguided efforts have, unfortunately, succeeded.

Never deny the diagnosis, but always deny the negative prognosis. Norman Cousins

Regardless of your position in the life of a child with a disability, recognize and then eliminate the Disability Double Standard:

—Professionals, educators, medical personnel, extended family members, etc.: (1) recognize that you would probably not deliver a negative prognosis for a child's future based on some other characteristic, so you shouldn't do so on the basis of disability (remember, you cannot predict the future; repeat that as a mantra every day); (2) recognize that parents of children with disabilities—like other parents—are also justified if and when they dismiss your negative opinion about their child; and (3) help parents maintain (or acquire) positive beliefs in their children and their children's potential.

—Parents: stop believing the nonsense others dish out about your child! If other parents wouldn't accept that nonsense, why should you? And why in the world would you choose to believe the negative words of others instead of believing in the worth and potential of your own child?

Question the conventional wisdom that has led to less-than-desirable outcomes for children and adults with disabilities. Take a different path. Explore options. Reject the status quo. Be bold, proactive, and positive, and celebrate the wonderful results!

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