

The **Whole** Person

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

Many years ago, during my son's early years, I was involved with several organizations of parents of children with disabilities. We came in all shapes and sizes, with different levels of experience, based on the ages of our children. We all had something to contribute to one another; we all had much to learn from each other.

By the time my son, Benjamin, was four, I had also learned a great deal from adults with developmental disabilities. So while I had only four years of personal experience, I was fortunate to be learning from adults who had thirty, forty, or fifty years of experience. One day, Paula, the parent of a two-year-old with cerebral palsy (the same diagnosis as my son) called me, and in a near panic-stricken voice, she said, "The ortho doc says this, the pedi-neurologist says that, the therapist says something else! Which one is right? Which one should I listen to? Which one is responsible?"

I responded that apparently none of the professionals saw her son as a Whole Person; each saw her two-year-old through the lens of their specific disciplines. Perhaps all were "right" in their own way. But she, as the parent, was responsible; she should not cede her parental authority to any professional. I suggested that she make her decision based on what she thought was right for her son and her family, within the context of her son being a Whole Person: a precious little two-year-old boy who was also his father's son, his sister's little brother, a valuable member of the family, and a kiddo who needed and deserved a wonderful, happy childhood.

Situations like Paula's are repeated again and again in the lives of children and adults with disabilities. In some cases, they're pulled this way and that, as parents, teachers, service providers, health care professionals, and/or others seem to vie for the top-dog position: "Let's focus on speech..." "But what about mobility..." "Oh, behavior is most important..."

And the list goes on and on. In my own son's earliest years, the diagnosis of cerebral palsy sent us on the chase for "independent walking" and "normal gross motor skills" via intensive physical and occupational therapies. At the two-year check-up with the pediatric neurologist (who had prescribed the therapies), I almost fell out of my chair when he asked, "And what about your son's speech? How's that going?" Benjamin talking? I hadn't even considered it, and apparently it wasn't high on the doctor's list, as this was the first time he mentioned it. Based on all the recommendations of the professionals, I was totally focused on the walking-stuff. That was my wake-up call that I was not seeing my son as a Whole Person!

Alas, this type of tunnel vision is insidious; it takes intentional and on-going efforts to keep it at bay. This was brought home to me years later when Benjamin was nine, and using a manual wheelchair. He couldn't push it very well on his own, but professionals assured us he would "in time." (But what about his life right now? Why does it seem that so many of our efforts are focused on "the future" instead of "today"?) I had thought about a power chair for him, but I was unknowingly still under the influence of the Medical Model in my thinking, which went like this: "At least with the manual wheelchair, he's still getting a little 'exercise' with his arms; if we got him a power chair, he'd lose that, so we better stick with the manual chair even though he can't really get himself from place-to-place on his own."

Once again, it took another's questions to open my eyes. This time, it was my friend, Tom, who also had cerebral palsy, used a power wheelchair, and lived a great life. He called one day from his home 700 miles away, and we first did some catching up. Then Tom asked why we hadn't gotten Benjamin a power chair, and I gave him the song-and-dance I described above. Tom responded with a big, impatient sigh,

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and said, “Kathie, Benjamin is going to be in middle school pretty soon. How’s he gonna’ get a girlfriend in that manual chair? What’s he gonna’ do—ask some girl to push him? He needs a power chair so he can say, ‘Come on, baby, sit in my lap and we’ll ride off into the sunset...’” I got it. I finally got it. And Benjamin got the power wheelchair and instantly began living a fuller, better, more self-determined life!

Why didn’t a health care professional, therapist, or other expert recommend a power chair so that Benjamin could be a more successful child, so he could have more self-assurance and more control over his life, so he would see himself differently, so others would see him differently, and more? My guess is that they didn’t see the Whole Person either. (In the big scheme of things, how important was getting a little “upper body/arm exercise” in the manual wheelchair as compared to the countless benefits Benjamin received from having a power chair? Duh!)

We’re often too focused on what a person with a disability *cannot* do. We test, assess, and analyze; write goals to address the “deficiencies;” and then spend hours, days, weeks, months, or even years trying to “fix the problems.” We spend time on things like: walking, talking, making eye contact, shoe-tying, hair-brushing, reading at grade level, handwriting, appropriate behavior, and . . . the list goes on and on and on and on. We may be so obsessed with the person’s perceived “deficits,” that we can’t even see her strengths. How much time and energy *do* we spend identifying what the person *can* do? How much time do we spend building on the person’s strengths, abilities, and interests?

Yet few people without disabilities would apply these machinations in their own lives: we usually ignore, hide, and/or minimize what we don’t do well, and focus on what we do well, what we enjoy, and other things that are important to us. And we certainly wouldn’t spend much time surrounded by people whose purpose was to “help us with our problems”!

Trying to remediate a person’s so-called problems often results in the person being in “special,”

segregated environments. What impact does *that* have on the Whole Person? What must it feel like to grow up feeling that you don’t belong and that you’re not good enough? What must it be like to be treated like you’re incompetent; to be “taken care of” like you’re a child, no matter your age; and to have few, if any, opportunities for increasing levels of personal responsibility and privileges, as you grow from year-to-year? Is this even on our radar screens?

If those of us without disabilities were treated like many people with disabilities—if we were forced to spend a lifetime trying to meet someone else’s standards of “normalcy,” to “get better,” to do what others wanted us to do, to be under the control of others, and to be in environments not of our own choosing—we would most likely exhibit extreme inappropriate behavior, would learn to be helpless, and would acquire a host of other less-than-desirable characteristics.

When we don’t focus on the Whole Person, all of us—the individual and those who care about him—miss so much! It’s impossible to find the words to describe the many joys our family has experienced once we focused on the Whole Person of Benjamin. As one example, imagine the joy I felt when I watched the pride on his face the first time he was able drive himself through the toy store, find the rack of cars and trains, and grab the one he wanted all by himself at age nine. This ordinary, but precious, event (which children without disabilities routinely experience) was possible only because of the power wheelchair. It was a statement of interdependence, self-reliance, making choices, and more . . . and these types of experiences are crucial components of a normal, successful life. Our focus on Benjamin as a Whole Person has enabled him to enjoy life-enhancing experiences every day; his abilities are maximized, his disability is minimized.

What if we recognized the importance of effective communication in any form, instead of focusing only on speech therapy? Can you imagine the joy when a mother hears—for the first time—“I love you, Mommy,” from her four-year-old as he uses his communication device? Can you imagine the joy of the parent of a *30-year-old* in the same situation?

The trouble with specialists is that they tend to think in grooves.

Elaine Morgan

What if we recognized the value of friendships? Everyone needs a friend or two! Many children and adults with disabilities are surrounded by people who are paid to provide services, but they have no real friends. Imagine the positive outcomes if a person had a real friend to laugh with, share secrets with, and more. Or what if he was a member of a Sunday school class, hobby club, or volunteer group? Imagine the significant and positive changes in a person's "inappropriate behavior" when he finally feels he belongs and when he's valued by others just the way he is.

What if we were more conscious of the need for children and adults with disabilities to be more responsible and to feel needed by others? Too many are made to feel helpless and needy, and we don't allow them to be responsible; in the process, we set them up to fail. Imagine the difference it could make in the person's life if she felt she was important and valuable to others.

When we spend time and energy to identify and build on a person's strengths—what she *can* do—we realize that what she cannot do isn't so important. Focusing on abilities can open the door to so many opportunities. So let's consider the following:

- Are we making an intentional effort to focus on the individual's spiritual, social, and emotional development and well-being, personally, as well as in the context of her role as a member of her family, school, neighborhood, community, etc.?
- Are we focused on the person living a chronologically (not "developmentally") age-appropriate and self-directed life? For example, is a six-year-old child able to enjoy the privileges and responsibilities like other six-year-olds? Is a 30-year-old treated like an adult and does he enjoy adult privileges and responsibilities?
- Are we ensuring the person has opportunities to participate in ordinary, age-appropriate activities, in inclusive environments?

The least a person can ask out of life is to be needed by someone.

Maia Wojciechowska

- Are we placing a high value on ensuring the person acquires the experiences needed to make her way in the world?
- Are we doing whatever it takes to provide the person with the assistive technology devices, supports, and/or accommodations so the scenarios above are possible?

When we don't focus on the Whole Person—when we reduce a person with a disability to an assortment of "problems," "deficits," etc.—our actions (or inactions) can inadvertently *retard* the person's growth, development, and potential! We can, in fact, generate more problems in the person's life, making the disability "bigger" than it really is. A disability is simply a medical diagnosis and it's just one of many elements of the Whole Person. It should not be the defining element, any more than your medical diagnosis or mine should define our lives.

No matter what role we play in the life of a person with a disability, we have a responsibility to *see* the Whole Person. Parents, however, have the greatest responsibility, because they *are* the parents, and because they're a *constant* in their child's life, while professionals will come and go. With this in mind, parents need to eat their Wheaties and stay strong when confronted with professionals, educators, and/or others who try to slice and dice the child into a series of "problems."

People who happen to have conditions we call "disabilities" are Whole Persons. They deserve to be treated as such: as individuals who have abilities, strengths, hopes, dreams, and needs, just like everyone else. They have much to contribute, they need the opportunities to do so, and we need what they have to offer—we *need their Whole Persons!*

Let's open our eyes and see beyond the diagnosis. There's a Whole Person, and a world of possibilities, waiting to be discovered!