The Power of Hope

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

He was born almost two months prematurely. Jaundice. Hydrocephalus ("water on the brain"). Grade III brain bleed (Grade IV was "the worst"). "Dr. Doom," the neonatalogist, was a harbinger of hopelessness and fear: "Take him home; do the best you can."

The hopelessness and fear continued; one doctor diagnosed the four-month-old with static encephalopathy (non-progressive permanent brain injury). The next doc added cerebral palsy; another diagnosed eye problems. They solemnly announced what the tiny infant would probably never do.

Therapies and early intervention services began, focused on what the baby was *not* doing. When the boy was five, a physical therapist (PT) said he "functioned at the level of an 8-month-old." More hopelessness and fear.

> **There were many ways of breaking a heart. Stories were full of hearts being broken by love, but what really broke a heart was taking away its dream—whatever the dream might be.**
>
> ***Pearl S. Buck***

The 4-pound-newborn is now a handsome, talented 25-year-old man—our son, Benjamin. And we recently mailed his graduation announcements: he'll earn his Bachelor's degree, with honors, in a few days. A Master's degree is next.

Benj can't write with a pencil—irrelevant—he uses a computer instead. He can't walk—not important—he uses a power wheelchair and other assistive devices. A PT might still say he's at the "8-month level" per a gross motor developmental scale since he didn't sit up and/or crawl at the "normal" time.

During the early years, we were surrounded by "helping professionals" who had great expertise in their fields, but who generated hopelessness and fear, coupled with dire warnings that we were "in denial" and needed to "be realistic." In addition, they routinely tested my son and told me everything he was not doing. Did I really need anyone to tell me this stuff? I lived with my son 24/7/365—I knew what he wasn't doing! With friends like these, who needs enemies? The experiences of many other families are similar to ours.

When our son was three, I participated in the Partners in Policymaking program (www.partnersinpolicymaking.com), where I learned from many leaders in the field, as well as from the experiences of adults with disabilities who were my classmates. This set us on a new and life-changing path, and we made changes in our attitudes and actions. Benjamin made the decision to stop traditional therapies at the age of six. We used techniques learned from therapists to help our son in more natural ways. No longer did we focus on what he couldn't do; we built on his strengths; provided the needed assistive technology, supports, and accommodations; and ensured he was always included, just like his sister and his friends. We made sure his disability was not the defining characteristic of his life. Benjamin's diagnoses have not been a barrier to his success.

But the only way for us to get to that point was to separate ourselves from the experts who generated doom and gloom, and to surround ourselves with people who believed in our son. These included teachers at a wonderfully inclusive school who believed all children could learn, as well as leaders in inclusive activities (Scouts, Campfire, 4-H, karate and drama lessons, and more) who could care less about Benjamin's diagnoses (YIPPEE), who met his needs, and who believed in him—and we're eternally grateful to them, for they helped pave the way to his success.

Do you see the irony of the situation? The "experts" in the disability arena are highly-trained professionals who are supposed to help people with disabilities and/or families. Many who work "in the system" are paid with taxpayer dollars. They occupy an elevated stature as the "go-to" professionals. And in our family's life, a few were somewhat helpful. But the cumulative impact of their negative prognoses, hopelessness, fear, and other detrimental attitudes and actions essentially outweighed the beneficial assistance. When we left Disability World, people who were *not* "disability experts" exuded hope and supported our dreams for our son.

Let me be clear. I'm not saying the professionals in our family's life—or any others in the field—are "bad people." They were kind and I know they cared about my son. And I'm sure they didn't intend to be negative or hurtful; they were speaking the truth, as they saw it. They were, I guess, just "doing their jobs." And perhaps therein lies the dilemma: they see their jobs as "helping" people with disabilities with their "problems." Thus, their focus is on a person's disability, diagnosis, and/or what the person cannot do, and hopelessness and fear are often the by-product. In the process, it seems, many professionals are unable or unwilling to see a person's abilities, potential, strengths, interests, etc., and to then build on those (which would generate *hopefulness*).

Part of this situation is, of course, a consequence of the service system: eligibility for services is based on a person's perceived deficits, problems, etc. So, okay, if people with disabilities and/or their families choose to access the services that are available to them, a focus on "problems" ensures eligibility. But then let's move on, shall we?

No matter what our attempts to inform, it is our ability to inspire that will turn the tides.
Syracuse

If you're a professional, are you generating hopelessness and fear or hopefulness and dreams? This is not hard to figure out: put yourself in the place of the person with a disability and/or family. And, please, let's stop the admonishments: "be realistic," "in denial," "still grieving," and other nonsense. These are not helpful, nor are they realistic! As a professional, examine your role—not your official job description—but your role in the lives of the people with disabilities and/or families. Your professional expertise is all for naught if you crush the hopes and dreams of the people you're supposed to help.

Sadly, many people with disabilities and/or families exist in a permanent state of hopelessness; they think this is the norm and often can't see their way out. Parents' hearts have been broken, not by a child's diagnosis, but by the hope-crushing negative prognoses of professionals, and the parents no longer dream for their child. There is no greater loss—for the parents and, of course, for the child, who grows into an adult with few hopes or dreams.

I'm always amazed and saddened that people with disabilities and/or families believe the negative things they're told by professionals. I have great respect for many professionals, but none knows "what's possible" for a person with a disability. And when professionals try to "predict the future" of a person, their track record is no better than the average fortune-teller as she peers into her crystal ball!

People with disabilities and families can, like our family, reclaim their hopes and dreams, by rediscovering their common sense, by focusing on strengths and abilities, and by surrounding themselves with people who share their beliefs and aspirations. And they may need to distance themselves from those who project doom and gloom into their lives.

Professionals can choose to use their power to generate hope—and better outcomes—in the lives of the people they serve. It's about what information they impart, their choice of words, their body language, and a focus on what's possible. It's about supporting dreams; nourishing the spirit of the person and/or family; operating from the "why not" attitude; trying to walk in the shoes of another; embracing the capacities of people with disabilities/families; and taking a leap of faith alongside the people they serve. These are the attitudes and actions of the *ordinary people* who made such a difference in our son's life; how wonderful if the professionals had also done so.

Inspiring others with the gift of hope isn't just the right thing to do for someone else—the hope you inspire will be reflected back to you, and *your* heart will also be filled with hope! Isn't it worth a try?
