

First, Do No Harm

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

“First, do no harm,” is a sentiment we’re familiar with. Contrary to popular belief, it’s not part of the Hippocratic Oath (the long-standing creed of physicians, named after Hippocrates, the “first physician”). But according to several Internet sources, “...to do good or to do no harm” is included in Hippocrates’ book, *Epidemics*, and it has also been attributed to Galen, another physician from the Ancient Greek era. Regardless of the source, it’s a precious concept that has great value and relevance to disability issues.

On a regular basis, we—parents, teachers, health care workers, service providers, and others—work diligently to help children and/or adults with disabilities. But in the process, is it possible we could also be causing harm?

My first awareness of the help/harm situation occurred when I wanted to learn from adults with developmental disabilities when Benjamin, my son who has a disability, was three. I figured (rightly) that those with personal experience had a lot of valuable info to share. Imagine my shock and dismay when they told me what it felt like to be taken to therapy (PT, OT, etc.). “My mom took me to therapy all my life so I would walk. But I was never able to walk—so I think I’m a big disappointment to my parents.” They shared the unspoken message therapies and interventions send to a child: “You are not OK the way you are, and we’re going to keep taking you to therapy until we say you’re OK by our standards [the able-bodied standard].” Finally, these adults said, “I wish my parents could have loved me just the way I am.”

Needless to say, as “therapy mom of the year,” this was an eye-opener for me. But it was so hard for me to hear. I was heavily invested in therapies for my son; it’s what “everyone” (professionals) said he needed. At the time, I valued the paid experts’ words more than the words of people with real-life personal experience. So I made no changes. With 20/20 hindsight, I later realized it was my ego that prevented me

from questioning the wisdom of professionals *and* my own actions. I didn’t want to believe professionals were fallible or that I might have been duped by the experts. And I surely didn’t want to believe that perhaps I should have taken more responsibility for investigating therapies, looking at different options, and so on. Yep, my ego (and the status quo) was to be preserved at all costs.

It wasn’t until three years later, when then six-year-old Benjamin tearfully pleaded, “I don’t want to go to therapy any more—I’ve been going all my life! Going to therapy doesn’t make me feel like a *regular* person!” My son’s words joined with the earlier words of the adults, and I finally got it: while therapy was intended to be helpful to my son’s body, it was also harming his spirit. Benjamin never went to therapy again; instead, we found more natural ways of helping him do what he wanted to do, using techniques learned from therapists along with our own common sense—in ways that didn’t crush my son’s spirit. “Thank you, Mommy,” he said, “for listening to *me*.”

From that day forward, my husband and I learned to always question if our efforts to assist Benjamin might also cause harm. We also learned to really listen to our son. For I sadly realized that he had been “telling” us he was unhappy about therapy for three years—like when he cried every time we drove into the parking lot of the clinic—but we didn’t “hear” him. Instead of really listening to him at that time, I leaned over and patted him on the leg and said “It’s OK, honey, I’ll bet they have some new toys for you to play with.” I had let my son down. Parents are supposed to protect their children, and we didn’t at that time.

Many might say, “But I didn’t *mean* to cause harm.” Neither did I. And I’ve learned that our intentions are irrelevant. You remember the famous saying: “The road to hell is paved with good intentions.” A counselor once taught me a valuable lesson on this

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issue when she said, “If I accidentally step on your toe, does it hurt any less because it wasn’t intentional?” Our *intentions* when helping are not as important as the *feelings* of the person on the receiving end of the help, and the *actual consequences* of our actions.

During the past decade or so, I’ve learned from many people with disabilities, families, and professionals. And here are some ways we may unintentionally cause harm to people with disabilities:

—*Talking about a person in front of her like she’s not there.* Do we think a person doesn’t hear or understand us? People of any age (including very young children), regardless of the type or level of disability, *can* understand our words or our tone of voice, body language, and other non-verbal communication.

—*Working on a person, through therapies, interventions, skill-training, or other methods in an attempt to change/fix them.* Instead of imposing our standards on them, we can ask them what they want to learn or do, and then work *with* them, not *on* them, to help them achieve what’s important to them.

—*Segregating people in any environment: special ed preschools, special ed classrooms, day programs, group homes, special sports/other activities, etc.* The messages of segregation are devastating: you don’t belong, you’re not good enough, you’re not like us. (See the article, “Lessons of Segregation” to learn more.)

—*Helping too much.* With the best of intentions, we may (1) try to get a person a job, (2) do a child’s schoolwork for him, and/or (3) take care of the person in a variety of different ways. The message this sends is: you’re not competent to do this for yourself. And the result of hearing this message over and over again? The person learns to be helpless.

—*Being overprotective.* Don’t we learn more from our mistakes than what we do right? When we’re overprotective, we essentially “retard” the person’s growth and development, robbing him of opportuni-

ties to learn. We’re also sending the message that the person is incompetent; and in too many instances, this becomes a self-fulfilling prophecy.

—*Having low expectations.* How can a child (who becomes an adult) believe in her own potential if no one else does? Haven’t we learned that people will live up or down to our expectations?

—*Allowing the person to be irresponsible.* Many adults with disabilities are routinely told that they can’t live on their own because they don’t have the skills to be responsible for themselves. Well, duh! Most, throughout their lives, have never been given the opportunity to be responsible! Again, when we don’t expect the person to be responsible, the person believes he’s incompetent.

—*Believing the “developmental age” myth.* For those who don’t know history, today’s “developmental age” concept is a variation of the nonsensical “industrial abilities” concept from the early 1900s institutions! We test and assess people with disabilities in a variety of domains: fine motor, gross motor, intellectual, behavioral, etc. Then, we often “globalize” one or more of these narrow domains to encompass the whole

person. We state, for example, that an 18-year-old “functions” at the level of a 10-year-old, based on the results of one particular test, ignoring the person’s other strengths or abilities. Worse, we treat him like a 10-year-old! How

can we expect him to “be” an 18-year-old under those circumstances?

These are just some examples; children and adults with disabilities can share others with us, if we’ll only ask! *We do* have good intentions; and it can be painful for us to recognize and acknowledge that our best efforts to help might inadvertently cause harm. But if we truly care about people with disabilities, then we must make a deliberate attempt to see things from their perspectives, to listen to and respect their feelings, and critically examine the consequences of our efforts. When trying to help, we must first do no harm.

Our intentions when helping are not as important as the feelings of the person on the receiving end of the help, and the actual consequences of our actions.