Rethinking Conventional Wisdom





Revolutionary Common Sense by Kathie Snow www.disabilityisnatural.com

Parents often go to extraordinary lengths to make sure their children receive the services, programs, and rights they're entitled to under disability laws, insurance benefits, or other sources. And this seems like a good and noble thing, but is it really?

Extraordinary parental efforts may occur within IEP (Individualized Education Program) meetings, which are often tension-filled skirmishes with educators. Or they may play out as a firm, determined interchange with service providers, therapists, or other professionals. But sometimes, during parents' Herculean efforts, the child actually become a sacrificial lamb, laid before the gods we know as Rights, Entitlements, and Laws. "Getting Services" becomes more important than the child's life.

"Karen" was not happy with her daughter's education. Twelve-year-old "Mandy" had enjoyed several successful and inclusive years in elementary school, but middle school was turning into a disaster. Karen had spent countless hours trying to work with the 7th grade educators, but to no avail. She was frustrated and angry. Simultaneously, Mandy was suffering: she was pulled out of the regular ed classroom several times a day to spend time in the resource room.

She was losing touch with her girlfriends—classmates she had known for the last several years in an inclusive elementary school—and this

made her sad and angry. This resulted in educators labeling Mandy with "behavior problems." Things couldn't be worse.

In what she described as her "weaker moments," Karen had been looking at options: a charter school, a private school, and homeschooling. But she was torn. She felt obligated to be an "advocate," and try to force the school to adhere to special ed law. I asked her why, and she struggled for an answer. And it's all too apparent from similar stories from other parents that they, too, feel this obligation. We may feel that we're not "good parents" if we're not doing everything possible to ensure our children's "rights" are being protected. But sometimes we need to put things in perspective and find a balance.

What if ensuring a student's educational "rights" are met causes more problems for the student and/or her family? Or if doing so sucks all the energy out of us, so we're no longer happy, loving parents? There are many other situations to consider, aren't there?

So I shared some wisdom with Karen that's served me well: "Never sacrifice your child or your family for a principle." Karen sighed happily. That's what her heart had been telling her—to do what was right for her child, regardless of the self-imposed pressure to hang in there and "fight it out"—she just had to give herself permission to do so.

"Julie" was prepared to sue the neighborhood school over the school's refusal to provide speech therapy for her four-year-old son. She didn't want to enroll him in the early childhood class, she only

> wanted the speech therapy that the school was obligated to provide under Special Ed law. Other than this one incident, she had a

great relationship with the school. She was an active volunteer in the classrooms of her two older children, and her four-year-old would go into an inclusive classroom when he turned five. Julie indicated her family had great health insurance that would cover private speech therapy. So I asked her why she would jeopardize her wonderful relationship with the school over

Never sacrifice your child or your family for a principle.

a couple of free 30-minute therapy sessions a week? After thinking for a minute or two, she slapped her forehead with the palm of her hand and said, "*What have I been thinking*?" Then she added, "So many friends have urged me to fight the school on this, but why *would* I risk making enemies of the people who love my kids, when we can get the therapy on our own?"

Similar situations occur when parents "do what they're told" by early intervention or early childhood specialists, therapists, or other professionals. "Joyce" felt compelled to accept all the therapies and home visits offered by the early intervention system, even though these services created disruptions in her family's life and ran Joyce ragged. Pressure from professionals to take advantage of her baby's entitlements was routine; Joyce also felt others might think she was a "bad parent" if she didn't do everything that was recommended. With the encouragement of friends, Joyce was able to cut back on the interventions and therapies, and no longer sacrificed her family's life in the name of services.

I know, from personal experience, how easy it is to follow conventional wisdom—the directives of the system. From the moment our children are diagnosed (sometimes at birth), the system (and the people in it) leads us down a different path to Disability World. We learn all about disability laws, entitlements, and services. Many of us acquire the "entitlement mentality," which clouds our vision as well as our common sense. In trying to do what's "right" (according to the service system), we may inadvertently do "wrong" for our children, our families, and ourselves.

Precious years of our children's young lives are sacrificed, and a family's privacy, autonomy, and well-being may be diminished when we listen to conventional wisdom instead of our own hearts. In some families, there is little joy and few hopes—the enormous amount of time and energy needed to battle the system, maintain the schedule of services, or do both at the same time, can weaken even the strongest parents.

In general, we can do better for our children than embrace all the services that are offered. If the system "worked," the lives of children and adults would be "better." But far too often, their lives are worse: the services they receive can lead to physical segregation, social isolation, helplessness, and dependency. The system—from my perspective—should be our last resort, not our first choice.

Instead of depending on special services and professionals, we can marshal our own resources, including our own families and friends, as well as the natural supports and generic services that exist in our communities (see other articles on that subject). Families of children without disabilities don't have to spend extraordinary amounts of time and energy "fighting" for their children's "rights." They have the time and energy to enjoy their children, relax with them, have fun with them, and just be a family. We can, too, when we're more thoughtful about what's really important, and then make the choices that will enable us to live the lives of our dreams. And we should always remember that we can choose to accept services or decline them! Ultimately, we can ask ourselves this question: "Will this [service, intervention, treatment, or whatever] make our lives better or worse?"

I've shared the "Never sacrifice your child or your family for a principle..." mantra during numerous presentations. For many parents, the words are like a splash of cold water in the face, snapping them out of the spell they had been under, allowing them to rediscover their common sense. But their common sense had never truly disappeared—it was just buried under the brainwashing of today's system and its conventional wisdom.

Professionals, educators, and others can best help children and families by listening instead of telling; following instead of leading; and respecting instead of commanding. Parents can best help their precious children when they follow their hearts.

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