

REFLECTIONS ON REFLECTIONS?

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

ON EARLY INTERVENTION SERVICES

I wish Early Intervention personnel had recognized and valued my little boy's strengths, instead of focusing on his "weaknesses" and "deficits." It seemed that the characteristics I identified as strengths were not "accepted" as important, since they weren't on any developmental charts. I tried to focus and build on my son's strengths; others tried to remediate his "deficits." (Later, I learned to disregard many "expert" opinions in which the "deficits" outnumbered the strengths.)

I wish my baby son had not been measured against the "norm," and then assigned a "developmental age." Every time he was tested or assessed, I was left feeling that he "didn't measure up" in the eyes of those who were there to help us. Trying to maintain a positive, hopeful attitude about his future after every test and assessment took every ounce of my strength. (And then one day I said, "No more formal tests, ever again." I also told others, such as educators, to never compare my son to other children, but to only compare him to himself: as in, what is he doing now that he wasn't doing six days, six weeks, or six months ago?)

I wish those who administer tests and assessments did things very differently. *Informal* assessments—observation of the child in a natural environment and believing parental observations—are more accurate and appropriate than formal, standardized tests. Instead of asking parents to "not interfere" in assessments/tests, professionals should *encourage* parental presence and *welcome and heed* parental suggestions. And in any type of assessment, a child's strengths, abilities, and interests should receive as much or more attention than the perceived "deficits."

I wish Early Intervention personnel had shared the importance of assistive technology (AT) devices that could have enabled my son to become more independent, instead of focusing on therapeutic interventions to "fix" his legs, hands, and other body parts. If I could do it all again, he would have had a power wheelchair when he was two, so he could explore and master his environment the way other two-year-olds do. When I asked about acquiring AT devices, others discouraged my ideas. Providing assistive technology, modifications, and accommodations can enhance a child's life and allow him to get on with the business of being a child, instead of living as a perpetual patient. (Later, my husband and I figured out and procured, on our own, AT devices which made an incredible difference in our son's life.)

I wish our lives—my life, my husband's life, my daughter's life, and my son's life—had not been turned topsy-turvy by the schedule of home visits and therapies. It was hard to lead "a normal life" with my husband, children, and friends—*doing what was really important to our family*—because of the demands of Early Intervention Services.

I wish I hadn't felt like my home, myself, and my children should be "perfect" on the days Early Intervention professionals came to our house. Even though no one ever implied that we were under scrutiny, feeling that you're being judged is a sensation that's hard to shake at the time.

I wish Early Intervention personnel had encouraged me to stay connected to the natural supports (extended family, friends, neighbors, and community activities) in my life, instead of—intentionally or unintentionally—encouraging dependence on them

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and other professionals in the system. I wish they had encouraged me to seek the valuable expertise of people who knew and loved my son (family and friends), instead of promoting the notion that only “experts” know what’s best.

I wish Early Intervention personnel had provided ideas on ways I could meet my son’s needs in the most natural ways: enrolling him in a typical baby swim class, for example, instead of receiving “water therapy” from a physical therapist. I would have preferred ideas on how to incorporate beneficial activities throughout the day, in the most natural ways possible, instead of traditional home programs that turned me into a “therapist” and turned our home into a therapy center. (Later, I learned how to do this on my own.)

I wish Early Intervention personnel spoke in plain English instead of professional, disability jargon. I quickly learned the lingo, in order to be on an equal footing with EI professionals. When I realized I sounded more like a professional than my son’s mother, I stopped. I wish parents would tell professionals, “Speak English (or whatever one’s native language is)!”

I wish Early Intervention Services, in general, didn’t cause parents to feel they’re incompetent in knowing how to best raise their babies who have developmental delays/disabilities. A neighbor had a baby at the same time I had my son; she didn’t have people telling her what to do on a regular basis. Why did *I* need that? (Later, I regained the feelings of confidence and competence I originally had. But I was angry that I had allowed myself to feel incompetent. Sadly, some parents never regain the self-confidence that may have been eroded by professional expertise.)

I wish Early Intervention Services had been offered as an *option*, not a mandate. Like many other parents, I didn’t feel I could say “no” to all that was offered. To do so, I felt, might put me at risk of

being labeled a “bad parent.” (Later, I did learn to say, “No,” despite this fear.) I wish parents felt they had the right—and had the courage—to be honest with professionals.

I wish someone would have given me the “big picture” of what Early Intervention Services might look like for the next three years, so I could have made an informed decision about whether my child and my family really wanted and needed the services offered. I wish people realized that dependence on Early Intervention professionals has the potential to lead to lifelong dependence on the system. I wish that Early Intervention professionals realized that all the love and care they give to parents leads moms and dads to believe the entire system works the same way. Many parents are in shock and become disillusioned when they hit the brick wall of Early Childhood Special Education (ages 3-5) as it’s practiced by most school districts. I wish Early Intervention professionals would maintain a healthy professional distance so parents do not become dependent on them.

Today, many EI professionals have made some progressive changes, moving to what they call a “coaching method,” wherein parents are seen as the “experts.” This is a step in the right direction—sort of! My concern is the role of a “coach.” In most instances, the coach—*not* the person who is *being* coached—is the one considered to have the expertise (and the power). So I think we still have a ways to go.

The Early Intervention system and the professionals who provide services have great power. On one hand, they have the power to help parents focus on their children’s perceived deficits, setting in motion a lifelong search for “cures” and “remedies,” which leads to perpetual clienthood, exclusion, and dependence. On the other hand, they have the power to help parents focus on their children’s strengths and acquire the belief that their children are fine, just the way they are, and to encourage families to maintain their self-reliance, inclusion, and interdependence. Which path would you want if it were you?