

Altered Parenting

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

During a presentation, I shared the experiences common to many parents (myself included) after a child is diagnosed with a disability: a prognosis is delivered, therapies and interventions are prescribed, and the lives of the child and the family are radically transformed. But, I emphasized, the day after the diagnosis, the child is no different than he/she was the day before; *the child didn't change*. Who changed? The parents. We change our dreams, the way we see our child, and the way we treat our child, primarily because of the negative information provided to us by physicians and/or other professionals.

A woman in the audience—who happened to be a pediatric nurse—piped up with, “Yep, that’s Altered Parenting!” I hadn’t heard this terminology before, and she explained that she saw Altered Parenting in most parents whose children were diagnosed with life-threatening illnesses. Often, the changes in the parents were immediate and visible to her—a stranger. She encouraged parents to *not* go down this path, but her advice had little impact.

I could see how this might happen to parents whose children had *life-threatening* illnesses. But why a similar experience for parents of children with developmental disabilities, whose conditions are usually *not* life-threatening? Perhaps because many parents experience what *feels* like death—the death of the *dream* of a “normal” child. And what does Altered Parenting lead to? An Altered Life for the child with a disability, as well as for other members of the family.

There are probably as many examples of Altered Parenting as there are parents. In general, it can include odd—and potentially harmful—behavior and a loss of common sense. One example is the usual practice of enrolling a child who is not yet talking in a segregated special ed preschool where other children are also not talking. If we want the child to learn to talk, he should be with other children who talk! Yet educators tell us the special ed preschool is what our children need, and we follow that advice, even though it makes no sense.

We may become so focused on trying to “fix” our children through therapies and interventions that we forget the really important things in life, like ensuring our children are always included so they’ll have friends and enjoy ordinary childhood experiences; learn to be responsible; receive a good education so they can become successful as adults; have whatever assistive technology devices, accommodations, and supports they need to do all of the above; and more.

Many parents haven’t heeded the lessons of adults with disabilities (and common sense), about the unintended negative consequences of years of pediatric therapies (that send “you’re not okay” messages) and the harmful outcomes of segregation in schools, recreation, and other places (that send “you’re not okay” and “you don’t belong” messages). We may have low expectations for our children with disabilities, and we do things to them that we would never do to our children who do not have disabilities.

A child can never be better than what his parents think of him.

Marcelene Cox

In addition, our actions on behalf of the child with the disability have a powerful impact on our other children and the family, as whole. The sanctity of the home, *for everyone*, can be compromised by home-based interventions/therapies. Brothers and sisters may have to play second fiddle to the child with a disability, and this can foster a host of negative outcomes. One parent may relinquish the spousal role, as he/she assumes the “caregiver” role of the child with a disability. When the marriage takes a backseat, the family is in jeopardy.

We may also become financially dependent on “the system” (embracing the Entitlement Mentality), and emotionally dependent on professionals, believing we’re not competent to raise our children without “experts” assuming some of our parental responsibility. Albert Einstein’s definition of insanity comes to mind: “Doing the same things over and over again, and expecting a different result.” Today, we’re doing many of the same things (interventions, therapies, special services, etc.) that parents of children with disabilities who came before us did, with the same dismal

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outcomes! Children with disabilities continue to be segregated, live unnatural lives, receive a substandard education, and more. These experiences contribute to the estimated 75-90 percent unemployment rate of adults with disabilities. This is probably *not* the dream of most parents *or their children*.

In short, our lives can become warped, and many think it's because of the child with the disability, and all the "stuff" that accompanies a disability diagnosis. But, again, it wasn't the child who changed; it was the parents. And no one is holding a gun to our heads to make us do all the things we do! Granted, we don't have the power to make everything perfect. Educators, for example, may stand in the way of an inclusive education for our children.

The bottom line: *our children are our responsibility*. Professionals may carve up our children into "pieces:" physical, occupational, and speech therapists, etc. concentrate on different body parts; early intervention targets birth-to-3, special ed preschool focuses on ages 3-to-5; and so on. As parents, we must be the ones who see the *whole child, across the lifespan*. Others focus on our children's "problems," we must focus on our precious and unique children, who have strengths and abilities, and who deserve a most wonderful childhood, just like their brothers and sisters. Let's end Altered Parenting and take back our lives!

Let's value and follow the natural wisdom of our parental instincts; *we know when something doesn't feel right!* We can stop listening to "helpful" professionals who don't believe in our children's potential. (With friends like that, who needs enemies?)

We can focus on what's really important: the child living a Real Life, included in all aspects of society, *just the way he or she is*. We need to stop trying to change our children through interventions, therapies, etc. We can use therapists as consultants, as necessary; they can help us learn how to incorporate beneficial activities into our children's lives in the most natural

ways possible, in ordinary, inclusive environments. When my son, Benjamin, was younger, karate lessons promoted better range of motion in his arms than occupational therapy!

We can recognize the value of assistive technology and accommodations, and provide those for our children. A child does not need to walk, talk, etc. to live a wonderful life, but she may need a power wheelchair, a communication device, etc. Let's provide our children with whatever they need to be successful, such as a computer for writing and/or learning, instead of holding them back because they "can't write" or "can't read at grade level," and so forth.

Let's treat our children like they don't have disabilities, such as expecting them to be responsible and giving them opportunities to do so, and ensuring they participate in age-appropriate activities (doing chores, getting an allowance, making friends, and doing the same kinds of things as their brothers/sisters). Let's not allow our children's diagnoses to run their lives.

Let's restore the hopes and dreams we had for our children before the diagnosis, and do whatever it takes to turn dreams into reality. If we don't dream out-loud for our children, how will they learn to dream for themselves?

We can ask: "Am I parenting my child with a disability in a significantly different way than my other children? Am I making decisions that are having a negative impact on my child and my family?"

We have the best of intentions, but our parental common sense and belief in our own competence can be eroded by professional interference. Many "experts" may come in and out of our children's lives (if we let them), but we must be *the constant*, and do whatever it takes to ensure our children live the wonderful lives they deserve. Altered Parenting leads to Altered Childhoods. If we want our children to live Real Lives, they need Real Parenting. And, no, it's not always easy, but our children are worth it, and they're counting on us.

Love means that the adult be genuinely concerned with the evolution of the true nature of the child. Children are not able to respond to a love which tries to fashion them according to the concept of an adult, no matter how good the latter's intention may be.

Dr. Gotthard Booth