

Disability is Natural!

Revolutionary Common Sense for Parents by Kathie Snow

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.”

The Developmental Disabilities Assistance and Bill of Rights Act

Read it again—especially the first nine words: “Disability is a natural part of the human experience.” There have *always* been people with disabilities in the world, and *there always will be*. Like gender and ethnicity, disability is simply one of many natural characteristics of being human. One in five Americans is a person with a disability. Some are born with disabilities; others acquire disabilities through accidents, illness, or the aging process. Many folks who do not presently have a disability will have one in the future (especially if we live long enough). How can disability *not* be natural? When we internalize the belief that disability is natural, and merge it with our common sense, we’ll create a new paradigm of disability.

In thinking about very young children with disabilities, adopting a new paradigm of disability is critically important. Before going further however, it’s important to look at the big picture—a startling and disturbing picture—that many parents of young children may be unaware.

Ready? Let’s begin with this: the unemployment rate of adults with significant disabilities is estimated to be 75 percent! Contrast this with the six percent unemployment rate of people who do not have disability labels. A few weeks ago, this unemployment rate was 5.9 percent, but when it changes even a tenth of a percent, it makes the news headlines. But the unemployment rate of individuals with disabilities never seems to make the news, does it? Many people with disability labels who are unemployed are living below the poverty line, subsisting on “disability welfare,” which includes SSI (Supplemental Security Income), Medicaid, and in some cases, food stamps.

A variety of issues have contributed to the shamefully high unemployment rate of people with disabilities. And

it seems that a variety of different “remedies” should have worked: the passage of federal special education law in 1975, to ensure children with disabilities are educated; the passage of the Americans with Disabilities Act in 1990, to eliminate discrimination based on disability; Vocational-Rehabilitation services to assist individuals with disabilities in the employment arena; and a wide variety of services, interventions, and treatments offered to children and adults with disability labels. Today, the United States has more services, programs, entitlements, and laws for people with disabilities than at any other time in our nation’s history, and more than any other country in the world. Still, the 75 percent unemployment rate remains relatively steady. What does this mean for parents of children with disability labels? That unless we start doing things significantly different *today*, our children will grow up to become part of the 75 percent of adults with disabilities who live below the poverty line, and who spend their days in sheltered workshops or adult daycare and their nights in group homes or other congregate living arrangements. Is this the dream you have for your child? It’s not the dream I have for my 16-

year-old son, Benjamin, and it’s certainly not the dream he has for himself!

We can change the lives of our children—today and in the future—when we adopt a new paradigm of

disability, and when we change the way we think, act, and speak about our children. First, however, let’s examine the current state of affairs, from a variety of perspectives.

Today’s conventional wisdom sees disability as an abnormality that needs to be fixed or remedied, to enable the person to achieve an “able-bodied standard” of “normalcy.” For generations, society has embraced this arrogant perspective and as a result, children and adults with disabilities have been incarcerated in institutions

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and other segregated settings (including public school special education classrooms); told they're "not ready" for inclusion in school, at work, and in the community until they've achieved a level of "readiness" as defined by professionals and others; been manipulated (physically, mentally, and emotionally) in therapies, special programs, and interventions; and, in general, been prevented from experiencing real lives.

The lives of many children and adults are aberrant, but not because of the disability. Their lives are abnormal because of all the "help" they receive when *clienthood replaces citizenship*. Many individuals with disabilities do not experience the ordinary (but precious) activities of being children, brothers or sisters, employees, friends, volunteers, or the many other typical roles and opportunities taken for granted by most Americans. The disability has defined who they are, and treatments and services to address the "problems" of the disability become the focus of their lives.

Is there anything more unfair: to dehumanize people in the name of "doing what's best" for them? How many individuals with disabilities have *asked* to be segregated, treated, poked and prodded, excluded, or told they don't meet someone else's definition of "normal?" How many—if given a choice—would continue in the role others have carved for them as "clients?" Who are *we* to invoke our standards on others? How dare we assume the mantle of superiority over women, men, girls, and boys who just happen to have disabilities!

When we believe disability is natural, we'll recognize that having a disability simply means a person has a body part—legs, arms, eyes, ears, brain, or whatever—that *works differently*. That's all! We'll know a disability cannot define a person's potential, humanity, or character. We'll know people with labels don't need to be "fixed" or "treated," to "minimize the effect of the disability" or achieve an "able-bodied standard."

Instead, we'll know that tools (assistive technology devices), accommodations, and support—not achieving normalcy or an artificial level of readiness—are what people with disabilities need to be successful. And these are the same things we all need. People *without* disabilities need tools (computers, electricity, telephones, and other devices), accommodations (each of us receive and/or create these for ourselves every day), and support (from family members, co-workers, friends, and others). *People with disabilities are more like people without disabilities than different*. And if the needs of a person with a disability *are* different from the so-called norm,

this shouldn't wreak havoc in his opportunity to lead a normal, ordinary, and fulfilling life.

After hearing that people with disabilities don't need to be "fixed," someone invariably asks, "But my child needs surgery [or something else]—are you saying people with disabilities don't need medical care?" Of course not! I'm not implying we should forego necessary medicines, treatments, and/or surgeries.

But we must *rethink* interventions, treatments (including physical, occupational, and other therapies), and specialized programs. All of these can have profound and negative effects on children and adults with disabilities and their families. They send the clear and spirit-killing message that the individual receiving the treatment is "not OK," and this message wounds again and again, each and every time the person is "treated" or "served."

Specialized services also foster dependency on the system and rob people with disabilities and their families of self-reliance, freedom, self-determination, privacy, and autonomy. When parents have the system to depend on, many frequently lose confidence in their ability to successfully parent their children. Children whose parents are dependent on the system learn by example, and they grow into adults who are dependent on the system.

In addition, dependence on the system causes many to unintentionally cut themselves off from the natural supports and generic services that exist in their communities. Why should one go to family, friends, neighbors, and typical resources in the community for help when there's a system that promises mandated entitlements?

But as many of us know first-hand, the system is unable to meet the needs of people with disabilities and families. Still, we continue banging our heads against the brick wall, advocating for more services, increased funding, and other changes in the system—not realizing that a veritable garden of natural supports is already growing in our own back yards. We just haven't seen them because we're lost in the maze of entitlements, laws, programs, and special services.

Now that we've looked at the big picture of "Disability World," let's look specifically at young children who have been given disability labels. Parents of very young children with disability labels have great power to influence the course of their children's lives.

First, they can focus on their children as children, first. A disability label is simply one of many characteristics of a child who has been labeled. Again, it's patently unfair to let a label determine a child's future: how he will spend his time, where he'll be educated, what he may do as an adult, and so forth.

There is nothing "wrong" with a child who has a disability, any more than there is something "wrong"

with a person who wears glasses, has pimples, or anything else! How must it make a child feel to always hear what is “wrong” with her? What we call “problems” are really needs. I don’t say I have a “problem” with my eyes; I say, “I need (or wear) glasses.” When we think and talk about our children, it’s imperative that we use language that’s respectful, dignified, and accurate (see the People First Language article at www.disabilityisnatural.com).

Second, parents can make the choice (and it *is* a choice) to have the same big dreams for their children they had before the disability diagnosis. On that “D-Day,” the hopes and dreams of many parents are crushed, and the loss of those dreams—not the actual disability diagnosis—can lead to hopelessness and despair, as well as a frenetic rush to get every service and entitlement in an effort to make the child “okay.” A child with a disability is perfect, just the way he is: he is already “okay.” So what if some of his body parts work differently? With the right accommodations, supports, and tools (assistive technology), he can be successful at home, in school, on the playground, and as an adult, in all areas of his life! The presence of a disability need not be a barrier to success!

It’s critically important that parents believe in and have big dreams—only then can the child dream for herself. And if someone says, “You’re not being realistic,” smile and say, “You’re right! We like being unrealistic; we like having high expectations. That’s how dreams come true!”

Third, parents can rethink the services and interventions that are offered. When my son, Benjamin, was very young, many of the services and interventions which were supposed to be helpful for him created chaos and tension in our family. The hours spent at therapies (including the drive to and from), along with doing “home programs,” took their toll on my ability to be a good mom to our daughter, Emily, and a good wife to my husband. And what did these do to Benjamin? Prevented him from being a real kid living a real life!

When I began to cut back on services and therapies, I went from being a “good mom” (in the eyes of some professionals) to a “non-compliant parent!” But I did what I had to do to ensure our family’s harmony, peace, autonomy, and privacy. We replaced therapies with more natural activities that worked for all of us and still met my son’s needs. And he went from being a “client” or a “patient” to being a real, live kid (and a brother and a son)!

Incorporating “therapeutic-like” activities throughout daily activities at home can replace traditional

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therapies for very young children. Karate, ballet, T-ball, and other community activities can do the same for older kids. Being with other children who speak (including brothers and sisters) is the best speech therapy in the world!

Fourth, parents can ensure they stay connected to their natural communities and environments (friends, neighbors, church groups, typical activities) to ensure their child is included from the beginning. “Special” services are usually provided in segregated, unnatural settings, which isolate children with disability labels and their families from their natural environments. This practice often leads to continued segregation (inclusion begets inclusion; segregation begets segregation). Children who are segregated and isolated grow into adults who are segregated and isolated.

Thus, the most inclusive and natural environment for preschoolers is staying home with mom, playing in the neighborhood, attending a typical preschool or daycare, and/or doing whatever the child would be doing if he didn’t have a disability. Neighborhood preschools, instead of special ed preschools, help children with disabilities succeed in the real world.

Fifth, and building on the previous paragraph, parents can take whatever steps are necessary to ensure their child lives a “Real Life.” To me, this means asking, “What would this child be doing if she didn’t have a disability?” Whatever it is, that’s what the child should be doing. This doesn’t mean that the child is expected to “be” like children who don’t have disabilities. It does mean, however, that we shouldn’t let a disability label rule a child’s life and get in the way of a child living her dreams.

When my son was five, he played T-ball with the other kids in the Park and Rec league. He used a smaller, fatter bat, along with other accommodations. When he was nine, he took karate lessons, while using his power wheelchair. As a teenager, he’s taken drama lessons and performed in several plays in our community.

Make a concerted effort to not let your child’s disability prevent him from doing what he wants to do. And don’t let others stand in your child’s way, either. When the T-ball coach gruffly said, “We’ve never done this before [include a child with a disability],” I replied, “We’ve never done it either, so we’ll learn together!” With the right supports, accommodations, and tools, your child can live his dreams.

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A large part of not letting a disability rule a child's life is providing him with the assistive technology devices he needs, and providing those at the "right time." When Benjamin was very young, I was heavily influenced by therapists and other health care professionals in their determination that, with enough therapy, Benjamin would walk one day. For six years, therapists worked on him, and he did walk in a walker. But it wasn't an efficient form of mobility; he had to really work hard, he tired easily, and he couldn't play with other kids on the playground at school. Over the years, I fortunately met successful adults who used wheelchairs, and I learned that walking wasn't the end-all and be-all. What *was* important was getting from point A to point B in the most efficient way possible! With no support from professionals, we got Benjamin a power wheelchair when he was nine and it changed his life! He was in control; he could go where he wanted, when he wanted.

If I had to do it over again, he would have had a power wheelchair when he was two, so he could have explored, learned from, and mastered his physical environment the way other two-year-olds do. As it was, my husband and I realized that by not providing Benjamin with effective mobility at the appropriate time (when children are usually mobile, at 18-24 months) we had *prevented* our son from experiencing the typical and vitally important activities which children learn from—which shape their views about themselves and the world.

As parents, we're often told that our children are "delayed." But these so-called delays can be eliminated if an 18-24 month-old child is provided with independent mobility (walker, power wheelchair, or whatever he needs). Ditto, a child who is not speaking! Two-year-olds learn so much by talking and the interactions and social relationships that come with oral communication. A child who isn't speaking, however, does not have to miss out on these important activities if he has a communication device!

Some parents and professionals believe we should not provide these tools to children: "If we get him a communication device [or wheelchair], he'll never learn

to talk [or walk]." When we take this attitude, we rob children of the invaluable experiences of communication and mobility—experiences that can set them on the path to success and inclusion.

What difference does it make *how* a child best communicates or moves? Isn't the fact that he *can* communicate and move more important than *how* he does these things? (Would you rather have your two-year-old say, "I love you, Mommy," with a communication device or not at all? Would you rather have your two-year-old race to hug you in his power wheelchair or not at all?) Many children with disabilities *do* become delayed in social, behavioral, and/or learning because they don't have communication or mobility. Isn't it important to recognize that assistive technology devices can both enable a child to maintain "typical development" and minimize "delays?"

Disability is a natural part of life—and the lives of children with disability labels can also be natural and successful.

As mentioned previously, we have traditionally seen disability as a "problem" within the person—a "problem" to be remedied, treated, or fixed. *But the problem never has been the disability.* The real problem is, and always has been, society's *attitude* about disability. We don't need to "fix" children with disabilities; we need to fix our own attitudes. We can no longer let children and adults with disabilities live unnatural lives and exist in the margins of society because of our mistaken assumptions. When our attitudes have evolved, we'll know that within families, among friends, and in the community, disability is irrelevant.

Believe that disability is natural; believe in your child and his future; know that your dreams can come true; let your child lead a real and natural life; ensure he has the supports, accommodations, and tools (assistive technology) to do what he would do if he didn't have a disability label; remember that a disability label is only a sociopolitical passport for services, not the defining characteristic of your child. And when you do all these things, the world—and your view of your child—will change before your eyes. More importantly, perhaps, the way your child sees himself will be forever changed.