

Why Do We Have PARALLEL WORLDS?

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

A 20-year-old woman moves away from home. Her parents know she still has a lot to learn. They trust she'll learn what she needs to know—through experience, just like they did, just like most young adults do.

A 35-year-old woman with a disability has lived in a group home for fifteen years. She wanted to move out on her own when she was 20, but her parents said she wasn't ready, so they put her in the group home. Now the group home staff tells her she's still not ready, and that she can't even consider living on her own until she meets the goals in her IHP (Individual Habilitation Plan), which include: cook efficiently, do laundry appropriately, wash the dishes within 20 minutes of finishing a meal, make the bed within 30 minutes of getting up, and so on and so on and so on.

A 16-year-old boy applies for a job at every fast food restaurant in his part of town. His parents and friends give him a little advice on how to handle a job interview. He finds a job and begins saving money for a car. He's on his way to adulthood.

A 16-year-old boy with a disability wants to get a part-time job. But no one thinks he's ready (or able) to do this on his own. So his parents, special ed teacher, and a vocational-rehabilitation counselor convene an IEP (Individualized Education Program) meeting to talk about this issue. The voc-rehab counselor and the special ed teacher will try to get him a job; they know best. Six months later, he's still waiting.

A 10-year-old girl struggles with math and reading. Her parents give her extra help at home and they enroll her in after-school classes at a private learning center. Her classroom teacher is giving her more help at school. Everyone knows she'll catch up.

A 10-year-old girl with a disability label struggles with math and reading. Educators believe—based on her IQ score—that she'll never master either. So her IEP goals are now focused on daily living skills in the special ed resource room. Her parents are told to get their daughter on the waiting list for adult services so she'll be assured of a group home placement when she ages out of special education services at age 22.

The mother of a 3-year-old wants her child to spend time with other young children. She visits several preschools close to her home (unannounced visits), interviews the directors and teachers about the 3-year-old Tuesday-Thursday half-day class, and talks to other parents whose children are enrolled at the preschool. She's determined to find the place that's right for her child!

The mother of a 3-year-old with a disability is told which special ed preschool her child will attend. She's not crazy about putting her child on the school bus five days a week for the 45-minute ride each way (at 8:30 am and 3:30 pm), and she doesn't visit the school to check it out. She'd really like to keep her child home with her—she can't imagine her son being away from her all day (and taking naps at school). She also thinks she's been doing a good job helping him learn new things. But she figures the professionals at the segregated special ed preschool must know best.

to a place they know little or nothing about? And why does this mother believe the experts' opinions that the only place that's appropriate for her child is a segregated environment?

Why don't the parents of the baby with a disability say no to the therapies and interventions that cause disruptions and discord in their family's life? If they truly believe their baby needs ongoing professional help, why don't they redesign the help so it's more natural and less intrusive, so they can ensure their baby lives the life of a baby, instead of a patient who needs to be "fixed" via therapies and interventions?

Yes, within the system of services for people with disabilities, sets of rules create PARALLEL WORLDS. And too many people with disabilities and their families exist in DISABILITY WORLD—a surreal world that isolates and segregates them from the REAL WORLD. DISABILITY WORLD is created by the service system and its rules. It continues to exist only because people with disabilities/family members choose to use THE SYSTEM and follow its RULES.

Service professionals are expected to enforce THE RULES. Many do so, without question. Others are beginning to see the unintended negative outcomes of these RULES, and they're bending (and sometimes breaking) many of the ridiculous RULES that are hurtful instead of helpful.

Some people with disabilities and family members follow THE RULES without question. Others try to bend the rules, and still others are saying no as they pack their bags and leave DISABILITY WORLD once and for all.

The path that's chosen—whether a person is a "provider" of services or a "recipient" of services—seems to be determined by one's belief system. If a person ("provider" or "recipient") believes people with disabilities and/or family members are needy, unable, and/or entitled, and

also believes that THE SYSTEM can provide all the answers, this person embraces THE RULES. And amazingly, there are many people who profess to hate THE SYSTEM and its RULES, but they continue to *defend and protect* both.

I've met educators, for example, who dislike the segregation of students with disabilities. But they stay in their jobs as special educators (educating students with disabilities in segregated special ed/resource rooms) while they attempt to "change the system." My friend, Charmaine—a special educator—tried this for a few years before she saw the light (or actually the dark). When she realized she could not

change her school alone, she shed her "special ed teacher" label, became a second grade teacher, and made sure second-graders who had disabilities were included in her classroom.

At the other end are parents who feel they are constantly "fighting THE SYSTEM" (and as a result, they're emotional and physical wrecks). Most of them are terribly unhappy with THE SYSTEM and its services and bureaucratic red tape, but they refuse to look into alternatives, determined to (1) get their child's "entitlements" and/or (2) "change the system." In the meantime, their children are in suspended animation—not getting what they really need (from any source possible), being segregated, living unnatural lives, and more.

If, on the other hand, a person believes that people with disabilities are competent, able, and "okay just the way they are," they try to bend or break THE SYSTEM'S RULES so they'll make more sense. If that doesn't work, parents and/or people with disabilities *cut their losses and move on*, using alternative sources of assistance; and professionals change careers (as my friend did). Still others deny

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the validity of today's conventional wisdom, and choose to live without THE SYSTEM and its RULES. My hope is that individuals and their families will begin to use THE SYSTEM as a last resort, instead of the first choice. I hope we'll look to the natural supports and generic services in our communities for the assistance an individual/family might need—and go to THE SYSTEM, again, only as a last resort.

If we pause and ask why we do what we do, and then wonder how we can do things differently, and when we act more humanely and consider the feelings and real needs of people with disabilities, change will come. Service providers can help by providing people with disabilities the assistance they need to meet their *real* life goals instead of focusing on the achievement of “life skills” which they, as service providers, don't always meet! And they can ask themselves, “How would I feel if someone wanted to write an IHP for *me*?” (Most, if not all, wouldn't stand for this!) Pondering gives rise to new ways of thinking.

People with disabilities and parents can take more personal responsibility for their lives and move away from dependence on the services that frequently make their lives worse, instead of better. They can and should decide what's important and right, instead of assuming others know best.

Each of us can create community connections to ensure individuals with disabilities are included, and that they receive assistance from the natural supports and generic services in their communities. Other articles on this subject are available at www.disabilityisnatural.com, and the strategies in my *Disability is Natural* book can lead us in new directions.

**There are no secrets.
There is no mystery.
There is only common sense.**

Onondaga Proverb

One overall belief can guide us: if it's not okay for people *without* disabilities, it's not okay for people *with* disabilities. For example:

- If it's not okay to make a 35-year-old *without* a disability live under the supervision of others until he can cook and do laundry, it's not okay to enforce that rule on a 35-year-old *with* a disability.
- If it's not okay to put a 3-year-old *without* a disability on a 45-minute bus ride to a segregated environment, it's not okay to do it to a 3-year-old *with* a disability.
- If it's not okay to talk about the “problems” of a person *without* a disability, in front of him, like he's not even there, while ignoring his strengths and abilities, it's not okay to do this to a person *with* a disability.

Consider the countless other situations in which you could apply this new way of thinking, which can help eliminate PARALLEL WORLDS. Then spend some time pondering all THE RULES (spoken and unspoken) that are applied to the individual(s) with disabilities in your life. Question if they reflect common sense—if they're relevant, meaningful, dignified, honest, and realistic. When you do, the bustling activity of your wondering brain—and the conclusions you reach—will astound you!