



Take a Walk in Their Shoes

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

Perhaps most—if not all—of the problems in the world could be solved if we understood each other better. What might happen if people of different nations, different religions, and different ethnic groups could walk in each other's shoes? Would world peace become a reality? Well, you and I may not be able to change the world overnight, but we can work miracles closer to home by trying to walk in the shoes of the people with disabilities in our lives.

No matter what our relationship with a person with a disability—whether as a family member, friend, educator, or professional—the ways we think and act have a powerful effect on that person. Most of us want “the best” for this person, which frequently means we do a great many things *to* or *for* the person. So what could be wrong with that? Lots.

This scenario reflects two faulty and dangerous beliefs: (1) the person is Not-OK (because of the disability) and (2) the person doesn't know what's best for himself (is incompetent), but *someone else* (parent, service provider, educator, or professional) does. Both of these perceptions are paternalistic, and they lead to an unequal relationship in which two people assume opposite roles: competent/incompetent, powerful/powerless, helper/helpee, provider/recipient, and so forth.

Before deciding to do anything *to/for* a person—and/or the family, in some cases—let's remember that services, treatments, interventions, and so forth, are *options* (choices), not mandates. State and federal laws *do* mandate that certain services be *offered* to people with disabilities, but there is no mandate that people

must *accept* and use the services, and we seem to forget this on a regular basis! So before doing anything *to/for* a person, the person/family needs to decide if the service is wanted and/or needed. And the first step in that process is ensuring the person/family is given a boatload of information about the service, including the pros and cons. A service/treatment may, on the surface, seem beneficial. But there may also be dangers, including: segregation and isolation, creating dependency on the system, stripping a person/family of autonomy and self-determination, turning the person into a “patient,” and more.

Next, the person (or family, in some cases) needs to be *asked* if she wants the service. People with disabilities and families always have the right to say no, and saying no to one service must not jeopardize the right to use other services, now or in the future. Professionals can be most helpful if they learn to ask, “Do

..... you *want* this service,” instead of assuming and/or insisting a person/family needs or will use the service. It's also important for individuals and families to learn as much as they can about the

service—on their own and by talking with others who have used the service. In other words, they need to get “all sides of the story.” Further, it's crucial to anticipate the short- and long-term outcomes of using the service. Again, we may mistakenly assume a service is appropriate, helpful, or beneficial, simply because it's offered, when it may actually have harmful outcomes or negative consequences!

Whether thinking about the services a person is currently receiving, or services that may be considered

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for the future, we can ask, “Is this needed, wanted, and/or appropriate?” Simultaneously, we can do whatever it takes to learn how a service may impact a person’s life. Oh, what we can learn when we ask questions and really listen to the person! We can also try to walk in his shoes, and use our fertile imaginations in an attempt to understand what his experiences are really like.

When my son, Benjamin, was diagnosed with cerebral palsy at the age of four months, I wedded him to intensive therapies. It’s what “everyone” said he needed and I believed it at the time. I dutifully took him to physical, occupational, and speech therapies several days each week.

During one physical therapy session when Benj was about two, the therapist continued an “exercise” she had been working on for a few weeks. The goal was to “improve” Benjamin’s posture. “Tina” sat Benj on a small bench, positioning his feet flat on the floor and the palms of his hands flat on the bench, next to his thighs. When his body was so arranged, his head and shoulders drooped forward. This was the “problem.” The purpose of this exercise was to enable Benjamin to hold his feet flat on the floor, keeping his knees and hips at a 90-degree angle, his palms flat on the bench, and his shoulders and head erect. So Tina sat behind Benj, pulled his shoulders back, and his head practically snapped to attention. Simultaneously, however, Benj’s palms rose off the bench.

“No, no,” Tina said, as she repositioned Benjamin’s palms flat on the bench. “Let’s do it again!” Each time she pulled back on his shoulders, his head moved into the “proper” position, but his palms lifted off the bench. So Tina pushed his hands back down and tried again—and again and again and again. It wasn’t working, but she didn’t give up! Benj was becoming agitated—tired of being pushed and pulled. Tina was tired of Benj “not cooperating.” Benj, from my perspective, was trying as hard as he could, and *I* was irritated and tired of watching Tina manipulate my son’s little body! I politely suggested she do something else.

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As a “good therapy mom” at the time, I always tried to learn how to do what the therapists did, so I could do it at home. I was curious why this exercise didn’t seem to work, so that night I tried it on myself. I sat on the piano bench with my feet flat on the floor, my knees and hips bent at 90 degrees, and attempted to place my palms flat on the bench next to my thighs, while holding my head and shoulders straight. Guess what? I couldn’t do it! My palms came up off the bench, too.

What was going on here? I asked my husband, Mark, and my daughter, Emily, to try it. They could do it! I thought I must be doing something wrong, so I did it again and still no luck! Then four-year-old Emily said (with the wisdom of a child), “Mommy, your arms are too short, that’s all!” And she was right: my arms simply weren’t long enough, and the same was true of Benj! Perhaps the therapist had been taught that the “average” person could assume this position. *But who’s average?*

At the next therapy session, I shared my discovery with Tina. She was skeptical until I sat on the bench and showed her. Tina stood with her mouth agape. My demonstration seemed to rattle her world—*what other therapeutic principles might also be erroneous?* For the first time (but not the last), I wondered if therapists and other professionals routinely tested their work on themselves. Did they question if their methods were appropriate for everyone or was the one-size-fits-all mentality the norm?

Had I not tried to walk in Benj’s shoes, I may have allowed Tina to continue her attempts to manipulate his body into a position he could never achieve. And the “failure” of this futile exercise would have landed squarely on little Benj—not on the therapist’s erroneous assumption that this was an appropriate technique for my son.

Since that experience, I have diligently tried to always see things through Benjamin’s eyes, knowing that even my best attempts cannot come close to his real-life experiences. When I’m unable to replicate what he’s experiencing or see things clearly from his perspective, I ask him to help me understand. And I try to really hear what he’s telling me. I listen to his

words, as well as his feelings and his behavior—*what's behind his words*. We all communicate in many ways.

Back to Benjamin's therapy experience, how many similar situations occur to other children and adults with disabilities each day? How many times have professionals, parents, educators, medical personnel, or others unintentionally caused emotional or physical distress or harm to children and adults with developmental disabilities while providing "help"? How many individuals have been described as failures, incompetent, uncooperative, low-functioning, disruptive, manipulative, inappropriate, subnormal, or any other labels because they don't meet an artificial standard, a developmental milestone, or some other counterfeit measure of achievement? Who among us—regardless of position, title, training, or expertise—has been awarded the power to judge?

Once we chose to question what was being done to/for Benjamin, my husband and I were better able to see what was really important: our son's spirit. We made changes—in our attitudes, in our actions, in the services our son received, and more—even though some told us our decisions were very wrong, according to conventional wisdom. Many of us are learning, however, that *conventional wisdom isn't concerned with a person's heart and mind*. Therefore, we must be.

Isn't it important to carefully consider how our actions affect the person? We can start by looking inside ourselves to identify our motives: do our actions benefit ourselves, or the person with a disability? We may truly believe that everything we do to/for a person is for *his* benefit. But deep introspection may prove us wrong.

Parents, for example, may work diligently to "improve" a child's appearance, behavior, or abilities because of their *own* embarrassment or discomfort. In other words, a child's "problem" may actually be the parents' problem! The same might be true for educators or other professionals. If a student isn't doing/behaving/looking "right," an educator may feel *she* will look bad—the "guilt by association" rationale. The belief that *we* could be judged by the

actions/appearance of another person may lead us to do things that just aren't right for the person.

The only solution to this dilemma is to not care what others think! How can we risk harm to another just so *we* won't look bad? Is how *we* appear to others more important than the hearts and minds of the people with disabilities in our lives? How might *you* feel if your mate was embarrassed by your size, hair (or lack thereof), or some other characteristic, and this resulted in your mate constantly trying to do things to/for you to solve "your problem"?

Many of us may do to others what we do to ourselves. Thus, if we're very judgmental of ourselves, we tend to judge others, *and* we believe others are always on the look-out to judge us. Teenagers, for example, are often harsh self-critics, fretting over the appearance of their hair, clothes, make-up, etc. In turn, they worry about what others—even strangers—think about their appearance. And, as the wheel of criticism goes around, they tend to look at others with a sharp eye. Hopefully, most emerge from this cocoon of insecurity.

Trying to walk in someone else's shoes can help shred the mask of disability.

Moving beyond the personal milieu, we may feel obligated to do certain things to/for a person within the context of our positions. Taking certain actions may be mandatory within the realm of services, bureaucratic policies, entitlements, and so forth. Thus, if a professional doesn't do this-or-that, he may feel he's not doing his job correctly.

For example, when Benj was in elementary school, I asked the occupational therapist to help him with keyboarding skills in the classroom. In a huff, she replied, "That's not therapy!" She believed she wouldn't be "doing her job" if she didn't pull him out of class and make him stack blocks. It didn't seem to matter to her that keyboard skills were what Benjamin really *needed*.

Services, treatments, policies, and entitlements are supposed to meet the needs of people. If these are *not* helping and are, in fact, *causing harm and/or are getting in the way of a person's success*, a big reality check is in order.

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We can ponder whether we're really doing what's *right* for a person or if we're simply "following the rules." The determination of what's *right* rests with the person, first, and his family, second—nowhere else! How would we feel if others decided what was right for us while disregarding our wants, needs, feelings, hopes, and desires?

The belief that we (or others) *know what's best* for a person drives many of our actions. Put under a microscope, this notion seems to reveal more about us than the person. If we take a peek through the lens, we may see arrogance or superiority within ourselves, coupled with the belief that the person is pitiful, incompetent, unable, or not-okay. What we learn about ourselves through brutally honest introspection may be a difficult pill to swallow, but it can help us become more caring human beings.

We may be so hung up on disability diagnoses and the value of their accoutrements (treatments, services, and so forth), that we no longer see the real person and what his life is really like. Trying to walk in someone else's shoes can help shred the mask of disability.

Before doing something to/for a person, let's do it to/for ourselves, whenever possible. For example, a therapist can attach electrodes to her *own* skin and try to imagine what this feels like to an eight-year-old child who has cerebral palsy. She can then imagine what it feels like when she cries at the discomfort, pain, or indignity and *no one listens to her cries*. A behavior therapist can have a co-worker be "in his face" for eight hours a day to mimic intensive "behavior therapy." A service provider or special ed teacher can have six of her co-workers sit around a table and talk her problems, in front of her, like she's not even there, and then they can write goals to address your problems.

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What other real-life activities can we do to/for ourselves (or have another person do to/for us) before making the decision to do these to/for a person with a disability? Think long and hard...

When it's not possible to replicate something, we can use our imaginations. Imagine losing your ability to communicate orally. You want a communication device, but others don't agree. They feel you need therapy to learn to speak again instead of a device because (1) you don't have the ability to use a device and/or (2) providing you with a communication device means (a) they'll have to give up on the belief that you'll ever learn to speak again and/or (b) you'll become dependent on the device and won't try to speak. But you don't care about therapy or learning to talk again; *you simply want an effective means to communicate!*

Here's another scenario: imagine you're told where you can/can't live or work based on someone else's *opinions* of your abilities and competence. (Let's never forget that what is *said* about people with disabilities including the results of assessments and tests, are only opinions—not facts.) See yourself with little or no control over your life, while other people (who may not know you, who may be younger than you, and/or who aren't really a part of your life) have infinite power and control over you. What would that feel like to you?

In the final analysis, it seems there are two practices that can help us do the right thing. First, common sense and basic respect dictate that we listen to the words and messages from children and adults with disabilities. Second, being empathetic—walking in someone else's shoes and trying to see things from his perspective—can be the light that guides our actions. It can be this simple: before doing something to/for a person with a disability, ask yourself, "What would I want if it were me?"