

Eyes Wide Open or Shut?

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

When our family recently moved from our Colorado home (for more than 20 years) back to our native Texas, we—like most home buyers—wanted to find the home that was “just right” for us. We didn’t expect perfection; we’re big do-it-yourselfers, so we were prepared to paint, add this, remove that, and so on.

We did, however, look for a home that was—or could easily become—wheelchair accessible for our son, Benjamin. So when searching through Internet real estate listings, imagine our delight when we discovered a home with a roll-in shower. *This was it*; we couldn’t ask for more! On our first house-hunting trip to Texas, we looked at that particular house and several others. We were thrilled with the home with the roll-in shower (Home #1), not interested in most of the others, but we also liked Home #2 that had a more open floor plan (good for wheelchair access) and a lovely screened-in back porch (something my husband always wanted). But Home #2 would require a total bathroom makeover for wheelchair accessibility.

We offered a contract on Home #1, but another buyer beat us to the punch. That house seemed perfect for us, and now we were back to square one.

Returning to Texas a few weeks later, we looked at Home #2 again. But, no, it would probably be too much work to do the bathroom, plus there were other renovations we’d need to do. And then—amazingly—we found Home #3 with an even bigger, better roll-in shower. Again, we offered a contract; again, other buyers got there first. This time we were absolutely distraught. The tides were against us; what did we do to deserve this, and did those other buyers even really *need* a roll-in shower or were they buying the home because of the large windows, high ceilings, and other lovely attributes?

We didn’t want to make a third house-hunting trip, so we visited Home #2 for a third time and then a fourth. Would this home work for us? We decided

it would—we’d remodel the bathroom and make the other changes—and the sale was a done deal.

Once the decision had been made, we were excited about the possibilities for our new (older) home. We pictured our furniture in it, imagined this and that, and patted ourselves on the back for finding the right home. Simultaneously, we thought about the two homes that had seemed “perfect” for us and realized how *wrong* they would have been! Home #1 had a detached garage that would have required pouring a concrete pathway to create an accessible path for Benjamin; there was little turn-around space in the kitchen; and after reviewing the photos we took, we realized that while the bathroom *did* have a roll-in shower, it also had no turn-around space—Benj would have had to drive in and back out. *What were we thinking?*

We realized similar issues with Home #3: it had only two bedrooms (we wanted three), it had a single carport (we needed a double garage for one car and to store lots of stuff), and it was a smaller house than the one we were moving from—where would we have put all our stuff and ourselves? Again, *what were we thinking?*

In hindsight, we realized we looked *only* at the roll-in showers, while other characteristics of those two houses were literally invisible to us. We didn’t look at the properties “as a whole;” we focused on one thing (roll-in shower) to the exclusion of everything else. We realized our “unsuccessful” offers were actually lucky breaks for us!

What does this have to do with disability issues? It seems that this is what often happens in the lives of children and adults with disabilities: others look primarily at one characteristic—the disability/diagnosis—and do not see the person as a whole. They don’t see positive characteristics, strengths, or abilities.

Do we see Johnny’s desire to “run” (or “elope”—where do people come up with these ideas on how to label people???) as a “problem behavior” and then

It’s not what you look at that matters, it’s what you see.
Henry David Thoreau

2 – Eyes Wide Open or Shut?

expend enormous efforts to “fix” this “problem” and also keep Johnny safe, by having a one-to-one aide hold firmly to Johnny’s arm? A recent national news story detailed a different perspective. When this little Johnny was young, and his parents realized he needed lots of movement in his life, they channeled what others saw as a negative into a positive. They helped him learn to run when and where it was safe in organized sports and other activities. Today, as a high school senior who happens to have autism, he recently ran close to a 4-minute mile, has been offered track scholarships to numerous universities, and he wants to run in the Olympics.

Are Maria’s “tantrums” really “problem behavior” or are they a wonderful demonstration of her emerging autonomy and desire for self-direction? (And could they also be a self-protective reaction or response to how she’s being treated by others? If so, aren’t we glad she understands the need to protect herself?)

Is Will’s preference to dismantle anything with a motor an “unhealthy obsession” or is it an indication of an insatiable curiosity that could lead to a career in small engine repair?

Our Benjamin didn’t talk until he was three and according to professionals, he was very delayed: couldn’t sit up, crawl, walk, and on and on. But as soon as was able to speak, he could also mimic his favorite TV shows and videos, including the British accent from his beloved *Thomas the Tank Engine* videos. We were amazed! Professionals, however, weren’t impressed; mimicry and an incredible auditory memory weren’t on their developmental tests, so these were ignored as strengths. But we encouraged Benj; as he grew up, he could mimic the anchor’s delivery of the nightly news headlines and much more. Later, we enrolled him in children’s drama classes, where he excelled.

What are you *not* seeing when you look at the person with a disability in your life? What might you *discover* if you looked at the person differently?

Discovery consists of seeing what everyone has seen and thinking what nobody has thought.

Dr. Albert Szent-Gyorgyi

Why not make a list of the person’s characteristics and carefully examine it? Ask the person with a disability, as well as others who know the person well, to contribute to the list. If we had made such a list when we were house-hunting, we most likely wouldn’t have wasted time, energy, and emotions, nor made offers on homes that would have been totally wrong for us.

When you look at the list, what characteristics are simply the individual’s personal idiosyncracies, are not related to the person’s diagnosis, and are not really a “problem” at all *if we don’t see them in that way*? We all have idiosyncracies, yet others don’t label them as problems and try to “fix” us; they love and accept us, warts and all.

What characteristics that we may have seen as “problems” are actually strengths or interests—like Will’s desire to take motors apart—that we can exploit and build on? Which represent typical behaviors or situations that we should *celebrate* as “normal”? For example, is a two-year-old with a disability simply being a “terrible two” when he throws a tantrum or does he have obsessive-compulsive disorder? Are the actions of a 16-year-old girl *really* “noncompliant behavior” or is she simply moody and irritable because she’s experiencing PMS (premenstrual syndrome)? Can we cut her some slack, like we’d want others to do for us? If a student with a disability is “behaving irresponsibly,” is that *because* of the disability or because it’s pretty typical behavior for his age group? And are we giving him plenty of opportunities to learn from his mistakes? We may spend so much time and energy trying to make people with disabilities “normal”—by trying to “fix what’s wrong”—that we’re unable to recognize, and therefore, *unable to value and respect*, normal and/or ordinary behaviors, attributes, or situations.

Look at the person and see what no one else has seen. Think what no one else has thought. Share your new perceptions with others. Open their eyes, as yours have been opened. In the process, you’ll change the life of a person with a disability, and your life will be changed as well.