


UNLEARNING EXCLUSION

How I Became a Part of the Solution

By Kathleen Balthrop Havener





No child is born with an aversion to sunglasses or walking sticks. No toddler is anything less than fascinated by wheeled vehicles of any kind—including wheelchairs. No child observes for the first time another person using sign to communicate and is inexplicably frightened or compelled to turn away.

Each of these is a learned behavior, not a reaction that occurs naturally. Along with the more complicated prejudices and aversions we may feel toward persons who experience disabilities, our prejudices, once ingrained, must be unlearned if we are to enjoy the benefit of ordinary, unspoiled, and comfortable relationships with everyone around us. If we are to include persons with disabilities other than our own—I believe that I and each of us lives with some quality, often carefully hidden, that renders us different from our neighbors—in our everyday lives and activities, we have to unlearn our reactions of fear, misunderstanding, ignorance, and laziness and replace them with appropriately focused, carefully thought-out, directed efforts to include.

MEETING CHALLENGES

Imagine yourself as a deaf person who has successfully made it through law school. You attend your first ABA meeting. Is a single event equipped with a sign language interpreter? Or imagine you're blind. Are the materials available in braille or via recorded technology? Now imagine yourself a wheelchair user. You may find that CLEs and other events in a single venue are located on different floors, or that they are located at different hotels, maybe even a bus trip away (on a bus you can't access). You can never get anywhere on time, and when you do, there's no arrangement for handicapped seating at the CLE. Don't even dream

Veer

of accepting an invitation to sit on the

dais. When you finally arrive at a new venue, you may very well find that the only accessible entrance is *not* where you've been deposited by the bus (that you couldn't ride), but rather is around the block. Networking receptions may be scheduled in beautiful but unretrofitted buildings, and you can't even get in. And when you do, the event—the bar, the food, the seating, the layout—is set up with fashionable but entirely useless (to you) bar-height tables and lovely counter-height chairs. You never see a speaker who addresses the audience from the floor. Instead you are treated to a lovely view of a sea of backsides.

Upstairs in your hotel room, you note that the brilliant designers have included a luxurious roll-in shower—inside a bathroom your wheelchair cannot access because the door is too narrow. And where shall you sit when you take your inaccessible shower? There is no shower chair. Do hotel room designers think you shower while sitting in your own wheelchair and then redirect your now shower-soaked chariot to dinner? Oh, and after that shower—why are the towels in every hotel room in America placed at a height where only a person over five feet tall can reach them? A sitting person has to air dry.

AN EDUCATION IN INCLUSION

I was supremely lucky to come from a family that taught from the beginning that humans are more alike than different. My parents were civil rights activists in the Deep South during the 1950s and 1960s. I had always known—from infancy I guess—that racial and ethnic divisions existed. But not in our house. My father was an old-fashioned small-town doctor, and he treated everyone. He had served in the Philippines during the war, and therefore he welcomed and our family hosted parties for the young Filipino doctors and their families. My own godparents were from Paraguay.

From Daddy's practice I knew that people suffered from illnesses or injuries that made them look or behave differently, and yet I was always clear that "inside their heads" they were no different from me. A classmate's mother had multiple sclerosis. Although she used a wheelchair all my life, she brought cupcakes to school on her daughter's birthday, she drove a car, she was a part of our lives. The gentleman who taught civics to me and every one of my eight siblings had survived polio and used crutches. My father's aunt had a permanent tracheotomy

ADVANCED STUDIES

It was a blessing in every way to come from a home where my parents accepted physical and mental differences just as they rejected racial and ethnic prejudices. But my very accepting upbringing was not enough. It took a life-changing event to teach me not only the importance but the "how-to" of inclusion.

On a late September afternoon in 1996, while working on a long-term assignment on behalf of a client involved in an administrative proceeding in Alaska, walking down a hall in our temporary

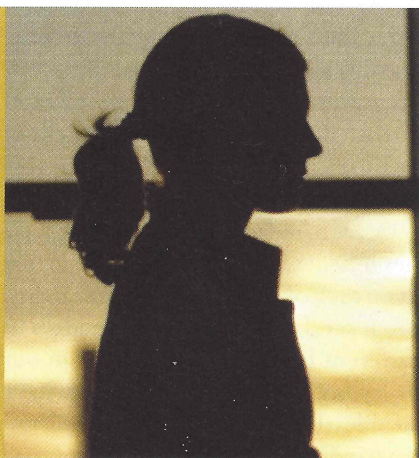
he suffered a spinal cord injury in a devastating 100-foot fall from a cliff into the shallows at a bend in the Chagrin River in the Cleveland Metroparks.

Apparently my reaction was unusual. I wasn't silent. I wasn't falling over myself with empathy. I didn't ignore that he had said it. I *wanted* to talk about it—or more accurately, I suppose, listen. I remember that I was intensely curious. I peppered Tom with questions about his accident and its consequences. I learned about the immediate treatment he had received after being revived (yes, revived) in the ER at the nearest hospital. He was at first totally paralyzed, able only to turn his head (which was discouraged) and speak. Tom received almost no intervention and shockingly little palliative care. He wasn't operated on for nearly three months. No one even washed his hair—caked with blood and mud and leaves from the river bottom and God-knows-what else—until he was to be moved from the first hospital to the second. It was 1981. The fear of malpractice lawsuits overcame the hospital's responsibility to try to improve Tom's prognosis.

Tom's story is one of fortitude, pain, unimaginable effort, years of rehab, and a stubborn refusal to be beaten. He returned to his junior year at The Ohio State University only six months after his fall, when—though left-handed—he could write only with a pencil held in the fist of his right hand. But his progress was fast. He soon learned to drive with hand controls. He graduated from college with a degree in journalism only one-quarter behind his cohort. After a year off to concentrate on further physical therapy and rehabilitation, he entered Case Western Reserve University Law School. He graduated from CWRU in 1987 and immediately went to work for a large national law firm based in Cleveland. And all these accomplishments preceded the passage of the Americans with Disabilities Act.

Although this article isn't Tom's story, it was Tom's story that opened the door to my own journey of learning what "inclusion" means to persons with disabilities. By the time I knew Tom at all, I knew he would be in my life for a long

It took a life-changing event to teach me the "how-to" of inclusion.



sometime in her forties, but she still managed to visit us from Nashville where she was the mother general of her convent. A young woman at our church had Down syndrome, but she participated fully in the life of our parish. She was one of the people I taught in a catechism class preparing to receive their First Eucharist. Most of the class was seven years old; I was 17; "Miss Janet" was 37. My father's sister was schizophrenic and at age seven had been injured in a house fire from which she never really recovered. She had the maturity and competence of a young child. When her own parents died, she came to live with our family lest she be institutionalized, a fate with which at some stage she had been threatened and that frightened her more than death. We learned that our aunt was different. She was entitled to the respect we accorded to any adult, while at the same time we knew to protect her from her own immaturity, just as we did our younger siblings.

offices in Anchorage, I heard a man's voice on speakerphone leaving someone (not me) a voice mail. I experienced a kind of shiver and inquired aloud, "Who is that man?"

"What man?" came a chorus of replies. I hurriedly responded, "The man speaking in that voice mail!" A still-invisible (and surely baffled) employee identified the speaker by name and ventured, "I think he has the office next door to yours."

"I declare," I announced, feigning a swoon à la Miss Scarlett, "I swear I would marry that man just to listen to him talk for the rest of my life." Nine months later I did.

Later that day, when introduced to Tom Havener in person for the first time, I discovered that he ambulated by means of a wheelchair. I don't remember reacting to that fact in any way. Soon thereafter—the first time we had an opportunity to really converse—Tom told me that 15 years earlier (when he was 20)

time, and I knew I had much to learn. I headed for the library.

Alas, there is no primer for learning what one must know if one's plans are to include a person who is mobility-impaired. I am glad that I am not ashamed of my ignorance but rather intent upon eradicating it. The first assist I received was a library copy of the memoir *Moving Violations* by former National Public Radio newscaster John Hockenberry. Hockenberry became a wheelchair user as a result of an automobile accident when he was 19. It was from *Moving Violations* that I learned that a person's wheelchair is a part of his person. It is ill-mannered to bump into a person's wheelchair without excusing oneself, exactly as it would be to bump into another's body without excusing oneself. I learned that no one is "confined" to a wheelchair—no one sleeps or bathes in a wheelchair. A person *uses* a wheelchair to ambulate. I learned that wordlessly starting to push a person using a wheelchair who appears to be struggling with an obstacle is as unacceptable as it would be to wordlessly begin pushing from behind any able-bodied person one might encounter walking on the street. Offering help is fine so long as one is gracious enough to accept the disabled individual's refusal of that help. Insisting on giving aid will embarrass both parties and may humiliate the intended beneficiary.

It was from setting up house with Tom that my daughters and I learned that not all kitchens are set up the same way. Coffee mugs, plates, and bowls go *under* the counters, not above. The same for the cooking equipment. The only things stored above Tom's reach in our house are things that I *know* he wouldn't use on his own. The stand mixer. A crockpot. Extra bags of sugar and flour. Champagne glasses. And where the ordinary glasses are stored, the bottom shelf soon became Tom's—and we typically leave at least one clean glass of any size available on the shelf within reach.

WHEN YOU ASSUME

Living and socializing with Tom taught me how many and how unbelievably stupid are the assumptions and habits that people need to unlearn. Tom telephones

a restaurant for reservations, drives us to dinner, and tips the valet (who inevitably hands the keys to me and not Tom). If we're lucky enough to be able to enter via the front door rather than through the kitchen, Tom announces our arrival to the *maitre-d'*. The *maitre-d'* either ignores Tom altogether and speaks directly to me, or—even more oddly—speaks to Tom near his ear and at the top of his



Living with Tom taught me how stupid are the assumptions people need to unlearn.

lungs. The priceless—and almost inevitable—question is “where would he like to sit?” Tom cannot walk. But his hearing is A-OK and he can speak for himself, thanks. Ask him.

Don't assume anything about him. Don't ask him if he envies his nephew who suffered a spinal cord injury and recovered. He can't walk, but he's not a ghoul. If an activity is being planned, don't fail to invite him or us because you can't imagine how we would accomplish it. That's our problem. We've been snorkeling in Jamaica, to the top of Zabriskie Point in Death Valley, through the streets of Paris, and on the *quai* along the Seine. We've traveled the road to Ensenada. We've been dogsledding and canoeing, and Tom can still snow ski. He spent a whole winter in Alaska, for heaven's sake. It's not like he avoids physical obstacles or challenges.

A friend of mine from the days before law school was injured in a car accident on the night of her high school prom. I knew her when we were both young mothers. Her second child was baptized during the same baptismal service as my third. We were close friends. I cannot tell you how many times I blushed to the roots of my hair when some unthinking

person would say to my friend, “Oh my goodness! Aren't you lucky that you and your husband 'got' babies who resemble you so much!” My friend would smile and thank the speaker. I would want to punch them. My friends' children were their own, not adopted. A physical disability need not exclude one from a happy and fulfilling sex life or from birthing a child.

FINAL ADVICE

Here are a few more easy tips. A sunken living room adds nothing to the design and beauty of your home. If your friend or sibling uses a wheelchair, don't buy a multi-story home of which he cannot access a single square inch without rather dramatic intervention unless you're trying to make him feel unwelcome. Adding a deck? Flush with your floor is as good as one step down. Remodeling? Thirty-six-inch-wide doors come standard and also allow Tom to enter the room. Putting in a fireplace? A knee-height hearth can be as lovely as a floor-level one, easier on your back, and accessible to a guest using a wheelchair. Planning a party? Make sure there's a place for people to sit, and if only one person is sitting, join him. He'll be so much more comfortable looking at your face instead of your derriere. And you might learn what it is about his voice. . . . ■

Kathleen Balthrop Havener (kbhavener@havenerlaw.com) is the founder of the Havener Law Firm LLC in Cleveland, Ohio, focusing on complex commercial litigation as well as complex commercial and government transactions.