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Roll a Mile on His Wheels: How to Include Persons with Disabilities

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 who observes another person using sign language for the first time is inexplicably frightened or compelled to turn away.

These are learned behaviors, not reactions that occur naturally. Along with the more complicated prejudices and aversions we may feel toward persons with visible disabilities, our prejudices, once ingrained, must be unlearned if we are to enjoy the benefits of ordinary, unspoiled, and comfortable relationships with everyone around us. If we are to include persons with disabilities (other than our own—for 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 overcome our laziness and unlearn our fear, misunderstanding, ignorance, and just plain stupidity and replace them with directed

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efforts to include. To accomplish this—if we ever can—requires us first to think about what it’s like to live the life of a disabled person.

Meeting Challenges

Imagine yourself as a deaf person who has successfully completed law school. Are there bar review courses available in sign language? Who or what provides you with the time signals or directions to “open the booklet” or “put down your pencil” at the bar exam? At your first bar association meeting or even your swearing-in, is there a sign language interpreter at any single event? Or imagine you’re blind. Are the written materials for the bar exam or CLEs available in braille or via recorded technology? Now, imagine yourself as a wheelchair user. You will find that CLEs and other events in a “single” venue are often located on different floors, even 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 wheelchair seating at the CLE. Don’t even dream 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 or that took 15 minutes to board, making you feel like you are in everybody’s way) but rather is around the block. Networking receptions may be scheduled in beautiful but un-retrofitted buildings, and you can’t even get in. If 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 multitude of backsides. The bathroom facilities are up three steps, and you can’t even get inside.

Upstairs, in your hotel room, you note that the brilliant designers have included a luxurious roll-in shower—inside a bathroom that 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 water-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 must air dry.

An Education in Inclusion

I was supremely lucky to come from a family that taught me that humans are more alike than different. My mother was Australian and met my father at a Red Cross dance when he was on furlough from fighting in New Guinea in late 1944. Both my parents were civil rights activists in the Deep South during the 1950s and 1960s. I always knew that cultural, 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 as part of his “island hopping” 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 medical practice, I knew that people suffered from illnesses or injuries that made them look or behave differently, and yet I was always clearly instructed that “inside their heads” they were no different from me.

A classmate’s mother had multiple sclerosis. Although she used a wheelchair all our lives, 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 sometime in her 40s, 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. She had the maturity and competence of a young child. When her 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 just different. She was entitled to the respect we accorded to any adult, while at the same time we knew we had to protect her from her own immaturity, just as we did our younger siblings.

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 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 voicemail!” A still-invisible (and surely baffled) colleague 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. In July, we made it to 26 years.

Later the same day I heard his voice, I was introduced to Tom Havener in person for the first time. I discovered then that he ambulated by means of a wheelchair. I don’t remember reacting to that fact in any way. Not too long thereafter—the first time we had an opportunity to really converse—over a beer at a bar in Anchorage, Tom told me that 15 years earlier (when he was 20 years old) he had a spinal cord injury that occurred when he experienced a catastrophic 100-foot fall from a cliff into the shallows at a bend in the Chagrin River in the Cleveland Metroparks.

Apparently, my reaction was out of the ordinary. I wasn’t silent. I wasn’t falling over myself with pity. I didn’t ignore that he had said it. I wasn’t embarrassed. I *wanted* to hear all about it. I was intensely curious. I peppered Tom with questions about his accident and its consequences. I learned that it took a rescue squad four hours to even get to him in the river. I heard about the immediate treatment he had received after being revived (yes, revived) in the emergency room 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 and God knows what else from the river bottom—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 Ohio State with a degree in journalism only one-quarter behind his cohort. After a gap year to concentrate on further physical therapy and rehabilitation, he entered Case Western Reserve University Law School (CWRU). 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 (entirely) 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 even a little, I knew he would be in my life for a long time. 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 was not ashamed of my ignorance but rather intent on eradicating it. The first assist I received was a library copy of the memoir *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* by former National Public Radio newscaster John Hockenberry. It had been published a year earlier, in 1995, so while it was relatively new then, it should tell you something that after almost 28 years, it is still in print. Hockenberry became a wheelchair user after 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 it. 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. (And from Tom, I learned that people actually *do* this!) 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 then-teenage daughters and I learned that not all kitchens are set up the same way. Coffee mugs, plates, and bowls went *under* the counters, not above. The same for the cooking equipment. The only things stored above Tom's reach in our house were things that we *knew* he wouldn't use on his own. The stand mixer. Extra bags of sugar and flour. Champagne glasses. And where the ordinary glasses were stored, the bottom shelf soon became Tom's—and we typically left 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 would telephone a restaurant for reservations, drive us to dinner, and tip the valet (who inevitably hands the keys to me and not Tom). If we were lucky enough to be able to enter via the front door rather than through the kitchen, Tom announced our arrival to the maître-d'. The maître-d' either ignored Tom altogether and spoke directly to me or—even more oddly—spoke to Tom but near his ear and at the top of his lungs. The priceless—and almost inevitable—question was, "where would he like to sit?" My forever response: "Wherever he tells you when you ask him." Tom cannot walk. But his hearing is A-OK, and he can speak for himself, thanks.

Don't assume *anything* about him. Don't ask him if he envies a friend's son who suffered a spinal cord injury and fully recovered. He can't walk, but he's not a ghoul. If an activity is being planned, don't fail to invite Tom or us because you can't imagine how we would accomplish it and get into the venue. That's our problem. We've been snorkeling in Jamaica, climbed to the top of Zabriskie Point in Death Valley, strolled the streets of Paris and along the Seine. We've traveled the road to Ensenada. We've been dogsledding and canoeing, and Tom was a skier when we met.

Tom spent a whole winter in Alaska, for heaven's sake. He doesn't avoid 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 with my third. We were good friends. I cannot tell you how often 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 inevitably wanted to punch them. My friends' children were their own, not adopted. A physical disability does not exclude one from a happy and fulfilling sex life or from birthing a child.

Final Advice

Here are a few more easy tips. If your friend or sibling uses a wheelchair, unless you're trying to make her feel unwelcome, don't buy a multi-story home where she cannot access a single square inch without rather dramatic intervention. Remodeling? Tom says that anytime one engages an architect or a general contractor to make changes to a home or work environment, the chosen professional should check out every angle, every door, every view, every turn while sitting in a wheelchair. Thirty-six-inch-wide doors come standard *and* allow Tom to enter the room. Your chic dining room ensemble with a counter-height table and gorgeous artsy stools won't allow a wheelchair user to break bread with you. Putting in a fireplace? A knee-height hearth is 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 guests 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.

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