

## Open Enrollment

Twelve years ago my husband suffered a stroke, and our lives were forever changed.

Dealing with the financial and medical problems associated with stroke recovery is difficult, but the confrontations we faced as new members of a growing minority group, *Persons with Disabilities (PWD)*, proved to be far more challenging and emotionally draining.

In addition to the usual discrimination issues most minority groups face, membership in the PWD comes with its own particular nemesis—inaccessibility, and given that *Persons with Disabilities* has an open door policy, all family members become enmeshed in circumventing or removing barriers.

We started in our own home first, by building ramps, widening doors, and installing bars in the bathrooms and by rearranging furniture, closets and cupboards. However, the obstacles outside our home were not so easily resolved. In fact, time and time again, no matter the circumstance, an access issue would crop up and cause our plans to go awry.

Our first disastrous event occurred during our trip to the Grand Canyon on Thanksgiving. We traveled by Amtrak Canyon which didn't stop at a station, but at a crossroads on the outskirts of Williams, Arizona. Therefore, we decided to enlist the expertise of a travel agent to arrange for an accessible vehicle to meet us at our destination and take us to our hotel. Everything had gone as planned and when the train arrived at the crossroads, a cab was already there waiting for

us. However, as the porters assisted my husband onto the train's lift, I noticed that the expression on the cab driver's face had metamorphosed from a grin to a grimace. As the train pulled away, he approached us and instantly began apologizing that his cab could not accommodate my husband's wheelchair. I was cold and tired, but I was not going to be stranded, especially in the middle of nowhere at two in the morning. Someone had made a mistake, and since it wasn't me, I made it clear that he'd better figure a way to get us to the hotel. He immediately began calling around, but couldn't locate anyone in Williams that had an accessible vehicle to transport us. Ultimately, his company dispatched a mechanic and another cab to our location to dismantle the wheelchair. The wheelchair parts and my husband were placed in one cab. The luggage and I were loaded in the second cab. We were grateful for a solution, but that didn't change the reality that this temporary fix had not eradicated the problem. The fact remained--we couldn't leave our hotel without following the same procedure. Thus, we had no choice but to return home.

Then there was the time we booked a trip to a five star resort. To guarantee that accessibility would not be an issue, I made all the arrangements and went to great lengths to reserve a handicapped accessible room. When we arrived, we were shown the room which was elegant and dramatic, and accessible---well, almost! The minute we saw the bed, we knew we were in trouble. A phone call was made to the front desk explaining that my husband couldn't transfer to the bed because it was too high. The bellman brought a stepping stool to our room to remedy the situation. As he smiled and handed me

the stepstool, I politely inquired, “Now, tell me again, how is my husband to get up these steps in his wheelchair?”

My husband slept the night in his chair, and we returned home the next day.

It was after that trip that I began thinking that we should limit our travel to day excursions. We booked our first trip to the Rose Parade and hoped it would be without the usual tribulations since it did not involve hotels or public transportation, but again we were wrong. It seems no one carefully plotted the route wheelchairs would have to take to get from the parking lot to the accessible viewing stands. Under normal circumstances traveling across grassy terrain in wheelchairs is not a good idea. Add rain to the equation, and you are guaranteed trouble!

Just imagine a man weighing about 170 pounds rolling across wet grass in a 350 pound wheelchair! Now picture the same man fifteen minutes later, surrounded by staff in white pants and red jackets. Add mud splattering up from mired wheels like a Fourth of July fireworks display—not a pretty sight!

Even a simple “night on the town” is problematic when you are a member of the PWD. Not being able to get into restaurants or not being able to use restrooms often are the realities and not the exception.

No one looks forward to facing altercations and mishaps, and I am no exception. By the time we were into our second year of membership, I’d let my life fall prey to the unspoken rule of the able bodied community: *make your own accommodations and remain silent, or stay at home.* Checking out events

beforehand and declining invitations to attend functions in private homes were tactics I incorporated to circumvent awkward moments. .

My husband, on the other hand, took a different approach to life's altercations. In his support groups, he learned about the American with Disabilities Act, federal laws that govern the treatment of the disabled, and that unlike the policing of other laws, most community leaders tended to either ignore the violations or skirted around the fact that the laws were not being implemented. Whereas I tried to avoid confrontation, he relished the challenge.

At each encounter, he'd listened patiently to all the excuses such as: "*I didn't know it was the law. I can't afford to make the changes. We are grandfathered in, so we don't have to comply. You are the first one to ever complain.*"

Then he'd ask, "When did you say you will be bringing these violations into compliance?" or "Would you like to hear from my attorney?"

Yes, his tactics have gained him a reputation. Good or bad? It depends on your perspective. Even after all these years, my husband has never let himself get discouraged by the rolled eyes and deep sighs of indifference, for he's proud of his many accomplishments. Surrounding communities now have more curb cuts and safe sidewalks, and all their sponsored events must be accessible. Because of his perseverance, many of our local stores and restaurants have cleared their aisles, have made doors easier to open, and have brought restrooms into compliance.

At first, I managed to support his endeavors and still keep a low profile. By being his chauffeur, his typist, his photographer, his voice on the phone, I didn't have to ruffle feathers. As a team, we were good cop, bad cop. But as the years progress, I too became an avid activist.

As a member of *Persons with Disabilities*, you also learn a new meaning for the phrase, "*misery loves company*". It was not the misery that created the bond between members, but our common resolve to make the world accessible. Within this comfort zone of new friends, we could find solutions and endure circumstances and issues that might have brought tears of embarrassment; instead, we were able to create tears of laughter.

For instance, every spring different disability groups meet in Sacramento for Political Action Day. Ed, my husband and I attended the rally on the steps of the capitol, and afterwards we separated to meet with our own legislators to personalize the ADA issues. To get to his senator's office, Ed had to wedge himself and his scooter into the small elevator leaving no room for anyone else. When the elevator arrived at his designated floor, the doors opened and closed too quickly, trapping Ed inside. Busy with our own concerns, we weren't aware of Ed's dilemma, and consequently, he made several round trips before a stranger finally did take note. His lifesaver waited for him to return to her floor, where she quickly climbed on his lap before the doors closed. The squashed pair traveled down to the first floor whereby she pushed the "hold the door open" button allowing Ed to escape. Of course, we greeted them with our tears of laughter.

Another incident took place as we left for home. Since there were so many “chair” passengers on the flight home, the airline decided to hurry the process of boarding by not using the transfer seat. Instead, each person was to use their personal wheelchairs to enter the plane. Once in the plane, stewards lifted and transfer each one to an aisle seat in the first six rows. Just as the flight attendant’s arms wrapped around Alice’s body to lift her, she let out a shrill squeal. Startled and bewildered, the steward stood frozen in time. As Alice gazed into his eyes, she announced that she hadn’t been hugged by such a cute man in a long time and wondered if he was available. Immediately, the rest of the group took the cue. One woman complained that Alice got more hug time than she did. Another ordered equal hug time and equal men. Then the men started protesting and demanded that, in fairness, the cute stewardesses be enlisted to help them. The crew soon joined with the tête-à-tête. Tears of laughter rolled down our cheeks as pandemonium reigned.

Once the flight crew had everyone loaded, everything returned to normal, but not for long. . .

Due to the fact that this was a commuter flight from Sacramento every seat was booked. As the other commuters began boarding, tired from their own day’s activities, one could hear grumblings about the delay. Finally, it was time to leave, and the pilot began his announcements by stating that this was a no smoking and no more complaining flight to Orange County. His comment got a chuckle from all passengers given that his statement was obviously in reference to the grumblings and fracas that took place during the boarding process. Then

he went on to explained that everyone could move about freely once the seatbelt lights went off except the aisle passengers in the first six rows. He told them that they must remain in their seats the whole flight--no exceptions! Immediately, a roar of laughter rose up from our group. The rest of the passengers sat in bewilderment until the message filtered back that those seats were occupied by wheelchair passengers. That did it! For the next hour, the laughter and the bantering continued until we pulled into the Orange County terminal.

Unfortunately, ADA enforcement is not a laughing matter, but one that demands serious attention. How fair is it to require someone who has a disability to enforce laws passed to protect them? In addition, those advocates who are well and strong enough to pursue violations are often embroiled in a "catch 22" situation. If they do nothing, nothing changes. If they request business to comply voluntarily nothing happens. Unfortunately, resorting to lawsuits to bring about compliance is disparaged in the arena of public opinion. The media even labels the proponents to this approach as extortionists. Conversely, violators of ADA are treated as victims and are showered with undeserved sympathy. Afraid of intimidation and stigma, many PWD members are inhibited from stepping forward to support enforcement of compliance issues.

The open enrollment policy of PWD is not just based on the "big three" criteria--- a germ, a gene, or an accident being a voucher for membership. Age is also an important factor. According to recent statistics, all of us **will** eventually experience some sort of disability due to the aging process, so isn't it imperative

that you understand and support compliance issues now before your own membership in the PWD is activated?

Remember that the attitudes and guidelines that are supported today will be the ones that will fashion your own treatment and accessibility issues in the future. Now I ask you, "Does that thought comfort you or scare you?"

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