

Looking Unabashedly: Reflections on Public Reactions to Disability

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This article explores issues of public reactions often encountered by persons with disabilities. A recent trip to Disneyland provides an opportunity to experience as well as reflect on interactions between those with and without disabilities.

Introduction

The bus is 20 minutes late. It arrives while I am on the phone, on hold, trying to find out where the bus is. It is here. We are going to Disneyland.

I am taking my son, who is 30 years old and multiply handicapped. He has cerebral palsy and developmental disabilities, among other things. He uses a wheelchair — not your average wheelchair, but an expensive custom-made chair with a head rest, chest straps, seat belt, and foot rest. It also has a big Plexiglas lap tray. Shawn cannot talk; he uses hand signs to say yes and no. His tray holds his communication device which speaks messages that we program for him. Today, we have programmed Disneyland messages, different rides to go on and things he might like to do. We also take a backpack bulging with supplies: extra bibs (Shawn drools profusely), diapers, water, formula, extra clothes, sunscreen, a jacket.

We are going to Disneyland on the Day of Prayer and Remembrance, the Friday following September 11. Our trip has been planned in advance for this day, and I decide not to disappoint Shawn, who has been looking forward to this for over a week. We must ride on Access, the door-to-door bus service. It takes 15 minutes to get Shawn on the bus and the wheelchair strapped down. Because we are late, we will have less time to spend at Disneyland. We made our Access reservations a week in advance, and our return trip time is already set. It takes us over an hour to get from Orange to Anaheim on Access. It is trips like these that make me long for our own wheelchair-accessible van.

Access will only take us as far as the Disneyland Hotel. We walk through part of Downtown Disney to the Monorail. This will be the first time we have ridden the Monorail. We wait at a special gate with the “wheelchair accessibility” sign, separate from the other passenger gates. We are the only ones at our gate. Other people (without wheelchairs) try to stand in line with us, but they are redirected to other gates. Two Disney employees put a wheelchair ramp down so I can roll Shawn into the Monorail. We are in the second-to-last car. A man walks by, stops at our car, says, “Here’s a couple a seats, Hon”. Hon walks right past us and the man follows. We have *this car* to ourselves.

My trips with Shawn are many-layered. There is doing and enjoying the actual activity. There is the layer of accessible transportation to and from the activity (Access), and the layer of accessibility within the activity (e.g., getting the wheelchair on and through the rides). Then, there is the layer of public reaction to seeing Shawn, who clearly looks severely disabled. We get lots of staring, lots of condescending smiles, and occasionally, comments from strangers. After 20-some years of taking Shawn out in public, I wish I could get used to public reactions. However, each time we go out it is a unique experience. I can never predict what kinds of reactions he will spark, and I am rarely prepared for how it makes me feel. I constantly wonder how it makes Shawn feel.

Disneyland is a great place to go with someone who looks really different and then analyze how people stare. Before these trips, I have to gear myself up, get ready to be stared at. I am a role model for how to respond when a person you love is constantly stared at in public. I feel like I have to be nice. I smile at everyone, make eye contact, even say "hi" to the kids. I have a theory about staring and being stared at: people who have not been exposed to or have not had experience with people with developmental disabilities tend to stare more, longer, than those who have some experience. You especially see this in children. Adults are too diplomatic; they have learned the *no staring* rule. They see us coming and grab their kids and move them out of the way. But children are curious; they are *interested*. In *Microsoft Word* (the '98 version), one of the synonyms for staring is "looking unabashedly". That is exactly what most children do. They stare *a lot*; their eyes get *really big*. Some kids do not stare at all. I believe that the children who do not stare are those who have peers with disabilities in their classrooms, in their schools, as their neighbors. Maybe for them, it is not all that unusual to see someone who is severely disabled. But most kids really stare, and many adults do, too. I would like to sit them all down with Shawn and answer every one of their questions, even give them wheelchair rides.

We arrive at Disneyland, in Tomorrowland. It is a very hot September afternoon. Shawn has expressed through his communication device that he wants to ride *It's A Small World* first. We stand in a separate line just for people in wheelchairs. This is one of the few rides that is totally wheelchair accessible; there is a special boat. We are the only ones in our boat. Shawn loves this ride. He keeps his head up the whole time and smiles, looking from side to side at all of the singing children. I am afraid his wheelchair might not be secure in the boat, so I frequently turn around in my seat to make sure he is okay (which he always is). I realize I am being too overprotective, so I try to time myself — *don't check until the next bend in the river*. I can never make it to the next bend without turning around to check. But it is nice and cool in this ride, and we enjoy it.

Next on our Disneyland schedule is the parade. We find wheelchair accessible parade viewing in the shade; we are the only people in this section. The parade is full of Disney characters: Snow White, dancing Seven Dwarfs, dancing hippopotami, the Little Mermaid (inside what looks to be a God-awful hot plastic bubble), dancing women butterflies — lots of dancing. When many of the characters pass us, they do this quick double-take as they see Shawn. Kisses are blown directly to him. Some of the characters grasp their hearts with both hands and then wave to him. We try to wave back and blow kisses back. The grand finale is the float with Mickey, Minnie, Donald, Pluto, and Goofy. They all wave, clutch their hearts, and blow kisses. Shawn waves back. He tries to blow kisses, but he is smiling too much.

To escape the heat, we go inside the *Golden Horseshoe Review*, a delightful stage show with a group of brothers playing fiddles. They are talented and funny. This is also a restaurant, where you can go up to the "bar" and order burgers, hot dogs and fries. I park Shawn at a table in the back and go stand in line. The show starts. I am still in line, but I am too busy keeping an eye on Shawn and not really watching the show. In places like Disneyland, I am petrified that something will happen to Shawn when I am temporarily apart from him, for instance when I am standing in line for food or in the restroom. He cannot yell for help, and he cannot push his wheelchair himself. I took one restroom break before we went on *Small World*. If there was a contest for the fastest (female) restroom user in Disneyland, I would win every time. So, in the Golden Horseshoe, I get out of the food line and go sit with him. I will wait to eat. We enjoy the show; I hold Shawn's hand as we clap to the music. Because we are sitting in the back, no one stares at us until they get up to leave. When the show is over, every one dashes for the exits. *Now*, Shawn is being stared at.

I really do not know how Shawn feels about staring, but I have an idea. A few years ago, we went to a Cher concert. During the intermission, I wanted to stay in our seats, but Shawn

wanted to go out and people-watch. He really likes to people-watch. I think he likes to be out there. He wants people to see people with disabilities. He is “in your face” about being disabled. *This is who I am*, he seems to be saying, *so deal with it*. A Cher concert is a good place for staring, because, trust me, Shawn was not the most unique-looking person there. We stared at the other concert goers, and they stared at us.

There is virtually no current research on staring and persons with disabilities. A very informal Internet poll was conducted by the Israel Mercaz Center for Inclusion, on their web site. Of those visiting the web site and answering the poll, 79% indicated that they stare at persons with physical disabilities (Mercaz Harmony International Center, n.d.). Some research was conducted in the 1960’s and 1970’s. One study (Langer, Fiske, Taylor, & Chanowitz, 1976) explored the “novel stimulus” hypothesis: people who are “novel” are stared at more, in an attempt to make them less novel. The researchers believe that lack of exposure to persons with disabilities creates a psychological conflict between wanting to stare and the desire to follow social norms against staring. This leads to increased discomfort by the “starer” and avoidance of the “staree.” (Boy, I could swear these folks have seen us at Disneyland). They conducted experiments in which college students were allowed to stare at someone with a disability (through a one-way mirror) then measured how closely the student sat next to the person when in the same room. Not surprisingly, they found that those students who were allowed to stare sat closer than those who were suddenly introduced to the person and asked to sit with them. (In their experiments, the person with a disability wore a large leg brace. Big woof. A leg brace is *nothing*. I wonder how closely the students would have sat if they had seen someone like Shawn.)

Although Langer *et al.* never mention integration either as a factor or solution in their hypothesis, I believe their study supports my theory — inclusion will help reduce the novelty of children and adults with disabilities. If inclusive education and community integration were more prevalent, children would stare less. Children without disabilities would grow up to be adults who are so comfortable around people with disabilities, there wouldn’t even be a *no staring* rule. This is one of my big dreams.

Shawn and I sit outside at a small restaurant where I finally get my cheeseburger and fries. Shawn cannot eat typical food because his mouth and esophageal muscles do not work properly. He has a gastrostomy tube that goes directly into his stomach. He “eats” special formula that is poured through a large syringe (kind of like a turkey baster) into the tube. I have an ongoing debate with myself about where to feed Shawn in public. Sometimes I think he should eat in the same places that everyone else eats — restaurants, outdoor seating areas (like where we are this evening). That’s integration, right? Other times, I think that maybe he wants privacy for this feeding ritual. I also worry about the other customers. Will it gross them out? Should I care? I suddenly decide to feed him right there, at our table, next to the family of six eating their burgers and chili dogs. The feeding goes smoothly. The other family hardly notices, and they do not stare much. Actually, they are talking about the Day of Prayer and Remembrance.

We are close to the one wheelchair-accessible station of the Disneyland Railroad, in New Orleans Square. It is almost time for us to go back to the Monorail to catch our Access ride home. I decide to risk being late and ride the Railroad. We have to ride the full circle and come back to New Orleans Square, because that is the only place one can get on and off with a wheelchair. The wheelchair accessible seating is in the caboose. At this point in the evening, I am no longer surprised by the fact that we have to walk the entire length of the train to get from the wheelchair accessible entrance gate to the caboose. We are on display for the entire train of customers, many of whom *are* staring. I feel like waving and marching parade-style or doing some sort of *Monty Python* “silly walk”, but I don’t. I smile and chat with Shawn.

We find our way back to Tomorrowland and the Monorail. Shawn is really excited about the Monorail; he smiles and laughs on our short trip to the Downtown Disney station. We are definitely running late, and I am somewhat anxious that Access will not wait for us. I push Shawn *very* rapidly to the pick-up location for Access. There is the bus! We introduce ourselves to the driver. As Shawn is loaded onto the bus, he starts to whine and cry. Are you sad because we are leaving, I ask? Yes, he signs. Well, we will come back another time, maybe Christmas. That stops the crying temporarily. *Hmmm*, he seems to be thinking, *Christmas*. We waive goodbye to Disneyland, and we go home.

References

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