# you should smile when you see me

## PROFILE OF DONNA SMITH, SENIOR DIRECTOR, EASTER SEALS PROJECT ACTION CONSULTING

*Interview location:*
*Easter Seals Office in Washington, DC*
*How we got there: WMATA Express Bus*
*In one word, she describes herself as "Persistent."*

*By Laura Lee Huttenbach*

Donna Smith, in 2016. (Photo credit Laura Lee Huttenbach.)

Donna Smith was 18 months old when doctors detected retinoblastoma, a rare form of cancer, and removed her right eye. For the next eighteen months, her mother took her on zoo trips and drilled her on all the colors before doctors took out her left eye, too. "I have a memory of colors, though," says Donna, adding that red and purple tend to dominate her wardrobe. "I understand matching," she continues, "but I also had two older sisters who would have cut off their right arm before they let me leave the house not dressed properly." ›

# it was all about how to find a way

We are on her morning commute, riding the Washington Metropolitan Area Transit Authority (WMATA) express bus from her home in Arlington, Virginia to her job at Easter Seals Headquarters in Downtown DC. At Easter Seals, Donna directs Project Action Consulting, which works to improve public transportation for people with disabilities. Normally on her commute, she'd be listening to an audio book.

I ask if she can see any spectrums of light.

"No," she says. "I'm totally blind."

"So it's just black?" I ask.

"No, it's not dark either," she says. "Dark is a visual perception, and I don't have that."

"Would it be like me looking at a piece of white paper?" I ask.

"There's not a good correlation that I can think of," she answers. Sometimes in sensitivity training, she says, instructors will ask students to wear a blindfold to mimic the experience of being blind. Donna doesn't think that's a good idea. "I try to discourage that," she says. "It tends to give you the worst case scenario, like what would happen if you stopped seeing today." She states that most seeing people, faced with a loss of their vision, would be capable of far more than they think.


Donna Smith with cane in 2015. (Photo used with permission from Donna Smith's personal collection.)

Her brown leather backpack is sitting in her lap and inside the mesh pocket is white cane, folded like a tent pole. "Is that an extra?" I ask.

"Yes, absolutely," she says. "I've probably had four canes break." They broke, she says, when cars ran them over. "Usually when they turn right on red too quickly, and they clip the end of the cane," she explains. When the tip—which looks like a marshmallow—breaks off, the cane is useless.

I ask how she avoids obstacles when she's walking with her cane. “I use a lot of sound cues when I travel,” she says. “It’s a bit of a hard concept if you haven’t experienced it, but it’s called echolocation—the sound and the movement of air between your ear and your next obstacle.” If she’s paying attention, she will usually hear things like the bumper of a parked car sticking out too far, though street noise or heavy rain can mess with her echolocation. In those cases, “I’m supposed to find the bumper with my cane before my body,” she says. “Using the cane is like a contact sport. In order for it to work right, you have to let it hit things.” It’s easier with a guide dog, she tells me, but the one she had, Farlow, just retired six months ago. She can’t bear the thought of giving Farlow away, so she’s figuring out if she wants to get another, which, she says, can take a lot of energy to train.

“People in general are pretty helpful,” she says. “If you’re not sure what to do, the best thing is just to ask, ‘Can I help with anything?’ If I need it, I’ll say yes.” One thing not to do, she remarks, is grab her by the arm and tug her up bus stairs or through crowded sidewalks. “If I need it,” she says, “let me take your arm.”

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The youngest of four children, Donna was born in Jackson, Mississippi in 1959, more than three decades before the first President Bush signed the Americans with Disabilities Act (ADA). Her early childhood in Mississippi also predates the Civil Rights Act (passed in 1964), Voting Rights Act (1965), or Fair Housing Act (1968). “In those times,” explains Donna, “the medical profession frequently recommended that people with disabilities be institutionalized.”

Thankfully, her story took a different narrative. “I was fortunate that the doctor who treated me was very insistent with my mother that [institutionalization] was not necessary,” she says. “It was all about how to find a way. not, ‘*Can* Donna accomplish these things?’ But, ‘*How*?’”

In Jackson, her family lived close to the State School for the Blind, a boarding school where kids from all over Mississippi came to live together. But Donna lived at home and rode to school every day with her mother. At sixteen, her life changed when she completed Orientation and Mobility (O and M) Training, where she learned cane travel. “It was very liberating,” she says. “My O and M instructor is still one of my favorite people of all time.” She went on to graduate from Mississippi State University with a degree in psychology, which she took to work in group homes with men who had intellectual disabilities and were trying to reintegrate into society.

In the 1980s, years before the ADA mandated that public transit be accessible for people with disabilities, Donna applied for paratransit service to take her to work. At that time paratransit service was a curb-to-curb or door-to-door specialized transportation service for people with disabilities, older adults or veterans, but trips had to be booked at least 24 hours in advance, which doesn't accommodate spontaneous planning. "My problem is I'm not the most patient person," explains Donna. "I remember my pickup time for work was anytime between 5:45 and 7:15 in the morning, which meant I had to be ready at 5:45 just in case they happened to come. I was like, *Okay, I'm not gonna do that.*" So she got familiar with Jackson's fixed route system, getting to know the regular drivers, routes, and passengers.

The ADA passed in 1990, and between that and improvements in technology, Donna's commute on the fixed route got easier. One of the best advancements, she says, is the automated voice enunciator. Before, she would have to rely on the bus operator to call out every stop—or, at a minimum, alert her when she was approaching her stop. "I'd be sitting here thinking, *Are they really going to remember to tell me when my stop is?*" Now, the enunciator takes care of the issue, and Donna can relax more during her commute.

> "***Are they really going to remember to tell me when my stop is?***"

In the 1990s, Donna worked at the Mississippi Center for Independent Living and the Coalition for Citizens with Disabilities—sister agencies in Mississippi. Her work was focused on training and technical assistance to help agencies comply with federal non-discriminatory legislation. In 2002, Easter Seals Project Action hired her as a Training and Technical Assistant Specialist in Washington, DC. "I never set out to work in transportation," she says. "I'd always worked on cross issues . . . I thought it might be kind of boring just to do transportation."

She told herself she'd try it out for a year or two before moving on to something else. "Fourteen years later," she says, laughing, "I'm still here." She came to realize that transit touches every aspect of a person's life. For example, "If you're not a driver, you can't choose where to live without considering if there's public transit," she says. "And you're not going to apply for a job in a place that you can't physically get to." We (people with disabilities) take these details into consideration for every plan we make, from doctor's appointments to grocery shopping. "So there's plenty within the industry that's captured my heart," she says. "I'm a transit nerd for real now. I love it. I don't see myself doing anything else."


Donna Smith and Farlow with Driver & Motorcoach. (Photo used with permission from Donna Smith's personal collection.)

As we are crossing the Potomac River I ask Donna about Project Action, which began in 1988 with a grant from the Federal Transit Administration (FTA). At the time, a grassroots organization called ADAPT (initially an acronym for Americans Disabled for Accessible Public Transit, it was changed in 1990 to Americans Disabled Attendant Programs Today) was calling for nonviolent protest and civil disobedience on behalf of people with disabilities. ADAPT demonstrations sometimes included protestors chaining themselves to buses to protest a lack of accessibility. Project Action was intended to bridge the gap between the protestors and the public transportation they sought to reform.

With the passage of the ADA, Project Action advised agencies providing transportation on how to meet the requirements of the new law. They worked with groups ranging from public transit organizations and taxicab companies to city planners, universities, and neighborhood associations. The Project maintained an informational hotline that offered free information and resources to customers and providers.

When Donna came on board in 2002, part of her job was staffing the phone lines. She also conducted workshops onsite, training agencies how to provide better customer service. When I ask for pointers, she offers several. First, she says, use "people-first" language. In other words, put the focus on the person before the disability—"people who use wheelchairs" versus "a wheelchair-bound person." She gets upset when she hears a bus operator say, "I was late on my route today because I had to board a wheelchair." Donna shakes her head. "You didn't just board a wheelchair," she says. "The wheelchair wasn't just out on the curb by itself. You boarded a person who was using a wheelchair."

To agencies, she wants to keep the message simple. "Yes, it's about being politically correct," she concedes, "and yes, it's about implementing the Americans with Disabilities Act. But really it's about serving customers. If we want people with disabilities to ride the fixed route system, 'cause it'll cost you less than the more expensive paratransit service, then teach your operators to be friendly and accepting and helpful." A trip on a fixed route, she says, costs an agency between four and six dollars, while paratransit costs ten times that much. "And work with your city planners to get better sidewalks with curb ramps," she continues. "Or accessible pedestrian signals so you can cross the street." She wants to create a society that's welcoming and inclusive of all people. "Whatever you do to make it accessible to people with disabilities makes it more accessible for other people," she says, noting that curb ramps also benefit people pushing strollers, pulling wheeled suitcases, or riding bicycles. "The primary message is that this is the public who needs your transportation," she says. "I should look like nothing but good business to you. You should smile when you see me."

Having a disability alone is not enough to qualify a person for paratransit. He or she must be deemed by the agency to be functionally unable to use the fixed route system. "They might do that by just asking questions," says Donna. "Or they might do that by going out with you and seeing how you catch the bus." The ADA mandates that an agency must determine a rider's functional ability, but it doesn't explain how to do that. As such, each agency has its own protocol.

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This is where Donna and Project Action step in. They have written a handbook on ADA Complementary Paratransit determinations and processes which is the basis for a two-day course offered through the National Transit Institute on how to conduct paratransit eligibility for potential applicants. The course, says Donna, teaches "the best, most thorough way to set up and implement a paratransit eligibility program."

These days she spends a lot of time in her office, applying for grants and chasing down contract leads. (At the end of 2014, the FTA didn't renew the grant for Project Action so today it functions like a consultancy service on a contractual basis.) But by far her favorite days on the job are when she's in the field, leading workshops and training agencies. "I'm a people person," she says. "I think there's something to learn from most people we meet." At the beginning of every workshop, she always gives a similar introduction, asking attendees to be verbal. "Don't raise your hand," she instructs them, "be verbal. Your arm is going to get very tired waiting on me to notice and call on you."

She's laughing as she's talking. "So I get to the end of my spiel, and I say, 'Okay, great—who's ready to be verbal?' Dead silence." I laugh, realizing suddenly that I've been nodding throughout her story. "So you use humor when you teach," I observe. "Of course," she says. "I try to keep it informal. People learn better if they're comfortable."

Donna had warned me that when we got to DC, she'd need to pay attention. We get off the bus two blocks from her downtown office. Approaching the crosswalk, I notice for the first time the raised dots on the pavement right before the street. I ask Donna about them. "Those are called detectable warning strips," she replies. "They're required by the ADA to indicate that if you keep going, you're gonna be in moving traffic." Traffic is moving today. At the first crossing we have an audible pedestrian signal. At the second crossing, Donna listens to parallel traffic to determine when it's safe to cross. She is familiar with these streets.

Donna Smith and her seeing eye dog, Farlow. (Photo used with permission from Donna Smith's personal collection.)

A truck is blocking the crosswalk, and Donna deftly navigates around it, but she begins to veer to the right as she crosses the street. Eventually she steps outside the crosswalk, and I tell her so. "Oh thanks," she says, safely returning to the zebra stripes. "There was a truck in the crosswalk, right? That threw me off."

On the sidewalk, she is tapping her white cane. "What I'm trying to do here is get a good echo against the wall," she explains, pointing to the side of the black granite building that houses her office. She leads me up the stairs and through the glass doors of the building.

In her office, she shows me some of the pictures on the wall—her daughter Erin, her partner Tom, and Farlow, the retired guide dog. It occurs to me that she might not know what I look like. "I've quit trying to guess," she says. When people offer her physical details—the color and length of their hair, for instance—she doesn't work hard to store the information. "I think I pay more attention to what people say, because it's one of the clues that I have, and it's one of the best ones." She can tell when people are smiling, though, and she has called me out on it a couple of times. "It's an extrapolation," she says. "It could be you sound really perky while you're scowling at me."

"I'm not!" I say sincerely. "You've elicited many smiles, Donna."

"I'd like to say that it's freed me of any types of bias," she says. "But I'd be wrong to say that. I understand the importance of those types of things." She is playing with her purple and silver bracelet as she talks, explaining that it's important for her to be noticed for who she is as a person. Often, strangers are so consumed by her blindness that they can't see other characteristics

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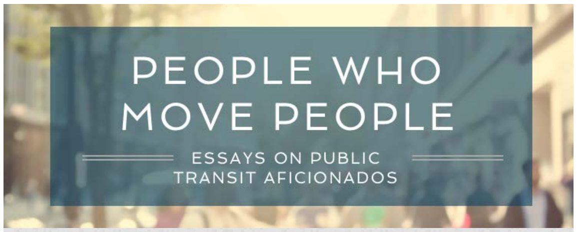
She tells me that when she was a young mother going out with her daughter, strangers would come up to her and say, "Your husband must be such a kind person. He must be really great to be taking care of you and your child." Donna raises her hands in exasperation. "The assumption was that I couldn't possibly be the primary breadwinner and caregiver, which I was." When I think about it, Donna is asking for what we all want—to be recognized for what we can do, by what we are doing, and not by what we lack. During our morning together, Donna has been consistently upbeat, humorous, and confident. "Was there ever a moment when you thought, *This is too* *hard?*" I ask. "Or when you wanted to give up?"

She takes a deep breath. When she first got to DC, she tells me, she had planned to take the MetroRail to work. "Once we were in the station, it was just so noisy," she says. When trains pull in, the sound "wipes out all of the other sound cues—it was like having somebody turn the light out." Overwhelmed, she went home sweaty and frustrated. "I was just sure there was no way I was gonna get to work," she says. It was a Wednesday, and the new job started Monday. A roundtrip taxi would run fifty bucks a day.

At home after the Metro station, she took a shower and cried. Her friends and family were 1,000 miles away in Mississippi. "Like I said, I'm not really patient," she tells me. "I got really impatient with myself, I said, *This is ridiculous. I know people who are blind in DC who go to work every single day. I just need to call them and say, 'Tell me how you do it.' So I did.*" She called a good friend, and he took Thursday off from work to make the trip himself. On Friday, he taught her how to do it, and he provided detailed notes in braille on index cards. He told her that eventually she'd get used to the noise of the train, and it wouldn't block out the rest of the sounds around her. In addition, the raised strips at the edge of the platform would let her know when she got too close. She studied her notes and practiced the route, and by Monday, she was ready for her commute.

So getting back to my question of giving up—the answer is really no. "Not doing it wasn't an option," she says. "I had a job. It was gonna happen. But it was way more than I was prepared for." Just like her first doctor had advised, life for her was never about the *if*. It was about the how. ■

*Writer Laura Lee Huttenbach's first book is "The Boy is Gone: Conversations with a Mau Mau General" (Ohio University Press, 2015). Her website is www.LLHuttenbach.com.*



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