

BARRIERS AND BELONGING

Personal Narratives of Disability

Edited by

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Shades of Shame

EMILY K. MICHAEL

On a hot, sunny morning in August, my mother and I drive up to the Low Vision Center, a building whose design does not match its title. The doctor's office is located in a historic district of Jacksonville, Florida, in an old house with wood floors and charming white railings. As we get out of the car, Mom dryly remarks, "This place was hard to find—you'd think the sign would be bigger or easier to read!"

It has been a few years since my last low-vision evaluation. These appointments differ from my yearly visits to the eye doctor, because the center's implements for measuring vision are tailored to folks like me. Unlike a conventional visit to the eye doctor, a low-vision evaluation focuses on how the patient lives with low vision. An ophthalmologist will dilate my pupils, shine a loathsome bright light into my already sensitive eyes, and scribble something on my chart. A low-vision specialist will suggest new methods

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for labeling household appliances or the use of yellow light bulbs to ease my eyestrain while reading.

Today, the doctor is friendly, helpful, and delightfully verbal, readily accommodating my requests for dimmer lighting in the examining room and always directing her questions and comments to me. She does not talk around me as if I were not present; she acknowledges that I am the expert on my own vision. She writes a new prescription for my glasses, designed to minimize the effects of nystagmus—the muscle weakness that makes my left eye dance unpredictable jigs. When she asks me to describe the most challenging aspects of my low vision, I explain that my light sensitivity causes most of my visual struggles. She asks if I've tried sunglasses, and I recount the ineffectual pairs I've worn, their lenses too dark or not dark enough. The doctor assures me that new styles and colors are available, so I decide to give sunglasses another chance.

One of the center's employees and I venture outside with a big bag of sunglasses to try. We stand on the sunny porch, and she hands me one pair after another, describing the color of the lenses and the shape of the frames. I try amber, black, gray, brown, and countless other lens colors. Finding the perfect pair of shades proves difficult. Because of my extreme sensitivity to light, I need glasses that cut the glare of our Florida sun. But I can't simply choose the darkest lenses—I need a high-contrast environment in order to make the best use of my vision. The glasses must eliminate a significant amount of sunlight, but they can't leave me staring into an abyss of muddy, indistinct colors.

I choose a black pair with reflective black lenses. Far from slim or stylish, the shades offer full coverage, fitting over my regular glasses to give me peripheral protection. They work beautifully, omitting the glare without destroying the palette of my surroundings. When I put them on, I feel ready to tackle the sunniest environments. I start to fantasize about spending more time outside—working in my parents' garden, exploring the extensive nature trails at my university, and planning picnics on the beach.

Like the white cane I have been using since high school, the sunglasses now claim a permanent place with me any time I leave my house. Out of necessity, I wear them in the car, and I am amazed at all the things that the glare rendered invisible. Passing cars, trees, buildings, and street signs come into focus as I stare out of the car window. I cannot read the signs, identify the types of cars or trees, or recognize the buildings, but I move closer to a visual understanding of my surroundings.

Though I dislike the look of the shades, they become part of my personal image. When I enter a bright, low-contrast environment, like a public restroom, I pop the sunglasses on, and my confidence rises. The space before me clarifies, and I can travel with greater ease. Then I catch a glimpse of myself

in the mirror above the sink, and my confidence plummets. The image in the mirror doesn't resemble a face. It's a quasi-human mouth and barely distinguishable nose leading into a void of black. When I'm behind the sunglasses, I can't recognize myself.

Friends try to soothe my insecurities; they insist that the shades are stylish, something Audrey Hepburn might wear. But I know that the sunglasses do not match my personal style. Since their function necessitates their bulky, cumbersome form, the comparison to Audrey's sunglasses elicits a twinge of resentment. While Audrey could wear whatever style she wanted, I must depend on shades so large that they won't fit in a conventional glasses case. Yet leaving them at home is unthinkable—I shudder to imagine myself in a bright environment without them.

Because I cannot easily hide them unless I bring a large purse, the shades feel like an inescapable stigma, a sign of difference I must acknowledge each time I face my distorted reflection. When I need to use the shades, I do so with a mixture of relief and resignation. Wearing the shades alleviates the discomfort caused by glare and sunshine, but, as I slide them on, I feel awkward and embarrassed—convinced that I embody the blind stereotype.

From behind the shades, I notice an unprecedented reticence coloring my social interactions. Servers, manicurists, sales assistants, librarians, and even nurses seem discomfited by the dark glasses. While wearing the shades, I find myself surrounded by people who direct their remarks to my companions to avoid communicating with me. Within a few words, I can recognize their awkward hesitation. In one case, a waitress whispers to a friend at the table, "Would she like a braille menu?" and I lean toward the sound of her voice to answer with an emphatic "No!" I sense that the shades create an indomitable barrier between me and the world—that the strength of this barrier symbolizes the intensity of my own deficit. Clearly, I will not find acceptance among a sighted majority that is so uncomfortable with my dark glasses.

My brother offers me a more appealing perspective by making me laugh at myself. When we walk together and I use my shades, he calls me Stevie or Ray. Since I sing and play the piano, I welcome these associations. His comments remind me that others have worn the shades and created powerful identities. His affectionate teasing helps me accept the sunglasses as a natural part of my apparel. He insists that the sunglasses do not change who I am; they don't make him uncomfortable. They provide protection, relief, and—as we catalogue the awkward vocal stumbling they elicit from others—an opportunity for endless joking.

Still, when I put on the sunglasses, I cannot avoid thoughts of hapless blind beggars and awkward blind girls. These negative associations accrue more force as those around me voice disfavor with the glasses. When people

ask pointedly, “Do you *really* need your sunglasses in here?” they convey the sense that the shades are only acceptable within specific parameters. Though I seldom hear objections when I wear the shades at the pool or the beach, my indoor use of the shades unnerves people around me. I wonder if people feel marked by association—perhaps even labeled as handlers or caregivers because they travel with me. In this view, removing a pair of sunglasses is more feasible than correcting a series of hasty, inappropriate labels.

Acceptance and disapproval aside, the shades remind people of how little they know about my vision. When others ask whether I really need to wear them, they are deliberately not asking, “How bad is your vision that you need those dark glasses in a room with average lighting?” If people think they have my vision figured out, my unpredictable use of the sunglasses destabilizes their theories. Suddenly they can’t calculate what I can see—and, by extension, what I can do.

Despite my struggle to understand what they signify for others, I cannot fight the shades: they are too practical. Slowly, the sunglasses find their way into most areas of my life. No longer confined to outside wear, they creep into bright classrooms, coffee shops, restaurants, even bookstores.

Months after getting the shades, I stand onstage with my university chorale as we rehearse our pieces for the night’s performance: a choral festival at a local community college. We’re singing on unfamiliar turf—a stage with lights I have never experienced before. In our campus theater where I usually perform, the soft red and blue stage lights don’t bother me; I don’t even carry my sunglasses onstage. However, this new venue uses harsh white lights. Their oppressive glare settles into my eyes with heat and heaviness. The sensation reminds me of the achy fatigue of dilated eyes—with pain superbly amplified. I feel like I’ve had my pupils dilated and spent several hours under direct sunlight. I manage to make it through the rehearsal with my eyes closed, my fists clenched at my sides. Knowing I’m the only one who can’t stand the lights, I feel foolish, weak, and embarrassed.

Seeing my discomfort, our conductor advises me to wear my sunglasses onstage. Since she assiduously monitors our performance attire for signs of difference, I am surprised that she will allow me to wear them. I grab the shades out of my purse and pop them on. When we return to the stage, the lights no longer distress me. My eyes feel soothed by the protective darkness of the shades. Now I can see our conductor standing before us—the black velvet folds of her outfit and the glint of her blond hair. I can distinguish the white keys of the piano and the bright rectangle of the sheet music on its stand. As the soreness fades from my eyes, I regain my confidence.

Unaccustomed to performing in sunglasses, I discover new challenges. Singing behind sunglasses feels drastically different from singing behind my normal glasses. When I breathe as a singer, I imagine air filling my whole

body, entering through my mouth or nose and the tiny space above my eyeballs. Behind the sunglasses, this stream of air, so necessary to producing a vivid, resonant tone, is imperceptible—blocked by a wall of plastic that outstrips my regular glasses. It's also hotter behind the shades, and I worry that my face will be less expressive.

The concert continues without incident until the other performing groups join us onstage for the finale. To accommodate the extra singers, I unfold my cane—which typically rests folded at my feet—and step to the right. While my fellow performers hold their binders of sheet music, I stand with the cane unfolded at my side. A singer from the other group leans toward me to hiss, “You’re blind, and you know your music so well!” This unsolicited attempt at praise reminds me that my shades and cane aren’t ambivalent props; I can’t pass for a musician among musicians.

I wonder why this singer, a stranger to me, uses the emblems of my blindness to evaluate my talent. Why should my musical skills be more impressive within the context of a white cane and dark glasses? I struggle to disarm these negative connotations and focus on how the cane and sunglasses facilitate my independence onstage.

I try to reconcile my vision of the shades and cane with what others see when I use these tools. For others, I think the shades especially mark an undesirable difference, because they seem to hide more than they reveal. Unlike an unconventional hair color, tattoo, or piercing that might inspire curiosity and promote conversation, the shades obscure my eyes and force others to stretch their communicating muscles. For some relatives and friends who have grown up with me, the shades distort my identity; they hide “the real me” from view. These people cannot see the world that the sunglasses give me. They see only a barrier between me and my environment.

My sunglasses are especially unwelcome in photographs, because photography helps to supplement our memories of a particular event. If I wear my shades in photos taken at important events, I taunt the viewer by refusing the camera visual access to my face. On the sunny afternoon of my first college graduation, my family members hold up their cameras, saying, “We want one of you without your sunglasses.” Similar sentiments arise during the rehearsal for my brother’s wedding. As the wedding coordinator helps us line up outside the church doors, a relative comments, “I’m sure you won’t need your sunglasses in the church.” If I won’t need the shades in the church, then they won’t appear in photographs. With a few camera clicks, we can erase the shades—and the disability that creates my need for them.

When people encourage me to take off the sunglasses, their voices full of concern or reassurance, I sense a powerful subtext: “Don’t you want to look like someone else?” Perhaps they think they are offering me a reprieve, an opportunity to set my disability aside. Maybe they imagine they are handing

me the keys to normalcy. Why wouldn't I want to take off the shades and adopt the look of a sighted woman?

Now that I have come to accept the sunglasses for what they are, a tool that augments my independence, removing them to appear normal seems absurd. To those who think that the dark glasses should be cast aside, I want to convey the world that comes to me from behind the shades. It is a space where I have exchanged fatigue, eyestrain, and an inability to visually understand my surroundings for relief, confidence, and a crisper visual reality. The sunglasses don't eliminate all my visual frustrations, but they help me make the best use of the vision I possess.

These shades invite me into the world. They make previously unthinkable situations accessible. Wearing them, I feel confident venturing across any stage, under any lights. When I graduated with my bachelor's degree two years ago, I walked across the stage with my white cane and dark glasses. I will graduate with my master's in a few days, and the shades will be an essential part of my regalia.

Once the sunglasses became a fixture of my performance attire, my entire chorus started calling me Stevie, a nickname I readily accepted. When I sang with a jazz combo last semester, the alto saxophone player confessed, "I see a cane and dark glasses on a girl in the pit, and I immediately think, Diane Schuur!" I am excited to hear these comparisons, to think that the shades could be an emblem of blindness without deficit. Maybe the shades hold the power to bridge the associative space between disability and talent. Maybe one day, someone will see the shades and think, *I wonder if that (blind) girl sings jazz.*

I am learning that the tradition of dark glasses and white canes can work for me, that it's my prerogative to wear and use what I need. I offer others a new perspective of me as I accept a different vision of myself. Reluctance and resignation have passed. I don't love the look of sunglasses, but I love how the world looks when I wear them.