

Breaking down the Barriers

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Nearly forty years ago, like the students profiled in this monograph, I faced adulthood and the challenges of moving from the familiar to an unfamiliar world. At this time, I could still see and hear and took a job teaching elementary reading in southern California, three thousand miles away from my family. There, I found an apartment on the beach and a group of friends.

But then, my health played a trick. I began to lose my sight due to a mysterious retinal hemorrhages. At twenty-six I became totally blind.

With no skills to perform daily tasks, I entered an excellent training program in Pittsburgh, Pennsylvania that restored my ability to function independent and my self-



1974; wedding photo of Sally holding the arm of new husband, Bob, bookend by her two siblings.

confidence. I decided not to continue teaching, since my Braille skills were slow and my faith in my ability to control mischievous third graders weak. I completed graduate school in social work, took a job as a child therapist, and later married. After my children were born, I became a writer, publishing books that dealt primarily with blindness. Because of my success as a writer, I've found a career as a motivational speaker and once again -- a teacher.

Soon after receiving personal adjustment to blindness training, I experienced hearing loss that also mystified doctors. At age twenty-eight in the middle of graduate school, I had to miss class due to appointments with the ear doctor and hospitalizations. In 1987 when my children were 11 and 8, I lost what I termed *significant* hearing in my left ear, making it hard to hear my children's voices. Soon I was forced to wear a hearing aid. In 1999, further hearing loss demanded that I wear a hearing aid in my right ear as well. Now at age sixty-three, I await new and even more powerful hearing aids that will enable me to continue my teaching career at Chatham College and duties for two writing groups which I facilitate. Fortunately, my speech remains intelligible and my residual hearing is sufficient enough for communication in most settings. However, my hearing continues to deteriorate. Even though I am totally blind and consider myself moderately deaf, I never self identified as a

deafblind person. I associated this group with the remarkable Laura Bridgman, whose biography I've just finished writing and have sold to a publisher. In fact, I have only recently come to realize that I am representative of one of the fastest growing segments of the deafblind population – adults over the age of sixty.

Interestingly enough, the stories in this monograph of these articulate students resonate with me. I understand the tedium of struggling to hear in crowded situations. I appreciate the experience of being the lone disabled person in a classroom or work place. Even the pressure of having to work harder to keep up with my non-disabled peers and the extra effort required to fulfill expectations imposed by those who think I represent all disabled people in the world. But I also enjoy the uniquely comical circumstances that result from having a disability. For instance, I sometimes hear more interesting dialogue than is actually spoken.

"I had a date last night," a friend began, and I interrupted.

"Did you and Gary split up?"

She laughed. "No. I said *debate*, not *date*."

But many interactions aren't humorous. I remember being the only blind graduate student with professors who didn't know how to administer tests to me. I explained that I'd bring a reader and typewriter and asked only one accommodation from them—a quiet room. Instead, my professors supplied me with access to the nearby lavatory with flushing toilets and gossiping coeds.

Thirty years later, federal laws and specialized technology have improved educational opportunities for many deafblind students. But there still seems to be too much social isolation of the kind experienced by Laura Bridgman and Helen Keller a century ago. Too many social barriers between deafblind students and the sighted and hearing public still exist today. Since I spent a bit less than half my life among the ranks of the hearing-sighted majority and am now functioning quite successfully as a deafblind adult, I offer a few ideas for how deafblind students might enhance their interactions in both social and educational settings.

Even though students with disabilities are no longer sequestered away from mainstream society, a deafblind student entering a room can still send as powerful an emotional charge as if he'd walked into that very room unclothed! By in large, people react



Sally preparing for a stroll through the neighborhood with dog guide, Marit (in the harness), son Joel (on the leash) and young daughter, Leslie (in backpack).

to deafblind students with anxiety, not hostility. The uneasy person is fearful he'll say or do the wrong thing, so he plays it safe and avoids interacting with the deafblind person altogether.

Personally, I understand this avoidance. During college, I had classes with a competent, intelligent man who was blind; however, I never spoke to him. He fascinated me, but I was afraid I'd goof and embarrass both him and myself. He needed readers to access his text books and other assigned materials; and two of my more self-confident pals volunteered and became good friends with him.

If people do react malevolently toward a deafblind person, more often than not they aren't just anxious, they're also frightened. Most people struggle to be in control. When they see someone who they perceive to be more dependent, they feel unsettled and may tease or taunt the individual.

I have witnessed this reaction particularly in children. Once after I'd spoken at an elementary school, the mother of a fourth grade girl who was blind phoned me in tears. The kids "were being so cruel," she said. The mother explained how the other children wouldn't let her daughter sit with them at lunch.

As the conversation continued, I learned that this little girl didn't know her way around the school building and waited for her classmates to guide her everywhere. At home, she had no chores and no ability to get herself a sandwich, snack, or even a glass of water. In contrast, I recall how my own children in fourth grade pushed at the boundaries to try their wings. It is typical for fourth graders to strive to be independent. The reality that this mother did not realize was that her daughter's apparent helplessness made her classmates uncomfortable.

We can calm fears by being as competent as possible, by arranging for a trained professional or trusted friend to orient us to new surroundings. We also might think of favors and help we can give others instead of feeling entitled to goodwill from each person we encounter.

Another way to reduce uneasiness is by sharing information. Whenever I visit schools to speak about writing, I always ask if any kids with sensory loss or a physical disability would like to come up and join me at the podium. I say a few words about disability issues, and these students who may have been formerly viewed as outcasts become my helpers. Students who are blind or deafblind demonstrate how to use their canes and their Braille watches. Once one of my little helpers stole the show. At the conclusion of my presentation, the kids in attendance asked my special helper, not me, all

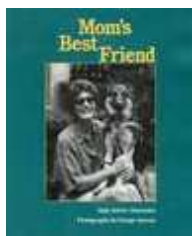
their questions of curiosity regarding blindness. The principal never needed to pay me to return.

Another strategy is to explain the rules of engagement, so to speak. People usually try their best; they don't want to offend a person with a disability by offering too much help. One of my rules of thumb is: "If I need assistance, I'll ask."

No matter how independent we are – we each can use a helping hand sometimes. So, I jokingly tell my sighted friends that I may use them much the same way I use taxi cabs, taking hold of their arm as they guide me from location "A" on to location "B" and then I will disembark when I am able to travel again from location "B" to the next location independently.

Another tactic is to answer questions, or even to anticipate them and address them before being asked. The first thing people want to know is how I became blind. If we as deafblind people explain what caused our disabilities, we can help to alleviate any fears regarding possible *contamination*. Over the years, I have learned that even the smallest amount of information can break down barriers.

Paying attention to our appearance also helps. During my life as a sighted person, I learned how much people judge us by our looks. I may be more vain than most, but there is a real phenomenon called "lookism," which is simply defined as discrimination against those who don't meet a commonly accepted standard of beauty and symmetry. Individuals viewed as overweight or obese are typically the targets of "lookism." But those of us with disabilities also suffer from this type of discrimination as well.



Cover of one of Sally's earlier literary works, *Mom's Best Friend* – a picture book about her first dog guide told from the perspective of her twelve year old daughter, Leslie. (MacMillan, 1992)

Most Americans are captivated by eye contact, which many blind and deafblind people are unable to accomplish. So the average person may speak not to us directly, but to our sighted companions. Whenever possible, I try to face the speaker to offer a response, and he usually catches on.

Some blind eyes, like mine, aren't attractive. Since I'm self-conscious about them, I wear sunglasses in the same way I wear make-up and jewelry – to improve my appearance. Other blind people may have *normal-looking* eyes or worry less about the physical appearance of their eyes. Because many deafblind individuals, like me, may lack complete sensory input, we may fill the void by developing unusual mannerisms to stimulate a remaining sense (i.e., rocking). When I was sighted, I remember seeing "blindisms" and thinking they



Sally on a walk through her neighborhood with present dog guide, Handley.

were strange. Now I too have developed my own set of “blindisms” such as playing with my fingernails and chewing gum. I hope these behaviors are less noticeable or odd.

Given that many of us who are deafblind don’t see everything clearly or at all, we may use less facial expression or fewer gestures. I’m reluctant to reach out to strangers because I’ve often missed my intended target and have landed on forbidden territory. However with friends and loved ones, I gesture, use some manual communication and hug them mercilessly.

I’ve come to realize that the lack of nonverbal communication or gestures that are not understood, can give an unconscious suggestion to an unknowledgeable sighted person that we aren’t kindred spirits. But by offering some communication attempts and good grooming, we can begin to close the gap between ourselves as deafblind people and those with whom we come into contact.

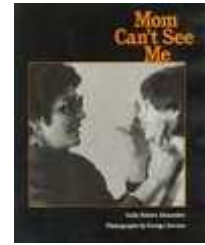
Finally, friends come from common interests. My friendships spring from work, church, community groups, and the classes I take. By joining clubs or organizations, we interact and get acquainted. Access to such functions may be a challenge; however, pitching in for gas or buying lunch for someone who offers you a lift is always appreciated.

I know deafblind teens that have made friends by becoming active members of their high school wrestling or swimming teams. By playing together, their teammates were able to overcome any fear, anxiety, or discomfort they may have had toward their deafblind teammate.



Cover of *Taking Hold: My Journey into Blindness*, Sally’s autobiography chronicling her adjustment to vision loss and quest to regain independence as a legally blind adult. (MacMillan, 1994)

As I, and many other deafblind students I’ve met over the years, can attest, barriers can and do crumble away. We’ve emerged from the veneer of our disabilities to become distinct individuals who, like the bright students in this monograph, have excelled despite great challenges. With initiative, self-awareness and support deafblind students can take better advantage of legislation and technological advances to enter the world with an improved balance of work, competence and meaningful relationships vital for a full life.



Cover of another of Sally’s earlier literary works, *Mom Can’t See Me* – a picture book about being the child of a blind mother told from the perspective of her nine year old daughter, Leslie. (MacMillan, 1990)



Cover of *On My Own: The Journey Continues* (1997) Sally’s sequel to *Taking Hold: My Journey Into Blindness*. This volume chronicles Sally’s new life as a legally blind adult who copes with the onset of hearing loss, complete vision loss and emotional setbacks.



Today, Sally enjoys a full life of adventure and achievement. Here she is seen swimming with dolphins.