BLIND SPOTS

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BLIND SPOTS

The Communicative Performance of Visual Impairment in Relationships and Social Interaction

By

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I dedicate this book to my parents, William and Sandra Frame, without whose loving support and sacrifice I could not have completed my degrees. They deserve honors conferred upon them as much, if not more, than I do. In addition, I dedicate this work to all those who have participated in my education. I greatly appreciate the time, energy, and sacrifice that my advisors, mentors, and teachers have invested in my life. Further, this book is dedicated to those who perform life with a visual impairment, especially I thank all those who willingly sacrificed their time to participate in my research. Finally, I dedicate this work, as I have my entire life, to my Lord Jesus Christ who died to purchase my salvation. It is through His strength alone that I am able to accomplish any good thing, and I give Him all the praise and glory.

PREFACE

Erving Goffman said, “All the world is not, of course, a stage, but the crucial ways in which it isn’t are not easy to specify” (1959, p. 72). The purpose of this research was to examine how a visual impairment affects the performance of the visually impaired actor in relationships and social interaction. To perform successfully, the visually impaired actor must be able to adapt to and perform competently within his or her assigned role, establish and maintain mutually satisfying relationships with other social actors, and know how to prepare for and manage the potential responses of the audience.

The primary methods employed in this study were survey research and qualitative interviews. A questionnaire was given to 188 individuals who are visually impaired, eight of whom also participated in in-depth telephone interviews. These primary methods were supplemented by autoethnographic stories and autobiographical accounts.

The interview results indicated that a visual impairment has both positive and negative effects on the self-concept, and that visually impaired individuals struggle with accepting the impairment and the loss of ability and independence that accompanies it. Further, a visual impairment may affect one’s ability to initiate and maintain relationships, and, therefore, the balancing of equity is important for visually impaired individuals in friendships, family, and romantic relationships. Finally, a visual impairment may affect public performance depending on the actor’s advance preparation and management of the responses of both self and the audience to the performance.

The survey results showed that individuals with more severe visual impairments tend to be more depressed, have lower levels of self-esteem, and be less satisfied with the emotional and instrumental support they receive. These effects, however, were moderated by a powerful others locus of control and perceived stigma. In addition, individuals who perceived their visual impairment to be more obvious were more depressed and believed more in the control of powerful others over their lives.

The results suggest the need for institutions and agencies that work with visually impaired individuals to include communicative, interpersonal, and social skills training in their educational and rehabilitation curricula.

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I also thank my good friend, Laura Ellingson, for her friendship and stimulating conversation. Much of my theorizing in the area of disability and visual impairment came about as a result of the discussions of disability and our own disability experiences that occurred as Laura transported me back and forth to class.

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THE CURTAIN RISES

Getting Situated

I wake up and peer at my watch—8:15 a.m. I can't believe I slept so late. Looking out the window makes me check again to make sure I see the correct time. It must be a gray morning, I reason. While dressing, I contemplate ironing my slightly wrinkled shorts. Then I realize the paradox of that thought. Here I am, going to my first support group meeting for persons who are visually impaired, and I'm worried that they will notice that my shorts are a little wrinkled. But then again, I notice. After confirmation from my friend (at whose house I had spent the night) that my shorts look fine, I finish getting ready.

I am somewhat apprehensive about attending this meeting. On the one hand, I feel guilty because I am attending only for the purpose of research. I want to write my dissertation on the communicative experiences of persons who are visually impaired, and I hope that I will find potential research questions and possibly research participants from this support group meeting.

I'm apprehensive because I have never been to a support group meeting for persons who are visually impaired. I guess I thought I didn't need to. I really don't know what to expect. The coordinator of the group had told me in a phone conversation that she wanted the group to be upbeat and positive, unlike the other support groups she had attended. She also told me about the group participants—they range in age from young adult to the elderly, have a variety of types and degrees of visual impairment, and generally number about 30 or so.

I had done research at a school for the blind several years ago. I remember being shocked that some of the students were substantially less visually impaired than I was. I never would have considered attending or needing to attend a school for the blind. But then, I had support from my family and friends, and attended a small private school where the teachers were willing to accommodate my visual impairment.

In the midst of my contemplation, my friend announces that it's time to leave. I arrive at the Lighthouse for the Blind about 15 minutes before the meeting is to start. I ask the receptionist where the Eyes Only meeting is being held. I follow her directions—through the double doors, around the blue partitions, and then turn to the left.

As I enter the meeting area, I am greeted by Becky, the coordinator, who seems to know immediately who I am. Becky is very cheerful and outgoing. She is of average height, full-figured, and appears to be in her late fifties or early sixties. I know from our telephone conversation that she has recently become visually impaired, although I am not sure how recently. She wears dark glasses but maneuvers independently, without a cane or other assistance.

Becky shows me where to sign in and explains that she has the group divided up at tables according to various diseases. There's a table for retinopathy, one for glaucoma, macular degeneration, diseases from birth, and other. I can't really place myself at any of these tables. I have a form of juvenile macular degeneration, which is rare and quite different from the senile form. At a glance, I can tell from the white hair and aged voices that the people at the macular degeneration table have the senile form. Although I was young when I was diagnosed, 10 years old, that doesn't qualify as a disease from birth. I question Becky and she suggests that I sit at the diseases from birth table. I find that I am the only one at that table.

Thus far the group consists largely of elderly persons. There are a few younger people, in their mid-thirties, who are helping Becky organize the group. As I wait for the meeting to begin, I take notes on what I have observed. Immediately I become aware that it is impossible to take notes unobtrusively. I have to hold the pad so close to my face, I feel self-conscious. Even as these thoughts enter my consciousness, I remember I am with others who are also visually impaired. I wonder if they are even capable of noticing the way I take notes.

This realization brings two thoughts to mind. First, I reconfirm what I had already decided—it's not very practical for me to use participant observation as a research method. I can easily fit into this group as a participant, but, being legally blind, I'm not exactly the best observer. Second, I can in some way understand how the sighted must feel around me. I am curious about, yet unable to understand what these people here see, just as my sighted friends and acquaintances want to know and understand what I see.

What do I see? What do others who are visually impaired see? Beyond what I or other persons with visual impairments can see, what is it like to go through life with a visual impairment? How does having a visual impairment affect one personally, relationally, and socially?

Introduction and Rationale

The stage is set. Fifteen minutes before curtain. The air is alive with electricity. The subdued but excited chatter of the crowd can be heard in the room where the cast is now assembled. The director gives his usual opening night pep talk, as if the actors really needed it. The cast is dismissed, and the stage manager yells, “Places everyone!” Just then, the director calls you and says, “You’ve become so good at this whole acting thing, it no longer seems a challenge for you. So, to liven things up a bit, I’ve decided that you will do tonight’s performance blindfolded.” Your jaw drops, and before you can protest the director has wrapped a thick black cloth around your eyes. He then says, “Good luck and break a leg!” You think to yourself, “I’ll be lucky if I don’t break a leg.”

This scenario is a bit ridiculous and would likely never happen in a real stage performance. But Shakespeare said, “All the world is a stage,” and many people have to perform their lives without vision. What is it like to perform life with a visual impairment? Many of us have, at some time, been involved in an exercise or game where we have been blindfolded and made to walk around, go up or down stairs, or (as in the popular child’s game) pin a tail on a donkey. From such experiences, most of us can at least imagine what blindness might be like.

But the term “visually impaired” also applies to many individuals who are not blind. “Legally blind” is a term that has been adopted to refer to individuals who have a corrected (if possible) visual acuity of 20/200 or worse. Thus, an object which a normally sighted person could see 200 or more feet away, the individual who is legally blind could see from only 20 feet away. This is a nice, neat definition, but how does it get translated into actual experience? Stephen Kuusisto, in his autobiographical work, *Planet of the Blind* (1998), describes his experience of legal blindness.

> . . . my vision loss is a form of “legal blindness”—a confusing phrase that means that I can see fractionally, though not enough to truly see. . . . Blindness is often perceived by the sighted as an either/or condition: one sees or does not see. But often a blind person experiences a series of veils: I stare at the world through smeared and broken windowpanes. (pp. 13, 5)

The following story illustrates my experience of legal blindness, which differs significantly from Kuusisto’s.

From the Front Row to the Balcony

Three friends from Indiana, my mom, and I went to see and hear the Florida Symphony Orchestra and the Master’s Chorale perform at the Tampa Bay Performing Arts Center. I got free tickets for all of us through my association with the Eyes Only support group. We were to meet outside the box office at 7:30. I had asked for clarification as to exactly where, and Cindy had expounded, “Oh just outside the box office there.” I knew that the box office had eight to ten windows and that many people met there. I wondered if I could find them and how they would find me (not the blind leading the blind, but rather, the blind finding the blind).