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The Perspectives of Graduate Students with Visual Disabilities: A Heuristic Case Study

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The Perspectives of Graduate Students with Visual Disabilities:
A Heuristic Case Study

by

Luis F. Pérez

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Special Education
College of Education
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study

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Dedication

I wish to dedicate this dissertation to my parents, who have believed in me at every step of my educational journey. Thank you for your unconditional love and support. I also want to dedicate it to my daughter, who provided much of my inspiration for pursuing this Ph.D. program and dissertation. I hope to inspire you to pursue your own dreams as much as you have inspired me to pursue mine. Finally, I wish to dedicate this dissertation to my co-researchers who so generously shared their life stories and experiences with me. I hope that together we have brought about a small change that will benefit others who want to follow in our footsteps.

Acknowledgments

I would like to sincerely thank all of my committee members for all of their support and encouragement. I am fortunate to have had the benefit of their expertise and support throughout this dissertation. Dr. David Allsopp served as my major professor and has been a true mentor in helping me grow as a teacher, researcher, and person. Dr. Karen Colucci and the rest of the special education department welcomed me with open arms when I decided to switch doctoral programs, one of the best decisions of my life. Dr. Patricia Alvarez-McHatton played a key role in encouraging me to pursue a more personal kind of research for this dissertation, and for that I am truly grateful. I first met Dr. Valerie Janesick when I enrolled in my first class and she was a new faculty member at USF. It is only appropriate that she is on my committee and will be there to see me complete this journey. Dr. Janesick has also mentored me in qualitative research methods and the methods section of this dissertation has benefitted greatly from her guidance and expertise.

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Table of Contents

List of Tables	iii
List of Figures	iv
Abstract	v
Chapter One: Introduction	1
Background and Personal Perspective	4
Heuristic Research	10
Liminality	11
Purpose	14
Exploratory Questions	14
Research Design	16
Significance and Usefulness of the Study	18
Definition of Terms	21
Summary of this Chapter	22
Chapter Two: Review of the Literature	23
Students with Visual Disabilities in Higher Education	24
Graduate Students with Visual Disabilities	28
Research on Lived Experience and Disability	34
Summary of this Chapter	44
Chapter Three: Methods	48
Framework for the Methods of this Study: Heuristic Research	49
Research Techniques Used in this Study	51
Participant Selection	54
Interviews and Other Data Collection Activities	57
Analytical Techniques in this Study	62
Role and Assumptions of the Researcher	70
Ethical Considerations	73
Summary of this Chapter	76
Chapter Four: Presentation of the Data	77
The Three Co-Researchers	78
Michael's Individual Depiction	82
Meet Michael	82
Process	87

Challenges	99
Empowering Factors	113
Summary of Michael's Depiction	119
Sarah's Individual Depiction	121
Meet Sarah	121
Process	123
Challenges	132
Empowering Factors	144
Summary of Sarah's Depiction	151
Maria's Individual Depiction	154
Meet Maria	154
Process	156
Challenges	165
Empowering Factors	173
Summary of Maria's Depiction	179
Group Depiction	183
Individual Portrait	196
Creative Synthesis	203
Chapter Five: Discussion	206
Impact on the Researcher	208
Key Findings	218
Empowering Factors	219
Barriers and Challenges	222
The Role of Institutional Support	226
Implications for Practice	228
Delimitations and Recommendations for Future Research	235
Summary and Conclusion	238
References	243
Appendices	249
Appendix A: Letter Advertising Study	249
Appendix B: Informed Consent Form	250
Appendix C: Demographic Questionnaire	251
Appendix D: Initial Interview Protocol	252
Appendix E: Peer Reviewer Form	254
About the Author	End Page

List of Tables

Table 1: The Six Stages of Heuristic Research (Moustakas, 1990)	63
Table 2: Participant's Demographic Data	79

List of Figures

Figure 1: Summary of Michael's Process	86
Figure 2: Summary of Michael's Challenges	99
Figure 3: Summary of Michael's Empowering Factors	113
Figure 4: Summary of Sarah's Process	123
Figure 5: Summary of Sarah's Challenges	132
Figure 6: Summary of Sarah's Empowering Factors	144
Figure 7: Summary of Maria's Process	156
Figure 8: Summary of Maria's Challenges	165
Figure 9: Summary of Maria's Empowering Factors	173
Figure 10: Summary of Group Challenges	184
Figure 11: Summary of Group Empowering Factors	185
Figure 12: Self-Portrait	204

Abstract

The concept of liminality describes the experiences of individuals who live “between and betwixt” as a result of their indeterminate status in society. This concept seems appropriate to describe the experiences of people who live with vision loss, because we simultaneously belong to two social or cultural groups. On the one hand we must navigate the mainstream society in which we live day to day, which we are often able to do with the vision we have left. On the other hand, our disability sets us apart from that mainstream society. This idea of living in “between and betwixt” the worlds of the blind and the sighted was the personal challenge that motivated me to pursue this autobiographic research through a heuristic framework. With heuristic research, the researcher is involved in the study as a first participant or co-researcher.

The purpose of this heuristic research study was to describe and explain the graduate school experiences of a selected group of graduate students who have visual disabilities in order to help me better understand my own experiences and identity as a graduate student with a visual disability. My exploratory questions that guided this study were:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?

3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

Employing heuristic research methods, I conducted responsive interviews with three purposefully selected co-researchers who also provided related documents for my review. Alternating periods of immersion and incubation, I examined the data in order to develop an individual depiction for each co-researcher, a group depiction, a detailed portrait of one of the co-researchers, and a creative synthesis that expressed my emerging self-understanding through an artistic approach. This creative synthesis captures my improved appreciation for my liminal status as something to be celebrated rather than overcome.

Analysis of the data yielded a number of common barriers or challenges faced by the co-researchers. These included a continuing lack of accessibility for both instructional materials and online content management systems, as well as feelings of social isolation, especially in relation to their non-disabled peers. To overcome these challenges, the co-researchers relied on the supportive relationships of their family members, their major professors and other staff within their departments. The co-researchers' personal characteristics of perseverance, resilience and resourcefulness also played a key role in their success, as did their ability to reframe their disabilities into a positive aspect of their lives. This reframing of their disabilities, along with their personal strengths, allowed the co-researchers to emerge as powerful advocates for themselves over the course of their graduate studies.

Chapter One:

Introduction

Overall, students with disabilities enroll in postsecondary education in smaller numbers than their peers without disabilities (Dowrick, Anderson, Heyer and Acosta, 2005; Gilmore and Bose, 2005). Students with visual disabilities make up a small subgroup within this population of college students who identify as having a disability. Henderson (2001) reported students who are blind or who have visual disabilities made up only 1% of first-year college students at four-year institutions in 2000 and this figure marked a decline from a peak enrollment of 2.4% in 1991. From this small subgroup, only a few students go on to pursue a graduate education. According to the U.S. Department of Education (2000), there were 161,000 students with disabilities enrolled in graduate programs during the 1999-2000 school year and of these only 1% (or 1,610) reported having a visual disability.

Given their small numbers, the research literature on the experiences of students with visual disabilities enrolled in graduate programs is limited. Sperr, Zischka, Paul and Warnke (1982) described the experiences of two of the authors who had visual disabilities as they pursued their graduate degrees in social work. However, the experiences described by the authors took place three decades ago, before important legislation such as the Americans with Disabilities Act (ADA) was enacted to protect the rights of people with disabilities. Furthermore, the authors did not explore the meaning of their experiences in great depth, possibly due to space constraints. More recently, Joshi

(2006) conducted a mixed-methods study focusing on the experiences of graduate students with visual disabilities who were enrolled in or who had recently completed clinical psychology or Master's level counseling programs. Joshi acknowledged that the use of telephone interviews and the selection of an instrument heavily weighted toward yes/no or multiple questions may have limited the participants' ability to more fully elaborate on their experiences. Working from the perspective of phenomenology, Galdi (2007) conducted telephone interviews with graduate students who reported having visual disabilities. In the discussion of her study's limitations, Galdi suggested face to face interviews with a smaller sample might have produced more detailed accounts of the participants' experiences and added to the richness of her study.

The purpose of this research was to add to the limited research literature on graduate students with visual disabilities by focusing on a smaller number of cases in order to conduct an in-depth exploration of the lived experiences of these graduate students. As my primary data collection method, I conducted face-to-face interviews with three graduate students who have identified themselves as having a visual disability. I also interviewed the graduate student participants on more than one occasion in order to ensure multiple opportunities to explore the different aspects of our lived experiences and to more fully develop the themes that emerged from the data. This approach allowed me to study these students' lived experiences in greater depth than would be possible with telephone interviews or surveys of a larger sample. The use of face-to-face interviews with a small number of students also helped with rapport building in order to build trust and facilitate more open exchanges with the graduate student participants.

In addition to the accounts provided by the graduate student participants, this study includes my autobiography as a key data source. Outside of the research literature, a few life histories of individuals with visual disabilities who attended graduate school have been published, such as David Hartman's *White Coat, White Cane* (1978) and Stephen Kuusisto's *Planet of the Blind* (1998). However, these life histories devoted only limited space to the graduate school experiences of the authors, and their focus was more on a factual description of the authors' experiences than on understanding what those experiences meant for them. To incorporate my autobiography into the research process, I conducted this research from the perspective of heuristic research. Heuristic research is focused around a question or problem which has been a personal challenge or puzzlement to the researcher in his or her quest to understand the self and the world in which he or she lives (Moustakas, 1990). In my case, the personal problem that motivated me to conduct this research was my own unresolved status as a person who lives between two worlds, those of the sighted and the blind. By conducting this research from the autobiographical perspective of heuristic research, I sought to examine more fully the meaning of disability in my own life in order to get closer to addressing the tensions that have prevented me from experiencing a whole self as person with a disability.

While my primary reason for pursuing this line of research was for me to gain self-understanding and self-acceptance as a person with a disability, I also intend for this research to have a social impact. Through this research, I have tried to provide a space where we, as graduate students with visual disabilities, can speak for ourselves about our lived experiences. My hope is that our accounts will provide valuable information and insights for future graduate students with visual disabilities who decide to follow in our

footsteps, as well as for faculty and administrators who are charged with providing accommodations and other supports for students with disabilities. Thus, I see my research as part of a larger political struggle to empower people with visual disabilities by promoting mutual understanding among the key actors involved in creating the conditions needed for us to succeed in the academy.

Background and Personal Perspective

Princely autocrats still reign on college faculties. Accordingly, higher education is a race. Semesters are timed contests. The speed of absorption is all that counts. In this race the visually impaired are reduced to depraved animals. Books float past our outstretched fingers (Kuusisto, 1998).

As a graduate student with a visual disability, I have intimate knowledge of the topic I chose to study. I was diagnosed with retinitis pigmentosa (RP), a degenerative disease of the retinas, in my late 20s, after I had already completed my undergraduate studies and entered the workforce. Today, I have about ten degrees of central vision left. In addition to my limited peripheral vision, my RP also affects my ability to see in low light environments as well as my depth perception. However, with the exception of the glasses I wear for my nearsightedness, my central vision has been largely unaffected by my RP. This sometimes makes it difficult to explain why I can read a book or watch television, but not drive.

Shortly after I was diagnosed with RP, I enrolled in graduate school in order to pursue a master's degree in instructional technology. I was able to successfully complete the requirements of that degree, and with the encouragement of my advisor I decided to pursue doctoral studies in the same field. After my first two years as a doctoral student, I

decided that a doctoral degree in special education would be more appropriate given my long term career goal of working with people with disabilities, and I made the switch into my current doctoral program.

When I first read the account of Kuusisto's graduate school experience included at the beginning of this section, I did not immediately see the connections to my own experience as a graduate student with a visual disability. After all, I had not had any confrontations with any of my professors over accommodations. On the contrary, some of my professors had gone out of their way to accommodate my needs as a graduate student, and I generally viewed my graduate school experience in a positive light. Furthermore, Kuusisto's experiences took place in the late 1970s, before important legislation such as the American with Disabilities Act (ADA) was passed to protect the rights of people with disabilities. Thus, I could rationalize that much of what Kuusisto referenced in his memoir could be interpreted as a sign of the times and did not apply to today's graduate school experience for students with visual disabilities.

However, as I met other graduate students who have visual disabilities, I learned not all of us have had a positive graduate school experience. As a result, I began to reconsider my assumption that Kuusisto's account did not reflect what many students with visual disabilities still experience in graduate school. As I listened to other students' accounts of their day-to-day experiences in graduate school, I also began to reassess my own feelings and recollections of my experiences. I realized that I often dismissed negative experiences I had as just another part of the day-to-day struggle of being a doctoral student, when in fact my vision loss played an important role in many of those experiences. I think the reason I could begin to examine my own feelings about being

blind is that I was finally in the company of other people who had similar experiences and could empathize with what I was feeling. As I began to look at my experience with a different, more perceptive lens, I slowly began to see myself as part of a larger struggle that connects me to other students with visual disabilities I have met at my university. Wanting to better understand the experience of visual disability, I made it the focus of a pilot study required in one of my research methods courses.

That pilot study employed a phenomenological approach to examine the graduate school experiences of a student who had a visual disability. During my presentation of the study's findings at a graduate student research symposium, I had a difficult time holding back my emotions, and I eventually ended up in tears after a sensitive question from one of the discussants. The question that caused me to end up in tears had to do with the approach I had taken to writing and presenting the summary of my phenomenological study for the symposium. The professor who asked the question thought my choice of language and overall approach reflected a conflicted position with regard to my own disability. To her, this was exemplified by my detachment as "the researcher" or "the author" in my paper, even though I had selected a method that she considered to be more personal in nature. As she later wrote in her feedback, she sensed from the way I had written the paper that I was not yet "comfortable enough in my own skin to engage in the more intimate qualitative methods," although she added this might come in time.

At first I was angry and offended that this professor would so publicly call into question my ability to speak for myself as a person with a disability, but after some reflection I accepted that there might be some truth to what she had said. Whether consciously or unconsciously, I had written myself almost entirely out of my paper and

avoided the tougher questions related to my own identity as a person who has a disability. However, if I could not own my own voice as a person with a disability, then how could I expect others to understand my experience? In reaction to the feedback I received at the symposium, I decided that I needed to immerse myself more fully in the study of qualitative research methods with the goal of finding an appropriate way to address the tensions I feel as a person who lives in between two worlds, those of the sighted and the blind. While I have a significant visual impairment, physically there is no indication that I have a disability. With the exception of the white cane I used for orientation and mobility, I can easily pass for someone who is sighted, especially if I am in a place I know well.

In the weeks after the symposium, I tried to immerse myself in the literature related to phenomenology, the study of lived experience. This made sense since I was interested in learning more about the lived experience of a particular group of people, and phenomenology is the study of lived experience. I also tried to immerse myself in the scholarly literature on visual disability in higher education, especially those studies that focused on the lived experiences of graduate students. My own pilot study was meant to address some of the limitations of Galdi's (2007) study of graduate students with visual disabilities, which she completed for her dissertation research. That study provided a good starting point for my inquiry, but as I continued to revisit it I began to see that aside from the methodological limitations I had tried to address in my pilot study, there was something missing that was far more important. I had a difficult time finding much of Galdi herself in her dissertation. Just as I had done in the reporting of my pilot study, she had written primarily in the third person in a style that reflected a distanced position in

relation to the phenomenon. In doing so, she was following the requirement of phenomenological research that the researcher practice epoche and set aside preconceptions and biases prior to pursuing the study (Thomas and Pollio, 2002). As I read and re-read Galdi's dissertation, I began to question whether phenomenology could be an appropriate method for the study of lived experience by someone who has lived through that same experience.

Around the same time, I came across an article by Gruppetta (2004) that focused on an approach called autophenomenography. According to Gruppetta's description, autophenomenography blends elements of autobiographical research with traditional phenomenological methods. With this approach, the researcher can act as a first informant of his or her own experience. While epoche is still practiced, the goal is not to set aside pre-conceived ideas about the phenomenon, but to become more aware of them and consider how they can add to the richness and depth of the study. My reading of Gruppetta's article is the reason I am writing this proposal from the first person perspective. However, as useful as Gruppetta's article was for exposing me to another alternative for phenomenological research, it was primarily an exploratory paper and lacked details on how to actually conduct autophenomenographical research.

Further online searches lead me to the work of Jacqueline Allen-Collinson, a researcher at the University of Exeter's Department of Sport and Health Sciences whose work employs autoethnographic methods to explore the embodied experience of the sporting body. Reading Allen-Collinson and Hockey's research encouraged me to continue my study of autophenomenographical research methods, but I found that their focus on sports limited its applicability to my personal interest in the study of disability.

As they stated in one paper, their focus is on the physical, rather than the social environment (Allen-Collinson and Hockey, 2010). Thus, there is an emphasis in the sensory aspect of lived experience in their work, which also considers kinesthetic elements such as movement and the location of the body in space.

Certainly, there is a sensory component to living with a visual disability. My experience of my own visual disability often includes unpleasant reactions to sudden changes in light levels, and I am also aware that my movements in low light or in unfamiliar environments differ from those of someone who is fully sighted. However, while these embodied aspects of my lived experience are important, they do not fully represent my lived experience as someone who has a visual disability. Thus, while I found Allen-Collinson and Hockey's research helpful, I decided that I needed to continue my immersion in the qualitative research literature in order to locate a perspective that would address the emotional and social aspects of lived experience, in addition to its embodied ones.

Along with my exploration of autophenomenography through Allen-Collinson and Hockey's work, I also read Clark Moustakas' *Phenomenological Research Methods* (1994) to broaden my understanding of research methods for the study of lived experience. I appreciated the step-by-step process for conducting phenomenological research Moustakas presented, and I was especially intrigued by his description of heuristic research in the first chapter of *Phenomenological Research Methods*. As a result, I next read *Heuristic Research Methods* (1990), where Moustakas explained heuristic research methodology in more detail. As I read Moustakas' description of heuristic research, I had a similar eureka, or "aha", moment as the one he describes often

happens during heuristic research. This term describes what happens when the researcher comes to a sudden insight after months of immersion with the data. In my case, after weeks of reading, I thought I had finally discovered a methodology that would be appropriate for the type of autobiographic inquiry I wanted to pursue.

Heuristic research is focused around a question or problem which has been a personal challenge or puzzlement to the researcher in his or her quest to understand the self and the world in which he or she lives (Moustakas, 1990). The heuristic process is autobiographic, and the person conducting the heuristic inquiry must have a direct, personal connection with the phenomenon that is the focus of the investigation.

Conducting my research from the autobiographical perspective of heuristic research allowed me to examine in detail the meaning of disability in my own life, and moved me closer to understanding the tensions that have prevented me from experiencing a whole self as a person with a disability. With heuristic research, I did not have to distance myself from the phenomenon of interest, as would be the case with phenomenology.

Heuristic Research

Heuristic comes from the Greek word *heuriskein*, which means to discover or to find (Moustakas, 1990). According to Moustakas, heuristic research refers to a process of internal search through which one discovers the nature and meaning of experience. The self of the researcher is present throughout the process, and as he or she comes to understand the phenomenon with increasing depth, there is also the experience of growing self-awareness and self-knowledge (Moustakas, 1990). This self-awareness and self-knowledge are achieved through a process of indwelling, or an inward turn in order to take a deeper, more extended gaze into some aspect of experience (Moustakas, 1990).

By focusing his or her attention inward, the researcher seeks to clear a space where he or she is able to tap into thoughts and feelings that are essential to clarifying the question or concern that gave rise to the inquiry in the first place. As will be explained in more detail in chapter three, heuristic research involves several stages that lead the researcher from initial engagement with the topic, to immersion in the data (through both self-dialogue and dialogue with others), to incubation, illumination, explication and the culmination of the research in a creative synthesis.

In the case of this research, the personal question that led me to pursue the research was my status as a person who lives in between two worlds, those of the blind and the sighted. My white mobility cane is one of the few indications the outside world usually has of my blindness. Furthermore, with the exception of my peripheral vision and my ability to see in low light, I can often function in the sighted world quite well. Thus, I have been able to continue in my job as a technology specialist who shoots and edits videos and photos. However, there are those moments every day when I am reminded of my vision loss, such as when I bump into an object that suddenly appears from my peripheral vision or when I miss a step on the stairs because of my limited depth perception. The fact that my vision loss is progressing so slowly, while a good thing, makes it feel like I'm living in limbo with regard to my disability, not fully blind, yet not fully sighted either. In the research literature, this concept of living in between two worlds has been described as the liminal state.

Liminality

The concept of liminality can be traced back to the work of the French ethnographer Arnold van Gennep, who in *The Rites of Passage* described three stages

that define any passage rite: separation, merger or transition, and reincorporation (Murphy, Scheer, Murphy and Mack, 1988). These three stages describe how during a passage rite an individual enters the initiation process as one kind of person, has his or her old identity nullified during a period of separation, and emerges with a new persona or identity during reincorporation (Murphy, Scheer, Murphy and Mack, 1988). The anthropologist Victor Turner further developed the middle stage of this process into what he defined as the liminal state. In the liminal state, the individual lives in social limbo because he or she does not yet have a firm social identity or role definition (Murphy, Scheer, Murphy and Mack, 1988). Turner described liminal beings as living ““neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony” (Turner, 1969, 95). In a later work, Turner distinguished between liminal entities (what he called “liminars”) and marginals. According to Turner, “marginals like liminars are also betwixt and between, but unlike ritual liminars they have no cultural assurance of a final stable resolution of their ambiguity” (Turner, 1974, 233).

Murphy, Scheer, Murphy and Mack (1988) applied the concept of liminality to physical disability. As they stated in their study of people with physical disabilities, many people with a physical disability live in a liminal state because they are neither sick nor well. They may no longer be under constant medical care for the accident or illness that caused their disability, but they may use a wheelchair, crutches, a white cane or other aid that indicates that they are not “well” either. To Murphy et al., this state of being resembles that of the initiate, who is neither boy nor man, in the passage rites described by van Gennep and Turner.

As with other liminars, society may respond to the indeterminate status of people with physical disabilities by setting up a social distance with those who are perceived as having the disability. According to Murphy et al. (1988) this social distance is reflected in the endemic physical isolation and non-communication among those who have a physical disability, resulting in their invisibility to the rest of society. However this invisibility is paradoxical. Because of their wheelchairs, crutches, seeing eye dogs or canes, people with physical disabilities are sufficiently striking to warrant awareness from everyone who sees them, but the convention is that it is not good manners to look (Murphy, Scheer, Murphy and Mack, 1988). Thus, even the perception of the liminar by others is ambivalent.

The concept of liminality seems appropriate to describe the experiences of people who experience vision loss. As liminars, we simultaneously belong to two social or cultural groups. On the one hand we must navigate the mainstream society in which we live day to day, which we are often able to do with the vision we have left. On the other hand, our disability sets us apart from that mainstream society. At times our ambiguous status may even allow us to move between mainstream society and the blind community. This aspect of living with vision loss has become more apparent to me the more I am around other people who have lost all of their sight.

I am used to being the only person with a visual disability in most situations, but when I am around people who are completely blind I have had to catch myself on more than one occasion behaving more like a sighted person. For instance, when speaking to someone who is completely blind, I have had to catch myself speaking to the person's companion instead of directly at him or her. Once I realized my behavior, I was

overcome with feelings of guilt. To me, this suggests that the ambiguous state of liminality is not just a challenge for society, but also for the person who has to navigate living in between and betwixt two worlds. It is this experience of liminality that represents the personal challenge I wanted to explore in depth with the heuristic research methods I selected for this study. Heuristic research was appropriate for this kind of inquiry because it is focused around a question or problem which has been a personal challenge to the researcher in his or her quest to understand the self and the world in which he or she lives (Moustakas, 1990).

Purpose

The purpose of the study was to describe and explain the graduate school experiences of a selected group of graduate students who have visual disabilities in order to better understand my own experiences and identity as a graduate student with a visual disability.

Exploratory Questions

The exploratory questions posed in this study were:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?
3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

The reason for including the two different dimensions of the graduate experience (academic and social) in the first two questions is that previous research (West et al., 1993) has shown these are two areas where students with visual disabilities experience barriers in higher education. In developing these questions, I tried to follow the guidelines suggested by Moustakas (1990) in *Heuristic Research Methods*. According to Moustakas, the heuristic research question should have the following characteristics:

- 1) *it should seek to reveal more fully the essence or meaning of a phenomenon of human experience.* The questions I developed clearly state that the inquiry will revolve around the experiences of a group of people (graduate students with visual disabilities), and the words “perceive” and “describe” refer to what visual disability is and means for us.
- 2) *it should seek to discover the qualitative aspects, rather than the quantitative dimensions, of the phenomenon.* The questions as worded do not disclose what methods I used to study the experiences of the co-researchers, and whether they were qualitative (interviews, document analysis, etc.) or quantitative (rating scales, tallies, etc.) research methods. However, the use of the word “how” in the first two questions denotes my openness to anything that emerged from the interviews I conducted with the participants and the documents they shared with me.
- 3) *it should engage one’s total self and evoke personal and passionate involvement and active participation in the process.* This is the most important requirement for a heuristic question. As I explained in an earlier section of this document, the experience I researched is one that I share with the other participants. Thus, I am intimately and autobiographically related to the question, and my presence in the research study has been clearly stated in three of the four questions.

- 4) *it should not seek to predict or determine causal relationships.* The questions I developed do not ask the word “why,” which implies an examination of causal relationships. Neither do they hint at any kind of theory development. Instead, the words “how” and “what” focus these questions on a detailed description of experience through the words of the participants.
- 5) *it should be illuminated through careful descriptions, illustrations, metaphors, poetry, dialogue and other creative renderings rather than by measurements, ratings and scores.* The first two questions clearly state that the focus is on descriptions of a particular experience. To keep the questions simple, clear and concrete as recommended by Moustakas (1990) I did not explicitly mention the methods I used in this study. The research design will be discussed in the next section, and a fuller description of methodology will be taken up in chapter three.

Research Design

Unlike previous studies of graduate students with visual disabilities, which have relied on telephone interviews (Joshi, 2006; Galdi, 2007), this study examined a small number of cases in depth through face-to-face interviews with selected participants. The number of cases is less important in case study research than what the selected cases contribute to our understanding of the topic at hand. As Stake (1995) stated, case study research is not sampling research and “the real business of case study is particularization, not generalization” (Stake, 1995, 8).

Within case study research, Stake defined two different kinds of cases: intrinsic and instrumental (Stake, 1995). With intrinsic case studies, a case is selected not because by studying it we may learn about other cases or about a general problem, but because we

need to learn about the particular case (Stake, 1995). In contrast, with instrumental case studies, the case is selected because it can help us understand something else (Stake, 1995). In this study, cases were selected because they could help me understand something else, with that something else being the experience of visual disability in graduate school. Thus, this study is an example of instrumental case study research. Furthermore, because more than one case was studied in detail, it is also a collective or multicase study.

Multicase study is a research design for closely examining a number of linked cases (Stake, 2006). While each case has a story to tell, the researcher's primary interest is in the collection of cases as a whole, or in a phenomenon exhibited in those cases (Stake, 2006). Stake (2006) used the term *quintain* to refer to the collection of cases that share a common characteristic or condition in a multicase study. According to Stake, in multicase study research, cases are selected for what they can contribute to the understanding of the *quintain*, that which we want to understand more fully and choose to study through its cases. In this study, the *quintain* was the experience of visual disability as a graduate student, and this experience was studied in depth by examining the experiences of individual students.

For this multicase study, I conducted interviews with three graduate students with visual disabilities. I conducted three interviews with each participant, and the interviews followed the "responsive interviewing" model developed by Rubin and Rubin (2005). With this model, the interviewer listens intently to the participants' responses and then formulates follow up questions based on what these participants have said. Following the first interview with each participant, I analyzed the transcript for emerging themes and

issues that needed clarification in follow-up interviews. To encourage the participants to reflect on their experiences between interviews, I asked them to keep a reflexive journal. In addition, I collected any relevant documents and artifacts about their experiences the participants were willing to share with me. These materials included an educational autobiography one of the students had written to fulfill a course requirement, as well as email correspondence participants deemed important to the understanding of their experiences. Throughout the study, I kept my own researcher reflective journal to capture my reflections of both the data and the research process. This researcher reflective journal was also an important source of data for the creative synthesis I prepared at the end of the study. I obtained informed consent from the participants at the beginning of the research study, and as I conducted the research, I did my best to honor ethical practices of research, including respect for the participants' confidentiality and privacy.

Significance and Usefulness of the Study

In addition to allowing me and the other participants to locate inner spaces where we can more closely examine the meaning of disability in our lives, I also aimed to provide us with a public space where we could speak for ourselves about our graduate school experiences. In this regard, the research took place from the perspective of disability studies, an interdisciplinary field of study that focuses on the contributions, experiences, history and culture of people with disabilities (Society for Disability Studies website, n.d.). The Society for Disability Studies, a professional organization for academics in the area of disability studies, offers guidelines for any program that defines itself as "disability studies" and two of these guidelines are as follows (Society for Disability Studies, n.d.):

- 1) it should challenge the view of disability as an individual deficit or defect that can be remedied solely through medical intervention or rehabilitation. Instead, a program in disability studies should explore models and theories that examine social, political, cultural and economic factors that define disability and help determine personal and collective responses to difference. By allowing all participants in this study, including me, to share how the social and cultural environment of the university impacts our ability to pursue a graduate education, this study should contribute to the understanding of disability as a social construction within the specific environment of the academy.
- 2) it should actively encourage participation by students and faculty with disabilities, and it should ensure physical and intellectual access. In this inquiry, all participants had a disability, as this was one of the criteria for participation. By allowing us to “tell our own stories”, the inquiry seeks to promote the inclusion of the perspectives of people with disabilities in the research agenda for the study of disability.

While this inquiry does not represent a “disability studies program” per se, the guidelines listed above should still apply because the goals of this inquiry are similar to those of a disability studies program. Both seek to improve the lives of people with disabilities by facilitating a better understanding of disability by those who are not disabled. While not a guideline of the Society for Disability Studies, I also believe strongly in the importance of this study as a medium for sharing lived experience among a small, often disconnected community of students. The hope is that the insights presented in this study will provide encouragement to other students with visual disabilities who might read the accounts provided by me and the other student

participants. I know that meeting other students with visual disabilities has been a source of strength and encouragement to me, and I hope the accounts “we” present in this study can do the same for other students in a similar position.

I also hope the autobiographical nature of this study will provide insights into the experiences of the few graduate students with visual disabilities who choose to pursue doctoral studies. After an extensive review of the literature, I was not able to identify any studies that explored the experiences of these students, as most research in this area has focused on students at the Master’s level. I believe an account of my own experiences as a doctoral student will not only provide valuable insights for other students with visual disabilities who wish to pursue doctoral education, but also for doctoral committees and other staff who provide support to doctoral students who have visual disabilities.

On a personal level, I hope the insights I have gained from conducting this research will empower me to be a better advocate for disability rights. In the future, I hope to continue the work I currently do as an advocate for improved access to information and technology by people with disabilities. However, in order to become a more effective advocate for the rights of others, I believe that I need to first be clear on my own identity as a person with a disability. In this area, I have been inspired by the work of other disability rights advocates, such as Caroline Casey. As I watched the video of a presentation she made at the TED conference in 2010, I was impressed not only by her skill as a presenter and story teller, but also by the way she came across as a person who is comfortable in her own skin and at peace with her disability. I wanted to achieve a similar feeling in my own life, and I think that pursuing a line of research that turns

inward toward the difficult questions related to the self has been an important step in that direction.

Definition of Terms

Disability. The definition of the term disability for this study follows the ADA definition, which recognizes the social construction of disability by also including people who are perceived as having a disability (Kaplan, n.d.). Under section 12102 of the ADA, disability means, in respect to an individual: 1) a physical or mental impairment that substantially limits one or more major life activities of such individual; 2) a record of such impairments; and 3) being regarded as having such an impairment (U. S. Department of Justice, 2009).

Blindness. The definition of blindness employed in this study is the one shared by the late Kenneth Jernigan, a past president of the National Federation of the Blind: “One is blind to the extent that the individual must devise alternative techniques to do efficiently those things which he would do if he had normal vision. An individual may properly be said to be ‘blind’ or a ‘blind person’ when he has to devise so many alternative techniques--that is, if he is to function efficiently--that his pattern of daily living is substantially altered” (Jernigan, 2005). This definition of blindness differs from the legal definition of blindness used by the Social Security Administration for determining access to benefits: visual acuity not greater than 20/200 in the better eye with correction or a field of vision of 20 degrees or less in the better eye (Social Security Administration, 2009). The Social Security definition follows the medical model of disability, while the definition presented by Jernigan is more inclusive and focuses on the functional and social aspects of disabilities instead of only its medical characteristics.

Visual Impairment. Visual impairment is: “any degree of visual loss that affects an individual’s ability to perform the tasks of daily life caused by a visual system that is not working properly or not formed correctly” (Moore, Graves and Patterson, 1997).

Summary of this Chapter

According to Moustakas, in writing a manuscript for a heuristic study, the researcher should include a section that describes the concerns, knowledge, and experiences from which their topic has emerged (Moustakas, 1990). In this chapter, I described how I arrived at my choice of heuristic research as the approach I took to explore a topic that is deeply personal to me. I also followed Moustakas' suggested outline and described the overall goals of this research from both a personal and social point of view, stated my exploratory questions, and defined some key terms.

In the next chapter, I will review, critique and synthesize the research literature relevant to the lived experiences of graduate students with visual disabilities. This review of the literature will be organized into the following sections:

- Students with visual disabilities in higher education.
- Graduate students with visual disabilities
- Lived experience and disability

Following my review of the limited literature on the experiences of graduate students with visual disabilities, I will describe the methods used in this study in chapter three.

Chapter Two:

Review of the Literature

The purpose of this study was to describe and explain the lived experiences of a selected group of graduate students with visual disabilities in order to help me better understand my own experiences as a graduate student with a visual disability. The exploratory questions addressed in this study were:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?
3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

To help me develop a better understanding of the meaning of my own experiences as a graduate student with a visual disability, I explored these questions through a heuristic case study design that involved in-depth interviews with three other graduate students who have visual disabilities. This chapter will provide some background on the topic of graduate students with visual disabilities and the limited research literature available on the experiences of these students. The literature review will be divided into three sections. The first section will provide background information about the

experiences of students with visual disabilities in higher education, while the second will focus more specifically on the experiences of graduate students. Due to limited literature on graduate students with visual disabilities, the literature review was expanded to include research that focused more generally on lived experience and disability. This research will be presented in the third section of this literature review.

Students with Visual Disabilities in Higher Education

Students with disabilities enroll in postsecondary education in smaller numbers than their peers without disabilities (Dowrick, Anderson, Heyer and Acosta, 2005; Gilmore and Bose, 2005), but their numbers in higher education appear to be growing. According to Stodden (2005), the proportion of first year full time students with disabilities tripled between 1978 and 1994, from 2.6% to 9.2%. Stodden (2005) reported the full range of students with disabilities, including part time and graduate students, to be 10.5% of the post-secondary student population in 1998. Galdi (2007) attributed this upward trend in the enrollment of student with disabilities in higher education to the enactment of legislation designed to protect the rights of people of disabilities, such as Section 504 of the Rehabilitation Act of 1973 and the American with Disabilities Act of 1990 (ADA).

Section 504 is a federal law designed to protect the rights of people with disabilities in all programs and activities that receive federal financial assistance, including public school districts, institutions of higher education, and other state and local education agencies (U.S. Department of Education Office of Civil Rights, n.d.). Section 504 states that “no otherwise qualified individual with a disability in the United States shall, solely by reason of her or his disability, be excluded from the participation in, be

denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance” (U. S. Department of Education Office of Civil Rights, n. d.). The American with Disabilities Act of 1990 (ADA) expanded the reach of Section 504 to include accommodations and services provided by state and local governments. Under Title 2, Subtitle A, the ADA prohibits discrimination on the basis of disability in all services, programs and activities provided to the public by state and local governments, including those that do not receive federal assistance (U.S. Department of Justice, 2009). Title III of the ADA goes even further and prohibits discrimination on the basis of disability in “places of public accommodation” (businesses and non-profit agencies that serve the public) and “commercial facilities” (U. S. Department of Justice, 2009). As entities that provide public accommodations and often receive federal or state funds, colleges and universities fall under the jurisdiction of many of the provisions of the ADA and Section 504 of the Rehabilitation Act of 1973.

There is some evidence that despite the enactment of legislation designed to protect their rights, students with disabilities still encounter barriers that make it difficult for them to succeed in higher education. West et al. (1993) surveyed 761 post-secondary students with a variety of disabilities, and 86% of them reported that they encountered barriers to their education due to their disabilities. These barriers included the inaccessibility of buildings for students with physical impairments, and difficulty in obtaining Braille materials and readers for students with sensory impairments (West et al.). Many students also reported they were unaware of the services and accommodations available to them, (West et al.) which suggests the offices set up to serve these students might not be doing a good job of outreach. Many of the students West et al. surveyed also

reported experiencing social isolation, as well as unfavorable attitudes from professors and other staff at their universities, such as a lack of understanding from professors and other staff regarding the accommodations or modifications these students had requested. The barriers faced by students with disabilities may lead many of these students to drop out before they complete their undergraduate education, and there is evidence of a gap in the graduation rates of these student compared to their peers who do not have disabilities. According to Dowrick, Anderson, Heyer and Acosta (2005), only 12% of students with disabilities graduate from college as compared to 23% for students without disabilities.

Like students with disabilities in general, students with visual disabilities make up a small subgroup within the larger college student population. Henderson (2001) reported students who are blind or visually impaired made up only 1% of first-year college students at four-year institutions in 2000 and this figure marked a decline from a peak enrollment of 2.4% in 1991. The small number of students with visual disabilities who enroll in college means that research on the barriers faced by these students is limited.

Hodges and Keller (1999) conducted in-depth interviews with six college seniors regarding their social integration on campus. These students indicated that transportation was a major problem for them because it hampered their time efficiency, lessened opportunities for social involvement through participation in campus activities, and limited where they could live (Hodges and Keller, 1999). However, despite these barriers all the students in this study reported that they were more socially integrated in college than they had been in high school. The strongest contributor to social involvement, according to Hodges and Keller, was personal initiative, such as being assertive and

initiating interactions with fellow students (Hodges and Keller, 1999). An important limitation of this study was that it might not have been representative of all college students with disabilities because all the participants had at least a 3.0 grade point average and were thus relatively successful in their academic programs. Thus, the experiences of students who were less successful as a result of various barriers they may have encountered were not reflected in the findings and conclusions of this study.

McBroom (1997) studied the transition experiences of 102 successful college students with visual disabilities at 66 colleges using structured telephone interviews. A strength of this study was the large sample size of students, especially for a study addressing a low-incidence population. The students, who were in their junior or senior year of a four-year college or in their second year of a community college, reported their preparation for college began in high school when they first explored colleges and aimed to match their needs with a college program (McBroom, 1997). They mentioned several factors that contributed to their success: being academically prepared, being knowledgeable about available services, seeking financial assistance, obtaining suitable housing, locating transportation and learning to navigate the campus, knowing how to use computers, managing time and money, being assertive and advocating for themselves, pre-registering for courses and placing book orders early so that the books could be available in Braille or audiotape (McBroom, 1997). As with the Hodges and Keller study, the focus was on students who were relatively successful, as demonstrated by the fact that they had completed at least half of their college experience at the time they were interviewed. Thus, these students had been able to figure out what they needed to do to survive in college, but other students who were not part of this study may not have

developed the same skills. Information about the experiences of students who did not complete their programs would provide insight into how those programs had failed those students and caused them to leave college without a degree.

Graduate Students with Visual Disabilities

Given their small numbers at the undergraduate level, the pool of students with visual disabilities who can pursue graduate education is also limited. According to the U.S. Department of Education (2000), there were 161,000 students with disabilities enrolled in graduate programs during the 1999-2000 school year and of these only 1% (or 1,610) reported having a visual disability. Within the limited research base on graduate students with disabilities, few scholars have focused on visual disabilities. To locate relevant articles for this literature review, I conducted an extensive search using the following online databases: PsycInfo (EBSCO), ERIC (Cambridge Scientific Abstracts) and ProQuest Dissertations and Theses Full Text. I searched using a combination of the following terms: “graduate students” and “visual impairments,” “blind,” “blindness,” and “visual disability.”

Sperr, Zischka, Paul and Warnke (1982) related the experiences of two of the authors, who had visual disabilities, as they pursued their graduate degrees in social work. According to Sperr, the biggest problem she faced as a graduate student was gaining access to the reading materials she needed for her courses. Sperr relied on both volunteer and paid readers to convert the print information into audio format so that it could be accessible to her. This process not only took some time, but it also resulted in additional expenses for Sperr that were not covered by any of the agencies that provided her with financial assistance while she was in school. Furthermore, the amount of time

required to convert materials also meant that Sperr had less time to complete assignments once she had access to the reading materials. As she explained, even if she gave the reader a book during the first week of classes, she could expect to have it in audio format by the second or third week, but midterms and assignments were usually due on the sixth and eighth weeks. This meant she often had a third less time to complete assignments, but she estimated it took her twice as long to complete the readings.

Overall, Sperr summarized the experience of recruiting and scheduling readers as being akin to “having a third full time job” in addition to course work and field work. All of these problems with obtaining accessible materials were compounded when dealing with readings that were placed on reserve at the library, because these materials could only be removed from the library with special permission, and only for a limited time. When permission was not granted, Sperr had to photocopy the materials herself for the reader. While more materials are now available in audio formats and students with disabilities may not always need a reader to convert materials, more recent research by Joshi (2006) confirmed that the accessibility of instructional materials remains a problem for graduate students with disabilities. Aside from the problems related to the accessibility of reading materials, Sperr did not focus on other aspects of her graduate school experience.

Her co-author, Linda Paul, expressed having some difficulty with the admissions process for graduate school. At one school, she felt she had made a strong impression during her interview, but the school later informed her it could not accept her because it could not find a field placement for her. According to Paul, the same school would later place several sighted students at the agency where it claimed she did not have a

placement. Once she was admitted to Fordham University, Paul viewed her field placement experience in a positive light. Her biggest challenge was in finding employment following her graduation from the program, a process that took her more than two years. She attributed some of the difficulty she encountered to prejudice on the part of prospective employers. In one case, the prospective employer had expressed strong interest in her qualifications and given her an appointment for the following week, then had cancelled the interview and told her “that it would be too difficult to teach you how to negotiate the agency.” Sperr and Paul provided anecdotal evidence of the problems faced by graduate students who have disabilities, but their paper did not address the meaning of these experiences for the authors in any depth. The authors did not attempt to follow any type of qualitative research methodology that would have allowed them to explore their experiences in more detail.

More recently, Joshi (2006) conducted a mixed-methods study focusing on the experiences of 19 graduate students with visual disabilities who were enrolled in or had recently completed clinical psychology or Master’s level counseling programs. All of the 19 students Joshi interviewed had vision that was poor enough that they required all print materials in alternate formats such as Braille or audio recordings. Data collection took place through semi-structured phone interviews that included questions about the participants’ experiences in various aspects of their graduate programs. Participants were asked about their experiences with the admissions process, internships and practica, and access to classroom materials. The questions were either yes/no or multiple choice, but the interview also included more open-ended questions where participants could answer in their own words.

The most common barrier cited by the students in Joshi's study was difficulty in gaining access to printed materials in the appropriate formats needed by students with visual disabilities, such as Braille or audio format. Some students indicated they had missed class changes and other important details due to the information being posted in print in a way that was not accessible to them. They especially found it difficult to locate sources in a timely manner for their research, and many students also said they had problems formatting their work in the required APA format. The inability to independently perform psychological assessments was also cited as a barrier that is specific to the profession of psychology and counseling. To administer assessments, students had to rely on sighted readers. On the positive side, the students in Joshi's study reported that materials were more accessible to them when they were available online.

Along with problems accessing instructional materials, attitudinal barriers were another theme that emerged during the interviews. Overall, Joshi observed that professors had a great deal of influence in the lives of the students. While many students said they had professors who were supportive and without whom they could not have gotten through their program, many also stated that they had to contend with professors who made their lives difficult. Students also referred to prejudicial attitudes from clinical supervisors for their practica and internships. With regard to peers, the students mostly considered them a positive part of their lives. They felt that peers were helpful both with class work and with helping to lessen their feelings of social isolation. Many of the participants in this study wished to have more disability awareness activities implemented in the curriculum of their graduate programs to address the attitudinal barriers they had encountered.

While Joshi's study provides evidence of the many barriers graduate students with visual disabilities face, she recognized in her discussion of limitations that the use of telephone interviews and the selection of an instrument heavily weighted toward yes/no or multiple choice questions may have limited the students' ability to more fully elaborate on their experiences. Joshi herself was a graduate student with a visual disability, and throughout her dissertation she interjected commentary about her own experiences with some of the aspects of graduate study covered in the study. However, the inclusion of the author's autobiographical information was done at a superficial level, and clearly the focus was on the responses of the other participants. A fuller consideration of the researcher's experiences may have added to the richness of this study.

Galdi's (2007) study was the only research I could locate that explored the lived experiences of graduate students with visual disabilities through a phenomenological approach. Galdi (herself a graduate student with a visual disability) explored the educational experiences of 15 graduate students with visual disabilities through semi-structured telephone interviews with each student and with a family member he or she nominated. In her study, Galdi identified the following barriers faced by these students: 1) negative attitudes of professors, 2) inaccessible educational materials, and 3) problems with transportation (Galdi, 2007). She also identified several factors that contributed to the academic success of these students despite the barriers they faced: 1) altruism, 2) perseverance, 3) resourcefulness, and 4) goal orientation (Galdi, 2007). The students mentioned two types of relationships that were important for their success: 1) familial relationships with parents, siblings, spouses, or their children, and 2) relationships with

mentors such as professors or members of organizations of the blind (Galdi, 2007). A limitation of this study was that the use of a single telephone interview with each participant might not have provided enough opportunity for the students to reflect on their answers and make meaning of their experiences.

In the discussion of her study's limitations, Galdi suggested that a study with fewer participants in a more localized geographical setting would allow for in-depth face-to-face interviews and result in more detailed, richer accounts of the students' experiences. She also recommended incorporating research from other qualitative traditions, including the biographical tradition. For example, she referenced a life history co-authored by Hartman and Asbell (1978) that focused on David Hartman's experience as a blind medical student who went on to become a medical doctor. According to Galdi, biographical life histories like the one co-authored by Hartman and Asbell can serve as educational success stories that can motivate other people with disabilities to pursue higher education. While Hartman's life history could still provide valuable insights for current graduate students with visual disabilities, the fact that it is now more than three decades old could limit its impact with today's students.

This study sought to add to the limited scholarly literature on graduate students with visual disabilities by addressing several limitations in Galdi's study. First, it focused on the lived experiences of a small group of students in a limited geographical area in order to allow for in-depth face-to-face interviews over an extended period of time. This approach provided more time for participants to reflect on their experiences, resulting in more in-depth accounts of those experiences. It also provided multiple opportunities for me to interact with the other participants in order to ask clarifying questions that allowed

us to elaborate on emerging themes in greater detail. Furthermore, the use of face-to-face interviews, rather than phone interviews, made it easier for me to build rapport with the other participants. This was important for building the trust needed for a true conversational partnership to develop between us.

Second, because Galdi selected a traditional phenomenological research method, she bracketed her own experience and almost left herself completely out of her dissertation. In contrast, for this study I followed a heuristic research design that allowed me to conduct it from an internal frame of reference. My autobiography (along with those of my participants) was a key source of data. Thus, this study provides the rich life histories mentioned by Galdi as an important source of inspiration for other graduate students with visual disabilities.

My review of the limited literature on graduate students with visual disabilities revealed several common themes. These included the importance of accessible instructional materials as well as access to transportation, and the students' own resourcefulness and initiative as demonstrated by their ability to proactively research universities that would match their needs and learn about the services available to them. Due to the limited research literature on students with visual disabilities in higher education, and on graduate students in particular, the literature review was expanded to include other works that focus on the study of disability and lived experience.

Research on Lived Experience and Disability

In order to locate other works that focused on the lived experience of disability, I returned to the same online databases I used to search for information about lived experience and visual disabilities and entered the terms "lived experience" and

“phenomenology” in combination with the more general term “disability.” A careful review of the abstracts from the search resulted in only two published works that were relevant to the current study. Fourie (2007) conducted what he defined as a retrospective qualitative self-study of his own experience living with retinitis pigmentosa (RP), the same retinal degenerative disease I have. Fourie did not explicitly identify his study as phenomenological research, but he appeared to have been influenced by phenomenologists such as Giorgi and Husserl, both of whom he cited in his introduction. According to Fourie, a primary goal of his research was to challenge the dominant position of Quality of Life studies within the research literature on visual disabilities. These kinds of studies, in Fourie’s opinion, focus on variables determined by researchers that do not necessarily reflect the real issues and concerns of people who have visual disabilities. Thus, he critiqued research in the field of visual disabilities for excluding the active participation of people with disabilities like himself, and for focusing on a deficit perspective.

At the time he conducted his study, Fourie was 36 years old, which is roughly the same age as me. Fourie worked as a speech and language therapist in a unit for deaf children in Ireland. He had a visual acuity of 20/20 but his visual field only extended out to about 14 degrees from the center. This is only slightly better than my own visual field, which extends out to about 10 degrees from the center. In the U.S., a visual field of less than 20 degrees is required to be eligible for benefits available to people who are registered as legally blind.

For his qualitative self-study, Fourie identified as retrospective data 12 emails about RP and issues related to blindness he had sent to family, friends and colleagues

over a period of about six months. The time period corresponded to the three months prior to Fourie receiving a white mobility cane, and approximately three months following that event. Fourie used the qualitative analysis program Atlas.ti to analyze the emails by arranging expressed ideas and themes into a semantic taxonomy. To develop this taxonomy, Fourie coded and classified each line of text in the emails. He then compared the codes and sorted them into families that represented themes grounded in the data. Along with his thematic taxonomy, Fourie developed theoretical memos which were arranged into their own categories. According to Fourie, these memos provided him with a framework for commenting on tendencies within the data.

Fourie organized the codes that emerged from his raw data into three overarching themes: diagnosis, impact and dealing. Diagnosis was arranged into two families, phenomenology of symptoms and consultation. Under phenomenology of symptoms, a key idea was Fourie's own need to communicate the sensory experience of RP in order to be understood by his correspondents. As Fourie explained, communicating with others about one's RP can be complicated by the apparently paradoxical nature of RP as an eye disease that only affects certain aspects of vision. Thus, a person with RP can read a newspaper and see a person clearly if they are standing across a room, but not be able to see that same person's face if they are up close. I would agree with Fourie that explaining that one is blind can be difficult when people see you doing things that are associated with having sight. For me, this is the case when people see me take out a camera to take a picture. The idea that I can take a picture, but am not able to drive, does not always neatly fit into the categories people want to use to describe people with disabilities. The fact that

I consider myself blind, but can do many of the activities enjoyed by sighted people is something I find myself having to explain over and over.

Under the theme of consultation, Fourie discussed his shock at the diagnosis of RP, and the resulting depression and feelings of frustration that followed his diagnosis. Fourie already suspected that he would be diagnosed with RP because of his family history (both his grandfather and father had been diagnosed with RP) but the diagnosis still came as a shock when it happened five months after his initial consultation. Unlike Fourie, I do not know of any other family members that have been diagnosed with RP, but I also suspected that I had RP long before my official diagnosis. I had been involved in a number of car accidents, including one that almost resulted in serious injury to another person, and each time the impact was in the same area of my field of vision. Thus, I knew that there was a possibility that I might have a problem with my peripheral vision even before my first visit to an ophthalmologist. While I was not shocked by my diagnosis, its emotional impact was similar for me as it was for Fourie.

For the theme of impact, Fourie organized the codes into four categories: psychological, social, mobility, an occupation. Fourie explained that after his diagnosis he experienced a long period of depression which he attributed to a grief response. The high incidence of depression among people who are diagnosed with visual disabilities has been documented by Brody (2001). Hayeems et al. (2005) described suffering in the context of RP as a “state of distress that occurs when a person’s integrity or life plan is threatened, disrupted or burdened.” He added that this distress lasts until the integrity is restored, either by eliminating the threat or by adjusting to it. However, for people with RP, the possibility of removing the threat is small due to the fact that there is no known

cure for the disease and it is progressive in nature. Thus, as Fourie explained, the major task of a person who has been newly diagnosed with RP or who has recently received a cane is to re-adjust their self-image.

In Fourie's case, changes to his identity and self-image were closely linked to the use of his mobility cane. To Fourie, the mobility cane made his disability more obvious in a society that values the "normal". It also signified a loss of autonomy and a threat to his adult status because it called into question his ability to be self-reliant and self-sufficient. The response by many people who have been diagnosed with a visual disability, myself included, may be to avoid using the cane even when it is necessary. This hiding behavior can have a negative impact on adjustment, and it also sends a contradictory message to the outside world. Even if it represented a challenge to his identity, Fourie recognized that the mobility cane also had a positive social impact for him. It allowed him to get to more places that were formerly off limits to him, and this lessened the social isolation he first felt after being diagnosed.

As factors that helped him cope with his disability, Fourie identified the following: framing blindness positively, entitlements, and counter depression. Several factors helped the author reframe how he viewed blindness. One was taking on challenges such as rock climbing that highlighted his ability to still do brave and dangerous things. Another was having a sense of humor, and "looking on the bright side" by comparing the more favorable conditions in his country of residence (Ireland) as compared to his native country (South Africa). The code entitlements focused on the author's need to understand his legal status in society by learning about the rights and protections that made him feel protected under the law. The code counter depression

encompassed all the practical steps the author took to improve his situation as a whole. These included using his cane to improve his mobility and combat social isolation, engaging in physical exercise, locating more factual information about his disability, and reading about the positive experiences of other people with the same disability. As Fourie wrote, understanding that he was not the only one with RP helped to move him away from a sense of isolation. I hope that my study has compiled similar stories that provide hope and encouragement to others facing the prospect of a life with retinitis pigmentosa or a similar visual disability.

At the time he conducted this study, Fourie was already out of school and employed. He mentioned having some anxiety in relation to a job interview, but overall he stated that he had a positive outlook with regard to his future prospects for employment. He was especially encouraged by the development of new assistive technologies, as well as by the statutory changes that made it the law for his employers to provide such accommodations. The fact that Fourie was already employed at the time of diagnosis may have influenced his attitudes with regard to the impact of visual disability on his prospects for the future. Graduate students entering the workforce for the first time or returning to work after a prolonged leave to attend school may have different attitudes and feelings about their prospects for the future than Fourie.

Furthermore, the experience of being newly diagnosed with a disability was central to Fourie's study. Many graduate students, myself included, may have a similar experience of finding out about our disabilities while in graduate school, but others may have been blind their whole lives or been diagnosed many years before they enrolled in graduate school. Their concerns may be different than those of someone who has been

recently diagnosed, but they are equally valid and should also be represented in the research literature.

Aside from Fourie's study, my search of online databases did not provide any other studies focusing on lived experience and disability that were relevant to the proposed study. I had better results by following the references in some of the articles that focused on lived experience in general. This was the case with a reference in Allen-Collinson and Hockey (2010) that pointed me to a book chapter by Toombs (1995) where she provided a powerful account of her lived experience with multiple sclerosis. As I read Toombs' accounts of her lived experience with chronic illness, I was deeply moved by the evocative language she used and by the honesty of her account. I was especially impressed with her willingness to share some of the most intimate details of her life with a chronic illness, such as how it had affected her ability to control even basic bodily functions. Even though my disability is different and does not involve the same bodily concerns, I resolved to strive for a similar honesty and openness in my own writing about my disability after reading Toombs's account.

Like Galdi, Toombs (1995) placed her work within the tradition of phenomenology. However, the phenomenological notion of lived body was central in Toombs's exploration of her lived experience with disability. The lived body was defined by Toombs not as an object among other objects of the world, but the body as we live it, our particular point of view on the world. According to Toombs, the body is a vehicle for looking out into the world and orienting ourselves as a Here against which everything is a There (Toombs, 1995). The lived body is also the locus of our intentions, the medium through which we not only find ourselves in the world, but also move towards that world

and organize it in terms of our projects (Toombs, 1995). To the lived body, objects present themselves as invitations for the body's possible actions. For example, a piece of paper is not just a physical object with a specified shape and dimensions, but "an instrument to capture our ideas in writing" or "a means to express ourselves in a letter."

In her account of living with multiple sclerosis, Toombs focused on the disruptions of this lived body that occur when one has a disability. For Toombs, the first of these disruptions is that of the body as intentional locus. In her case, this disruption was brought about by the loss of her mobility as her illness progressed. This loss of mobility anchored her to the Here and transformed her relationship to lived space so that objects that were once "near" were now "far" based on her changed ability to navigate her environment. Also, objects that were once taken for granted and used without much thinking were now overt problems for her body. As a result, the surrounding world felt different to Toombs than it did prior to her loss of mobility, and she described it as overtly obstructive and non-accommodating, in ways that made actions which used to be effortless now effortful. According to Toombs, the need to continuously learn and relearn how to solve the problems presented by the objects in the surrounding world is what differentiates the experience of someone who has had abilities and then lost them to a progressive illness or disability from those who have never had those abilities.

While Toombs' accounts of her lived experience centered on the embodied aspect of lived space in her experience, she also considered the emotional impact of her disability. Thus, she expressed having feelings of shame related to her disability, as well as experiencing frustration, irritation and even downright anger at her body's inability to do the same things it used to be able to do in the past. She called this the "frustration of

intentionality.” (Toombs, 1995). Sometimes, her anger was directed at the thoughtless behavior of others, such as when somebody parked illegally in one of the spots designated for people with disabilities. I would agree with Toombs that the biggest problem with this anger is that the person with a disability does not always have easy ways to express it. While for some people the disability itself may prevent them from physically or verbally expressing their emotions, for others it may be a desire to present a strong persona to a world that already sees us as being less because of our disabilities. I would include myself in the latter group.

The impact of disability on self-worth was another key theme in Toombs’ writing about her disability. More specifically, she referred to the disruption in the person’s identity as a result of having a disability. As Toombs stated, our sense of who we are is intimately related to the roles we occupy and the goals and aspirations we have for ourselves (Toombs, 1995). However, with a chronic, progressive disability such as multiple sclerosis (or my own disability, retinitis pigmentosa) all of those roles are disrupted in ways that reduce our worth as a person. In Toombs’ case, the diagnosis of multiple sclerosis resulted in others telling her that she “should take it easy” or put aside projects and activities because of her disability. These changes in others’ expectations can become a self-fulfilling prophecy for the person who has the disability. Self-worth may also change in response to changes in how our bodies move and function, what Toombs defines as our corporeal style. In a society that celebrates physical fitness, productivity, sexuality and youth, the person who staggers, uses crutches, a cane, or a wheelchair is seen as being far from the ideal. As a result, the person who has a disability can develop feelings of shame about his or her body.

Another disruption Toombs examined was that of temporal experience. The physical demands of impaired embodiment may ground one in the present moment, requiring disproportionate attention to the here and now. As routine activities begin to take more time than they used to, or more time in comparison to others, the person who has a disability may experience being “out of sync” as he or she experiences disrupted time. Furthermore, the unpredictable nature of progressive illness also means living with uncertainty about the future. This makes thinking about the future problematic and further grounds the person who has a disability in the present moment. For me, this has been the most difficult aspect of my disability. Even as I have pursued a graduate degree in order to improve my career prospects, I have had to face my fears of the future and doubts about my ability to find employment after graduation on a daily basis. As Toombs has done, my response has been to focus on the present, and to turn my attention from the imagined difficulties of the future to the concrete ones of the present. While this may be a productive emotional response for allowing me cope with the uncertainty that my disability presents, it has also at times kept me from taking a more proactive approach to planning for the future.

Despite the fact that multiple sclerosis and visual disability are significantly different, the experience of disability shared by Toombs raised many issues that are common to people like me who have progressive disabilities: the disruption of identity, living with uncertainty about the future, and the frustration of intentionality. For this reason, much of what Toombs discussed resonated with me as someone who is living with progressive vision loss. However, while Toombs’s account was rich in detail and moving, there was little information in her work about the process she had undergone to

arrive at her current thinking with regard to her disability. Thus, while her work provided a good model for the way that I might report the findings of my own study, it did not provide sufficient guidance on how to actually develop a research project of my own that would focus on visual disability. Despite this limitation, her work did present an approach to the study of lived experience that was autobiographic in nature. As a result of being exposed to Toombs's approach to the study of her disability, I was encouraged to examine more closely the assumptions of the different strands of phenomenology in order to develop a rationale for the autobiographic methods of this study which I will outline in more detail in the next chapter.

Summary of this Chapter

In this chapter, I have provided a context for this inquiry by summarizing the limited literature with regard to graduate students with visual disabilities. I first provided background information about students with visual disabilities in higher education before focusing more specifically on the few studies that have addressed the experiences of graduate students. As I reviewed the literature on graduate students with visual disabilities some key themes emerged: the importance of accessible instructional materials (Sperr, Zischka, Paul and Warnke, 1982; Joshi, 2006; Galdi, 2007), the impact of negative attitudes about disability by faculty (Joshi, 2006; Galdi, 2007) and the importance of supportive relationships to the students with visual disabilities (Joshi, 2006; Galdi, 2007).

My review of the limited literature on graduate students with visual disabilities revealed a need for greater depth. The few studies available on this topic have examined it from a distance through the use of telephone interviews (Joshi, 2006; Galdi, 2007) or

instruments that allowed little room for full expression by relying on yes/no or multiple-choice questions (Joshi, 2006). Even when the author of the research was a graduate student with a visual disability, the selection of a particular approach to phenomenology resulted in an account that distanced the author from the phenomenon under study by bracketing her experience (Galdi, 2007). These methodological choices may have been the result of the researchers including relatively large samples in their studies. In contrast, this study focused on a smaller sample of three students in order to explore the experiences of these students in greater depth through the use of face-to-face interviews in a more intimate setting.

Due to the limited research on the experiences of graduate students with disabilities, I expanded the literature review to include other accounts of lived experience and disability. A more general search focusing on lived experience and disability revealed a few examples of research authored by people with disabilities that presented the kind of in-depth exploration of disability I sought for myself in this study. These studies not only presented intimate accounts of the authors' experiences with disability, but also suggested alternative approaches to the study of lived experience that did not require me to leave my own lived experience out of the research project. A common theme in this research was the negative impact of the disability on each author's self-image and self-worth. While Toombs (1995) described these changes as a series of disruptions that transformed her relationship to lived space and lived time, Fourie (2007) focused on how his disability affected his autonomy and challenged his status as an adult trying to live independently in society. Both authors reported feelings of shame with regard to their disability, especially as it became more visible to others. For Toombs these

feelings were associated with her loss of mobility and the need to use of a wheelchair, while for Fourie these feelings were closely linked to the need to use a white cane to navigate his environment.

While the literature on disability and lived experience I reviewed touched on many of the negative aspects of having a disability, it also addressed those factors that led to the authors feeling empowered to cope with changes in their identity as their disabilities progressed. Both Toombs (1995) and Fourie (2007) indicated that a reframing of the relationship with the objects associated with the disability (a wheelchair for Toombs and a mobility cane in Fourie's case) might be a helpful step toward facilitating adjustment to the disability. For Fourie, this meant shifting his focus to how his mobility cane allowed him to go places where he could not previously go and decreased his social isolation. Along with this change in perception, he addressed other strategies he adopted in order to feel more empowered, such as learning more about his disability and pursuing activities that focused on his personal strengths. Overall, as I read these authors' work I felt empowered as I saw examples of people of disabilities who had learned how to cope with their changing identities as people with disabilities and pursued productive careers as researchers in their respective fields.

By expanding my literature review to include research that focused more broadly on disability and lived experience, I was able to identify research that focused on the autobiographical experience of disability. This research addressed the inner dimensions of disability (such as how it impacts on the person's self-perception and feelings of self worth). In contrast, the research I identified that focused more specifically on the experiences of graduate students with visual disabilities primarily focused on the more

practical concerns of the external world that impact on these students' experiences (such as the accessibility of learning materials or access to transportation). By adopting the heuristic approach which I will describe in more detail in chapter three, I aimed to bridge this gap in the understanding of the external factors that impact our experiences as graduate students with visual disabilities and the inner world that includes our perceptions of ourselves and our identities as people with disabilities.

Chapter Three:

Methods

The purpose of this study was to describe and explain the lived experiences of a selected group of graduate students who have visual disabilities in order to help me better understand my own experiences as a graduate student with a visual disability. The heuristic research design that I selected for this study is autobiographic and aims at providing self-awareness and self-knowledge through dialogue with others who have had similar experiences. The exploratory questions that guided this heuristic study were:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?
3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

In this chapter, I will explain the methods I used to collect and analyze data pertaining to the graduate school experiences of students with visual disabilities. I will explain the design of the research, including participant selection, data collection, and analytical practices. I will also explore my dual role of researcher and participant in this study in order to identify some of the assumptions that have shaped my interpretation of

the data, and I will address some of the ethical concerns I needed to address as I did this research.

Framework for the Methods of this Study: Heuristic Research

Moustakas (1990) described heuristic research as a “way of engaging in scientific search through methods and processes aimed at discovery; a way of self-inquiry and dialogue with others aimed at finding the underlying meanings of important human experiences” (p. 15). In order to understand the meaning of an experience, the heuristic researcher must also develop a dialogue with people who have had, are having, or will have the experience (Moustakas, 1990). This dialogue must take place under an atmosphere of trust and openness that encourages the other person to share their experience in an unqualified, free and unrestrained manner. Moustakas stated that our most significant awarenesses and understandings develop from the kind of dialogue that relates our own internal search with an empathic understanding of others. However, even when examining the experiences of co-researchers, heuristic research always relates back to an internal frame of reference (Moustakas, 1990).

Heuristic research, with its focus on the meanings of lived experience, shares a common goal with phenomenology. However, Douglas and Moustakas (1985) made some important distinctions between heuristic research and phenomenology. Whereas phenomenology encourages a kind of detachment from the phenomenon under investigation, heuristic research emphasizes connectedness and relationship among the people who have experienced that phenomenon (Douglas and Moustakas, 1985). The outcomes of the two types of research are also different. With phenomenology, the researcher concludes with a description of the structures of the experience, but heuristic

research concludes with a depiction of the essential meanings of the experience along with a portrayal of the personal question that motivated the researcher's quest to know (Douglas and Moustakas, 1985).

While phenomenology focuses on distilling the essence of experiences and generally loses the person in the process of descriptive analysis, heuristic research leads to a presentation of new understandings in a way that clearly presents each participant as a whole person (Douglas and Moustakas, 1985). In other words, the research participants remain visible throughout the process of data analysis in heuristic research. This last point was key in my decision to select heuristic research as the method for this study. The community of blind graduate students is already a community with few representations in either popular media or the academic literature. In presenting the experiences of members of that community I wanted to make sure that they remained visible throughout the process, rather than fade into the background and continue to be invisible.

In addition to the social aim of providing a space for other students with visual disabilities to share their stories, I went into this research hoping the dialogue with the other participants and the intensive self-reflection required to conduct a heuristic study would provide me with an opportunity to explore my own identity as a person with a disability in depth. The demands of my academic life as a graduate student have left me with little time to engage in any kind of deep exploration of my own identity with regard to my disability, and I have often had a difficult time talking to others about my situation. I hoped this research experience would help me uncover the many layers that make up my identity as a member of several marginalized groups (Hispanic, immigrant, person with a disability). At the same time, in keeping in line with the connection of the personal

to the social in heuristic research, I also hoped this study would provide insights that could help other graduate students with disabilities understand their own experiences.

Research Techniques Used in this Study

In this study, I sought to describe and explain the lived experiences of a selected group of graduate students with visual disabilities at the same time that I examined my own experiences of visual disability in graduate school. The focus on description and explanation, rather than on the identification of cause and effect relationships, places this research in the qualitative research tradition (Janesick, 2004). According to Janesick (2004) qualitative research is holistic and seeks to understand the whole picture of the social context under study through personal, face-to-face, and immediate interactions in a given setting. My selection of qualitative research methods for this study was based on my assumptions and beliefs about the topic I chose to study. I believe the best way to learn about lived experience is to talk directly with people who have similar experiences in order to obtain different perspectives about the phenomenon of interest. Thus, the primary data collection method for this study was face-to-face interviews with each participant. To assist with interpretation, I also maintained a researcher reflective journal and collected relevant documents from the participants. However, the interview was the primary way in which I interacted directly with the participants in order to achieve a more in-depth understanding of our shared experiences. Janesick (2004) defined the interview as:

A meeting of two persons to exchange information and ideas through questions and responses, resulting in communication and joint construction of meaning about a particular topic (p. 72).

Patton (2002) described three basic approaches for conducting interviews in qualitative research: informal conversational interviews, interviews that follow a general interview guide with topics and issues to be explored, and standardized open-ended interviews where each participant responds to the same set of carefully worded questions. Moustakas (1990) suggested a conversational interview with participants is more clearly consistent with the rhythm and flow of heuristic research and its search for meaning than more standardized interviewing methods. According to Moustakas, the conversational interview is the preferred approach for heuristic research because it opens the possibility for a dialogue between the principal investigator and the other participants that encourages expression, elucidation and disclosure on the part of all involved. Although general questions can be formulated before the interview, I agree with Moustakas that authentic, genuine dialogue cannot be planned. Such a dialogue depends more on empathic listening on both sides of the interview situation, rather than on the probing questioning by the researcher associated with more standardized approaches to interviewing.

For this study, I relied on the responsive interviewing model described by Rubin and Rubin (2005), an approach that provides some of the structure of the interview guide while also allowing for the flexibility of the informal conversational interview. With responsive interviewing, the researcher adopts a flexible research design that recognizes the uniqueness of interviewees by customizing the questions posed during the interview for each participant rather than asking the same questions of all participants. The researcher listens carefully to what each participant is saying during the interview, then

responds to and asks further questions about what he or she hears rather than relying only on a set of predetermined questions.

Responsive interviewing is based on an understanding that the interviewer and interviewee enter into a relationship when they come together for an interview. Rubin and Rubin described this relationship as a “conversational partnership” because this term “has the advantage of emphasizing the active role of the interviewee in shaping the discussion and guiding what paths the research should take” (p. 14). The term “conversational partner” also suggests a congenial and cooperative relationship in responsive interviewing, with both interviewer and interviewee working together to achieve a shared meaning (Rubin and Rubin, 2005). To more accurately describe the cooperative relationship that developed between me and the other participants in this study, it may be more appropriate to also refer to us as co-researchers who had a mutual desire to have a better understanding of the meaning of disability in our lives through an in-depth exploration of our experiences.

To focus in depth on our experiences, I selected to examine a smaller number of cases for this study. By interviewing only three graduate students who met the criteria for inclusion, I had an opportunity to conduct more than one interview and to explore the phenomenon in depth using the responsive interviewing techniques described by Rubin and Rubin. It is my belief that the responsive interviewing approach helped create an environment where authentic dialogue could take place and all conversational partners in this study were able to share their ideas and feelings openly and honestly so that we could come to more fully understand our common experiences.

Participant Selection

In selecting my co-researchers for this study, I employed a purposeful sampling method to intentionally select participants who could provide me with the most and best information about the phenomenon of interest (Mayan, 2009). With purposeful sampling, the aim is not to make generalizations to a larger population based on statistical probability theory, but to select participants who will allow the researcher to understand the phenomenon in depth (Mayan, 2009). Thus, the number of cases is less important with this approach than what the selected cases contribute to the understanding of the topic at hand. Similarly, with case study research the researcher selects a particular case and comes to know it well, not for how it is different to other cases, but for how it is unique (Stake, 1995). In order to choose my co-researchers in a purposeful way, I selected some criteria for inclusion in this study. To be included as a co-researcher, each student needed to:

- have been enrolled for at least one semester of graduate studies in the last two years.
- self-identify as having a visual disability
- be willing to participate in the study through three face-to-face interviews and by sharing relevant documents.

The first criterion was to ensure the graduate students I selected had some experience with the phenomenon that was the focus of this study. The focus on current students or recent graduates was to ensure that the students were not too far removed from their experiences and could recall them in great detail during the interviews.

One of my concerns about pursuing this type of research was that I would not be able to find a sufficient number of participants given how few students with visual

disabilities enroll in graduate school. However, through personal contacts I was able to identify three graduate students with visual disabilities who agreed to participate in this research. After meeting informally with these students, I determined they had experience with the phenomenon of interest, could speak about it in depth, and thus could provide me with the rich data I was looking for with this study. I asked these students if they could recommend other students they knew who would meet the criteria for inclusion in this study, but this personal networking was not productive in helping me locate additional participants.

To recruit additional participants, I contacted the Students with Disabilities Services (SDS) office at my university. Through their mailing list for students who receive accommodations, this office helped me distribute information about the study to students with visual disabilities on my campus and other satellite campuses. I also contacted the local Division of Blind Services (DBS) office. DBS falls under the state's Department of Education and provides assistance and counseling to students who are blind or have a visual impairment. I am a DBS client because I am legally blind and have received some support from them in the past.

After the university's Institutional Review Board (IRB) approved the study, I sent a letter to SDS and DBS with a description of the study and my contact information (Appendix A). Once a potential participant contacted me, I followed up with them by email or phone call to arrange an initial meeting. At that meeting, I determined if the student met the criteria for inclusion in the study and could speak in detail about the phenomenon of interest. Only two students contacted me as a result of my recruiting efforts through SDS or DBS, and neither student met the inclusion criteria. However, I

have remained in contact with one of the students and meet with her on a regular basis to offer support and to build the community of blind students on campus. While my contacts with her do not fall within the scope of this research, I feel that if I can offer her advice and support that may contribute to her success as an undergraduate student and help prepare her for graduate school if she chooses that path. That aspect of my contact with her falls under the broader social goals of this research.

Once I identified the three students who would be potential participants in this study, at that point I provided each student with an informed consent form (Appendix B). I asked each student if he or she needed the informed consent form in an alternative format, but all of the students asked that I send them the form in electronic form so that they could read it with their assistive technology on the computer. Since all of the students had some functional vision, they were able to sign the form once it was printed. The informed consent form explained in detail the purpose of the study as well as the expectations for the study participants and the researcher's responsibilities. I made every effort possible to include sufficient information in the informed consent materials for potential participants to make an informed decision regarding participation in the study. I also made it clear to the potential participants that they could contact me at any time if they had questions about the study, that they had the right to withdraw from the study at any time after they agreed to participate, and that they would have an opportunity to review my descriptions of their experiences before they were compiled into a formal report of the research. Once I receive a signed consent form from each potential participant, I contacted him or her to schedule the first of the three interviews which were the primary data collection method for this study.

Interviews and Other Data Collection Activities

Interviewing allowed me to collect rich descriptions of the experiences of my co-researchers. After I received the informed consent materials from each student, I contacted him or her to schedule the first of three interviews. These interviews lasted approximately one hour each. On a couple of occasions, the interview had to be cut short due to time constraints (i.e. the student had to go to a meeting or class). However, in each case I explained to my co-researcher that we would have other opportunities to explore the topic. I also encouraged my co-researchers to continue exploring the topic through the journals I had asked them to keep throughout the duration of the study. Moustakas (1990) has stated that the dialogue of heuristic interviewing should not be ruled by the clock but by experiential time. Thus, I explained to my co-researchers that while we were setting aside a certain amount of time for each interview, they should feel free to continue sharing until they felt they had told their story to a point of natural closing. At the same time, as a graduate student myself I am well aware of the time demands placed on graduate students, and I tried to be mindful of my co-researchers' needs in this regard. Most of the interviews took place in an office I reserved for that purpose. A few had to be done in other places (i.e. the student's home or office, or a room in the student union building) where we were assured of a quiet place to engage in conversation while having a good level of privacy.

Prior to the first interview, I sent each co-researcher a questionnaire he or she could use to provide basic demographic information. The questions in this questionnaire (Appendix C) were used to collect factual information about each participant (such as age, gender, degree program, etc.) that would be used to provide the reader with some

context for my co-researcher's experiences. I chose to collect this information with a questionnaire based on my experience with a similar pilot study. I felt that the focus on factual information at the beginning of the first interview of that study set a tone that made it difficult for a more natural sharing of experience to occur. By using a questionnaire that was filled out ahead of time, I was able to maximize the amount of time we had to explore the meanings of each co-researcher's experiences during the interviews.

Interviews followed the structure suggested by Rubin and Rubin (2005). Rubin and Rubin's responsive interview model consists of three types of questions: main questions, follow-up questions and probes. Main questions are prepared prior to the interview and translate the research topic into terms co-researchers can understand and discuss. During the interviews, follow-up questions and probes, which are specific to the comments and observations made by co-researchers, can supplement these main questions. The follow-up questions are intended to encourage elaboration of key themes and issues that arise during the interview itself. The probes are used to keep the conversation going while asking for additional detail and clarification.

In addition to describing the different types of questions, Rubin and Rubin described several patterns in which questioning can proceed. My approach more closely matched the "river and channel" pattern. With this approach, the researcher has prepared a list of questions ahead of time, but he or she may stay with one question at length in order to pursue a specific topic in great depth, even if this means that some of the main questions are skipped or saved for a second interview. Since I was interested in

examining the experiences of the graduate student participants in great detail, the “river and channel” approach was appropriate because it emphasizes depth over breadth.

The content of the main questions was determined from a review of the literature and my analysis of a similar pilot study with one graduate student who has a visual disability. As Rubin and Rubin (2005) stated, these questions are intended to translate the exploratory questions into terms co-researchers can understand and discuss. The main questions, along with some possible follow-up questions, were as follows (see also Appendix D):

1. Can you tell me how it was that you came to be in graduate school?
 - a. Possible follow-up question (PFQ): What were your reasons for pursuing graduate study?
 - b. PFQ: How did you decide on your current program of study?
 - c. PFQ: What was the admissions process like for you?
2. How would you describe your experiences in your graduate school courses?
 - a. PFQ: What have your experiences been like with faculty?
 - b. PFQ: What have your experiences been like with other students?
 - c. PFQ: If you use them, what have your experiences been like with support services at the university?
 - d. PDQ: Can you describe what a typical week is like for you?
3. How would you describe your involvement in the social life of your university?
 - a. PFQ: What has influenced your level of involvement in social activities at the university?

- b. PFQ: What do you consider your most important social relationships at the university?
Can you describe how you developed these relationships?
- c. PFQ: What do these relationships mean to you?
- 4. What are some challenges you have faced while enrolled in graduate school?
 - a. PFQ: What did you do in response to those challenges?
 - b. PFQ: Who were some key people that helped you with those challenges? How did you come to know them?
 - c. PFQ: What personal characteristics do you think helped you in dealing with those challenges?
- 5. When have you felt most empowered in graduate school?
 - a. PFQ: What has been your greatest accomplishment in graduate school? Can you describe how that felt?
 - b. What personal characteristics do you think contributed to that achievement?
- 6. What does being a graduate student with a visual disability mean to you?
 - a. PFQ: What does your disability mean to you at this stage of your life?
 - b. PFQ: What aspects of your experience as a graduate student do you feel have been influenced by your disability?
 - c. PFQ: What do you think has been a defining moment in relation to your experience in graduate school?
- 7. If you could talk to someone who has a visual disability and is considering graduate school, what advice would you give to them?
 - a. PFQ: What do you wish you had known before you decided to enroll in graduate school?

- b. PFQ: What would you do differently in relation to your graduate school experience?
- 8. Where do you see yourself after you complete your degree?
 - a. PFQ: What motivates you to keep going with your studies?
 - b. PFQ: What is your top career goal?
 - c. PFQ: How do you think your graduate school experience has prepared you to pursue that goal?
- 9. Is there anything else you think I should know that has not been asked?

Based on my co-researchers' responses, additional follow-up questions were posed during the course of the interviews to address unexpected topics brought up during our conversations. The second and third interviews also consisted of follow-up questions and probes that allowed me to seek clarification of important topics mentioned during the first interview. As part of informed consent, I had permission to audiotape each interview so that it could be transcribed for analysis. To record each interview, I used a Zoom H1 digital voice recorder. Janesick (2004) emphasizes the importance of preparation in conducting effective interviews. In addition to having a good number of questions, this includes making sure the recorder has sufficient battery power to last through the interview and a backup is available should the recorder fail. In addition to my primary recorder, I also had an iPod touch with several voice recording applications that I had used in the past to record long interviews. To facilitate my immersion in the data, I decided to transcribe as many of the recordings as possible myself. However, I also employed a local transcriber to do some of the transcription during the second round of interviews to expedite the analysis phase of this study.

As recommended by Janesick (2010), at the first interview I also asked each co-researcher to keep a reflexive journal where he or she could note any thoughts, dreams, and ideas that arose in the course of their day-to-day experience. These journals would allow my co-researchers to capture important insights that might come into their consciousness during the time we were apart. Since all of the co-researchers had significant vision loss and were not easily able to write in a notebook, I suggested using their preferred assistive technology to compile their thoughts in a word processing document that could be emailed to me or saved to a removable drive I provided to them.

I took extensive notes after each interview to facilitate the analysis of the interview transcripts. These notes included information such as the date, the setting of the interview, and any other information that could be helpful during transcription and analysis of the interviews. Throughout the study, I also asked my co-researchers if there were relevant documents they would like to share with me. Additional documents shared by participants included an educational autobiography one of the students had submitted to fulfill a course requirement, as well as several emails to faculty and advisors they deemed relevant to the understanding of their experiences.

Analytical Techniques in this Study

According to Janesick (2004) stated, time in field requires equal time in analysis. A long, intensive engagement with the data is also a key component of the heuristic research method I selected. As Moustakas (1990) stated, with heuristic research the researcher will engage with the topic in a back and forth rhythm and flow, approaching the data and then retreating again, until all of its varied meanings are revealed (Moustakas, 1990). Moustakas described a six-stage process that should guide the

researcher in conducting the heuristic inquiry. The six stages as outlined in *Heuristic Research Methods* are: initial engagement, immersion, incubation, illumination, explication and creative synthesis (Table 1).

Table 1

The Six Stages of Heuristic Research (Moustakas, 1990)

Stage	Description
Initial engagement	Identifying a question that is personally meaningful.
Immersion	Living the question and seeking all opportunities to connect with it.
Incubation	Retreating from the initial intense focus on the question in order to allow the inner, tacit dimension to do its work.
Illumination	Awakening to new understandings and experiencing the eureka moment.
Explication	Identifying the core themes of the experience.
Creative synthesis	Developing a synthesis that combines narrative and artistic forms and allows each person to remain present in the research.

During the initial engagement, the researcher engages his or her autobiography to select a topic and questions that are personally meaningful (Moustakas, 1990). Once the researcher has identified a question or problem, he or she then engages in a period of immersion where the goal is to live the question in waking, sleeping and even dreaming states (Sela-Smith, 2002). During this period, the researcher tries to remain open to all opportunities where meanings may be expressed that will help him or her better understand the question or problem. He or she will seek out every possible opportunity to connect with the question or problem, whether in public settings, social contexts or professional roles. People, places, readings, virtually anything that will connect him or

her to the question are considered, and the researcher continues to engage in self-dialogue around the question or issued that initiated the inquiry.

I engaged my topic in a number of ways, such as by reading several autobiographies by other individuals with visual disabilities and serving as a mentor to a former soldier who became blind as a result of injuries he suffered while serving in Iraq. I was also invited to speak about my experiences at several events, including one for the Foundation Fighting Blindness. At those events I was able to interact with other people who are living with vision loss, and those conversations helped with my understanding of vision loss and my own experience with that process. These experiences also caused me to ask many questions about my own identity as a person with a visual disability, which is exactly what is called for during the period of immersion of heuristic research

After a period of intense focus on the question, the researcher then retreats and allows the inner tacit dimensions to take over during incubation (Moustakas, 1990; Sela-Smith, 2002). Incubation eventually gives way to a natural return to the question or problem, a process Moustakas defined as illumination. He stressed that this phase of the process can only occur naturally when the researcher is open and receptive to tacit understanding and intuition. While a degree of reflexivity is required, the researcher must allow tacit workings to take place without conscious striving or concentration. Moustakas described illumination as a natural awakening to new understandings, a correction of formerly distorted understandings, or the discovery of new meanings (Moustakas, 1990). He compared this process to the eureka moment Archimedes had when he unexpectedly discovered the principle of buoyancy while taking a bath.

Once illumination occurs, the researcher attempts to fully examine what has awakened in consciousness by pursuing a full elucidation of the themes and descriptive qualities of the experience being investigated. The researcher may derive some of these understandings from conversation and dialogue with others, but he or she must continue to practice focusing, in-dwelling, self-dialogue and self disclosure. Concentrated attention to the inward space continues in order to examine all textures and nuances of the phenomenon. The outcome of the explication phase is a comprehensive depiction of the core themes of the experience.

In the final phase of the heuristic process, the researcher develops a creative synthesis that is usually a narrative depiction but may also include poetry, artwork, and other creative forms. Moustakas stressed the need for periods of meditation and solitude where the researcher can engage in intensive focusing, out of which the inspiration for the creative synthesis would arise. The creative synthesis is the culmination of a process of self-searching that involves focusing, in-dwelling and the practice of intuition at every step, from development of the question to its presentation in the form of a creative synthesis.

As I conducted the interviews and transcribed the recordings, I followed the outline for data analysis presented by Moustakas in *Heuristic Research Methods*. First, I gathered all of the available data for each participant: transcripts of our interviews, my interview notes, my own journal entries, any email exchanges between us, and other documents submitted by the participants. For each participant, I then entered into a period of immersion with this data. During this period of immersion, I read and re-read the transcripts and other documents for each participant in order to understand the experience

both as a whole and its details. Following a sufficient period of immersion, I then set the data aside for a while, to return to it after a period of rest in order to look at it with a fresh perspective and renewed energy. This cycle of review, rest and return to the data also fit well into my own personal needs as a researcher with a disability. Because of my own visual disability, extended periods of time on the computer or reading text can lead to eye fatigue and painful headaches. Following a pattern of data review that had more of an ebb and flow to it not only met the requirements of heuristic research, but also accommodated my disability.

As I reviewed the interview transcripts and other materials, I took extensive notes with the goal of determining some core themes and qualities manifested in the data. Through further study of the raw data and these notes, I developed an individual depiction of each person's experience. This individual depiction retains the language and examples drawn from each participant's experience as represented in the interview transcripts and other documents they shared with me. I shared this individual depiction with each participant so that he or she could affirm its accuracy and comprehensiveness and suggest additions and deletions where necessary. As I reviewed the data at this stage I was guided by two questions that I asked of the data in front of me: does each participant's individual depiction of the experience fit the data from which it was developed? and does it include the themes and qualities essential to the experience (Moustakas, 1990). Only when I was confident that I had a satisfactory answer to these questions for all participants did I proceed to the next stage of the heuristic research process, building a composite description of the students' experiences as a group.

In developing the composite depiction, I once again engaged in a period of immersion where I alternated between intervals of intense study of the data and rest. When I felt that I had thoroughly internalized my co-researchers' individual experiences, I attempted to construct a composite depiction that represents the common themes and qualities of our experiences as a group. This composite depiction includes verbatim excerpts from the interview transcripts that contribute to an accurate, vivid, and clear representation of the experience from the perspectives of individual co-researchers and the group as a whole.

After writing the composite depiction, I returned one more time to the raw data and the individual depictions in order to select one co-researcher for whom I developed an individual portrait based on the core themes and raw data of the interview transcripts and the individual depictions. In building this individual portrait, I have included background material gathered during preliminary contacts and meetings or contained in documents or in the demographic questionnaire filled out by each co-researcher prior to the interviews. According to Moustakas, this portrait should be presented in such a way that both the phenomenon investigated and the individual person emerge in a vital and unified manner. This is in keeping with the requirement that heuristic research preserve the essence of the person in experience.

The final step in the heuristic process is the development of a creative synthesis of the experience. In crafting this synthesis, the researcher takes on the role of scientist-artist in order to develop an aesthetic rendition of the core themes and essential meanings of the phenomenon (Moustakas, 1990). The rendition is meant to represent the tacit-intuitive knowledge that has been incubating over months through the processes of immersion,

illumination and explication of heuristic research. For this study, I chose to take a self-portrait with my iPhone to represent the idea of turning a mirror on the self, and I created a poem that captures my lived experience as a person who lives in between and betwixt.

The requirement for rigor was addressed in a number of other ways in this study. Mayan (2009) and Janesick (2004) recommended member checks, prolonged engagement in the setting, and triangulation of the data as strategies that can be used to ensure credibility. In this study, member checks took place at several points. First, I made sure each participant received a copy of the transcripts as soon as possible after they were completed. This was to allow each person to correct any inaccuracies in the transcripts. Another member check took place once I had created the individual depiction of each participant's experience. Prolonged engagement occurred because I interviewed each participant on three occasions, rather than relying on a single interview for data collection. In addition to these interviews, participants were able to share their experiences in other ways over the course of the study, such as through other relevant documents they shared with me.

Janesick (2004) defined triangulation as the use of multiple and different sources of data to provide corroborated evidence. With regard to triangulation, there were different methods of data collection in this study (interviews and documents submitted by the participants). However, because this is an autobiographic study that blends personal introspection and interviews with other people who have had similar experiences, crystallization might be a better way to describe how findings were validated. As Richardson and St. Pierre (2008) have stated, triangulation assumes there is a "single point" or object to be triangulated, whereas crystallization considers multiple angles of

approach to a phenomenon (just as a crystal refracts lights in different ways depending on where you stand in relation to it).

In this study, crystallization was pursued through the conversations I had with my peer reviewer about the narrative I constructed as I conducted this research. The peer reviewer was another doctoral student who has experience with qualitative research involving people with disabilities. Through conversations with the peer reviewer at key points in the study, we brought to the discussion of the text different professional and personal perspectives that have hopefully brought to light different interpretations or insights than any one of us would be able to come up with on our own. Crystallization was also aided by the researcher reflexive journal I maintained throughout the study to aid analysis and reflection. Janesick (2004) described the journal as a member check of one's own thinking done on paper (p. 146). For heuristic research, self-dialogue is an important part of the research process, and the reflective journal helped me as the researcher to make that inner dialogue more explicit.

In addition to crystallization, I aimed for authenticity as I analyzed and interpreted the raw data and developed the depictions included in this study. Lawrence-Lightfoot and Davis (1997) suggested authenticity may be a better standard for qualitative research than reliability and validity when the goal is to link inquiry to public discourse and social transformation by speaking to broader audiences. With regard to this study, that broader audience represents not only other students with visual disabilities, but the faculty members and other staff who work with those students and who can have an impact on their lives. According to Lawrence-Lightfoot and Davis, authenticity occurs when there is resonance, a “yes, of course” experience that they also call the “click of recognition.”

For a portrayal to have authenticity, it must have resonance for three different audiences: the co-researchers who have shared their story and who should see themselves reflected in the final report, the readers who will not find any reason to disbelieve the findings presented in that report, and the primary researcher whose deep knowledge of the experience will allow him or her to see the “truth value” of his or her own work (Lawrence-Lightfoot and Davis, 1997). For this study, I have strived for resonance and authenticity by presenting the accounts of my own experience and those of my researchers with as much transparency and honesty as possible, while at the same time recognizing that my interpretations are but one possibility, one way of “seeing.”

Role and Assumptions of the Researcher

As Janesick (2004) noted, the researcher is the primary research instrument in qualitative work. For this reason, qualitative researchers need to be explicit about the assumptions they bring to their research because doing so can enhance the study by providing a contextual frame for the reader to properly interpret the researcher’s conclusions (Gruppetta, 2004). In this regard, I recognize that as a graduate student with a visual disability, I brought certain biases and assumptions to this research study based on my personal experiences. For this reason, I define my role as that of a researcher/participant rather than as that of a detached observer, and I understand that my connection to the phenomenon under study may have influenced my interpretation of the data and interactions that emerged from this research. To address the influence of my personal experiences on my role as the researcher, I attempted to make my biases and assumptions as explicit as possible as I conducted this study. One way I tried to do that

was by maintaining a researcher reflective journal that provided opportunities for introspection about my researcher role throughout the study.

One of the assumptions that I brought to this research was that as a graduate student who has a visual disability I would share many commonalities with the other participants in this study. While we may have some differences based on age, gender, program of study and other demographic factors, I found that we have many more commonalities based on our similar experiences as graduate students with visual disabilities at the same university. In this sense I felt that I had an insider status when I communicated with the other students I interviewed for this study. Consequently, I also assumed that this insider status would mean that the other participants and I would share a common vocabulary that would make it easier for us to communicate with each other about the essential components of our lived experiences as graduate students with visual disabilities.

The researcher's role as an insider is also a key assumption of the autobiographic methods I selected for this study. In contrast to the bracketing that takes place with phenomenology, autobiographic research methods such as auto-ethnography, autophenomenography and heuristic research assume an insider perspective for the researcher. Ellis and Bochner (2000) defined auto-ethnography as a type of research that combines the personal with the cultural, but Gruppette (2004) suggested autophenomenography as a more appropriate term when a phenomenon or experience, rather than a cultural place, is the subject of the inquiry. As an approach that focuses on the researcher as a participant and key informant of his or her own experience, autophenomenography establishes research bias unequivocally and recognizes that the

researcher's interest in a phenomenon is usually related to his or her personal story (Gruppetta, 2004). I propose that the heuristic research methods I selected for this study fall under the umbrella of autophenomenographic research because heuristic research is also autobiographic and examines lived experience from the inner frame of reference of the researcher's life story.

With autophenomenography, the author of the study is not only a first participant in the study and a key informant of his or her own experience, but also extends empathy to the experiences of the other participants in order to add to the in-depth nature of the study (Gruppetta, 2004). Similarly, Moustakas (1990) stated that with heuristic research our most significant awarenesses are developed not only from our own internal searches, but also from our attunement and empathetic understandings of others. The researcher who engages in autophenomenographical research is considered a full insider by virtue of being a native, and the insider perspective gives him or her access to insights that would normally be withheld from the researcher (Gruppetta, 2004). A key assumption for this study is that I have been able to build on my insider status to create an environment through responsive interviewing where the other participants were willing to openly share their experiences with me. As an insider, the researcher in autophenomenography is also close enough to the native culture to understand its norms and be in a position to clarify meanings normally misunderstood by outsiders (Gruppetta, 2004). Thus, another assumption for this study is that my insider status has allowed me to contribute insights to the study that might be taken for granted by other researchers who have not lived the experience of visual disability.

Ethical Considerations

Rubin and Rubin (2005) stressed that the conversational partnership of the responsive interview is based on a personal relationship between the interviewer and interviewees. According to Rubin and Rubin, this personal relationship generates ethical obligations for the researcher, because it can result in private information being shared. To ensure confidentiality and privacy, I assigned a unique identification number to each participant, and I kept all of the materials associated with a participant in a folder labeled with their unique identifier. I informed potential participants that I would share transcripts and notes from this research with an outside reviewer who would assist me during the analysis stage of this research. However, I only identified the participants' data with their unique identifiers in order to protect their identities from the outside reader. I stored all materials related to this research in a locked cabinet in my office to ensure I could control access to the participant's confidential information. After all the interviews were transcribed, I created a CD with a backup of the interviews and I deleted the original recordings from the digital recorder used during the interviews. I plan to destroy this backup CD, which will be stored in a locked cabinet, three years after the publication of this dissertation.

While the individual's need for privacy is an important component for ethical research practice that should be respected by all researchers, a personal relationship between the researcher and the participants can also have some benefits for the research project. As Ellis and Berger (2003) have stated, "researcher involvement can help subjects feel more comfortable sharing information and close the hierarchical gap between researchers and respondents that traditional interviewing engenders" (p. 159).

However, this kind of open sharing can only take place when there are also “safe spaces” for participants, and one way to ensure that these spaces exist is to make sure participants understand the privacy implications of the research and the steps taken by the researcher to safeguard the participants’ privacy. Out of respect for the participants’ privacy, I have used pseudonyms to protect each participant’s identity when I present or write up this research.

While participation in this study should have presented little risk of harm to the participants, I was aware that a series of in-depth interviews might pose a burden on students who already have busy academic schedules to manage. As a fellow blind student, I was well aware of the extra time demands that a disability can impose on students as they pursue their academic goals. In order to minimize the impact of the time commitment required from each participant, I did everything possible to schedule the interviews at times that were convenient to the students and did not interfere with each student’s normal academic routine.

Another important ethical consideration concerns the personal relationship that may develop between the researcher and the other participants in a research study. This would be especially likely in a case where the researcher has extended contact with participants over a period of time, as is the case in the proposed study. De Laine (2000) warned that the “researcher who demonstrates empathy and care and engages on an emotional level with subjects can enter the ground of the therapist, but without the same training” (p.2). Thomas and Pollio (2002) agree with Delaine and cited cases where the interviews were cathartic and participants sent cards and flowers to interviewers to thank them for the beneficial release of emotions that occurred during their sessions. In any

research that involves sensitive topics the possibility for such catharsis exists, and the researcher may not always have the professional training to be in a position to adequately address the emotional needs of participants. To address this ethical dilemma, I compiled a list of professionals on campus that I could refer participants to as needed.

The initiator of the research too, as another participant in the study, can also end up opening up to aspects of his or her experience that have been previously unexamined. As Ellis and Bochner (2000) assert, the researcher too can experience emotional pain from the vulnerability that results from revealing their personal stories. Yet revealing the personal self to others can also often be cathartic and lead to personal growth. Co-researchers can be valuable reflectors of possible areas of resistance that may be out of conscious awareness to the person pursuing a heuristic study (Sela-Smith, 2002). Conducting a dialogue with co-researchers can lead the researcher to recognize forms of denial, projection or incomplete search so that he or she can continue the self-search into deeper or more distant tacit dimensions of experience.

An example of how this process can work is presented in *Heuristic Research Methods* (Moustakas, 1990). Moustakas explained how Humphreys sought to validate his heuristic study by mailing a comprehensive description of the experience to his co-researchers so that they could verify its accuracy and comprehensiveness. Three of the co-researchers found that the description did not include important qualities related to the “dark side” of the experience. Based on this feedback, Humphreys returned to his own heuristic process and reexamined the darker side of his own experience. According to Humphreys, the result was a more expansive understanding of his own search. I hope that by exposing my own perceptions of my disability to the scrutiny of others in a supportive

dialogue of heuristic inquiry I have been able to achieve a similar more expansive understanding of my own identity as a person with a disability.

Summary of This Chapter

In conducting this inquiry, I attempted to follow a heuristic design that allowed all participants (including me) to be present in the telling of our own stories about visual disability and the graduate school experience. My hope is that other graduate students with similar experiences will also gain insights about their own experiences and feel empowered after reading the depictions presented in this study. The inquiry aims to add to the limited literature on graduate students with visual disabilities in order to inform practices and policies that impact on the ability of these students to successfully complete graduate studies. I employed in-depth face-to-face interviews supported by field notes and my researcher reflexive journal in order to identify barriers and empowering factors that have shaped our experiences in graduate school. In this chapter I have described the heuristic research framework that guided me in conducting the study, as well as key details of the study's design such as participant selection, interviewing, and analysis techniques. In the next chapter, I will present the data from my interviews, field notes and my researcher reflexive journal.

Chapter Four:

Presentation of the Data

The purpose of the study was to describe and explain the graduate school experiences of a selected group of graduate students who have visual disabilities in order to better understand my own experiences and identity as a graduate student with a visual disability.

The exploratory questions that guided this study were:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?
3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

As described in chapter three, the techniques of data collection included three interviews with each purposefully selected co-researcher, my own researcher reflexive journal and interview notes, and documents collected from the participants. In this chapter, I begin by detailing the demographic information for the co-researchers in order to provide a context for their experiences. I then present key themes that emerged during my immersion with the data within the framework of heuristic research. Thus, I present

each co-researcher's experience first as an individual depiction, then as part of a composite description that brings together common themes for all co-researchers. Heuristic research also calls for an individual portrait where the researcher selects one co-researcher and builds the portrait based on both data gathered from the interview transcripts and background material gathered during preliminary contacts and meetings or contained in documents or in the demographic questionnaire filled out by each co-researcher prior to the interviews. The chapter concludes with a creative synthesis that brings together the co-researchers' experiences with my own experience as a graduate student who has a visual disability.

Each individual depiction begins with a brief introduction from my researcher reflexive journal and interview notes. I then present the key themes that emerged during my time of immersion with the interview transcripts and documents for each co-researcher. Direct quotations from the transcripts illustrate the perspectives of the co-researchers in their own voices. Shorter quotes appear in quotation marks, while longer quotes appear in block format. Whenever clarification of a quotation was needed, it appears in brackets. Words and phrases that are redundant or may distract the reader were replaced with ellipses. Throughout this chapter, I have also included my reflections as I examined the data and interacted with the participants. These reflections present the internal dialogue I engaged in as another participant in this research.

The Three Co-Researchers

As explained in chapter three, the three co-researchers were purposefully selected because they met the following criteria:

1. They were enrolled for at least one semester of graduate studies in the last two years.
2. They had to be willing to self-identify as having a visual disability.
3. They had to be willing to participate in the study through three face-to-face interviews and by sharing relevant documents.

Basic demographic information as provided in a demographic questionnaire the co-researchers completed prior to the first interview is summarized in Table 2.

Table 2

Co-Researchers' Demographic Data*

Data Collected	Michael Bolotin	Maria Keller	Sarah Bridgman
Age	43	51	31
Ethnicity	Caucasian	Caucasian	Trinidadian American
Employment Status	Graduate Assistant	Unemployed	Graduate Assistant
Program of Study	Student Affairs	Social Work	Counselor Education
Semesters Completed	4	4	7 **
Grade Point Average	3.4	3.8	3.98

* All names are pseudonyms.

**Doctoral student working on dissertation.

Note: All names are pseudonyms.

One co-researcher (Maria) had recently graduated with her master's degree, one (Michael) was in the final year of a master's program, and one (Sarah) was a doctoral student working on her dissertation. All of the co-researchers were married and had children. One (Maria) was a grandparent. All of the co-researchers would be considered non-traditional students, with ages ranging from 31 to 53 years old. Only one of the co-researchers (Sarah) was a person of color, and she defined herself as Trinidadian-American. In addition to her visual disability and ethnicity as a person of color, Sarah defined herself as a person with albinism.

I conducted three interviews with each co-researcher. Since two of the co-researchers were current students, I interviewed them on campus, usually in an office I had reserved for that purpose. The only exceptions were the second interview with Sarah, which took place in the graduate student office where she worked, and the second interview with Michael, which took place in a room at the student union building where he was studying for his comprehensive exam. In each case, we were assured of having a good deal of privacy at each location. In the case of Maria, I met her at three different places: the first time we met at a local community college that was halfway between the university and her home, the second time we met at her home, and the third time we met in my office at the university since she was already on campus for a meeting. With the exception of Sarah, I already knew the other participants prior to my decision to pursue this research. I believe this fact, along with our common experience as students and as people with visual disabilities, facilitated the candid and open sharing that took place during our conversations. In Sarah's case, her name was provided by one of her

professors whom I had met in my role as a technology integration specialist for the university. Even though I did not know her prior to this study, a single phone conversation was all it took for us to build some familiarity with each other based on our common experiences as doctoral students with visual disabilities.

To respect the co-researchers' privacy, I have decided to refer to them using a pseudonym. When I thought about each co-researcher's experience, all I could think about were the pioneers in the history of education for people with visual disabilities. In many ways, each of the students I interviewed is a pioneer in his or her own right, paving the way for future students with visual disabilities who want to pursue a similar path. To capture each co-researcher's role as a pioneer for other students with visual disabilities, I selected the name of a significant historical figure who had a visual disability. Thus, Michael's last name is that of Jacob Bolotin, who became the first congenitally blind person to attend medical school and become a licensed physician in the U.S. Maria and Sarah are named after Laura Bridgman and Helen Keller, two of the first students with visual disabilities to receive an education at the Perkins Institution (now School) for the Blind in Boston. The selection of the names does not imply any similarities in experiences or backgrounds between the historical figures and the graduate students I interviewed. All of the students in this study have some functional vision, whereas the historical figures were born without any. The pseudonym in each case is meant only as a symbol of each student's drive to succeed and perseverance.

In writing each depiction, I have decided to organize the themes into three categories: process, challenges, and empowering factors. The first category is meant to capture the way in which each student's perception and understanding of his or her

disability evolved over time as he or she progressed through his or her program. It also captures how my own understanding of my disability has evolved over time, and thus relates the data to research questions one and two. The second and third categories address research questions three and four, which are more concerned with the insights this research may have for faculty, administrators and other professionals who work with graduate students with visual disabilities.

Michael's Individual Depiction

Meet Michael

Michael was first diagnosed with his visual disability, Leber's optic neuropathy, as a teenager. Leber's optic neuropathy is an inherited condition that primarily affects males, and it results in a significant loss of visual acuity. Between Michael's junior and senior years in high school his vision deteriorated rapidly over a period of three to four months, until his visual acuity was about 20-400 in each eye. His current visual acuity is only slightly better, at approximately 20-300 in each eye. Despite this significant visual impairment, Michael does not use a white cane or any other kind of mobility aid. While he uses a screen reader on his work and personal computers, his preferred assistive technology is a CCTV, a device that magnifies printed material for Michael. He owns a couple of the devices, including a bigger model he leaves in his study space in the library and a portable one he can carry in his bag along with his books. According to Michael, he prefers the CCTV because he considers himself a visual learner who finds it more difficult to process information when he only listens to it with the screen reader. He said that "when it comes to reading a textbook or reading a journal article or something like that I want to see it because I'm just a visual learner, and I only like to read things once

and it's kind of ingrained in my mind but my mind wonders too easily when I listen to things.”

Michael is a white male in his early 40s. He is a non-traditional student who returned to school to complete his undergraduate degree after turning 40. Between starting his undergraduate degree and his return to school fifteen years later, Michael had worked in retail for a local supermarket chain. He is married and has a five-year-old son who so far does not exhibit any of the symptoms of Leber's. I sensed that this has been a great relief to Michael.

So I have a 5 yr. old son and I'm very confident that he's not going to come up with my eye condition because of what I've been told and what I know from medical professionals. So that makes me very comfortable. I'm happy with that, very happy with that, for his sake.

Michael's diagnosis appeared to have been more difficult for his parents, especially his mother, than it was for him. The way in which the diagnosis was explained, which emphasized the hereditary basis of the condition, seemed to have made it more difficult for Michael's mother to cope with her son's diagnosis.

Every doctor would say 'this is inherited from you, the parent, and this is why your son has this eye condition.' It was harder I think for my mom. My dad kind of dealt with it a little differently but I just remember seeing my mom breaking down at doctors' appointments. In the exam room, walking out the doors, a basket case, upset. That was hard to observe.

Following his diagnosis during his senior year, Michael graduated from high school and then enrolled at his current university to pursue an undergraduate degree.

Struggling academically, he decided to leave his program and instead pursued a two-year degree at a local community college. After one more attempt at a bachelor's degree, Michael decided to drop out of college and went to work full time for a supermarket chain around the same time he got married. He worked for the supermarket chain for the next fifteen years. When his wife became pregnant with his son he decided to return to school to pursue a degree in education. After failing to be admitted into the college of education, he instead enrolled in an interdisciplinary liberal arts program, which he completed successfully before starting graduate studies at the same university.

I first met Michael in the spring of 2009, when he contacted me via email to arrange a lunch meeting. At the time, Michael was about to complete his bachelor's degree and his advisor suggested he contact me to get more information about graduate school and my experiences as a student with a visual disability. Throughout that summer, I met Michael for lunch a few more times and through our conversations we found out more about each other's backgrounds and experiences as students and as people with visual disabilities. When I decided to pursue this study, Michael was the first person I considered as a potential participant. By then, he was in the second year of a master's degree in student affairs. I thought our familiarity and comfort with each other would be a good foundation for an honest discussion of the challenges and positive experiences we have both experienced as graduate students who live with vision loss.

Of the three participants in this study, Michael was the one I had the most personal contact with outside of a formal research context. Soon after our first interview he asked me if I would like to join him as a volunteer at a community service event sponsored by the university's student government. Later, he also asked me if I would join

him as a speaker at an event for a new group for students with disabilities he was organizing. In both cases, his requests challenged me to consider my role as the researcher in this study. As I noted in my researcher reflexive journal, I wondered if I should establish some boundaries and decline the invitation. However, as I thought about it more, I decided that joining Michael in the campus activities would be a great opportunity to continue to get to know his experience better. In the short time that I observed Michael interacting with undergraduate students at the event I was able to witness his ability to connect with those students despite a significant age difference. In large part this was due to Michael's friendly, outgoing nature. The event was also a great opportunity to make our presence as students with visual disabilities on campus more visible. Thus, I felt that my participation was consistent with the social aims of this research.

Michael was the first person I interviewed for this study. As I noted in my reflexive journal afterwards, the interview proceeded naturally and other than a few times where I sought clarification I did not have to probe too much to get Michael much to share his experiences. I left that first interview feeling confident that Michael would provide me with the rich data I was looking for with this study, as he seemed ready to speak about his experiences in a sincere and unguarded way. Michael is also a visual learner and thinker who has not let his visual disability stop him from using rich imagery to describe his experiences. For example, he shared a metaphor toward the end of the first interview that compared being a graduate student with a visual disability to "swimming across the Atlantic Ocean." That metaphor made a big impression on me and I found myself going back to it at various times during this dissertation. I found it empowering to

know that yes, the journey is long and arduous, but at the same time we do have a “support boat” (in our mentors, friends and family) to help us complete it.

As I noted in my reflexive journal, I could feel myself starting to get emotional toward the end of our first interview. Even though I had met Michael a few times before, our conversations had centered on family and our day-to-day lives as parents, employees and students. The first interview was really the first time I had ever spoken in-depth to another person with a similar experience to mine. As I felt my eyes starting to water toward the end of the first interview, it was not out of sadness, but rather out of elation to have finally found someone who understood what it is like to be someone with a visual disability attempting graduate school. I left that interview on a high note, and wrote in my reflexive journal that “my whole life I’ve had to go through this alone, but now I have found someone who ‘gets it.’”

Now that I have provided a brief introduction to Michael, I will present the key themes of his experience that emerged from my immersion with his interview transcripts and related documents, as well as from my own my reflective journal.

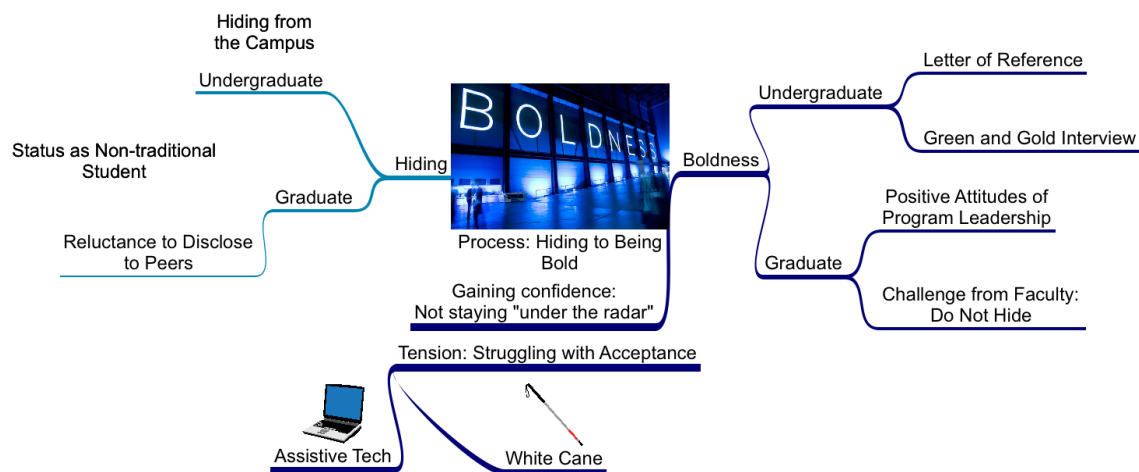


Figure 1. Visual summary of Michael’s process.

Process

Figure 1 is a visual summary of Michael's process, his evolving understanding of his visual disability while he was a graduate student. A key theme in that process is the idea of going from hiding to being bold and no longer willing to go "under the radar."

From hiding to being bold. According to Michael, one of the key differences between his undergraduate and graduate experiences was that as an undergraduate he tried to hide his disability from others in order to blend in with his peers. As a non-traditional student he already felt different from the other students, and he did not want his disability to be one more thing that pointed out his difference to them.

For undergrad I was a lot more guarded about my vision, because I wasn't in a cohort. I was on my own. I was just an undergrad student in a very broad based undergrad liberal arts program. I just didn't talk about it. I didn't want to put myself on blast. I didn't want to be vulnerable in that way, I really didn't. I wanted them to accept me. I mean I already felt like I had so many things against me. I was a non-traditional student, I just, I was different from them. And I didn't want any other strikes against me, I guess. And so I didn't talk about my vision disability. I would hide in the library as an undergrad and hide in the study carrel using the CCTV partly because I was hiding. I literally was hiding from the campus. I just wanted to do my thing. I wanted to go to class, I wanted to be a campus tour guide because those were two areas I was comfortable.

According to Michael, a turning point in how he thought about his disability occurred when he asked one of his undergraduate professors to write a

letter of reference for his application to be a campus tour guide. In that letter, the professor surprised Michael by mentioning his visual disability. While at first Michael was upset that the professor had shared this private information about him, reading the letter caused him to reconsider how open he wanted to be about his disability going forward.

It caught me by surprise, because it was just a simple letter of reference to be a [name of campus tour guide student organization]. It wasn't to get into graduate school but she shared a copy of it with me, which I was appreciative of and I took a look at it. I read it and it said, 'you know, Michael is a good student. Michael comes to class prepared, engages the class and you know, is an asset to my class. And by the way, Michael has a significant vision disability. He still performs at a level that I feel exceeds some of the other mainstream students in my class.' I read that, I thought 'Oh my goodness! Why did you say that about me, why did you put me out like that and put me on blast here in this letter of reference.' I felt a little nervous at that point, you know. That's my business to tell and here she put it in a letter of reference. But it was kind of a turning point and I still remember as you can tell and that was 2008 [4 years prior]. And it made me think. If other people, when they write a letter of reference about me, are willing to share something as significant as a very personal, hidden disability as it is. Because it is pretty significantly hidden, being I'm legally blind in some ways, because you're not in a chair and you're not walking with a limp and it's just easy to mask sometimes for me. It

kind of helped me to start to think more than I ever had in the previous 20-25 years that I had this vision disability. To finally think that 25 years later after being diagnosed, wow! You know, how open am I going to be from here forward? How open should I be now and how guarded should I remain? Because I was always very, very guarded, very guarded still. Pretty guarded about it. But that letter of reference to be a [campus tour guide] from just an undergrad teacher...really kind of encouraged me to be a little bit more comfortable with my vision.

In addition to a letter of reference, another requirement for becoming a campus tour guide was a series of interviews. At those interviews, Michael took the bold step of mentioning that he had a visual disability, and that experience gave him more confidence for discussing his visual disability when he applied to his graduate program.

I actually was open and shared with them, 'I have this significant visual disability. I'm legally blind. I feel confident that I can perform this role on a volunteer basis here at USF and, you know, I'm really interested in pursuing this. I hope that you'll, you know, understand my situation and you know trust that I will do my best and not do anything to make you look bad or make me look bad'...Well that experience in the interview for [campus tour guide], you know, where I got this inspiration of being real forthcoming and open with the interviewers, that kind of snowballed to the next stage, which was going into this graduate program.

During his initial contacts with the staff of his graduate program, Michael was impressed by the positive attitude of the program director, who encouraged him to not hide his disability.

It helped me with that boldness, the fact that Dr. M was very accepting of my challenge, my visual challenge, my disability. He was very accepting and you know he told me, he said, 'you know I don't want you to try and fake it and mainstream.' I don't remember the exact words, but just the impression. 'I don't want you to fake it and try to mainstream through this graduate program and hide your disability. I want you to basically you know, make it work for you,' is the impression I got from him. That he was ok with it. He wanted me to do my best, to apply successfully to the program...I think all those things, rolled up together, you know he was very positive in the way he spoke to me about my disability. That he didn't think it was going to be a challenge for him or the faculty or the program at all. He was like, 'if you're up for it, we're up for it' basically, in so many words.

Despite these reassurances, soon after he started the program Michael was confronted with a situation where he again sought to hide his disability. However, the faculty member challenged Michael to not hide from the rest of his cohort by taking assessments at the disabilities services office. Instead, she encouraged him to use whatever technology he needed to bring to class to complete his work along with the other students.

It was like being a kid again because I had to explain to her, 'you know, hey I'm a student in your class but I have this disability.' She says 'Wow, I'd really like to learn more about that.' And I said, 'really? Ok if you want.' She said 'come to my office,' and we arranged and went to her office and we talked. I said, 'is there any way I can do that quiz at the Student Disability Services Office and then come to class or maybe take it earlier in the day at your office or something?' And she said, 'well how will you be taking the test or the quiz, the assessment? At class, outside of class?' and I said 'well, using a CCTV' and she said 'well, can you bring the CCTV to class?' [Michael] 'Maybe, is that your preference?' and she said 'Yes!, that's my preference.' Maybe she could tell by the way I spoke with her privately in her office, you know, being sheepish as far as asking if I could take the test outside of class and kind of that sort of thing and hide my disability. I think she was wanting to really challenge me to continue to try to scratch that surface of, you know, being a little more bold.

Overall, the support from the faculty and the leadership of his program provided an environment where Michael felt more confident and willing to discuss his disability than he was as an undergraduate. Michael does not seem to have encountered the negative attitudes from faculty and staff Galdi (2007) cited as one of the barriers for graduate students with visual disabilities.

Certain elements helped me, certain elements being the support of the directors, the leadership of the program, and the faculty. Certain elements

I think helped me with the graduate program, to be more confident and willing to allow myself to be vulnerable as a graduate student as opposed to an undergraduate student. So I think the cohort component and the, you know, the intimacy of having more familiarity with the faculty and the leadership of the program really helped me as a student with a vision disability to allow others to understand my situation and see me using technology I needed to use, a CCTV, things like that. So it has been a good experience in that regard, and I think the support of the faculty and the leadership of the program has been instrumental in helping me kind of get past scratching the surface to allowing people to see past my guarded facade.

Disclosure to peers. While Michael was becoming more comfortable about discussing his disability with his professors and other staff in his program, the disclosure of his disability to his peers was a process that he still found challenging. With his professors and other staff in his program, Michael thought he had a responsibility to disclose his disability to them. With his peers, he felt disclosing such information would lead them to treat him differently based on that knowledge. Michael added that his status as a non-traditional student enrolled in a program that caters primarily to younger students was an important factor in limiting his openness with his peers when it came to his disability. He was already set apart by his status as a non-traditional student, and he did not want to introduce yet another difference between himself and his peers.

Honestly, I cannot recall any significant conversation with any of my cohort members where I disclosed to them that I was legally blind. I don't recall doing that and I do know, I know for a fact as a graduate student I was pretty guarded with my peers. Not my leaders but my peers... The leadership of the program, Dr. M., Dr. H., I felt they truly deserved to know because they were making decisions on who was being accepted in the program and who was not accepted in the program. They were making decisions about how they were going to plan this cohort. They were responsible for these people, to nurture them and help them to grow as higher ed professionals. The cohort members, in my regard, I wanted to kind of, I wanted them to make their opinions of me independent of that knowledge...I'm already going to be set apart from them obviously, you know, just different features, you know. I'm not as youthful looking, maybe I'm not as fit as them. And so I don't want to highlight my differences and highlight that even more significantly by introducing my significant disability of being legally blind. I don't want to cloud that relationship any further...And so I found myself becoming guarded again, because I didn't want to become vulnerable. I didn't want to seem different from them. So I would work extra hard to try and hide it and extra hard to try and be real prepared for a meeting or real prepared to do my part of the project.

Michael said he did not really mind discussing his disability with his peers if it ever came up in conversation, but it was taking the lead to self-disclose and start the conversation that still presented a challenge to him.

Honestly, deep down I don't mind sharing my visual situation with others. It's just getting to that point that is very awkward and a burden for me. Getting to that point you know...I am not that aggressive. I would rather build a little relationship, you know, talk about the weather, talk about sports, talk about current events. And hopefully that person will feel confident enough to say to me, 'hey you don't see too good do you? You have bad vision, a visual disability? What do you see? How do you see?' For me, that's how it has to go. Because, you know, I'm not comfortable enough to come right out and say, 'Hey, by the way, my name's Michael and I'm legally blind, and when I look at you I can't tell if you have a mustache' and all these things. And that's a little bit too aggressive for me and I just don't want to put that information out there.

For Michael, disclosing his disability was a process that he had to ease into on a case-by-case basis. I was able to examine this process in more detail in one of the documents Michael shared with me, an email he had sent to an admissions professional at another school where he had to complete an internship in order to graduate from his program. As I read the document and the sections of the transcripts where Michael discussed the experience, I could see the way in which Michael had to work up to the point where he would finally disclose his visual disability.

I told him in the email, I said, 'hey, Dr. J., I appreciate you being willing to work with us. My wife and son are coming along with me. You know, I am,' I put it out

there, 'I am a non-traditional student.' I was very guarded about it. I mean it was the last thing in that email was that I have a visual disability. I told him everything about me. I have a wife and son, I'm a non-traditional student, I'm a very hard working student, oh and by the way I'm legally blind. I mean I talked about every topic in that email before I had to talk about that. I told him everything, you know, in that email. I'm very capable, very mobility capable, have a laptop with JAWS [screen reader software] on it, and all this good stuff. And that, you know, I definitely don't ask for any sort of special considerations, you know. I just do my best and I'll do my best for him. I wanted to reassure him.

While Michael acknowledged that he still at times tries to hide his disability from others because it is what he has been used to doing for most of his life, he also felt he had made some progress in learning to be more comfortable about it.

After almost thirty years of having this legally blind situation in my life, I still, you know, try to fake it. And I still try to, you know, get by acting like, you know, I don't have it, I'm not legally blind... I've been hiding, I've been visually impaired since 18, and I'm 43 now. So, you know, for 25yrs. I've been hiding, doing the best that I can to hide that I don't see well. And now I'm at a point where I still don't want to advertise, you know, tell every one on the sidewalk, 'Hey, you know I don't see too good.' But I, I'm at a more comfortable place now...As an undergraduate student no matter what your situation, but particularly with a visual disability, you can make it work and find ways to kind of work around things and to try like I did and hide your disability. Find yourself on graduation day wearing a cap and gown. But with graduate school you can't do that. You cannot hide in

graduate school. No matter who you are, but particularly if you have a visual disability. You cannot hide it. You have to pick up that baggage everyday. As an undergrad you can leave that baggage at home. You can, you can leave that baggage on the curb sometimes and hide like I did. And as an undergrad you can, you can go under the radar as an undergrad. But as a graduate student with a visual disability, you cannot go under the radar. As far as accomplishment, I think not trying to keep myself under the radar as a graduate student has really been rewarding.

I was able to observe firsthand that Michael was no longer attempting to stay “under the radar.” He had taken the initiative to start a new student group for students with disabilities, and I was able to observe how comfortable he was presiding over that group’s first public meeting in the student union building. Michael’s role in organizing the event, and the confidence and self-assuredness he projected as he addressed those in attendance to me represented a significant step in a long journey for him. Starting as an undergraduate who essentially hid from the rest of the campus, Michael had over time started to reveal more of himself to others, to the point where he was able to present himself as a person with a visual disability in a public forum. Looking back at his experiences as a graduate student, Michael appreciated the personal growth that had resulted from his willingness to take on the challenge of pursuing a graduate education.

So this program has been good for me in that way. It's helped me to become more confident about not hiding so much...being in an academic environment really helped me with that because when I worked for [a

supermarket chain] for 15 years I was able to hide there. Because, you know, after the initial year or 2 years of working there and they could see that I was going to be able to do the work that they needed me to do, and I could do it safely and productively and work well with others. After that, after the first 2 years of working for [supermarket chain], putting produce stock on the shelf, it was home free! I was able to hide. Because they knew me, they knew my limitations and you know, I was in my comfort zone. I was in a cocoon, you know, I was able to hide. Here not so much. You know, when you're in an academic environment you're not putting stock on the shelves. You're having to do things that are mental, that require you use different senses and your faculties and, yeah I really just had to find internal strength and be bold and move forward.

Acceptance of the disability. Two words that came up many times during our conversations were “hiding” and “bold.” These two words represent the two extremes of the continuum of self-disclosure where Michael currently lives. Whereas as an undergraduate he tried his best to completely hide his disability, as a graduate student Michael said he was more bold about it. However, while he expressed that he now has more confidence and is more comfortable with his status as a person with a disability, he also sometimes appeared to contradict himself by admitting that he still tried “to fake it and act like I don’t have a visual disability.” Rather than representing a contradiction, these words and phrases to me instead represent a tension, the tension Michael experiences as a person who lives in a liminal status where he has enough functional vision to “pass” but not

enough to be fully sighted either. This is similar to the liminal status Murphy, Scheer, Murphy and Mack (1988) describe, where a person is neither under constant medical care for an accident or illness, but may use a wheelchair, crutches, a white cane, or other aids that indicate he or she is not “well” either. While Michael does not use a white cane, the CCTV was a similar visual indicator of his difference when he used it in the classroom.

As I got to know Michael more, I found it interesting that he did not use a mobility cane despite what I observed to be a significant visual disability. However, as Fourie (2007) noted, the use of a mobility cane signifies a loss of autonomy in a society that values the “normal” and for this reason many people who have been diagnosed with a visual disability may avoid its use even when it is necessary. Michael was definitely aware that he was “not as fit, not as youthful looking” as the rest of his cohort members, and the use of a white cane would only highlight that more. Reflecting back on my own struggles with acceptance with the white cane, I could understand why Michael would try to delay the use of aids that emphasize his difference to others (such as a white cane or even a screen reader). I remember many times during my early days as a cane user when I “forgot” to bring my cane to work or school. It was only through a lot of what I considered “nagging” by others (my girlfriend at the time, friends) that I eventually came to make use of the cane a habit. Today, it is like my keys, watch or cell phone, and I never leave home without it. In time, Michael may come to have a similar relationship with the aids he may need to use if and when his vision deteriorates further, but for now they appear to signify the inner tensions he

experiences as a person with a significant but relatively easy to hide visual disability.

Challenges

As a graduate student with a significant visual disability, Michael faced a number of challenges in and out of the classroom. Figure 2 provides a visual summary of these challenges.

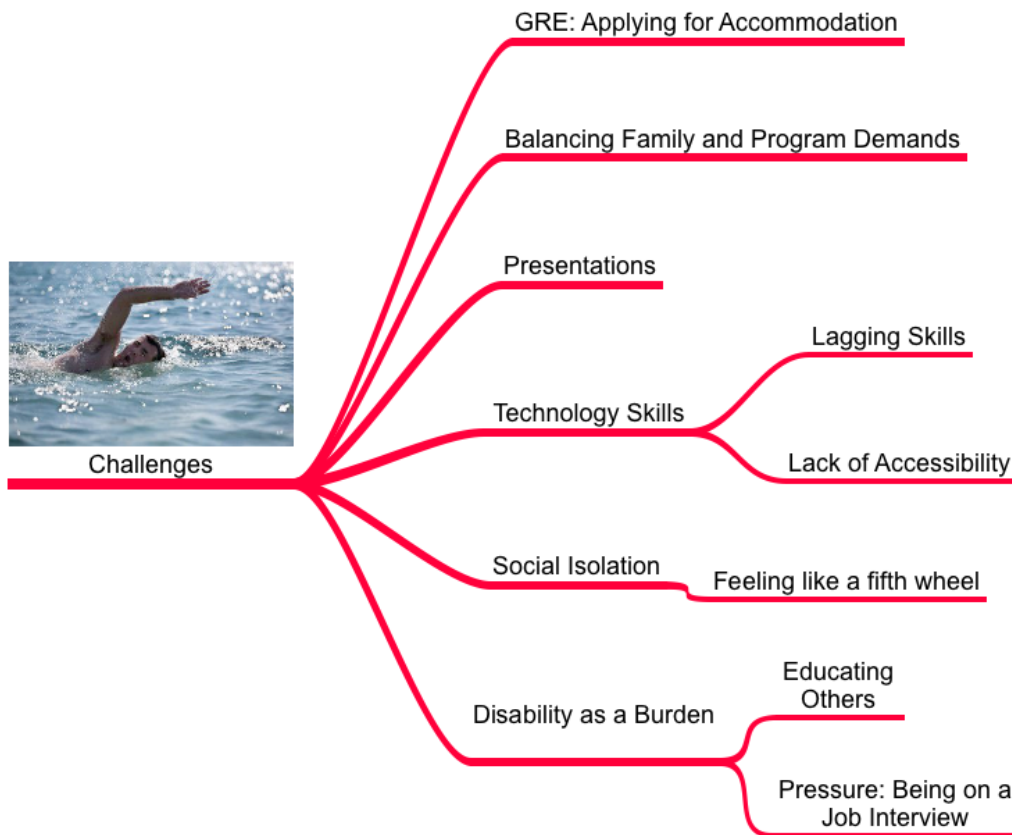


Figure 2. Visual summary of Michael’s challenges.

Gaining an accommodation for the entrance exam. In order to be able to take the Graduate Record Examination (GRE) with his preferred accommodation, which was the paper and pencil version of the test rather than the electronic one, Michael had to

make a special request to the Educational Testing Service (ETS). While his request was eventually granted, the process for obtaining that accommodation from ETS added to his anxiety leading into the test. Michael felt that taking the paper and pencil version of the test gave him the best chance to do his best based on his learning style and how comfortable he is with the use of a CCTV for magnification.

It was a challenge to take the test, the GRE, because I had to make a special application to, like a big request of the ETS people to take the test as a paper test. I didn't want to take the test on a computer. It was a pain! It was a real pain because I think ETS they had a kind of method in place for this type of request for an accommodation to take it on paper but honestly the preference is everybody take it on computer. And hey, if you need some sort of accommodation for your visual disability, then there is always electronic. And I just wasn't going to be comfortable with that... I prefer paper and pencil, and so I had to go to the ETS website, look very carefully for the accommodations link or tab, print out this 15 page bulletin which had about ten pages of information of how to go about the process and five pages of forms to fill out. Had to go get a very current doctor's eye exam with peripheral fields and all that good stuff. It was absolutely current. They wouldn't take anything two or three years old. Went through all those hoops... I felt like I was going to be able to perform better with paper and pencil. Because again, just like how I go about reading things, whether it's the newspaper, journal articles, textbooks, even a paper that I've written that I'm proofreading that might be ten pages long. I will print that out and proofread it manually with my CCTV rather than have the screen reader read to me because of

attention span and just my preference. So for me, I definitely felt that for me to do the best I could on the GRE, I had to take it with paper and pencil.

In the process of applying for an accommodation Michael found out that even if he had wanted to take the electronic version of the test, a computer with the JAWS screen reader software was not available in the testing center lab where he would take the test. In the end, taking the test in a paper and pencil version turned out to be the only option available to Michael.

Balancing school and family life. When it came to his academics, Michael recognized early on in the program that he would have to dedicate extra time and effort to his preparation compared to his peers. It was important for Michael that his peers not see him as being different from them, and this desire drove him to not only work extra hard, but also to become guarded about his disability in order to focus on the academics.

I found myself becoming guarded again, because I didn't want to become vulnerable. I didn't want to seem different from them. So I would work extra hard to try and hide it and extra hard to try and be real prepared for a meeting, or real prepared to do my part of the project.

In addition to the fact that it took longer for Michael to complete his work due to his visual disability, he also had a family at home that needed his attention during the week. As a result, Michael stated that he spent most of his weekends in the library working on his assignments, and he always tried to plan at least one week ahead.

I have family responsibilities and so on the weekend is when I catch up on studying. They [other students in his program] can study you know from 8 pm to midnight or 9 pm to midnight during weeknights. From 9 pm to midnight during

weeknights I'm doing laundry and dishes and chores at home and helping my wife. I can't be studying at those typical hours. So I study on the weekends. A typical week for me starts the week prior and I will plan ahead. I will start working early. Because, again because of my vision disability, I don't work that fast. I'm in the library at least 15 hours on the weekends reading, preparing for the week ahead.

All of the time spent studying on the weekends meant sacrificing some time with his wife and son, but Michael felt this sacrifice was necessary for him to achieve academic success as a student with a visual disability.

I told myself, 'Michael, you have to prepare early. You have to prepare completely, fully and as best as you can because this is super important.' And you know, visual disability or no visual disability you've got to put the effort in to make this work. And it's working. Being in graduate school as a student with a significant visual disability, being legally blind, having to put in so much extra time to get the studying done to be prepared, to not look foolish, all those things have definitely cut into my time with my wife and son during graduate school. Sometimes I think I allowed it, but it was a necessity. It was truly a necessity to achieve, you know, some academic success. You know, academic success is not more important than my family, but academic success is important right now to be able to complete this program. To do well in my day to day job interview like I feel like I've been doing and just have some personal satisfaction.

The idea of being on a "job interview" everyday featured prominently in our discussion during the last interview, when we started to discuss Michael's plans after

graduation. Michael thought it was important for him to do well and make a good impression because he wants to work in higher education (possibly at his current university) after graduation. Thus, he saw his performance in graduate school as a “job interview” of sorts, and he put some pressure on himself to always make a good impression about his abilities, with both his peers as well as the professors in the program.

Through this graduate program I basically felt like I'm at a job interview everyday on campus. I'm really cognizant of the way I act. Cognizant of the way I interact with others and the work I do. And I've just been really aware that I'm going to have a little bit of a different path to getting a professional full time position.

In addition to the pressure Michael placed on himself to make a good impression through his work, the acknowledgement of his extra efforts by his peers was another source of motivation and encouragement for Michael. Even though Michael had few conversations with his peers about his experiences as a student with a visual disability, the few times his peers showed they were aware of Michael's special challenges and his efforts to overcome them made a lasting impression on him.

And you know people have said to me, now in the second year of this graduate program, two people have said to me I remember specifically a guy named K. C, a girl B. F. and it was very rewarding when they said this to me. They said, ‘you know, we can see that you work extra hard. You have to work much harder than anybody else to do presentations. You have to basically memorize the information on that PowerPoint’...they said, ‘you know, we admire that, you know, it takes a lot of extra work.’ And again, only two people mentioned it, but if two people

mention it I know there must be 20 that, you know, feel that inside. And it makes me happy, makes me proud to know that they see my effort, they see my extra effort and I'm going to keep working hard.

Presentations. Presentations were especially challenging for Michael. They caused him a great deal of anxiety and required extra preparation time because he had to memorize the content of his slides. However, he had come up with his own strategies to help him prepare for them.

Some challenges are the presentations that we have to do in graduate school. A lot of presentations, PowerPoint presentations. They stress me out because again, it's a lot of material that you have to do a lot of work in advance. I have to work, start planning ahead to kind of gather my information, decipher that, have time set aside or read it with a CCTV because I am such a visual person and prefer to, you know, print out journal articles rather than have the screen reader read it to me...one thing that worked for me to overcome that challenge is I will read on to cassette tape my PowerPoint slides. I'll read them on to cassette tapes and listen to it over and over. You know, in the car, on the way home, on the bus on the way to school. I will just be listening to it over and over and when I can I will sit with a tape recorder and I'll re-listen to it sitting in front of the CCTV so I can flip through the different pages of the PowerPoint slides. And that will help me to kind of understand the progression and information, the progression from slide to slide, what's on the slide. And when I go in to do the presentation I have it memorized and I'm ready to go slide by slide and speak knowledgably about what's on the slide and move on from there.

While presentations created some anxiety for Michael, they were also one of the more rewarding aspects of his experience as a student. Michael felt that doing the presentations without any special kind of accommodation helped him feel that he was held to the same standard as other students in his program.

So one of the biggest challenges is doing presentations. The preparation, all the work leading up to the presentation and then dealing with the anxiety of actually standing in front of the group and sharing information. So then I overcome that challenge by again over preparing and doing what I have to do. Accepting the burden, picking up my baggage and really just take on the challenge and try my best to overcome it. And I feel very comfortable with all the presentations that I've done in my graduate program so far. That, you know, I've done a good job and that I have helped to inform the people in my cohort and to demonstrate competency to my instructors and earn the grades that I've gotten... I feel very comfortable with all that stuff and I definitely don't feel that anybody in my cohort, anybody in my graduate program, has made any special circumstance or any special considerations for me based on the fact that I have a visual disability. I truly feel that I've earned my grades and I feel very competent and comfortable with that.

Lagging technology skills. According to Michael, technology was a challenge to him because he had not become proficient with it before he started losing his eyesight as a teenager. Now that he had to depend on it more to access information, he felt he was lagging behind in his technology skills. However, his attitude toward technology had

changed over the years and he was now more willing to work on developing his technology skills.

You know, I lost my vision at age 18 and so I wasn't into computers as a teenager. I wasn't into computers or technology of any kind at the time I lost my vision. I certainly didn't want anything to do with computers or technology at that time. When I lost my vision, I just kind of wanted to figure it out and figure out what I was doing with the rest of my life from there forward. And so the one thing about my disability that I think and I know is a real hardship and a real deficit for me is with technology. I would like to embrace technology right now because actually, I'm liking it. I like email, I like Microsoft Word, and I like learning new things.

Michael considered himself to be making progress when it came to improving his technology skills, and he felt this gave him more independence and added to his productivity as a graduate student. In turn, this meant that he did not have to place as much of a burden on his wife, who at the start of the program was helping him type many of his papers after he had written them longhand.

I don't want to put that on my wife to have to type my papers. I wanted the luxury of hand writing it just because it was easier for me, taking the easy path. I want to you know challenge myself and I do. So, the second year of this program has been fulfilling for me in that regard that I've been able to find some new independence with the help of technology, with Microsoft Word. And I know Microsoft Word is like the bottom of the barrel when it comes to challenging software, but for me I feel like I'm at the mountain top by being able to use MS Word, by being able to do attachments and do it quickly.

While Michael felt he had made some progress in learning some of the basic software he needed to use as a graduate student, he still considered himself to be at a disadvantage when it came to technology due to his difficulties with accessing information on the Web with his assistive technology. The way in which information was formatted often caused compatibility issues with his screen reader that made accessing content on some of the information systems used at the university difficult for Michael.

I've really depended on him [a close friend who was a former technology instructor] a lot to help me with web research because I'm bad at research. In a graduate program you need to have good web research skills. With JAWS, I mean, to do web research for me is a real pain because of the content and because it's confusing to me. Because like I'll look at something and not realize you have to click here to see more or to go deeper into an issue or a topic. And the way it's designed, the way it's presented, because it seems a lot of web material is kind of hidden in the background. You know, they give you like a little snippet, like a paragraph or a little tiny abstract. And then, you know, read more and I miss that part... When it comes to my disability I am really at a loss, really behind what my true working potential could be if I had no visual disability because the technology I use, JAWS software it's good but it's not great and it has limitations. It doesn't cooperate with everything like it should. It doesn't work with DegreeWorks. It does not work well with Banner, and so I avoid it. And Banner is critical, especially in higher education. Banner is used in a lot of different schools, a lot of different universities.

While use of the Blackboard learning management system varied from course to course, Michael recognized that, like Banner and DegreeWorks, Blackboard is a common system in use at many universities. Thus, he understood that becoming proficient with Blackboard was important for future employment in his chosen field of student affairs. Also, not being proficient with Blackboard meant he still had to rely on his wife when he needed to access information in that system.

For my graduate program the faculty were very limited to how much they used Blackboard and required us to use Blackboard. I am not real good with navigating Blackboard, but I'm trying to get better...I've avoided it, and I've allowed it to be a barrier. It has been a little bit of a barrier, you know. I depend on my wife to help me with Blackboard a lot. Even as an undergrad I would come home, you know, put my son to bed. I would say 'hey, can you help me look something up on Blackboard?' I know Blackboard is a necessity just like Banner. I know it's a necessity in higher education. It's a necessity for the students and also for professionals and I will embrace it. I'm not going to graduate and say I don't need to deal with Blackboard ever again. No, no, no... I plan on making good use of my time this summer after I graduate and if I can't find a job, I'll basically treat this summer as if it's one more semester. And the material I'm going to be learning is technology. That's going to be my next area of accomplishment. The next frontier for me is to learn the technology that I've avoided as an undergrad and grad student. Because number one, I avoided it and number two, I use the excuse that I didn't have time to learn it. I'll have the time.

Acceptance of the disability and assistive technology. When it came to assistive technology, Michael told me that his preferred technology is a CCTV, a device that uses a camera to magnify information in textbooks and other printed material. According to Michael, the CCTV worked better than a screen reader like JAWS for him due to his visual learning style.

I use JAWS on my work computer and my laptop computer and I like JAWS. I'm glad to have it available. I spent a long time avoiding it, avoiding computers because I didn't want to be reminded of my eye condition by having to use a computer that talks to me and all this stuff. And so I'm kind of a late bloomer with JAWS and I'm not an expert at it but I use it proficiently on a daily basis... When it comes to reading a text book or reading a journal article or something like that I want to see it because I'm just a visual learner. I only like to read things once and it's kind of ingrained in my mind but my mind wonders too easily when I listen to things.

Michael acknowledged that aside from his learning style preference, there was also an affective component to his challenges with technology that involved his struggle with acceptance of his disability.

I still have a hard time with acceptance of my eye condition. So any little bit of being able to use the vision I have, to kind of like take me back to before I had this vision issue, any sort of capability that I can lean upon to make me feel "normal" by using a CCTV and reading a hard page, hard cover book as opposed to listening to something on tape or CD or from a Daisy reader, I much prefer that. It just really sticks with me more, gives me more satisfaction.

Like Michael, I have often described myself as a visual learner, and I rely on magnification rather than a screen reader as the primary accommodation for my visual disability. I noted in my researcher reflexive journal that Michael's responses on this topic of technology forced me to think about the true nature of my technology use. Despite the fact that I have extensive training in the use of a screen reader, I still primarily rely on magnification for the same reasons as Michael, because it allows me to hold on to my remaining vision rather than being reminded of the amount of it I have lost.

Social isolation. Michael was not close with many of his peers in his program. Outside of one other student who like himself was also a non-traditional student with a wife and child, Michael did not develop any meaningful friendships with other members of his cohort. According to Michael, he felt he was "the fifth wheel in this cohort, and I have definitely been banned on an island and I don't know why exactly." While Michael believed some of the distance between him and his cohort members may have been due to the fact that he's a non-traditional student, he attributed most of it to his disability.

Mostly because of my disability, and the reason for that is because I think they're just unsure. Unsure about, you know, what I can and can't do. Unsure about what sort of complications might come up in a group setting. Because there is a lot of group work again and we don't get to choose our group members, which is good I'm glad about that because It would be cliquish in that regard. But I think if I were to say, give like a percentage, I'd say the percentage of hesitancy of my cohort members to really embrace me because I'm a non-traditional student, I'm maybe close to twice their age, I think the percentage of that influence would probably be maybe 15%. But 85% I think of the influence upon them to kind of

really be cautious and not real engaging with me is my disability...it's just unfortunate for them. It's unfortunate. But you know I can't waste too much time worrying about it. But probably 85% of the reason is because of my vision.

One of the few times Michael had a significant interaction with members of his cohort occurred toward the very end of his program, in the days leading up to his comprehensive exam. Michael had taken the bold step of emailing some of the notes he was using to study for the exam to the rest of the cohort. To his surprise, a few classmates responded that they appreciated his willingness to share the notes, and they even invited him to participate in study sessions at the library.

I thought, you know what, I'm going to send this out to everybody and it was a real risk but I took the risk and actually two or three people emailed me back and said, 'wow, thanks for sending this Word doc out, these are good notes, you know'... it was nice to get that feedback. And then I had a huge surprise, like 3 days before the exam. The exam was on a Friday and three days before, I think it was Tuesday or Wednesday, anyway, I got an email, a surprise email from this girl in my program that you know doesn't even talk to me that much. She's busy in her own world and everything. She's a nice girl. She sends me this email, real short, and it says 'hey, two or three of us are getting together at the library late this afternoon around five or so to study for comps.'

Overall, Michael was not too concerned that he did not have strong relationships with his cohort members, because as he put it, "school comes first and my cohort members come second and so I'm going to take care of school first."

Disability as a burden. The word “burden” immediately came up when I asked Michael to reflect on the meaning of his visual disability at this stage of his life.

I see my vision disability as a person and as a graduate student being a burden because it reminds me that I'm different. It reminds me that I don't have the same exact capabilities as some of the other people I'm peers with.

In addition to highlighting his differences from his peers, Michael saw his disability as a burden due to the additional responsibility he felt he had for educating others (including his peers) about the potential and abilities of students like himself. While Michael wished he did not have this responsibility thrust upon him, he recognized it as a fact of life for someone in his position.

Yeah, a little bit of a burden because you know it's an added responsibility on top of you know my class work, going to class, preparing for class. A burden is really the best description to say what its like to be a graduate student with a significant disability for me... a burden to be an example to others that, you know, 43 years old, goodness, I just want to be a guy. I just want to be a dad and a father, a husband, and a student. Get on with a career. I don't want to be an example to others and you know help them to grow as an individual. I mean, I, you know I say I don't want to, but when I say that I don't mean I don't want to in that you know I don't want to see them grow. I do want to see them grow. But I don't want that extra responsibility on my shoulders. But it's there and so I accept it.

One factor that helped Michael in accepting the responsibility was his ability to look beyond his personal experience to the impact he has had on his classmates, and in

turn to the impact on lives of future students with visual disabilities his classmates will work with during their own careers in higher education.

I'm happy to leave them with an impression that when they get out into their careers in student affairs that when they encounter a student with visual disability who is maybe legally blind like myself or completely blind or whatever the disability may be, that that student is capable. That student can achieve academically. That student can integrate to the campus... 'Hey, I was in graduate program with a guy who was legally blind and he just worked extra hard and he got the work done and, you know, he knew this is what he wanted to do.' So, basically encourage undergrad students that they might interact with and let them know it's possible and you just have to be very committed. And so yeah, I'm proud to have that impact on the members of my cohort.

Empowering Factors

A number of empowering factors that helped Michael navigate the challenges he faced as a graduate student with a significant visual disability are visually summarized in figure 3.

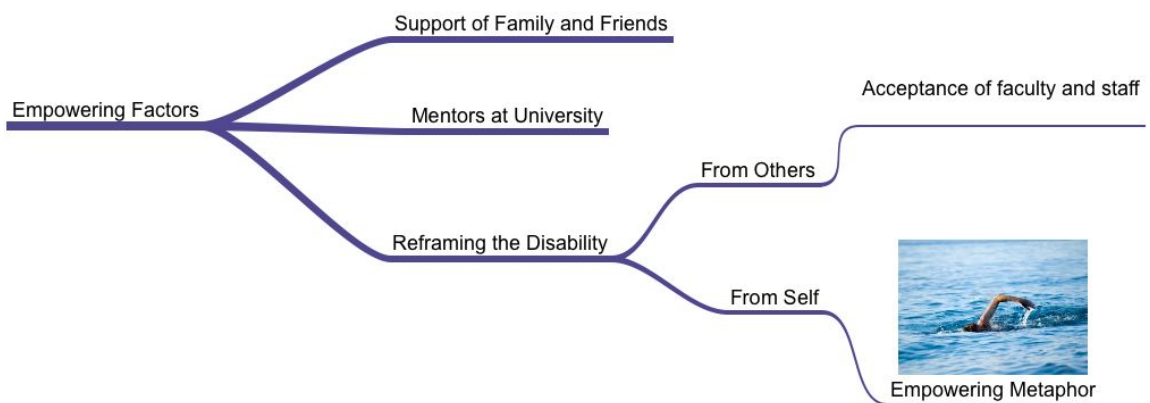


Figure 3. Visual summary of Michael's empowering factors.

Supportive relationships with family and friends. When I asked Michael what factors had contributed to his success in graduate school, he quickly pointed to the support of his immediate family. Galdi (2007) identified these familial relationships as one important factor that contributed to the success of the students in her study of graduate students with visual disabilities. Beyond the practical concerns related to his transportation needs and other logistic issues, the moral support his family had provided was also important to Michael.

As a graduate student, strengths that have helped me have been the support of my family, my wife and son. My parents have been very supportive and mostly their support has been, you know, logistically, transportation here or there. Also just kind of basically moral support, ‘hey, you can do this but we know it takes a lot of your time’ ... she [his wife] has been very supportive as far as helping me with time management, helping me stay motivated, helping with doing research at times to write a paper, to do web research. There is literally no way I could have gotten through this graduate program, or the undergrad program, but this graduate program without her help, her assistance , her support.

Along with family, Michael mentioned the support of a close friend who helped him with his technology questions. This person had actually been his JAWS instructor at the local Lighthouse for the Blind, but Michael had remained in touch with him after the class and the two had reconnected when Michael’s friend had started a job closer to campus.

I knew I needed better JAWS skills because I had really let them go. Because I had been working at [local supermarket], not using email, or JAWS or anything.

And I knew I needed a refresher course. I took the JAWS training course at the Tampa Lighthouse in fall 2007 leading up to starting back in college in Spring 2008 and he taught me JAWS. And, you know, we got along good through the class. I did good in the class. I felt comfortable with the class. I felt like I could really start using JAWS regularly and I did when I got back in school. We stayed in touch and he had a career change from the Lighthouse to real close here to the campus so we began getting connected because we were in such close proximity. And we would meet once a week and he would help me with web research because I'm bad at web research.

While Michael did not develop many close friendships with his peers, he did become close with one other student who was also a non-traditional student like himself.

This one guy and I, we really connected. His name is A. So he's not a traditional student too, he's 30, he's got a wife and child, you know. We support each other, help each other stay on track in the program, like you know assignments to do and that sort of thing. When we had class a certain week we texted each other.

Supportive relationships with mentors. Aside from his family and friends, Michael mentioned several professionals on campus he sought out as mentors throughout his program. Mentors were the other type of relationship Galdi (2007) found to be important for determining the success of graduate students with visual disabilities in her study. For Michael, these mentors included staff in the student affairs and admissions offices he had first met as an undergraduate student during his time as a campus tour guide. On several occasions, Michael had collaborated with these professionals to complete school projects, and he considered the ability to build such relationships to be

an essential skill that had allowed him to achieve success as a graduate student with a visual disability.

Skills that have allowed me to be successful in my graduate program as a student with a visual disability, I would say relationships have been a skill. Building relationships, effective relationships. People that I can go to and say, 'hey I'm trying to learn this particular material in my graduate program. Trying to do a paper on this. You know, in your professional experience as a professional in the higher ed world, you know, what kind of an angle should I pursue? You know what sort of journal should I look at to get information on this?' So collaboration with people who are already in the profession has been helpful to me. So I think, you know, for me as a legally blind student in a graduate program I think it has been important to be confident in kind of the image that I created as an undergrad and confident in the character and personality that I've demonstrated on campus in building these relationships with people who are professionals.

To Michael, these professional relationships he had nurtured since his days as an undergraduate were so important that he recommended future graduate students with visual disabilities should strongly consider staying at the same university where they completed their undergraduate degrees. If that is not possible, Michael suggested the new student should make every effort to arrive on campus early to start building mentoring relationships with key people at their new university who would be helpful to them.

For students who are staying at the same institution, I think that is very helpful. You know, you've already got a track record in place. You've already got some relationships with some undergrad instructors who are going to write letters of

recommendation for you. You've already got a familiarity with the campus. You've got a familiarity with, a little bit with probably the program you're going into because it's probably going to build upon what you did for undergrad. And it's just really going to help you to stay at the same university, the same institution for grad school that you did for undergrad... If not, if they cannot stay at the same school as they did their undergrad I would encourage them to, from the first day on campus, before the program even starts, go a week early before classes start, and just start to introduce yourself to people. Get out there, say 'hey my name is so and so, and I'm here for a graduate program. I'm new to the campus and let me introduce myself'...from the very beginning of that graduate program to make themselves known on campus to particular individuals and really to anybody but particularly to people that they can build relationships with that they go to for mentoring. Because that's what a lot of graduate programs are all about is mentoring, I mean not only doing some research and writing papers.

Reframing the disability. As I reviewed the transcripts of my conversations with Michael, I could see two examples of the kind of reframing cited by Fourie (2007) as an important step for changing how the person who has the disability comes to understand it. This kind of reframing focuses on the positive aspects of the disability rather than the negative ones. The first kind of reframing I observed in the transcripts was on the part of Michael's advisor, who emphasized the contributions Michael could make to the program rather than the challenges his disability would present.

The fact that you know, I really respected this man because so many people had spoken so highly of him. His position as far as making decisions for this graduate

program and being a faculty member in this particular graduate program here at USF. I think all those things rolled up together, you know he was very positive in the way he spoke to me about my disability. That he didn't think it was going to be a challenge for him or the faculty or the program at all. He was like, 'if you're up for it, we're up for it' basically in so many words.... Dr. T. M. said back in January 2010, he said 'you know, I think this is going to be a great experience for you academically, to grow and to you know learn about a whole new career path and higher education. But also for the other students in the cohort to see you, to see your effort, to see you know how you do things differently from them,' and he said 'I think it would be a great win win.'

In addition to the way in which others reframed his disability and emphasized Michael's unique contribution to this program, I saw some evidence that Michael himself had come up with his own ways of reframing the disability for himself. While there were many times when Michael used words such as "burden" and "baggage" to define what the disability meant to him, he also shared a powerful metaphor that allowed him to redefine his approach to his studies in a more empowering way. This is the metaphor I mentioned at the beginning of this depiction, and I would like to reference it again as I bring it to a close to emphasize the drive and determination Michael has exhibited in pursuing a graduate education.

I said Dr. M. for me this graduate program is going to be like swimming across the ocean from North America to Europe. Swimming all the way across the Atlantic and you know when you try and do a swim, a trans-Atlantic swim like that you need to have a support team such as my wife and son and my friends here

on campus. You need to have support equipment and I said you know you typically have a boat you swim along side for support and to watch out for you. That's your support network. But you cannot swim across the ocean 24 hours a day, 7 days a week. You have to at some point come up out of the water get on the boat. Take a rest, eat, sleep, and then get back in the water and go at it again. And I told him, I said 'that's how I want to approach this graduate program, like I'm swimming across the Atlantic from America to Britain.' I told him, 'I'm going to keep swimming.'

Summary of Michael's Individual Depiction

The word burden came up a few times in our conversations as Michael described how he felt his disability placed additional demands on him that another student without a disability would not have, such as the extra effort and planning required for his academics and his perceived responsibility to educate his peers about people with disability. To cope with these burdens, Michael relied on a number of supportive relationships, starting with his family and close friends, and including faculty and other staff at his university. His family, especially his wife, not only provided support in a practical sense by assisting with transportation and other day to day needs, but also moral support and understanding of the time demands of graduate school. The faculty in his program encouraged Michael to not hide and to continue to be "bold" about his disability. Other staff and close friends either mentored Michael, helped him with school projects, or helped him develop his technology skills. Michael described all of these relationships as his "support boat" in the metaphor he used to keep himself going during his graduate program, that of "swimming across the Atlantic Ocean." These supportive relationships

were so important to Michael that he would recommend future graduate students with visual disabilities either stay at the same university as their undergraduate degree or arrive early at a new university to start building a network of such relationships as early as possible in their program.

While Michael developed many supportive relationships in graduate school, he was not close with many of his peers in his program. Only toward the very end of his program, around the time of his comprehensive examination, did he engage in meaningful interactions with peers in his program. This occurred when he sent out a message that resulted in the formation of a small study group for the examination. The lack of close relationships with his peers did not seem to concern Michael too much because of his strong focus on his academics and his family. Overall, Michael described his graduate experience in positive terms and he believes it has led him to develop greater independence and self-confidence as he goes forward in life. If there was one area where he felt he was still at a disadvantage it was with regard to technology. However, Michael embraced this challenge and recognized the importance of improving his technology skills for future employment. Thus, he was looking forward to the few months following graduation as a time when he could focus on improving his technology skills, particularly with regard to the information systems commonly used in higher education. Because I believe so strongly that researchers should give back to their participants as much as they receive during the research process, I offered my assistance with learning Blackboard to Michael, and we have continued to have a meaningful relationship in the months since our interviews took place.

Sarah's Individual Depiction

Meet Sarah

I first met Sarah through her major professor, who is a frequent visitor to the computer lab where I work as a technology specialist for the faculty in my college. During one of his visits to the lab, we started discussing my progress as a doctoral student and I mentioned that I planned to do my dissertation on the experiences of graduate students with visual disabilities. When he heard about my topic, he told me he knew someone who could help with my research, and he immediately went up to his department to see if he could find Sarah so he could make an introduction. Following a brief introduction where we shared email addresses, my next contact with Sarah would be a few months later over the phone. Once my university's Institutional Review Board approved the study, I called Sarah to see if she was still willing to participate in this research. Even though it was our first extended conversation with each other, our common experiences as doctoral students made it easy for us to quickly develop rapport, and we were already sharing some of our challenges with each other after a few minutes on the phone. I determined that Sarah would provide the rich data I was looking for with this study, and I arranged to drop off the informed consent forms at her office and set up a time for our first meeting.

When we started the interviews, Sarah was preparing for the defense of her dissertation the following month, which she did successfully between our second and third interviews. As I got to know Sarah, my first impressions of her as a focused, driven individual were confirmed. When I asked her during our first interview what a typical week as a graduate student was like for her, she told me she usually took more than the

full load of courses (four or five instead of the typical three) and taught two or three courses (she was teaching two at the time of our interviews). Despite this busy schedule, she had managed to keep close to a 4.0 GPA, published six peer-reviewed articles, and presented at more than sixty local, state and regional conferences, all while juggling her responsibilities as a wife, mom to two young children (ages four and six), and daughter (Sarah shared a home with her parents while attending graduate school). As if that were not enough, her family was also caring for her father who was in the middle to late stages of Alzheimer's.

Sarah identified herself as a person with albinism who is legally blind. Due to her albinism, she also has problems with light sensitivity and nystagmus, a condition that results in involuntary eye movements. During our conversations, Sarah pointed to the nystagmus as an aspect of her disability that had caused her to struggle with self-consciousness and self-confidence throughout much of her life. Her younger brother not only has the same condition, but is also a doctoral student at another university. According to Sarah, her brother and her have at times engaged in a sibling rivalry to see who would complete the doctorate first, and she used the friendly competition with her brother for motivation. Aside from her disability, Sarah described herself as a Caribbean-American or Trinidadian-American woman. Now in her early 30s, Sarah completed her Master's degree in counseling from the same university where she was pursuing her doctorate in counselor education. She came into the field of counseling as a career switcher after working in the loans department of a bank for a few years after college. She explained that she had decided to go into counseling after she realized that her job at the bank already involved counseling clients who were facing difficult situations such as

the loss of their homes. Sarah’s future career goal is to become a university professor in her field of counselor education. Now that I have introduced you to Sarah, I will turn my attention to the key themes that emerged from my study of her interview transcripts and related transcripts, as well as my notes and reflections in my reflexive journal.

Process

A visual summary of the themes related to Sarah’s process, her evolving understanding of her visual disability during graduate school, appears in figure 4. A key theme of her process was Sarah’s ability to become an advocate for herself in order to get the accommodations she needed to be successful.

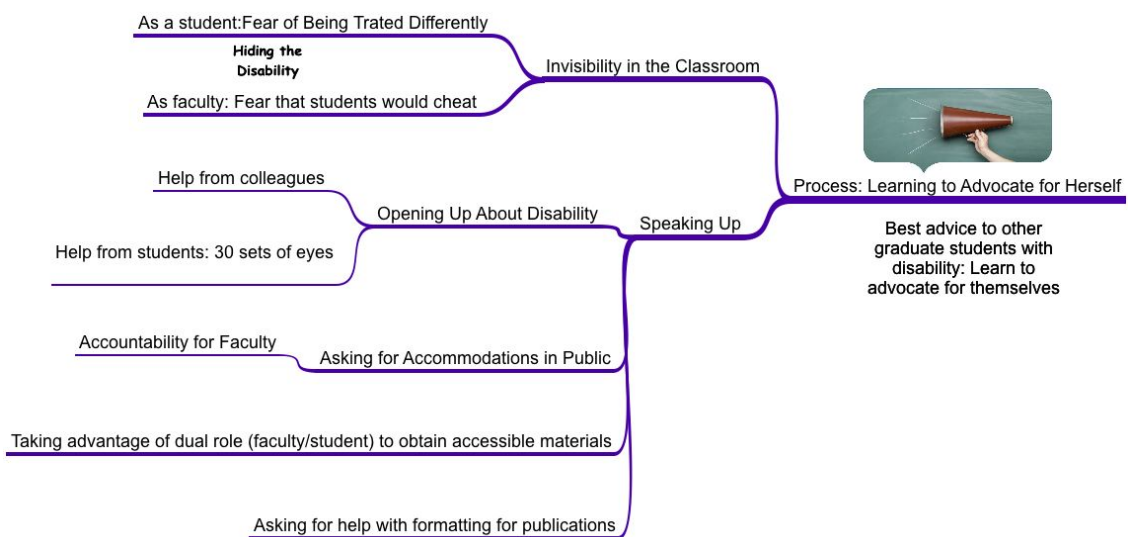


Figure 4. Visual summary of Sarah’s process.

Becoming an advocate for herself. Sarah did not perceive a significant change in the attitudes and behaviors of others toward her as a person with a disability during her time as a graduate student. Instead, she perceived the change to be in herself as she became more assertive and proactive in her relationships, especially with peers. Whereas as a Master’s student Sarah would allow the actions of others to hurt her feelings when

she perceived them to be insensitive toward her needs, as a doctoral student Sarah was more willing to speak up for herself when others ignored her needs.

I really had to tone back my feelings because sometimes my feelings would get hurt. For instance, let's say if all my colleagues were going somewhere and no one asked me if I needed a ride because they know that I don't drive. And I'm like they know I don't drive, why didn't anyone ask me for a ride? And that always happened in the master's program. And I could perceive it as being more sensitivity in the doctoral program, but I perceive it as a change in me, because in the masters program I was a lot younger. The doctoral program I've had time to mature and now I'm like 'if you guys are going there, I need a ride.' But before in the masters program I would just sit there and hope that somebody would ask me for a ride, you know, ask me if I could get a ride. But now I'm like, I need a ride and then they'll be like, you know, sure, whatever. But before I probably would have told you that they weren't as accepting, but it was more that I wasn't speaking up for myself. I wasn't advocating for myself.

Sarah seemed to understand that because she did not always use a cane or have a guide dog this sometimes made her disability "invisible" to both faculty and her peers. She became aware of this aspect of her identity as a person with a visual disability when she was unintentionally excluded from classroom discussions focusing on disability-related topics that personally impacted her, and the realization motivated her to be more outspoken in advocating for herself.

I've always had to in the program advocate for myself because I find that being legally blind is I consider it that unless you have a cane it's like an invisible

disability. So they may pay attention if you're a minority to make sure that they you know consider you in the conversation if we're having conversation about multi-culturalism in class. But when you have the conversation about ableism they always forget that there is someone in the class that is disabled. Unless I pointedly say well, you know, I have had some of those exact issues that you're talking about in class... When we talk about social justice and people not having access and things like that they forget that I'm sitting right there and I don't drive and there are a lot of places I don't have access to and how it impacts me.

For Sarah, advocating for herself not only meant being more assertive and letting others know about her needs, but also opening up about her disability and being more patient when others ask questions about it. In the past, she had been reluctant to speak to others about her disability because she felt they would treat her differently based on that information.

Before I used to, it always used to be a fear of mine to tell my students that I have a visual disability or to tell my colleagues because then a lot of times people start treating me differently and I didn't like that. I didn't like people to treat me like, you know you tell them you have a visual disability and they want to treat you like your legs broken or something. Like, 'Oh, you know, are you sure you can make it over there,' or 'can you see that?' And I'm like I can hear you, I'm not deaf you know. Or 'did you know that's there?' I'm like, 'I've been walking by myself on this campus for years without your help and I can still do it.' Or 'why don't you use a cane?' I don't need it here, I'm ok, you know. And that's what you know would always bother me... I am who I am, and my vision is getting worse.

It's not getting any better. So I learn to speak up for myself and if you don't like it, fine. If you do it's fine, you know. And I also have been more accepting of people asking me lots of questions when they find out that I have a disability.

Then I realize they are just really trying to get a handle on what your disability is and it's, you know, you've lived with it all your life but for them it's new.

A key benefit of sharing information about her disability with peers for Sarah was that in some cases they had become advocates on Sarah's behalf when they realized she could not see something in the classroom. Furthermore, her colleagues who knew about her disability helped lessen some of the social awkwardness that may have developed between Sarah and her students in the courses she had to teach as a graduate student.

In classes and stuff my colleagues that know I have a disability, they'll speak up for me sometimes before I even have an opportunity to speak up for myself.

Because sometimes there's something I'm not seeing but I don't know that I'm not seeing it, you know... So it's like if I'm not seeing what I didn't know I wasn't seeing it they'll be like '(Sarah), Do you see this?' And I'm like, 'No, I don't see it.' And then they'll tell whoever is doing the presentation or the instructor 'Oh, she can't see this, you know, can I go make a copy for her, can I go enlarge this for her or whatever?' And then they have stepped up in many cases and even in little things which are important for us, I think, in networking and relationships. I may have students for classes that I may co-teach with another colleague or something. They'll see me and they will say to the other professor, the other teacher, 'Oh, you know, I saw (Sarah), or I saw Mrs. C., and she didn't say anything to me and she is so, you know, rude or whatever.' And they [her

colleagues] will tell them, 'you know she's legally blind right? She didn't see you. So if you see her you need to make it obvious that you see her.'

Sarah had initially been reluctant to share that she had a disability with her students because she feared they would cheat if they knew about her vision loss. However, she soon realized that she had developed her own strategies to compensate for her disability in the classroom and to keep students on task to make it less likely that they would cheat. Also, by allowing her students to know about her disability, they had become an extra help for her in navigating the classroom environment. Based on her positive experiences with her students, Sarah had been more proactive about sharing that she had a disability when presenting at conferences and workshops in her other professional roles.

I compensate for my vision. I will walk around the classroom because I can't see. I feel that even my presence, my proximity, will help. Because if they're on the computer and I'm standing right behind them, whether or not I can see their screen, they're a lot less inclined to keep it on Facebook if I'm there... a lot of them, they help me when I don't see something. They'll be like 'Oh, Mrs. C., do you know that that's there?' Or, you know, 'you have a visual disability, so I'm going to tell you that this is here.' And so it kind of gives me, you know, 28-35 eyes, pairs of eyes, instead of just me doing something silly and them wondering why... I also do a lot of workshops and seminars and conference presentations and stuff like that. And I'll tell the people in the room, I'm like, 'if you're raising your hand and I don't call on you it's not because I'm ignoring you, it's because I didn't see you. So either someone else tell me or you just give me your answer,

you know.' So, yeah, because I think that it makes them upset because they think that you're ignoring them when really you don't see them.

Proactive strategies for accommodations. As a student, Sarah found that receiving accommodations from her professors had become easier as a graduate student than it was when she was an undergraduate student, but this was still an area where Sarah had to continue to advocate for herself. She had even come up with a strategy that involved asking the faculty member for her accommodations in public so that other students would not only hold the faculty member accountable but also accommodate for her themselves.

Professors especially, some of them you know you can tell them everyday and even, I noticed there's no difference. If you give them an accommodation or you don't they still don't remember, you know. They'll still come to class with their lecture and have not emailed it to you ahead of time or have not printed it out and enlarged it. But I just realized that the differences are in me. I've become a lot more comfortable with myself. It's common and I used to take offense to it but then as a professor myself I realize that a lot of times you're just trying to get to class and you may forget the other student that needed an additional accommodation. And it wasn't intentional. It was just that you were hoping that the lecture itself was ready, not the lecture plus what they need. It was a common thing, but it was different than when I was in my undergrad. There were some professors that just flat out refused to accommodate and I haven't had that in my graduate program... I have to constantly remind them. And then if you say it in

front of other students, then you'll find that other students will start, I mean for me, I found that other students start to accommodate for me as well.

Another area of her graduate school experience where Sarah had learned to be proactive was in getting access to textbooks and other educational materials. As an undergraduate student she had relied on the disability services office of her university to scan the print version of the book in order to convert it into a digital format she could access on the computer. As a graduate student Sarah had found her own way of accessing instructional materials by contacting the publishers directly. She found she could take advantage of her role as an instructor to acquire the digital versions of the books, which were more accessible to her. Furthermore, the wider overall availability of content in digital formats, such as audiobooks, meant she did not always have to rely on an accommodation for getting access to accessible instructional materials. Sarah preferred the audiobooks because they had become more popular and commonplace with all students, and using them did not emphasize her disability to others.

They (disability services) would do the scanning of all my books to make electronic copies of them for me and that was really helpful because I could enlarge it. But now moving to my doctoral program I have this dual title now, I'm an instructor/student. If my professor doesn't provide me with a book, I just contact the publisher and get an electronic book. But when I was in my master's program I was just a student so I wasn't aware of all these other resources that were out there. To be able to contact the publisher and say, 'you don't have an electronic book for sale but do you have an electronic version?' And a lot of times they do and they'll send it to you if you say you're an instructor with a disability.

They (student disability services) have to take the book out of the binding and literally just scan it. Page by page by page and then send it to you in a CD. I mean burn it on a CD and then give it to you in a PDF version. So you know a lot of the books they are automatically doing electronic versions, of a lot of the textbooks. And now a lot of the publishers are selling the electronic versions to students and they're selling it at a discounted price. Now it's a regular occurrence, a lot of things that used to be an accommodation. I've noticed something that was really big as an accommodation was audio books, and now audio books are everywhere!... and now with audio books, it's like everybody is listening to audio books so it's no big deal. And then the electronic books, you see a lot of people enlarging books on their computer as they're reading it or whatever. So things that used to make me feel awkward or different are a common everyday thing now.

As a doctoral student, Sarah also had to be proactive in her relationships with the editors of the journals where she submitted articles for publication. Formatting was sometimes difficult for Sarah due to her visual disability, but she found that when she requested it the editors were willing to help with formatting once the article was accepted for publication. Sarah felt being open about her disability in that situation prevented misunderstandings about her abilities.

The editors of the journals that I work with if I tell them that I have a disability and if, you know, if they could double-check it for me after they've sent me confirmation that they're going to publish the article they will go through and do that for you. Really quickly too, because what I've learned again is it's easy for them but it's not easy for me...Being proactive and not being embarrassed or you

know secretive about your disability. Because then if you do that sometimes, what I've found, is that you kind of look, it makes you look incompetent. If you have a paper, for instance, where the parenthesis in your APA style is outside the period instead of inside the period. People are like 'does she know this?' but it could have just been an oversight literally. So people seem to be more accommodating of you whenever you say that and then they are not, you know, weary of telling you mistakes that you've made. Because they now understand that it may not have been that, you know, it's not a content issue, it's just an issue with formatting.

To Sarah, the ability to advocate and speak up for herself was so important to her success that she considered it the best piece of advice she could provide to any future graduate student with a visual disability. According to Sarah, it is important for students with disabilities to not assume others know or understand their needs. Instead, she recommended these students should be proactive and seek to inform those charged with providing accommodations of their specific needs.

I would say that if any student wants to get to grad school they need to make sure that everyone around them is doing their job. Student disability services, they're supposed to help you to the best of their abilities. But you also have to let them know what additional accommodations you may need that they may not necessarily be aware of that you need...If you're not proactive you'll get left in the dust in grad school. Because people really expect other people to continue holding their hands and they don't. You know, even though my major professor helped me a lot, I also hunted him down a lot. Like literally standing outside of his office pacing back and forth. Waiting on him, you know, because I knew that I needed

help. I think that's the biggest thing, advocating for yourself. And you know, don't make assumptions that people know.

Challenges

Figure 5 presents a visual summary of Sarah's challenges as she pursued her two graduate degrees. Along with external factors such as access to transportation, these challenges also include Sarah's struggles with her self-esteem and her perceived social isolation.

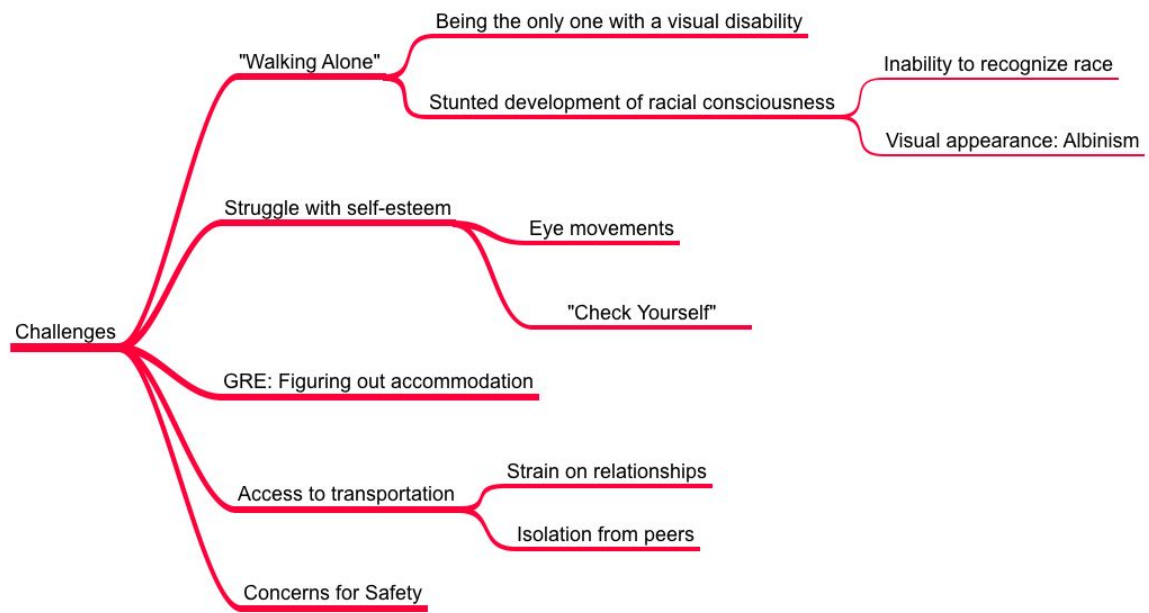


Figure 5. Visual summary of Sarah's challenges.

The GRE. Sarah considered the Graduate Record Examination (GRE) the first hurdle she had to overcome in order to pursue a graduate education. According to Sarah, the test was only going to be available to her in a paper and pencil format. I'm guessing the reason for this is that the lab where she was going to take the test did not have the assistive technology needed for her to take it on the computer. In the end, Sarah decided to take the test without the accommodation and figured out on her own how to enlarge the

content on the computer. However, the uncertainty of not knowing what the testing experience would be like ahead of time caused a great deal of anxiety.

The biggest first hurdle for me was the GRE. The GRE to me was a very difficult task. In addition to being a difficult task, the process of applying for accommodations and different things like that was not at the time, it's probably a lot easier now, but at the time wasn't as straight forward as I thought it could have been. And then when you apply for accommodations it was a paper test that they enlarge when to me I thought, I felt, that if they were using technology anyway they could have enlarged the text, used ZoomText on the test and allowed me to do it on the screen because that's how I'm used to doing it.... So when I found out that they were just going to do it paper-based, I said 'no I'll just take it on the computer.' And when I came in I figured out a way to enlarge the font on the screen and then I just used it on the computer. So that was the first thing, just worrying about it for me. I'm a chronic worrier. The worrying about what's going to be there.

Struggles with self-esteem. According to Sarah, one factor that had prevented her from becoming a strong advocate for herself earlier in her program was her struggle with self-confidence and self-esteem. The outward appearance of her disability, especially the involuntary eye movements caused by her nystagmus, had caused Sarah to struggle with her self-confidence in social situations. A reduced self-worth is one of the responses to changes in how our bodies move and function, what Toombs (1995) defines as our corporeal style, that can result in the person who has a disability developing feelings of shame around his or her physical appearance.

I wish I had started advocating for myself a lot earlier. I think it probably would have put me further than I am now. I wish that I had had more confidence in myself a lot earlier because I think that, unfortunately, sometimes not being able to see well sometimes I think it impacted my confidence just dealing with people. Meeting people has always been a thing that has been ridden with anxiety for me, because I'm always like, oh are they going to be talking about my eyes, are they going to be wondering why my eyes are moving back and forth and not understanding what I'm saying... for interviews or anything like that, I have a severe nystagmus, so my eyes float. And interviews for me are nerve racking because I always wonder if the person is going to be looking at my eyes instead of listening to what I'm saying, wondering why are my eyes moving from side to side. And some people have come right out and asked me, which has increased my anxiety because I'm like, oh people do notice... I realized that, hey, a lot of times just like with my clients that I talk to, that's internal. So, you know, I wish that I had known that or felt more confident in myself earlier.

Access to transportation. From the start of her graduate school experience, the lack of access to transportation was a challenge for Sarah. She explained that budget cuts had led to reduced routes for her busses and as a result she was forced to rely on her mother more for her transportation to and from school because of the amount of time it would take to get there on the bus.

The biggest issue that happened was a lot of the budget cuts. I really saw a difference in transportation because of the economy. What they started doing was looking at how frequently people were using busses in certain areas. Even if you

were using it, you're only one person and they don't care about just one person. So, a lot of the bus routes in our area over the last couple of years have cut down to where they only come once every 2 hours. And when I try to look to see ok, maybe the route has changed. Maybe things are different. Maybe I can get from where I am to where I need to go in less time, but it's still 2 hours 45 minutes to get from [her home] to [the university] on the bus...Where the transportation is the most abundant is not necessarily where you want to live, you know, so I've had to depend on my mom. My mom drives me, drives me most places. Or my husband, but my husband now works in [a neighboring city] so now its all my mom.

Sarah felt that her limited access to transportation placed some strain on her relationships. She felt that if she could transport herself places she would be able to use her time more efficiently.

Family, like having children and friends, because when you're in graduate school it takes a lot out of your life. I mean there are things that you wish you could do with your children or with your husband or your significant that you can't necessarily do. But if you were able to take a break, jump in your car, go do something and come back, or, you know, you were able to get yourself around I think it would be a lot easier...I think it puts a strain on relationships. For instance, when I get out of class at night, because a lot of our classes finish at night, I have to have someone here to pick me up and take me home. My husband, who works in [a neighboring city], he'll come down and he'll work late to come and pick me up at nine and take me home. For him, I know he says he's ok with it. I mean we've been married for ten years now. But it's like I still feel that I wish he

didn't have to do this. I wish I could just, you know, transport myself and get to where I need to go.

Sarah also felt her inability to drive had adversely impacted her ability to develop close relationships with other students in her program. While Sarah did not consider it unusual for graduate students to have few such relationships due to the general lack of time many of them face as a result of their demanding programs, she felt that if she had better access to transportation it would improve her ability to be more socially integrated with her classmates.

I think when you get into graduate school people are working and doing their own thing. They'll come from work and meet up with other classmates or whatever some place. And if you're a person who doesn't drive, it's difficult for you to get those places. And a lot of times, because you don't drive, unless they can give you a ride they don't really even mention it to you, you know. So when I first came in, I was really by myself. I felt like I was in a cohort of one...I find is that as graduate students we have so little time to do that anyway. Because whatever time you're not doing school work you really want to spend with your family or doing something for yourself. And we don't really get to do that, so I find that we have very limited social life as is.

As Sarah looked ahead to her career after graduation, the issue of access to transportation was something that was on her mind as she started to consider where she would like to live and work.

It's an issue. I really want to move out of [her current city] to try to find a place that has better transportation. But I would not know where to go really in [her

state], if I wanted to stay in [her state]. Because [a neighboring city] I found is equally spread out. [A city within the same state], I have some friends down there and they complain about the transportation system bitterly down there. They said that sometimes the bus will see people at the stop and it won't even stop. So, you know, it's like where do you go that has great transportation. And so we looked up on the Internet the top places to live for people with disabilities. And, you know, we're hoping that if my husband doesn't get a permanent job where he's at, hopefully I'll look for a job, and he'll look for a job, in one of those cities and try to possibly move someplace where it [transportation] is better.

Mobility and anxiety about safety. In addition to transportation to and from school, getting around on campus sometimes caused anxiety for Sarah. That was especially the case during her early years in graduate school, when she was not as familiar with the campus. As a doctoral student who had attended the same university for her Master's degree, she was more familiar with the campus and this eased her anxiety, but concerns about her safety at night still lingered.

I won't even talk about getting around on campus the first couple of times that I came here. That was for me I mean, just anxiety provoking. I'm just like ok, what if I get lost. And then this building has 2 buildings... For the doctorate program it was no big deal because by then I was coming back to the same program... I'll tell you something that I have anxiety about, walking around at night on campus. It didn't use to really occur to me that it was my vision that probably made it hard until I was walking with my husband one night and I was like 'it's so dark out here I can't see anything' and he was like 'I can see fine.'

I asked Sarah if she used a white cane, and she said she did, but primarily to help with her interactions with other people. While she was familiar enough with the campus that she could get around without her white cane, she found that the visibility of the white cane served as a cue for other people to recognize her disability when she was out in public.

I have a cane and I use it specially to travel to Chicago all the time. I would use it there and when I would go to New York all the time, I'd use it there. In Tampa I really don't use it. Unless, like one time, when I used to walk back and forth to the hospital or go to a hospital that's right across [a busy street near the university]. I would have to cross [the same street near the university]. I would pop out my cane. I carry my cane in my bag whether or not I always use it because one of the people who worked with me told me 'even if you don't need it, use it so other people see you.' And so that's what I would use it for. So, if I'm riding the bus I use it because then it prompts the bus driver to tell me what bus it is without me trying to guess. So I still use it as an adult. I still see a purpose in it.

Along with the need to find suitable transportation, the inability to see well at night was another concern that was on Sarah's mind as she considered where she would like to work after graduation.

I have problems, of course, seeing during the day. So at night it's just like people literally look like shadows to me. Like they just come out of nowhere. And that's just a safety issue for me. So when I think about being a professor, I know that I will be teaching in graduate programs, because counselor ed is 99% graduate programs. And I know I'll be teaching at night and even though I want more

independence at lot of times I'm like ok, but would I even be able to have my independence coming out of work at night to walk to a bus stop by myself, to then take the bus or take the train to go home, all of those things. I mean, I don't know if it's things that everyone thinks about but it's just things that are always running through my mind.

Isolation and the feeling of “walking alone.” Sarah felt she was “walking alone” in her journey through life as a person with a visual disability because other than her family few people around her shared her experience. To explore that part of herself, she had to reach outside her university community by joining advocacy groups where she was able to interact with other people with visual disabilities.

I literally feel like I'm walking alone. So my identity then as a person with a disability I feel it's lost in a way...It would be like, you know, being the only African American person walking around in a room full of European Americans all the time. You know, you really don't have anyone else to share that personal experience with...I've always found that in my program I feel alone in that sense. And so that identity I feel I connect more like if I go to conferences like the National Federation of the blind or something. I feel more at home or, I don't know how to say it, at peace with my identity as a visually impaired person there, but everywhere else I always feel lonely. I feel like as a minority woman I'm, you know, I feel like I have comrades so to speak, but in this program as a person with a disability, with a visual disability, I've always felt alone.

Even though there was one other student with a disability in her program, Sarah found it difficult to establish a connection with that person because of the differences in

their disabilities. Overall, she found that even with other people with visual disabilities, there are significant differences based on factors such as the onset of the disability.

I have tried to foster that relationship but I think that he was disabled later in life and I was born disabled, so I find that that seems to put a marked difference between people. I think a lot of times people lump everyone with disabilities in one thing, even people with blindness. I find when I've gone to NFB conferences or even our Florida division conferences and meetings, I find there's a difference between people who are totally blind and people who are legally blind. Then there's a difference between people who were born blind and between people who have gone blind or are going blind. Because people who are born blind, they haven't known anything different. So people who, you know, go blind, they did know at one point what it was like to see and now they don't. So a lot of times they have to go through that grieving process, to which I really can't grieve something I never had. So with him he just not too long ago, probably ten or fifteen years ago, it wasn't even that long ago, that he got in an accident and he became wheelchair bound. So a lot of times I've tried to talk to him about his disability but he doesn't really talk about it much.

Consciousness as a person of color. Aside from her disability, an aspect of her identity Sarah had begun to explore in more depth as a graduate student was her status as a person of color with a visual disability. One of the documents she shared with me, a paper she submitted for one of her courses, focused on this aspect of her identity. A key theme in that paper, and one which Sarah and I also discussed during our conversations, was the difficulty her visual impairment created for her in finding her own ethnic

identity. She stated that not being able to recognize other people's physical appearance had "stunted" (this was the word she used in her paper) her development of a race consciousness.

I always say that there was a world that I wasn't aware of because I couldn't fully see people until I really got up on them. I would try to judge what their race or ethnicity was from their voice, but I've been wrong so many times so I stopped doing that. So I was like hey, unless this person tells me what they are then it's not important to me. They just are who they are, because unless I get really close to your face and even then what I've learned is you can't really tell what people are...It really made me feel a little bit on the outside. Like, you know, should I be more race conscious than I am? Should I be more prejudice than I am? Maybe I lost out on being prejudiced because I can't really judge you by what I see.

Along with her inability to accurately identify people's race or ethnicity due to her visual disability, another factor Sarah felt had influenced her ability to develop an identity as a person of color, and to become part of a community based on that identity, was her physical appearance as a person with albinism.

I have not had similar experiences to other people who may be well, I'll say, similar in ethnicity to me. Similar in gender as far as female because my program is primarily female, which counseling is primarily a female field. But when we are talking as far as albinism, I always have felt like it gave me a different type of identity when compared to other Caribbean American women. In my program, we've been pretty lucky as far as we have a lot of minority women in my program. So we do identify really well together, but I've always found that I had to make it

known that I was a minority because of my albinism. I don't think people ever thought that I was white or European American. I don't really know what they thought I was. But they would say 'you know, we're going to have an event for minority women' and then I wouldn't be invited. So then I knew that, you know, I was not recognized as that.

Sarah's development of an ethnic consciousness was complicated by the fact that she lives in a liminal status (betwixt and between) in two different dimensions of her life: as a person with albinism who does not easily fit in with other members of her ethnic group, and as a person with a visual disability who is neither fully sighted nor fully blind. Because Sarah was the only other participant who was a person of color, Sarah and I shared this common experience of learning how to manage shifting identities in multiple dimensions, not just with respect to our visual disabilities. I shared with Sarah that I felt my identity as a Hispanic male had become less important to me as my disability progressed and I came to be recognized more for my white cane than by other aspects of my identity. She shared that she had a similar experience when she informed other people about her disability. As she stated, "when I tell someone I'm legally blind all of a sudden then my disability is out front, you know. It's like can you see that? Before they weren't saying anything but other things about you go to the background, you know."

As a result of Sarah not having a strong connection to a community of peers who had a similar experience, she felt she experienced her disability mostly in isolation. This meant that sometimes she had to "check herself," meaning that she had to get out from within herself and gain a different perspective about her disability.

Sometimes I tend to start to feel sorry for myself because of my disability. I say that it is something that I check myself on as a counselor. It's always been something for me that I used to think would make me a subpar counselor. Because I said ok, you know, they talk about, you know, look your client in the eyes and all this other kind of thing and that's so important as a counselor. But I would always avoid looking my clients in the eyes, for instance, because I didn't want them to see that I had nystagmus and that my eyes move. And I didn't want them to be like 'what's wrong with you,' you know, 'why are your eyes moving everywhere.' And why I say it makes me check myself is because when I start to get too in my head with this disability and I ask my client, 'oh, by the way, if you see my eyes moving or whatever it's because of this' and this may be their third or fourth session with me, they'll be like 'until you said something I didn't even notice that,' you know. And it makes you realize that you have to get from within yourself because many times I think we hold ourselves back. It's like we, we're inside thinking oh, everybody knows I can't see and everybody knows that, you know. Maybe so and so saw me stumble on that, or maybe someone saw my arm hit the wall because I didn't see it there. I've even run into poles sometimes that I did not see that it was there and I think everybody was staring at me and everyone thinks I'm a loser. And then you realize, just like you're internal, so is everybody else, and they really could care less a lot of times about your disability or your ability. So I think that with my disability it helps to keep a check on myself.

Empowering Factors

Sarah reported having a number of important relationships that helped her cope with the obstacles she encountered in graduate school as a student with a visual disability. Along with these supportive relationships, Sarah also started to see her disability as an asset, and this change of perspective empowered her to think about her disability differently. Figure 6 is a visual summary of Sarah's empowering factors.

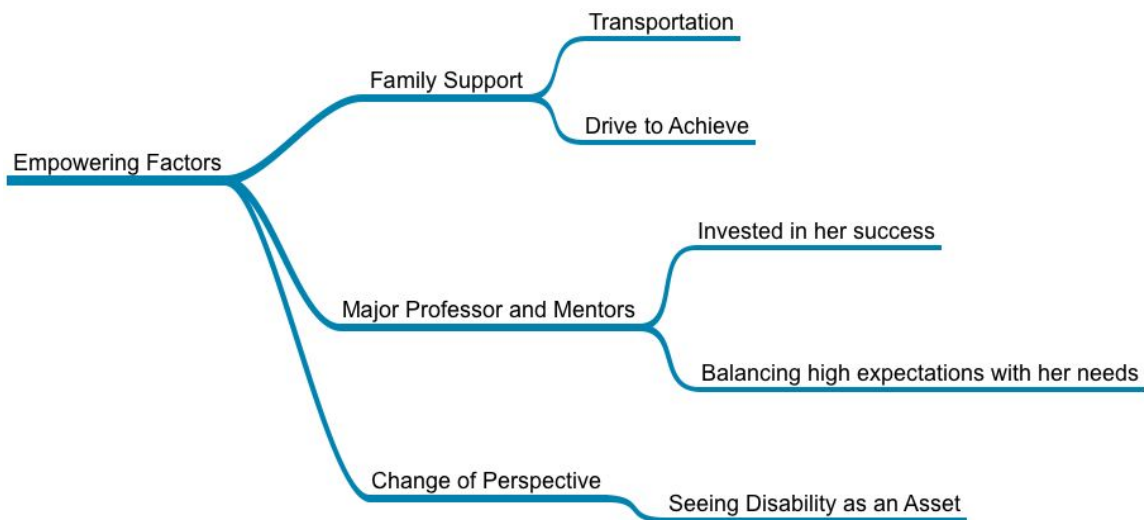


Figure 6. Visual summary of Sarah's empowering factors.

Supportive relationships with family and friends. Sarah identified a number of supportive relationships that allowed her to overcome some of the challenges she faced as a graduate student, including those resulting from her inability to drive. Sarah was especially grateful for the support of her mother, who provided the bulk of her transportation to and from school.

Definitely my mom. My mom, without her, I wouldn't be here everyday. She definitely makes where I have to go a priority in her life. I find that that's very hard to find in people, to where if you have an emergency that comes up, it's not an inconvenience to them that you have an emergency. Or let's say I forgot

something at the school that I need, it's not like 'oh you forgot it, well you can just get it tomorrow.' Because, you know, if you could drive you would just jump in your car and go get it. But you know I don't have that opportunity, so my mom definitely.

Aside from the practical support her mother provided with transportation, Sarah believed her strong drive to achieve came from her parents.

I would say that two things. You know, someone telling me that I can't do something it's always made me want to do it more... I think my drive, my husband calls it my overdrive. He's like 'you're in overdrive, you're not in drive.' I am. I've always been in overdrive to be the best at what I do, regardless of whether or not I've had a disability. I think it really comes from my family. My dad was always that type of person, all the way. He always said in elementary school through college he got straight As. He never got a B. He would not accept it. He was always like 'you be the best, and if you are a dog catcher you better be the number one dog catcher. If you're a garbage man, you better be the best at what you do. You take pride in what you do.' And, you know, my parents never treated us as if we had a disability. My mom, even to this day, she always said as long as you're striving for something bigger than yourself I will be there to support you through it.

The support of her brother, who is also legally blind and pursuing his own doctorate at another university, was especially important to Sarah because he was someone who could empathize with her experience as a graduate student and as a person

with visual disability. At the same time, the two siblings had a friendly competition to see who would complete the doctorate first and that fed into Sarah's drive to achieve.

I think the biggest thing that has supported me throughout was having a sibling that was also legally blind. He's legally blind, he's also albino and he's also getting his Ph.D. just like me. We're doing a lot of the same things and he was a primary support to me... My brother and I we both wanted to be number one and we worked and worked until we were able to do those things, you know, beyond our vision. And I say my brother because my brother is legally blind as well, and he also has the same kind of drive... Both of us have always had that drive and I think it's always come from our parents. You know, they said 'there's always, there's a lot of people out there that are worse off than you are, so just because you have a vision problem, so what,' that's what my mom used to say... We compete. I'm graduating first and trust me, he went into his program first, into his doctoral program, but I was still working at the time. I was also helping to take care of my dad. I am graduating first. I'm older. I'm 31 and he's 30 and I'm like 'I'm graduating first, you're not graduating before me,' so he still has a year left and I will be graduating in May. So I beat him... both of us have always had that drive and I think it's always come from our parents.

While her family's support was important to Sarah, Sarah clarified that this support went beyond just moral support. In the case of her parents it included knowing how to advocate for their children in order to get them access to the services they needed to do well academically over the years.

I've been really blessed to meet a lot of people that were personally invested in me all the way through my life. In addition to that support, having family support has been important, because I've met people with disabilities that did not have any support from their families and that can make things extremely hard. Not only having support, because your family can support you, but also supporting you in getting services and the aid you need in school for your disability. Because they can support you overall but not know how to connect to different divisions or government entities to make sure you get the support you need. So to have parents that knew where to go to get what was needed and in addition to that, you know, my support from my parents.

Sarah also appreciated the sacrifices her husband had to make so that she could pursue her dream of a doctorate degree. At the same time, she did not overlook some of the strain the demands of being a graduate student had put on her relationship with her husband, which she attributed to her inability to transport herself.

My husband has been a huge support as far as, especially in the first couple of years whenever it's primarily coursework, he took over, you know, dealing with the kids and everything else along with his job. He was a huge support...I think that graduate school and relationships is difficult in itself, but when you have a visual disability and you're in graduate school and you're in a relationship I think it makes it ten times more difficult...When you're in graduate school it takes a lot out of your life. I mean there's things that you wish you could do with your children or with your husband or your significant other that you can't necessarily do. But if you were able to take a break, jump in your car, go do something and

come back, or, you know, you were able to get yourself around, I think it would be a lot easier.

While Sarah considered herself to not be as socially integrated with her peers as she wanted to be, she did have one close friend she had met early in the program. It was clear from our conversation that her friend had been a big source of support for Sarah, and the two had become so close that Sarah trusted friend enough to let her take care of her two kids when she had to travel for conference presentations.

There's like really one student in the program that I'm really good friends with, but other than that I found that students in the program that I thought were more friends were using me as like a mentor or an advisor than they use me as a friend. So I would say that not much... She was first year, so she was more motivated than I was at the time. She would say 'well, you know, you remember when we did this project and you did most of it so now since you're stressed I'll do most of it.' So sharing the burden so to speak. So yeah, lots of people that have supported me, absolutely. She'll either travel with me or she has stayed with my kids so my husband can travel with me. So that's a huge, huge help in that way. I mean we've really become very close over the last couple of years.

Supportive relationship with major professor and other mentors. Within her program, Sarah focused on her positive relationship with her major professor as a key factor that contributed to her success. Sarah especially valued the way in which her major professor pushed her to strive for more by holding her to the same high standard as other students.

I'm just writing the dedication and acknowledgement to my dissertation and I wrote in my major professor when normally they go into your acknowledgement section. He, well, he has been my major professor in my doctoral program and then just a professor in my master's program and the thing that always I always liked about him is he never treated me like I had a disability. Meaning that he's always had held me to 150% of the standard. Like if everybody else was turning in an assignment he would be like 'ok Sarah, this assignment is an A, but is it publishable? Probably not, so how would you make this publishable?' So he's always pushed me to do more and be more, you know... Treating me always, never treating me as a disabled person, I think it's the biggest, you know, it's the biggest contribution that he's made to my program. And always holding me to a higher standard than a person what would you call them 'able?'

Sarah especially appreciated the way in which her major professor mentored her in a way that balanced his high expectations for her with the special needs she had as a student with a visual disability.

He has always told me that, he says that he forgets that I'm legally blind a lot of times. He's like 'I forget.' He will say 'oh didn't Sarah see that?' and then he'll realize that you didn't see it. But he reminds me of my dad, because my dad used to do the same thing and he, you know, he really mentors me. I've probably done probably over 65 national, state, and regional presentations since I've been here. And if I get accepted to something and his name is on it he always goes with me and I've seen other professors that have not gone with their students... He stayed with me the entire time. Took me to all the sessions, made sure I got to all the

sessions on time. He reads things to me as I'm passing by. He told me like a while ago, 'the reason why I do these things is because you're a hard worker and you're a very dependable person and I don't ever want that to come in the way of you being able to move forward.' And I think that, you know, I'm pretty lucky to have met him in this program because I realized that a lot of other people do not have professors that are vested in their success... For him to say that he forgets my disability, he forgets it but when it counts he remembers. So, you know, that's the important thing to me.

Overall, Sarah felt thankful that she had as much support from her professors and others within her program as she did.

There's another professor... she helped me out a lot and has really supported me even now through the job search process. So I think I've been very, very blessed with the amount of people that are personally invested in my success, which I found is a difference. Because you may be assigned an advisor, but they may not feel personally invested, that 'if you make it like they've made it' kind of thing. And I have a lot of people that it feels like when I'm successful, they feel successful. So really lucky.

Change of perspective and seeing her disability as an asset. Sarah's change in perspective with regard to her disability, which came from her learning to "check herself" when she started to feel sorry for herself, meant that she came to see her experience as a person with a visual disability as an asset she could use to her advantage rather than as a hindrance.

I say I use my visual disability a lot of times to help open doors for me. When I was a singer, the National Federation of the Blind has a performing arts division and I got hooked up there. And then I started, I got a leadership in that division and then used that identity to help get me on radio shows and different things like that because it made me different. And so, sometimes one thing that makes you different, you feel that it's a disadvantage, but it's an advantage because it helps people pay attention to what you're doing. I tell people 'oh and I'm legally blind,' and that peeks their interest. So like 'oh, you did this and you're legally blind.' So sometimes use your disability. Use it as, you know, to make more things available to you that may not have been necessarily. Yeah, use it as an asset. Yes, instead of a deficiency... I think that this really helped me to recognize that in a positive way. This is what makes me different. And it wasn't because I can't do something or because I can't see something or because I, you know, I can't get somewhere immediately that I want to. I often only recognize my disability in times of crisis instead of recognizing it in times of success.

Summary of Sarah's Depiction

Sarah considered the support of her family to be essential to her success as a graduate student with a visual disability. She attributed her drive to achieve to her parents, who encouraged her to strive to be the best at whatever path she chose to pursue in life. In addition to her parent's moral support, her mother provided the bulk of the transportation for Sarah, who is unable to drive due to her visual disability and lives in a city with limited transportation options. The support of her husband was also important to Sarah, but she worried about the strain on her personal relationships caused by the

demands of her program and her reliance on others for transportation. Along with her parents and husband, her brother was another source of support for Sarah because he shared the same experience of being a doctoral student and a person with a disability and albinism. At the same time, Sarah engaged in a sibling rivalry with her brother over who would graduate with the Ph.D. first, and this competition appeared to be a motivating factor for Sarah.

Overall, Sarah described her graduate school experience in positive terms. She felt that in addition to her family she had a number of supportive relationships with people in her department who were invested in her success as a graduate student. One of these relationships was with her major professor, whom she felt held her to a high standard but balanced his high expectations with the support Sarah needed to complete the requirements of her program. Another was with a fellow graduate student who became a close friend and helped Sarah with her children whenever she had to travel to conferences. Other than that one close friend, however, Sarah did not have any other significant relationships with peers within her program. She explained this lack of a social connection with her peers was the result of pursuing a demanding academic program that made it difficult to balance family and academic demands while leaving any time for social activities. Her inability to drive was another factor Sarah felt had limited her ability to become more socially engaged within her graduate program.

When asked about the meaning of her disability at this point in her life, Sarah said she had often considered herself to be “walking alone” as a person with a visual disability. She explained that outside of the few times each year when she attended conferences and other events sponsored by advocacy groups for the blind, she did not get

to interact much with other people who had a similar experience to hers. As a result, she experienced her disability mostly in her head and she said she had to occasionally “check herself” when she started focusing on the negative aspects of her disability and feeling sorry for herself. Earlier in her graduate school years, Sarah had struggled with self-confidence and self-esteem in relation to her disability. The physical appearance of her eyes, including the involuntary eye movements caused by her nystagmus, caused Sarah to be especially self-conscious, and this resulted in a great deal of anxiety for her in social situations. However, over time Sarah came to realize that other people did not notice the movement of her eyes as much as she thought, and this eased her anxiety. At the same time that Sarah became less self-conscious about her disability, she also learned to appreciate the more positive aspects of being a person with a disability. For example, Sarah told me that she now saw her disability as something that made her unique, something that made people take notice of her accomplishments and helped her stand out from other doctoral students. Empowered by her changed perspective about her disability, Sarah had become an advocate for herself and developed a number of strategies for obtaining the accommodations she needed in order to perform well as a graduate student, teaching assistant and aspiring researcher.

Even though Sarah had become more comfortable in her identity as a person with a disability, she was just starting to examine her identity as a person of color. According to Sarah, her inability to see other people’s appearance and to accurately determine their race or ethnicity had “stunted” her development of an ethnic consciousness. Furthermore, her personal appearance as a person with albinism made it difficult for Sarah to be easily identified with a specific ethnic group. From our conversations, I got the sense that this is

an aspect of her identity Sarah struggles with and is only now starting to explore. As I explained to her, my experience in this area has been similar to hers in some ways, but different in others.

Like Sarah, I have noticed that as my disability progresses and I rely more on my white cane, my identity as a person with a visual disability sometimes overshadows my cultural identity as a person of Hispanic descent. The white cane is a highly visible object that clearly identifies me as a person with a disability. As with Sarah, my physical appearance is more ambiguous and difficult for some people to place culturally, especially if they do not hear me speak and notice my slight accent. Thus, as in Sarah's case, I can see why it might be easier for people who meet me for the first time to approach me first as a person with a disability rather than as a Hispanic male. However, a key difference between Sarah's experience and mine is that since I was diagnosed as an adult I had time to develop a strong ethnic consciousness before I learned about my disability. In Sarah's case, her cultural and ethnic background is an aspect of her identity she is just starting to explore.

Maria's Individual Depiction

Meet Maria

I first met Maria through her husband, who was the president of the local chapter for one of the national advocacy organizations for the blind. After meeting him at an on-campus event, I had briefly joined the chapter for several meetings when I was pursuing my Master's degree, and even volunteered for a short time to help with the chapter's website. I also worked with Maria and her husband on a video promoting white cane safety for blind pedestrians that was featured on the website. Unfortunately, the chapter

dissolved and I only had limited contact with Maria and her husband after that. However, when I contacted Maria to see if she would be willing to participate in this study, she was quick to agree to share her experiences with me.

Maria is a white female in her early 50s. In addition to being married, Maria has an adult daughter from a previous relationship who has a young daughter herself. Maria is a devoted grandmother and I could tell from the way her face lit up when talking about her granddaughter that the time she is able to spend with her granddaughter is important to Maria. In addition to school, Maria is involved in her community through her church, where she teaches a middle school class during the week and helps out with services on the weekends and at holidays. Maria also volunteers at the hospice center where her late mother received care. In the past, she had also volunteered at the same agency where she completed her internship as a graduate student in social work.

Maria graduated with a Master's degree in social work in the spring of 2011. As an undergraduate, Maria pursued a degree in criminal justice but for her graduate degree she decided to switch to social work hoping to improve her employment prospects. As she explained, many of the jobs in criminal justice require not only a Bachelor's degree but also a few years of experience, which she did not have. They also typically require a valid driver's license and Maria is unable to drive due to her visual disability. Maria hoped that as a human services field, social work would be more accommodating of her disability, but almost a year after graduation she still found herself unemployed and wondering if she should go back to school for additional education.

Maria's visual disability is the result of a hereditary condition called Marfan's syndrome that affects the body's connective tissue. People with this condition tend to be

very tall and to have long limbs and fingers. They can also suffer from heart and lung problems due to the way in which Marfan's weakens connective tissue. In Maria's case, the condition resulted in a number of eye problems dating back to childhood, including detached retinas and other problems with her corneas and lenses. Over the years, she has had over 20 surgeries to address these problems. By the time she was in her mid-30s she had completely lost her eyesight in her right eye, and a post-operation complication with a retina surgery on her left eye left her almost completely blind for a period of two years. At that time, she had a corneal transplant that restored some of her vision until she suffered an injury to her left eye in the middle of her graduate program that again left her without her eyesight. This injury, which I will describe in more detail in the next section, was a defining moment of Maria's graduate school experience.

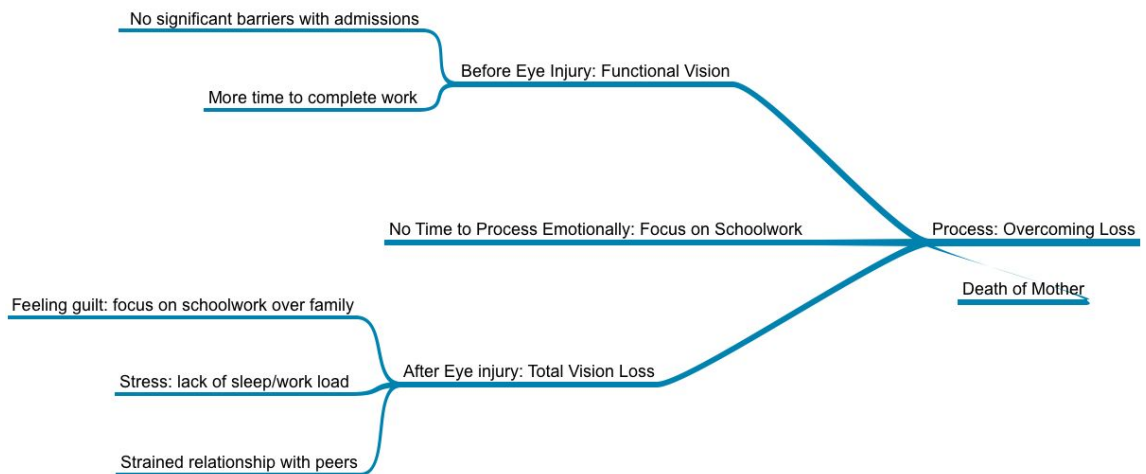


Figure 7. Visual summary of Maria's process.

Process

Maria's experience in graduate school was shaped by two difficult events: the death of her mother and the serious eye injury that caused her to temporarily lose all of

her eyesight. Figure 7 is a visual summary of Maria's process, her way of making sense of these difficult events in her life while she was in graduate school.

Coping with an eye injury and complete loss of vision. According to Maria, she did not encounter any significant barriers in the admissions process for her program because at the time she had some functional vision. Similarly, the first two semesters in her program Maria was able to use her remaining functional vision to complete her schoolwork, even though sometimes it took longer for her to complete assignments due to her visual disability. The third semester, however, her situation changed dramatically after she suffered a serious eye injury that resulted in the complete loss of her eyesight.

That [getting into the program] was really simple. At that time I had some usable vision, so I could read print. I could read the computer screen. I filled out the application, I got the letters of recommendation, I wrote my letter, and I sent it off and I didn't have any problems getting into the program at all...But you know, there's a big difference when you can read the computer screen and when you can't, you know. So the first two semesters were, there were things that may have taken me longer to do because of my visual impairment, you know, in reading things, using JAWS. I didn't use anything on tape. I got everything scanned, which that can be a problem. But it was the third semester, when I went totally blind, when things got rough.

Maria is referring to the serious eye injury she suffered during the third semester of her program (which was also about the half-way point of the program). While getting out of bed one day, she struck her eye on the corner of a nearby table, causing her eye to actually "blow out" (the vitreous liquid inside the eye actually came out of the eye along

with her lens implant). The injury required immediate emergency surgery, and it caused Maria to miss two classes and to eventually take an incomplete in one of her research courses (the only incomplete she received during her program, she proudly told me). While Maria said she was already familiar with the experience of complete vision loss, as she had completely lost her vision once before prior to receiving the now damaged implant, the injury did cause her to panic due to her fear that she might not be able to keep up with the schoolwork and fail her courses.

At first, the day it happened I thought ‘oh I'm just going to have to bail out of this semester’ and then it was like, ‘no, you're not going to do that, you're going to do whatever it takes and you're just going to get through it.’ So after the surgery I wrote my professors and said ‘this is what’s going on, this is how long I'll be out,’ which I only missed two classes. I did have to take an incomplete in one of my classes and that was the research class. But I did finish that on time and I got a ‘B’ in that class and I was ok with that ‘B.’ Usually I'm not ok with a ‘B,’ but I was ok with that ‘B.’ Again there was a lot of fear, there was a lot of panic, you know, ‘how am going to get this done?’ Although I was determined to do it, I would say I was probably moody because of the stress of it.

Maria said she did not really have time to fully process her emotional reaction to the injury. After the initial fear and panic, her focus quickly turned to what she needed to do to keep up with her schoolwork as she recovered from the injury. This included asking her husband to take over the household while she focused on her studies.

I didn't really have time to deal with the emotional part of losing the sight. I just had to basically push through that and just look to not fail, I had to ignore that...I

told my husband that was it. I said if I am going to get through this semester everything in this house is yours. You have to do the cleaning, you have to do the cooking, and you have to do the grocery shopping. You have to do everything because all my time is going to be spent on schoolwork, and it was.

While at times Maria felt guilty that she had to focus on her schoolwork at the expense of her family, she felt it was a sacrifice she had to make in order to achieve her goal of finishing the program. During this time Maria was stressed not only due to the amount of work she had to do to keep up in her academics, but also by the lack of sleep as she pushed herself to work even harder in order to achieve her goal.

I was always stressed. I don't think there was a time that I didn't feel that there wasn't something to do, every single minute of every single day. If I took a break, except for with my granddaughter, and then sometimes I had to cancel that. If I was doing anything but schoolwork I felt guilty. Because it just, you know, it just seemed like that's what I had to do to pass and get through and get done, you know, and get it accomplished. You know, what was I sleeping, maybe five to six hours a night...and I know that lack of sleep, you know, affects everything. It affects the way you think, it affects the way you work, you know, the way you view things.

Changes after the eye injury. Maria thought her professors were accommodating of her needs both when she lost her vision due to the eye injury. However, while her professors may have been well intentioned, they did not always know how to provide materials in a format Maria could access with her assistive technology. Furthermore, during this time Maria also experienced a number of problems

with access to the Blackboard course management system used in some of her online classes. I will discuss these challenges, and Maria's efforts to overcome them, in a separate section.

Maria felt her past experiences with complete vision loss helped with some of the adjustments she had to make after the injury. Other than a few rides to campus with a classmate who lived close to her house, after a few trips on the paratransit service for people with disabilities Maria began taking the city bus and traveling independently as she had before her accident.

I had lost my sight before, so it wasn't that being totally blind was foreign to me. You know, I lost my sight in 1997, so I've had a lot of time to adjust, you know. I've gone through this roller coaster ride. Not being able to see, being able to see, not being able... The first challenge going back to campus the first day was just getting from one class to the other. You know, because when you have sight and then you don't, it sounds silly but your stride is different at first, but I don't think I ever got lost... The thing about it is that at that point, I had lost my sight before so it wasn't that being totally blind was foreign to me. However, it was pretty inconvenient... I remember one classmate who lives close, she said she could pick me up. I think I let that happen once, twice and then I was like oh no and then I used paratransit a couple times and I'm no, I'll use the bus. So as time got on, I started adapting and adjusting, and things got easier, you know, with the traveling independently.

One area where Maria felt there was a significant change was in her relationships with her peers in her program, which she described as "strained" after the accident.

The first two semesters it was good. There was a handful of us that were older, more mature, in our 40s, 50s and 60s. We kind of hung out together, but also I seemed to be able to talk to the younger generation and we all seemed to respect each other. I never seemed to have any interpersonal problems with anyone in the cohort...It became strained the third semester, when I lost my vision. That was an interesting experience actually, but the first two semesters it was good... This woman, what was really interesting was that she was the only person that was new to our cohort that semester. So she didn't even know me. But as soon as she found out about the injury and that I was totally blind she just stepped in and said 'let me know, I'll do anything I can for you,' where some students who I went to school with for two semesters couldn't talk to me anymore. They just acted like I didn't exist... There were people in my cohort sometimes I wonder if some of them didn't even know what happened because there were some people the semester before that I would talk to and things like that. Well, not seeing them, of course, I didn't know they were around to speak to them. However, as time went on I knew at times I could hear their names. They were around, and they had talked to me since that [the eye injury] happened. There were some people who I considered my friends who didn't communicate. I mean it was like 'Hi, how you doing?' and so on but, really, really as far as that friendship went, they pulled back.

Even before the injury, Maria said she did not have much time to dedicate to the social aspect of her graduate school experience. What little free time she had after doing her schoolwork and caring for her mother she decided to spend with her family,

especially her granddaughter. According to Maria, the time she spent with her granddaughter was important for helping her deal with the stress she was experiencing in her life.

There were a couple of ladies, we used to do things together, but there's really only right now one person that I talk to on a regular basis. Usually via email, due to transportation and then just life... While we were in school we didn't do a whole lot outside. Some of them did. Some of them went to [a local amusement park], things like that, but for me I was just focused on getting stuff done. Being that it took longer for me to do it, I really didn't have any free time. The free time I had was for my husband and my grandchild and my daughter, and my mother. My mother was in hospice care the whole time I was in graduate school, so that basically I stayed family oriented during that time... She [her granddaughter] was my break. She was the thing that stopped the focus of school, you know. When she was at home I could be a kid again. I would watch cartoons with her. We'd go to the park, we'd color, we'd play. So when she was there, there was no school. School didn't exist. I didn't listen to books. I didn't listen to my emails. I mean, I didn't do any of that. I just stayed away from it. And she usually came over, unless I had a big project, one night a week.

Coping with the loss of her mother. In addition to her injury and complete loss of vision, which took place the third semester, Maria had to cope with the loss of her mother her last semester in the program. Caring for her late mother placed added stress on Maria by further limiting the amount of rest and sleep she was able to get. Despite all of the stress on her life, Maria pushed forward in her program and only required two

extensions for her assignments after the death of her mother, when she took a week away from school to mourn her loss.

The fourth semester, you know, my mother died. And I took care of her, and I was lucky to get two to three hours sleep. I would alternate with my brother and stay over at my dad and mom's house for two or three nights and then my brother would come and I would go home. It was like I would sleep eight hours every two to three nights, for three weeks. And then she passed away. And of course, I missed a week of class, two days of class when that happened as well. And that was the only time I asked for extensions for anything that was due, and I think that was for two projects. I got a week extended on two projects.

Overall, Maria thought her graduate school experience was challenging and even overwhelming at times, but she also described it as a rewarding experience and she felt she had received the support she needed from faculty and other students throughout her program. She especially appreciated the fact that she was in a cohort.

In general, I thought it was overwhelming. It was the hardest thing I've ever done. I mean it was fast. You had a lot to learn in a short period of time, and it was like, 'am I really going to retain any of this?' you know, because you're learning so much. But I enjoyed it immensely though. Absolutely enjoyed it...The struggles. I had struggles, the third and fourth semesters. Personal struggles, physical struggles in the third semester, but the overall experience, the cohort, was wonderful. You basically had the same cohort throughout the whole program. Very supportive. All women except for two men, and so it was a good experience. It was. And then the faculty, was very supportive, very supportive.

At the time I interviewed her Maria was the only participant who had already graduated from her program. She told me one of her proudest moments was when she was selected to be the speaker at the hooding ceremony for the graduating cohort. This selection helped her see that while she may not have developed strong relationships with most of her cohort members, they still had a lot of respect for her and her accomplishment.

I was chosen by my cohort. We did a hooding ceremony, the social work cohort did a hooding ceremony in [student union building] and I was chosen by them to be the student speaker at the hooding ceremony. So that I think that even though I didn't feel like I created bonds where we continued our relationship outside of the cohort I realized then that though people may have been uncomfortable around me they saw me differently than what I perceived how they saw me. You know, because they saw me, what I was doing, as getting something done. I did it because it was something I had to do, you know, but I guess there was admiration for me from them, towards me, you know.

I too feel a great deal of admiration for Maria after listening to her experiences as a graduate student. I admire her work ethic, persistence and strength that allowed her to successfully complete her graduate degree even after suffering a traumatic eye injury that resulted in the complete loss of her eyesight halfway through her program. This sudden loss of her eyesight resulted in a number of challenges for Maria, which I explore in the next section.

Challenges

Some of the challenges Maria encountered while in graduate school included a lack of accessibility for the various instructional materials she needed to do her schoolwork, challenges related to formatting, and her difficult relationship with her university's disability services office. Figure 8 provides a visual summary of these challenges, which I will explore in more detail in this section.

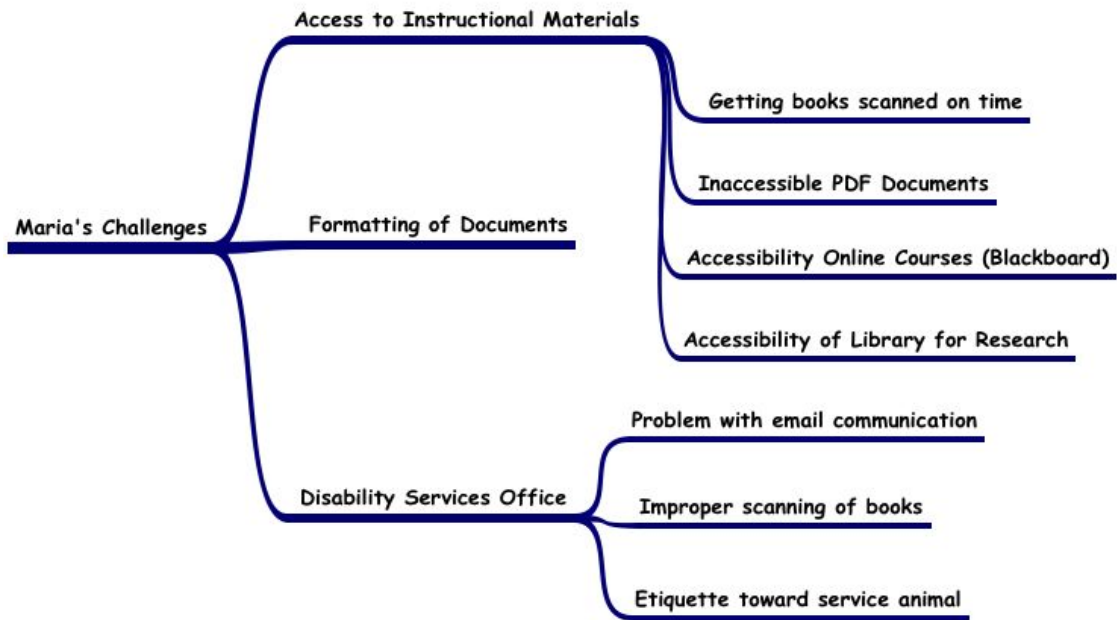


Figure 8. Visual summary of Maria's challenges.

Relationship with disability services. Before her eye injury, Maria received a letter of accommodation from the disability services office at the beginning of each semester. This letter provided information to her instructors on the accommodations Maria was entitled to in her courses. Her injury coincided with the disability service office's transition to a new procedure for requesting accommodations, including a new online system that caused some difficulty for Maria. After struggling to access the online system with her screen reader software, Maria requested to have all communications

from the disability services office go to her personal e-mail address which she knew how to access with her preferred assistive technology. The office of disability services denied her request, claiming it conflicted with university policy. I could tell from Maria's changes in tone and body language when discussing this experience that her relationship with the disability services office had been a major source of frustration for her after her injury.

I'm not sure if it was the third or fourth semester, you had to start getting them [letters of accommodation] online instead of going into the office and getting them. The students with disabilities office was probably the worst office I had to deal with when it came to receiving accommodations when I went totally blind. I struggled with Blackboard and accessing email on Blackboard through [the university website] so I asked them if they would please email me at my Verizon address. All of my instructors had no problem with emailing me to my Verizon address. The students disabled services said it was against their policy to email me outside of the [university] email address.

Maria's primary accommodation through the student disability services office was to get her books scanned into a digital format at the beginning of the semester, but she explained that on at least one occasion her books were scanned with the pages out of order, making them unusable to her. Even when the books were scanned with the pages in the right order, Maria found that the way in which the content was organized sometimes made it difficult for her to understand the content.

The students' disabled services, I didn't get much from them. When they scan textbooks, they don't critique them. So if there are text blocks somewhere else it's

going to blend right in with your main text. It's not separated out, which can be very confusing at times, because all of a sudden you'll be reading something that is dealing with something else than what you're focusing on. It's like sometimes you need to have a split brain to bring it all back together for yourself, if that makes sense.

Aside from the practical issues related to the scanning of her textbooks, Maria also felt the disability services office staff sometimes showed a lack of etiquette toward her as a client with a visual disability. For example, one of the staff often petted Maria's service dog without asking for permission. When I asked Maria if she ever complained about this behavior, she explained that she did not because she worried that doing so might lead to a delay in the scanning of her textbooks.

What I thought was really strange was one staff member every time I walked in there petted my guide dog, every single time. And you know when you go into an office where people deal with disabilities you have an expectation that they should know better than to walk up and pet a service animal. And though I am assertive a lot of the times, I think a lot of people fall into this with disabilities that a lot of times you're not as assertive when somebody is doing something for you even though you really have that right to have that done for you. You're afraid of either repercussions, or that the job won't get done as fast as you need it to get done, you know.

Toombs (1995) described how she was often frustrated when she was not able to express her anger at others' thoughtless behaviors toward her as a person with disability. In Maria's description of this experience with the student disability services office I see a

similar example of a person with a disability who is not able to freely express her frustration with other people's thoughtless actions. I also see an example of how issues of power sometimes come into play when a person with a disability is silenced due to his or her dependence on the services provided by an individual or an organization. As I have gotten to know Maria, I have come to know her as a strong, assertive person who would not normally hesitate to speak up for herself. The fact that she would not speak up in this situation is an example of how Maria's status as a client in her relationship with the disability services office sometimes worked to silence and disempower her as a student with a disability.

Accessibility of instructional materials. Maria experienced a number of issues related to the availability and accessibility of educational materials over the course of her program, and these issues took on more importance following her injury when Maria was more dependent on her assistive technology. Before she could get the office of disability services to scan her books into a more accessible digital format, Maria first had to acquire physical copies of the books she needed for her courses. However, professors did not always place their orders with the college bookstore in a timely fashion, and even when they did Maria still had to wait for approval from the agency that helped pay for the books before the bookstore made them available to her. This process, which Maria described as a "bureaucratic nightmare" for her, often made it difficult for Maria to obtain the books early enough for the disability services office to have them scanned by the beginning of classes. When Maria did get her book orders done ahead of time, the number of books that had to be scanned and the limited resources of the disability services office still resulted in delays with the scanning.

You only have a limited time to get your books and this is a big deal. You have a limited time to get your books, get them scanned and be ready for the first day of class. To get that done is like pulling teeth. You know, I had one teacher one time that I was able to get two books from her before the semester and get them to be scanned weeks ahead of time, you know, during the break, but that's not the reality of things. The reality of things is you get eight to ten books and you need them in two weeks and that office doesn't work that way. They have other people they have to scan for, so that's where the university falls short, in the student being able to get their books without having to pay for them out of their pocket because then you have DBS involved that says they're going to pay for these books. The bookstore doesn't want to get them to you unless somebody is going to pay for them, you know. So it becomes a bureaucratic nightmare to get your textbooks scanned and ready at the beginning of classes.

Aside from the delays in the conversion of her textbooks into a more accessible format, the accessibility of other documents she was required to read was also a problem for Maria. She explained that many professors did not know the correct way to convert scanned documents into an accessible version of the PDF format that could be read by her screen reader. A similar issue impacted her ability to conduct research through the library. Many of the documents she needed for her research were scanned in a way that prevented them from being read by her screen reader.

The other problem I had with accommodations from professors because they didn't understand the OCR (Optical Character Recognition) and the PDF files. So what I would have to do with those is print them out, scan them myself or have

somebody else do that for me. I ended up having to hire a student reader for that, the third semester... There was a problem with that because the professor would scan the documents and save them in PDF but it wouldn't, it read it as a blank document for me. So I would have to print it out and I would have to rescan it.

Both Joshi (2006) and Galdi (2007) cited a lack of accessible educational materials as one of the key barriers for graduate students with visual disabilities. Maria also experienced some of the problems that Joshi (2006) identified as barriers related to a lack of access to research materials. However, Maria was able to find some help that partially addressed these difficulties with research.

I had to use [one of the special libraries on her campus] to do my research for me, because I had a hard time using JAWS to collect research articles and scholarly journals. So I would give them the topic and they would send me a list and then they would pull those articles for me and send them. Some of them I couldn't read, again they were not OCR, and some of them I could...She [the librarian] didn't understand all that. If they were PDF and it read I would keep that one, and if it was PDF and it didn't, JAWS didn't read it to me, then I would send her a note and she would get them in a text file, a Word doc.

Accessibility of online classes. In addition to the lack of accessibility for PDF documents, Maria also could not access the quizzes in her online courses when they were administered through the university's Blackboard content management system. The professor had to come up with an alternative way to administer these quizzes to Maria. While Maria was able to complete the quizzes when they were provided in a Microsoft Word document, she thought this workaround did not provide an equivalent educational

experience to that of her classmates. Maria was frustrated she did not always know if she had the correct answer because she did not get the same kind of feedback as the other students. When they took their practice quizzes online they were able to tell which questions they were getting wrong, which helped them better prepare for the final graded quiz.

Blackboard was my biggest [challenge] because, for instance, in one of my classes you had to take quizzes through Blackboard and it was a timed quiz and I couldn't do it. The teacher had to accommodate for that, but where I fell short, I thought, there is because you could, on Blackboard, take that quiz for practice as many times as you wanted and if you got a question wrong you knew what question you got wrong. What ended up happening with me is I would get the questions in a Word document from my instructor. Basically, I found the answers and by the time it was time to take the quiz I never was able to get it checked out whether that answer was right or wrong. So I didn't have that advantage of knowing if I had answered those questions correctly on being given the quiz questions before you had to take it. And most people took the quiz online, the final quiz that you were graded on, and I got mine the same way [as the practice quizzes]. She would send them to me in a Word doc and I'd send it. I'd fill it out and send it back to her.

Maria also encountered problems with the submission of her assignments through the Blackboard content management system, but another student agreed to help her with this problem by submitting Maria's assignments under her account.

Another student what I would have them do, is for one of my classes we had, it was a virtual, we had several virtual, we went to class but there were like seven classes that were virtual out of this, and so we had to post things on Blackboard. I would send my posts to her in a Word document and she would go into Blackboard and post it for me and she would do it under her account. I didn't give her my access but she would put my name on it so the professor would know it was from me and it was my post. So she would do those posts for me. So that was, you know, something minimal that somebody else could do and I didn't have to pay, because I was limited in my reader hours as well.

Formatting. Maria struggled with the APA formatting required in her program. Difficulties with formatting were another challenge Joshi (2006) also identified in her research with graduate students with visual disabilities. Again, Maria was able to work around this challenge by seeking assistance from a classmate who was able to check the appropriate formatting for her.

The citation page and formatting, making sure my document was formatted correctly, you know, that was one of my challenges. In Word 2007, I wasn't familiar with all the ribbons and those things, so that was a challenge for me... If I wrote a paper, first I'd write part of it, send it to [her husband], and he'd go through it and do any critiques or editing because he's like the grammar man and punctuation man. He got all that. So he'd read it and then after he was done I'd send it to her to look at the formatting.

Empowering Factors

Along with her strong personality, Maria counted on a number of supportive relationships that helped her cope with the challenges she faced in graduate school. These supportive relationships were important empowering factors for Maria, and they are visually represented in figure 9.

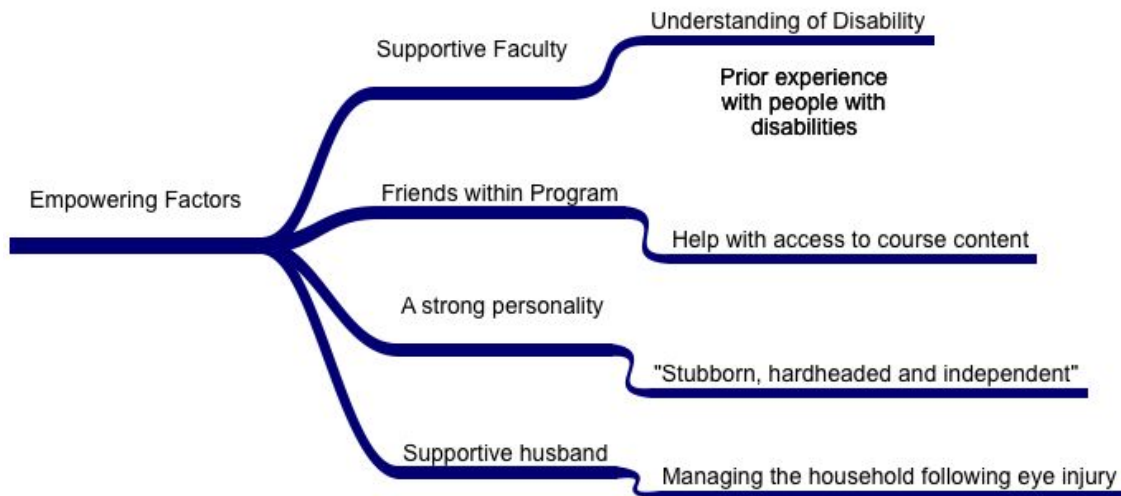


Figure 9. Visual Summary of Maria’s empowering factors.

Support from faculty and classmates. As stated earlier in this chapter, Maria was not close to many of her peers, but a few of them did offer to help her with her schoolwork when they started the program. However, as the cohort moved through the program and the stress started to build, Maria felt uncomfortable asking them to help her on top of their own work. Following her injury, Maria hired one of her classmates as a reader that was paid by the state agency that supports students with disabilities. In addition to the paid reader, Maria also at times relied on the kindness of a few classmates who helped her with retrieving documents and submitting assignments through

Blackboard. These students' help was important because Maria had a limited number of paid reader hours from the state agency.

At first, you know, several people in my cohort were like 'whatever you need, we'll help you out.' But once they got stressed out in the third semester, because we had this big research class where we had to do our own research and create it and do it and do the whole thing, people started freaking out...I hired a reader, someone in my cohort, the older woman, because she needed money. So she would, a lot of times, what she would do was read my project I had to submit to make sure it was in a good format, to basically to look at the format of things...There were like seven classes that were virtual out of this and so we had to post things on Blackboard. I would send my posts to her [a fellow student who was not the paid reader] in a Word document and she would go into Blackboard and post it for me and she would do it under her account. I didn't give her my access but she would put my name on it so the professor would know it was from me and it was my post. So she would do those posts for me...And then there was another woman who would try and help me get things off of Blackboard that the teacher would post up that I wouldn't get and she would send those to me via email. So, she was very helpful with that. And this woman, what was really interesting was that she was the only person that was new to our cohort that semester. So she didn't even know me, but as soon as she found out about the injury and that I was totally blind she just stepped in and said 'let me know and I'll do anything I can for you.'

In addition to a few classmates who helped Maria overcome the access challenges presented by the Blackboard content management system and formatting, there was also a faculty member who played an important supportive role for her. While Maria said most of the faculty in her program were supportive toward her, what made this faculty member stand out was the fact that her husband was a wheelchair user. Maria felt a strong connection to this professor based on a common experience and understanding of the attitudinal barriers people with disabilities and minorities face.

I had one professor, her husband was a paraplegic. She would, she was always checking in with and asking, 'everything ok? is there anything we need to discuss? anything we need to talk about?' We were always communicating via email as well...She really made a point to work with me and check in with me, you know, she was very supportive, but not custodial either. But she would just check in and say 'how are you doing on this,' you know, 'do you need any, anything to help you get through that project?' You know, she and I were I don't, you know, I don't want to say friends because, you know, that wasn't our relationship. However, she knew some of the stereotypes that people dealt with because she was Hispanic and her husband was in a wheelchair, and she dealt with that when she would go somewhere like on a cruise and people would stop her in the hotel thinking that she was one of the housekeepers. And then of course her husband would go with her. She would see things that they wanted to help them with that he didn't need. But there were other things that were available, such as higher beds for her to get him out of the wheelchair and into bed, and

which she couldn't do because he was too heavy for her, you know...So she understood barriers that existed, both structural barriers and attitudinal barriers.

Another person whose help Maria appreciated was her internship supervisor. Maria's program had an internship requirement, and for that experience she was paired with a supervisor who herself had a disability. Maria appreciated the fact that her supervisor shared a similar experience as a person with a disability, even if the two had different disabilities. Furthermore, her supervisor knew about JAWS and was even able to provide some on-the-job instruction in that software when Maria lost her vision following her injury.

What was really cool about my supervisor is she's in a wheelchair. So when she interviewed me I was like 'oh thank god, she'll get it,' you know, at least part of it, you know. Then what I realized about her the third semester, once they did put JAWS on my computer the third semester at the [agency where Maria did her internship] because I didn't have it there the first two. I didn't really need it for what I was doing, and the third semester I did of course, having no vision at all. She came in my office one day and she saw I was trying to figure something out using JAWS and she was instructing me because she could understand JAWS. She had worked in college with a friend who was blind and she helped that person out with reading and things like that. So it was nice that we had that to work with and I had that support.

Maria definitely appreciated the support she received from the faculty and staff in her department, but it was important to her that these relationships not have a "custodial" element to them. By this she meant that she wanted to be treated in a way that valued her

as an independent, capable person. Thus, while Maria appreciated her internship supervisor's willingness to help her with JAWS, she did not agree that she should always accept help, even if she did not need it. It was important for Maria to learn how to do things for herself when she was capable of doing so, rather than always relying on others in those situations.

She was wonderful and accepting of someone with a disability. But there were times when she had a take whatever anyone wants to give you kind of mind. Say, if the office individuals at this place, the administrative staff, wanted to do something for me that I felt I was able to do myself, she was like, 'if they want to do it, let them do it.' Or, you know, 'Have them do it, they can do it for you!' If I couldn't do it, absolutely, I had no problem having them do it for me. However, if it was challenging but I could still do it with some training and, you know, knowledge of how something worked to do it, you know, that's the way I choose to do things.

I can appreciate Maria's thoughts on this topic because I am often the recipient of what she would describe as "custodial" treatment when I travel. While sometimes I may need help when navigating a busy airport I have never visited before, most of the time I can get around just fine with the help of my white cane. However, even when I appear to be orienting myself confidently, people will come up to me and insist on helping me. A few times, the other person has just grabbed me by the arm without asking first. When this happens, I not only feel like my personal space has been violated, but also like my ability to take care of myself in public has come into question. Even the language that is often used in these situations challenges my capabilities as a person with a disability.

Rather than “would you like some assistance?” I am more likely to hear “do you need assistance?” This may seem like a small issue, but I mention it to bring attention to the nuances that should be attended to when providing support to students with disabilities. Despite good intentions, providing help in a way that does not show respect for the person with a disability’s dignity and right to self-determination can do some harm to that person’s self-worth.

Support from husband and friends. Outside of school, Maria relied on her husband and a few close friends for help. After her eye injury, she told her husband if she was to get through the semester “everything in this house is yours.” What she meant was that her husband would have to take care of the cleaning, grocery shopping and other household chores so that she would have more time to focus on her studies. As described in the section on challenges, her husband also often checked Maria’s writing and offered suggestions related to grammar before Maria would send it to her reader, who would check the formatting prior to submitting the assignment. Aside from her husband, there was a friend who lived nearby who on one occasion helped Maria by typing an entire book she needed for school that could not be scanned on time.

One of my friends in [a nearby town], I sent her a textbook because I needed it immediately. I had scanned like a chapter, two chapters, and I mailed it to her Express Mail. She typed the whole book, her and another friend, in a weekend and sent it back. That was only a little book, thank goodness! But still to have somebody physically type that whole book.

Maria’s personality. Maria described herself as “stubborn, hardheaded and independent.” To Maria, it was this stubbornness that had pushed her to complete what

she had started even after the setbacks from her eye injury. However, she recognized that sometimes this stubbornness came across as being rude to other people, and this is something that she wants to work on going forward in her life.

I'm just stubborn and hardheaded and independent. That's me. It's like when I make my mind up to do something, it's going to get done and this was important to get done at that time. So yeah, I think that me being pretty bull-headed and independent had a lot to do with that...A lot of my stubbornness and independence comes in the way of maybe sometimes being rude, and I'm trying to be different about that.

Summary of Maria's Depiction

Even before she suffered her eye injury halfway through her program, Maria already had a significant visual impairment. However, at that time she had enough remaining functional vision that the admissions process and the first few semesters in her program presented few problems for her. The situation changed dramatically following her injury, when a number of challenges arose for Maria that were related to the accessibility of textbooks and other educational materials. With her complete loss of vision after the injury, Maria had to rely more on her screen reader software to access information than before, and this made the accessibility of textbooks and other educational materials more important to her. Maria tried to ensure her textbooks were in an accessible format by having the disability services office scan them into a digital format that could be read aloud by screen reader software. The scanning process took time and professors did not always submit their book orders to the bookstore early enough for it to take place by the beginning of the semester. Even when the books were

scanned on time, the way in which information was organized in the digital version often made the content more difficult to understand for Maria. When the professors themselves scanned the materials for a class, they did not always know how to properly scan them in a way that resulted in an accessible PDF document, and this often resulted in documents that could not be read by the screen reader at all. This was also a problem when it came to the library resources Maria needed in order to conduct her research for assigned projects, though in this regard Maria received help from the library staff to minimize the impact of the lack of access.

Aside from the barriers created when educational materials were not accessible, Maria also encountered a number of problems when taking online classes offered through the Blackboard content management system. In addition to needing some help to download course content and to submit assignments, Maria was not able to complete the online quizzes in one of her courses using her screen reader software. As a workaround, the professor would send her the questions in a Word document to be completed offline and submitted to her via email. However, Maria felt this workaround resulted in a different educational experience for her compared to her classmates, who were able to get additional feedback to help them know areas where they needed to focus their study.

Following her injury, Maria received support from a number of people who helped her with the barriers she encountered. Her husband took over many of the household duties to allow her to have more time to dedicate to her studies, and he also helped with her schoolwork by checking her papers for grammar and style. While Maria was not close to most of her peers, she developed close relationships with two classmates who helped her by downloading course content and posting her assignments on

Blackboard. One of these students also became a paid reader for Maria, and one of her duties was to check Maria's papers for the correct APA formatting required in their program. Formatting was especially difficult for Maria following her injury, when she did not have any functional vision to check for appropriate APA formatting.

One area where Maria felt strongly she had not been supported as well as she could have been was in her relationship with the student disability services office. A key issue in that relationship was a lack of communication, which was made more difficult by the disability service office's unwillingness to send emails to Maria using the preferred account she knew how to access with assistive technology. Aside from the issues with the email communication, the relationship was strained by what Maria felt was a lack of sensitivity and etiquette in the way the staff from the disability services office approached her as a person with a visual disability. One example she provided was that the staff would often pet her service dog even when it was in harness, indicating the dog was on duty and should not be distracted. Even though Maria is a strong person who is not usually afraid to speak up for herself, her status as a client who depended on the disability services office for the scanning of her textbooks prevented her from complaining about the staff's actions. The example Maria provided is a good example of the ways in which power works in small ways to silence students from disability due to their status as clients who depend on university staff for key services.

Overall, Maria viewed her experience as a graduate student in a positive light, and she thought she had been well supported throughout her program by the faculty and staff. She became especially close with one faculty member who had experience with disability because her husband was a wheelchair user. Maria felt comfortable talking to this

professor based on the common understandings of disability they shared, and the two continued to communicate on a regular basis throughout Maria's time in graduate school. The professor would often check in with Maria to see if she needed assistance with her school projects, or just someone to talk to with regard to her experiences in the program. The supervisor Maria was paired with for her internship was also a person with a disability. Though the two did not always see eye to eye regarding when and how to accept help from others, Maria appreciated not only knowing someone with a similar experience, but also the additional training with the JAWS screen reader the supervisor was able to provide.

Along with the help Maria received from her husband, friends, classmates and faculty, her determination and drive to complete her program should not be underestimated as a key factor in helping her succeed in graduate school. As Maria explained, "I'm just stubborn and hardheaded and independent, that's me." Without this stubbornness and inner drive, Maria would have probably been overwhelmed and considered quitting her program in the days following her injury. Her determination caused her to focus and work even harder to prove that she could complete what she started, and her reward for this hard work was being selected as the commencement speaker for her cohort. Even though she did not have many close relationships with her peers, her selection as the commencement speaker was proof of their respect for Maria.

As the one co-researcher who had completed her program at the time of our interviews, Maria often expressed frustration with her inability to find employment following graduation. Whenever we discussed this aspect of Maria's experience, I felt some anxiety about my own prospects for life after graduation. This is a topic that I have

mostly avoided throughout my time in graduate school. According to Toombs (1995), a temporal disruption in which the future becomes problematic may occur with progressive conditions like mine due to the uncertainty inherent in them. Not knowing how long I can count on having my eyesight in the future has made it difficult for me to plan for it at times. I have to admit that the statistics on the high unemployment rate of people with visual disabilities also has added to my anxiety about the future. However, the fact that all three of my co-researchers were able to either find a job, or in Maria's case, start a business has eased my anxiety about the future somewhat. My co-researcher's determination to achieve their goals has thus been a source of inspiration and encouragement to me in that way.

Group Depiction

In keeping with the heuristic process outlined by Moustakas (1990), I will now move from an examination of each individual participant's experiences to a group depiction that explores our shared experiences as graduate students with visual disabilities. This group depiction is told in the first person plural because it also includes my experiences as a co-researcher who has sought to understand my own graduate school experience through this research. I invite you to view this group depiction as a layered work, a group portrait in which diverse and overlapping voices come together to express the different textures found in the group depiction, a new work that captures the key themes found in our shared experiences. Sometimes our individual voices will be in the foreground of this portrait as direct quotes from the interviews and documents are drawn upon to help paint the portrait but these individual voices should be viewed as parts of a whole, simultaneously expressing both the diversity and commonality of our experiences.

Figures 10 and 11 are visual representations of the challenges we encountered as graduate students with visual disabilities, and the empowering factors that helped us meet those challenges.

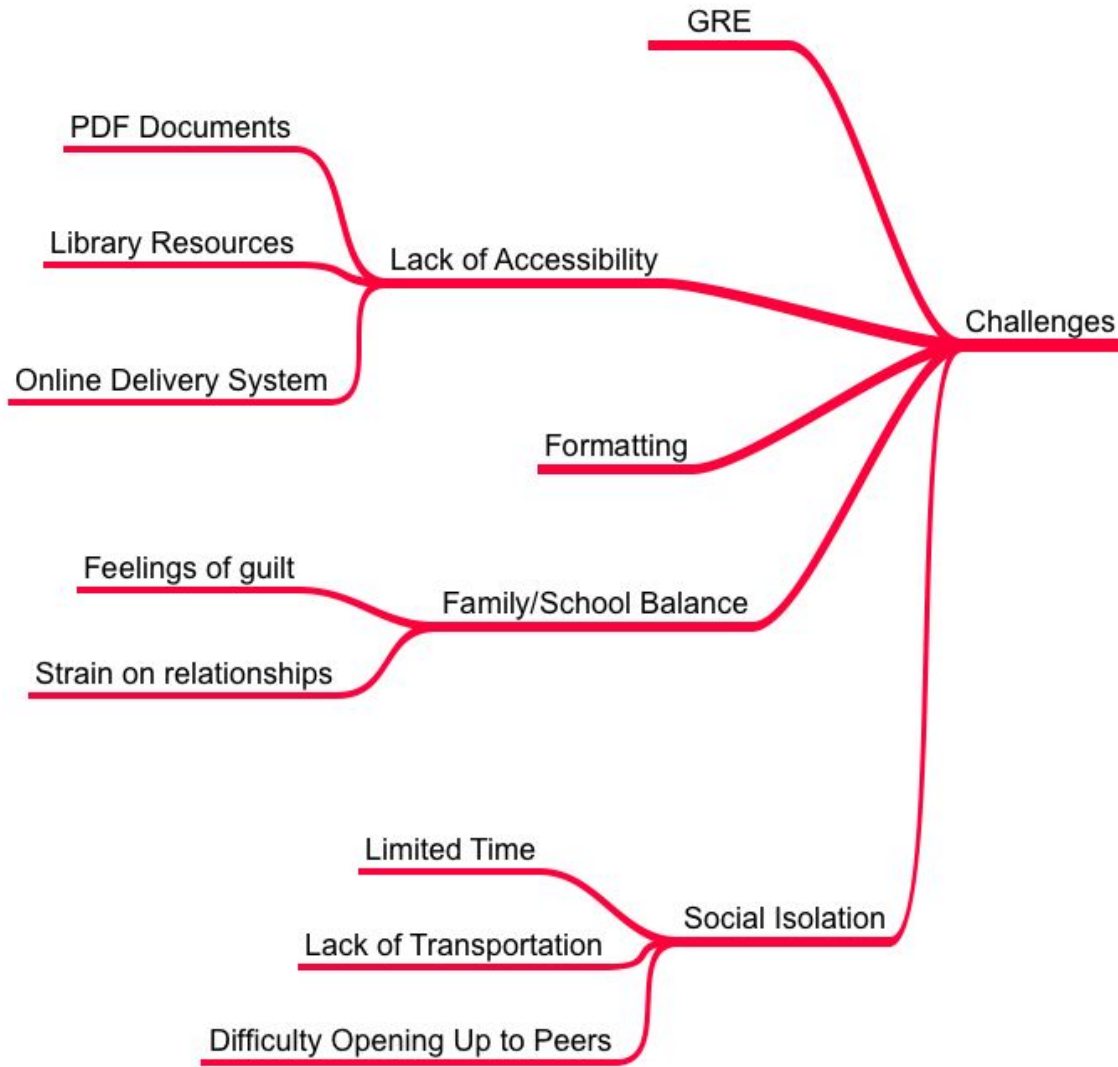


Figure 10. Visual summary of our challenges.

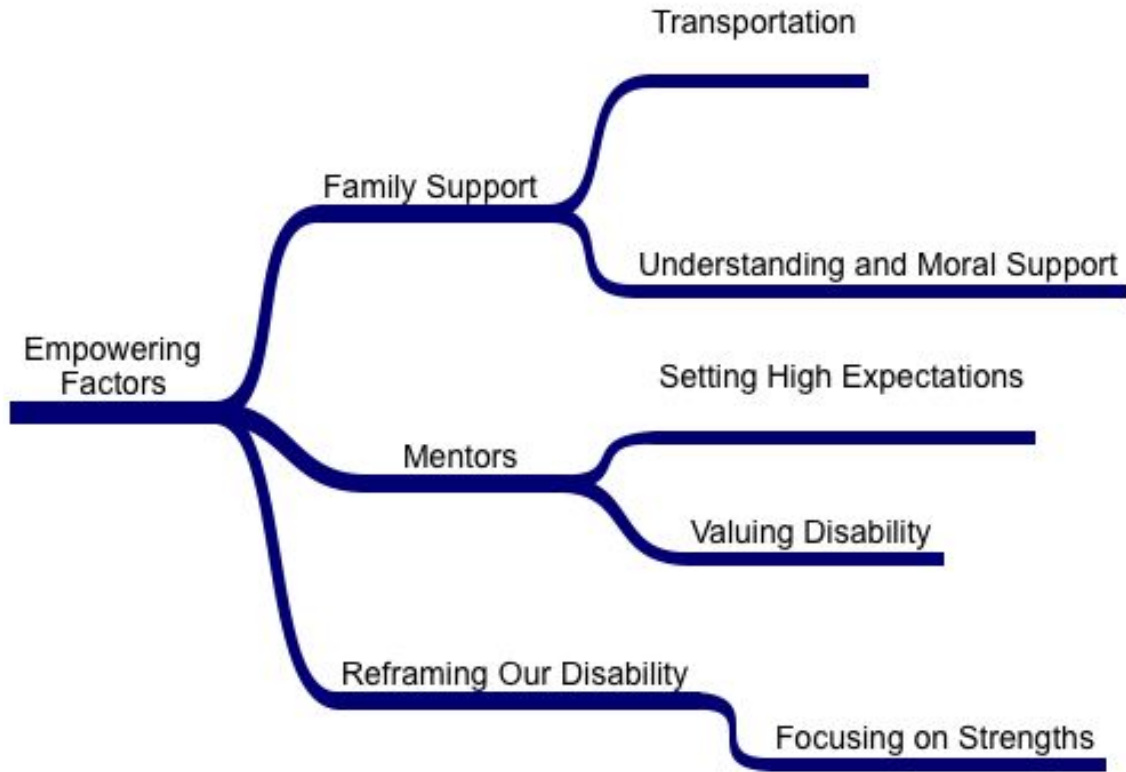


Figure 11. Visual summary of our empowering factors.

Our journey as graduate students with visual disabilities begins before we even set foot on campus to start our programs, when we first decide to pursue graduate studies and complete the requirements for admission. The Graduate Record Examination (GRE) is one of those requirements, and depending on the amount of remaining vision we have and our level of comfort with technology, we may need different types of accommodations for the test. Regardless of the accommodation we need, we view the GRE as the first big hurdle or obstacle that stands in the way of our goals.

It was a challenge to take the test, the GRE, because I had to make a special application. Like a big request of the ETS people to take the test as a paper test. I didn't want to take the test on a computer. It was a pain! (Michael)

The biggest first hurdle for me was the GRE. The GRE to me was a very difficult task. When I found out that they were just going to do it paper-based, I said ‘no, I’ll just take it on the computer.’ And when I came in I figured out a way to enlarge the font on the screen and then I just used it on the computer. So that was the first thing, just worrying about it for me. (Sarah)

Once we have successfully enrolled in our respective programs, those of us who rely on assistive technology discover that many of the instructional materials for our courses are not accessible with the assistive technologies we have learned over the years, such as our screen reader software. Many of the websites we need to visit to conduct our research often lack basic accessibility features, and when professors scan required readings into PDF documents they often do so in a way that makes those documents inaccessible to us. The lack of accessibility for PDF documents is also a barrier when we need to do research that involves downloading documents from the library.

With JAWS, I mean, to do web research for me is a real pain because of the content and because it’s confusing to me. Like I’ll look at something and not realize you have to click here to see more or to go deeper into an issue or a topic. The way it’s designed, the way it’s presented, because it seems a lot of web material is kind of hidden in the background. (Michael)

I had to use [one of the special libraries on her campus] to do my research for me, because I had a hard time using JAWS to collect research articles and scholarly journals. So I would give them the topic and they would send me a list and then they would pull those articles for me and send them, and some of them I couldn’t read. Again, they were not OCR, and some of them I could....The other problem I

had with accommodations was from professors, because they didn't understand the OCR (Optical Character Recognition) and the PDF files. So what I would have to do with those is print them out, scan them myself or have somebody else do that for me. I ended up having to hire a student reader for that, the third semester. (Maria)

Aside from the instructional materials themselves, the content management system used at the university presents a number of accessibility barriers for those of us who rely on assistive technology, especially when it is used to deliver online courses. To get around this challenge, we often have to rely on other people (family members or friends) to retrieve information and post assignments for us in the content management system.

It has been a little bit of a barrier you know. I depend on my wife to help me with Blackboard a lot. (Michael)

Blackboard was my biggest [challenge] because, for instance, one of my classes you had to take quizzes through Blackboard and it was a timed quiz and I couldn't do it... One of my classes we had, it was a virtual class, and so we had to post things on Blackboard. I would send my posts to her [a classmate] in a Word document and she would go into Blackboard and post it for me.

We also often have difficulty with the correct formatting of our documents, and this is another area where we often have to ask for assistance.

The citation page and formatting, making sure my document was formatted correctly, you know, that was one of my challenges. (Maria)

The editors of the journals that I work with if I tell them that I have a disability and if, you know, if they could double-check it for me after they've sent me confirmation that they're going to publish the article. They will go through and do that for you, really quickly too, because what I've learned again, is it's easy for them, but it's not easy for me. (Sarah)

A number of supportive relationships allow us to meet the challenges we encounter as graduate students. Our husbands, wives, parents and siblings support us by not only helping with our transportation needs, but also by helping us stay motivated and showing their moral support and understanding of the demands of our programs.

She [his wife] has been very supportive as far as helping me with time management, helping me stay motivated, helping with doing research at times to write a paper, to do web research. There is literally no way I could have gotten through this graduate program, or the undergrad program, but especially this graduate program, without her help, her assistance, her support. (Michael)

Definitely my mom, my mom, without her I wouldn't be here everyday and she definitely makes where I have to go a priority in her life... My mom, even to this day, she always said as long as you're striving for something bigger than yourself I will be there to support you throughout it. (Sarah)

I told my husband that was it. I said if I am going to get through this semester everything in this house is yours. You have to do the cleaning, you have to do the cooking, you have to do the grocery shopping, you have to do everything because all my time is going to be spent on schoolwork, and it was. And he did, to the best of his ability. (Maria)

Despite the support and understanding our loved ones show us, we still struggle with balancing family needs and the demands of our programs. Sometimes we worry about the strain our focus on our academic work might place on our relationships, while at other times we feel guilty when we take time away from our studies to spend it with our families.

Having to put in so much extra time to get the studying done, to be prepared, to not look foolish, all those things have definitely cut into my time with my wife and son during graduate school. Sometimes I think I allowed it, but it was a necessity. It was truly a necessity to achieve you know some academic success. You know not that academic success is more important than my family but academic success is important right now to be able to complete this program to do well in my day to day job interview like I feel like I've been doing and just have some personal satisfaction. (Michael)

I think that graduate school and relationships is difficult in itself, but when you have a visual disability and you're in graduate school and you're in a relationship, I think it makes it ten times more difficult... When you're in graduate school, it takes a lot out of your life. I mean there's things that you wish you could do with your children or with your husband or your significant other that you can't necessarily do, but if you were able to take a break, jump in your car, go do something and come back, or, you know, you were able to get yourself around, I think it would be a lot easier. (Sarah)

If I was doing anything but schoolwork I felt guilty, because it just, you know, it just seemed like that's what I had to do to pass and get through and get done, you know, and get it accomplished. (Maria)

In addition to our families and the support they provide to us outside of school, we also look to our major professors and other advisors within our programs for mentoring and support. We are empowered when these key individuals within our programs hold us to the same high standards as other students and at the same time acknowledge and value our visual disabilities.

It helped me with that boldness, the fact that Dr. M was very accepting of my challenge, my visual challenge, my disability. He was very accepting and you know he told me, he said, 'you know, I don't want you to try and fake it and mainstream'... Certain elements helped me. Certain elements being the support of the directors, the leadership of the program, and the faculty. Certain elements I think helped me with the graduate program with, to be more confident and willing to allow myself to be vulnerable as a graduate student. (Michael)

The thing that I always liked about him is he never treated me like I had a disability, meaning that he's always had held me to 150% of the standard. Like if everybody else was like turning in an assignment he would be like 'ok Sarah, this assignment is an A, but is it publishable?'...Treating me always, never treating me as a disabled person. I think it's the biggest, you know, it's the biggest contribution that he's made to my program, and always holding me to a higher standard than a person, what would you call them, 'able'? (Sarah)

Outside of our academic programs, the support we receive from the university is mainly in the form of accommodations provided through an office of disability services. While most of us come to rely on these accommodations at one time or another during our graduate studies, in general our interactions with that office are limited by a number of factors. One is our desire to be independent and do as much as we can without assistance as we struggle to understand and accept our disabilities. Another is that as we get to know our professors better we find that reaching out to them individually often results in us receiving the accommodations we need without the need to involve the student disability services office.

As far as student disability services, I am a very independent person...And part of that independence comes from you know still after almost 30 yrs. of having this legally blind situation in my life I still, you know, try to fake it and still try you get by acting like you know I don't have, I'm not legally blind...My relationship with student disability services has been very limited in my college career and mostly, you know, because I have limited that relationship. (Michael)

I used it my entire masters. I used the student disability services, but for my doctoral program I really didn't use it because I know my professors more on an individual basis now, so I just tell them what I need. (Sarah)

Socially, our engagement with the university community is also limited. While we develop close relationships with a few of our classmates, overall we see ourselves as being socially isolated from the rest of our peers, as a "fifth wheel" (Michael) or as someone who "walks alone." (Sarah)

I don't know, it's like I definitely have been a fifth wheel in this cohort and I have definitely been banned on an island and don't know why exactly. I've really tried to, you know, fit in and to, you know, reach out also. I went and helped a guy move. And it just hasn't really clicked... Mostly because of my disability, and the reason for that is because I think they're just unsure, unsure about, you know, what I can and can't do. (Michael)

I've always found that in my program I feel alone in that sense and so that identity I feel I connect more with outside my university. Like if I go to conferences like the National Federation of the blind or something I feel more at home or I don't know how to say it, at peace with my identity as a visually impaired person there. But I feel everywhere else I always feel lonely. I feel like, as a minority woman, I'm, you know, I feel like I have comrades so to speak, but in this program as a person with a disability, with a visual disability, I've always felt alone. (Sarah)

It became strained the third semester when I lost my vision. That was an interesting experience, actually. But the first two semesters it was good... Students who I went to school with for two semesters couldn't talk to me anymore. They just acted like I didn't exist. (Maria)

A number of factors contribute to the distance we often feel exists between our peers and us. One of the most significant is the general lack of time we experience due to the extra effort required for us to complete our schoolwork as a result of our visual disabilities. Another is our limited access to transportation, which makes it difficult for us to participate in some of the social activities that would allow us to get to know our peers better and establish stronger relationships with them.

While we were in school we didn't do a whole lot outside. Some of them did, some of them went to Busch Gardens, things like that, but for me I was just focused on getting stuff done. Being that it took longer for me to do it, I really didn't have any free time. The free time I had was for my husband and my grandchild and my daughter, and my mother. (Maria)

I think when you get into graduate school people are working and doing their own thing. So they'll come from work and meet up with other classmates or whatever some place and if you're a person who doesn't drive in [her city] it's difficult for you to get to those places. And a lot of times, because you don't drive unless they can give you a ride, they don't really even mention it to you, you know. So when I first came in, I was really by myself. I felt like I was in a cohort of one. (Sarah)

Aside from the more practical factors related to a lack of time or our limited access to transportation, another factor that may contribute to our social isolation is the fact that we often find it difficult to speak about our visual disabilities openly with our peers, because in some cases we are still not comfortable with our own disabilities.

Honestly, deep down I don't mind sharing my visual situation with others. It's just getting to that point that is very awkward and a burden for me... You know, I'm not comfortable enough to come right out and say, 'Hey, by the way, my name's Michael and I'm legally blind and when I look at you I can't tell if you have a mustache,' and all these things and that's a little bit too aggressive for me and I just don't want to put that information out there. (Michael)

I used to, it always used to be a fear of mine, to tell my students that I have a visual disability or to tell my colleagues because then a lot of times people start treating me differently, and I didn't like that. I didn't like people to treat me like, you know, you tell them you have a visual disability and they want to treat you like your legs are broken or something. (Sarah)

Even if we are not always comfortable with being perceived as a person with a disability, over time we find a way to reframe our visual disabilities for ourselves in a way that is more empowering to us. Some of the ways in which we attempt to do this reframing include emphasizing the positive aspects of our disability, and changing our perspective through the use of metaphors that help to drive us toward accomplishing our goals and remind us of the support we have available.

I use my visual disability a lot of times to help open doors for me... You feel that it's a disadvantage, but it's an advantage, because it helps people pay attention to what you're doing. I tell people 'oh, and I'm legally blind' and that piques their interest. So like 'oh you did this, and you're legally blind.' So sometimes use your disability. Use it as, you know, to make more things, you know, available to you that may not have been necessarily. Yeah, use it as an asset instead of a deficiency. (Sarah)

I said, 'Dr. M., for me this graduate program is going to be like swimming across the ocean from North America to Europe. Swimming all the way across the Atlantic and, you know, when you try and do a swim, a trans-Atlantic swim like that, you need to have a support team such as my wife and son and my friends here on campus'... I told him, I said 'that's how I want to approach this graduate

program, like I'm swimming across the Atlantic from America to Britain.' I told him, 'I'm going to keep swimming.' (Michael)

As we come to understand our visual disabilities differently, we also come to realize that the best way to ensure our needs are met and we are successful as graduate students is to speak up and advocate for ourselves. Thus, we stop trying to hide and remain in the background, but instead become more assertive in asking for what we need to succeed.

I've been hiding. I've been visually impaired since 18 and I'm 43 now. So, you know, for 25 years, I've been hiding. Doing the best that I can to hide that I don't see well...But as a graduate student with a visual disability, you cannot go under the radar. As far as accomplishment I think, not trying to keep myself under the radar as a graduate student has really been rewarding. (Michael)

If you're not proactive, you'll get left in the dust in grad school. People really expect other people to continue holding their hands and they don't. You know, even though my major professor helped me a lot, I hunted him down a lot, like literally standing outside of his office pacing back and forth waiting on him, you know, because I knew that I needed help. I think that's the biggest thing, advocating for yourself. (Sarah)

Overall, we think the graduate school experience has been one of the most difficult challenges we have encountered in our lives, but also one of the most rewarding accomplishments, one that has transformed us into far more confident people than we were when we started our programs.

I'm a totally different person than I was when I first came in. Leaving with my Ph.D. I feel like I'm a lot more self-sufficient. I mean prior to when I came in I would have never thought that I would be looking at programs to move to as a faculty member...I've applied to Seattle, New York, Maryland, other places. I even applied to a place in Dubai but before I wouldn't have done that. I would have been scared, you know, to move to those places, but now I'm like, you know, with all the things that I've done in this program I can do anything. (Sarah)

This program has been good for me in that way. It's helped me to become more confident about not hiding so much. (Michael)

Individual Portrait

After the group depiction, the heuristic researcher selects one co-researcher for an in-depth portrait. Rather than selecting one person who is representative of the entire group, for this portrait I have selected the co-researcher whose experience most closely matches my own. I have followed this course of action for two reasons: the diversity of the group and the small number of participants makes it difficult to find one student who exemplifies our group as a whole, and selecting a person whose experience closely matches my own is in keeping with the heuristic research requirement of remaining close to the internal frame of reference.

The participant I have selected for this portrait is Sarah. In addition to the fact that we were the only two co-researchers who were pursuing doctoral degrees at the time of the interviews, Sarah and I share a number of similarities in our backgrounds. We are both people of color who lived in other countries for much of our childhood, me in my native country of the Dominican Republic, Sarah in the many locations where her father

was stationed as a member of the military. From kindergarten to twelfth grade, she attended 14 different schools due to her family's frequent moves as his father got reassigned to new posts. According to Sarah, because her father was in the military for 21 years after she was born, the military lifestyle was all she knew growing up. To be sure, there are also some differences between Sarah and I. I am divorced and she is married, and while we are both parents, my daughter is close to becoming a teenager and Sarah has younger children. We are also a decade apart in age. However, I feel that our common experience as doctoral students means there is more that unites us in a common experience than separates us. The ease with which we were able to communicate, even though we had not met prior to this research, was to me good evidence of that common bond we shared.

When I first met Sarah the thing that impressed me the most about her was her drive and ambition. As I got to know her better she became an inspiration and a role model to me, especially since she was able to accomplish the goal I was aiming for and graduated with her doctorate just as my data collection was coming to an end. According to Sarah, her drive came from her family, who had high expectations for her growing up and encouraged her to do her best in whatever path she chose in life. Her father had once told her

Be the best, and if you're a dog catcher, you better be the number one dog catcher. If you're a garbage man, you better be the best at what you do. You take pride in what you do and, you know, my parents never treated me as if I had a disability.

Sarah and her brother, who is also legally blind, were encouraged by their parents to “do things that were beyond our vision.” As an example, she related an experience from high school. Despite the fact that most of the time she could not see the rifles when they were thrown at her as part of the drills, she joined her brother as members of the number one high school drill team in the nation.

There were a couple of times that the person that was about ten feet in front of me that was flipping the weapon behind their back to me, there's a couple of times when it hit me in my head. I didn't see it until it got too close. But I started learning how to hold my hands out in front of me, because my drill sergeant was like ‘don't flinch, don't move, because if it's coming you'll mess up, just let it hit you’...It was scary because the team was number one. My brother and I, we both wanted to be number one, and we worked and worked until we were able to do those things, you know, beyond our vision.

Sarah's drive and ambition, which she said came from her parents, were evident when she first decided to pursue her doctorate. At the time, she had just given birth to her second child and also had a toddler at home but she wanted to continue in her job as a guidance counselor at a local school while also pursuing full-time doctoral studies. Her mother, who provided most of her transportation, eventually convinced Sarah that she had to make a choice, and Sarah decided to leave her job to enroll in her doctoral program as a full-time student. As a doctoral student, Sarah had six peer-reviewed publications to her credit, and she had done more than 60 presentations at state, regional and national conferences. She had also taken an active role in several professional organizations in her field, serving as president in a couple at the state level and as a

student representative to a national one. Sarah accomplished all of this despite her heavy course load, which averaged 17 to 18 credits each semester (nine is the usual number of credits for a full-time graduate student) while also teaching three courses. She also had a consulting practice and met with patients at least two days a week.

A downside to Sarah's hectic schedule is that she had put aside some of her hobbies and other outside interests. She explained that at the start of graduate school she had been in a band that performed on weekends and she even travelled for performances. However, she promised her husband that she would focus on school to try to get her degree as soon as possible, and she stopped performing after her second year in graduate school. Sarah missed singing and performing, as she found it to be a good stress reliever for her. She had also stopped exercising on a regular basis, even though she felt exercising made her feel more grounded. Aside from her schoolwork, Sarah's other focus was her family.

Sarah, her husband, and her two children were living with her parents when I interviewed her. While Sarah and her husband had planned to move out before she graduated from the doctoral program, her mother had convinced them to stay longer. She probably appreciated having Sarah and her grandchildren around while she faced the difficult task of caring for Sarah's father, who is now in the mid to late stages of Alzheimer's disease. Sarah described her father's illness as a big blow to her family. From the way she spoke about him, I could tell Sarah missed seeing the strong person her father had been prior to being diagnosed with his illness. Sarah explained that he had been a chief in the Air Force and was considered among the top one percent of all non-commissioned officers in that branch of the military. He had once told Sarah that he

always got straight As in school, all the way from elementary school through college. Like her father, Sarah had an outstanding academic record. She had completed her coursework for the Ph.D. with an almost perfect 3.98 grade point average.

Sarah's dissertation research focused on bullying prevention, a topic that was important to her because she had been bullied herself as a child. For the first few years she was in school, Sarah had attended all white private schools where as a person with albinism she found it relatively easy to "blend in," but this changed when she moved to a public school setting for middle school. She wrote "throughout middle school I was a victim of constant bullying. I welcomed anyone who was willing to be my friend, however I did not have many."

According to Sarah, she had found it difficult to understand where she fit in culturally because of her status as a person with albinism and her visual disability. She stated that her understanding of how her culture differed from that of her peers was delayed because she was not able to see other people's racial features with her limited vision. Sarah was aware that other people stared at her and her brother, who is also a person with albinism, but it was not until a painful incident that she began to realize her difference from the rest of her peers. This incident involved her hair.

I had a friend in the middle school I attended who was of African-American and German descent. She had the most beautiful hair. I wanted to have my hair weaved as well, but at the time no one sold hair extensions in my color. I asked my mom to weave black hair in my head. I looked horrible. However, my mom let me ride around the neighborhood with the braids in my hair and waited for the kids in the neighborhood to tell me how horrible it looked. I ran inside and begged

for it to be taken out. I felt out of place and as if I did not belong to any culture at all.

Complicating things for Sarah was the fact that she comes from a bi-cultural family and does not look like the rest of her family members. As a person with albinism, Sarah is light skinned and has light hair even though she comes from an African American and Trinidadian family. Her mother is from Trinidad and Tobago and her father, who is African American, is from Georgia. However, Sarah explained that she did not grow up knowing her African American relatives in Georgia because she rarely visited with them. She spent a lot more time with her Trinidadian relatives, and was more familiar with their foods and customs. She had been able to avoid the issue of race growing up because most people have a difficult time identifying her race.

Growing up in the military, primarily in base housing, also helped Sarah avoid the issue of race. She told me that “it wasn’t like you’re Army and you’re black, or you’re Air Force and you’re white, it was Air Force, Army, Navy, Marines, and that was that.” However, Sarah remembers one incident that brought her face-to-face with the issue of race: while living in Germany one of the other children called her brother and her the N word. According to Sarah, that incident stayed with her for a long time, and it eventually forced her to start exploring her cultural identity by learning more about African American and Trinidadian history and culture. She considers herself a work a progress as far as her cultural and racial identity goes, but she thinks she is becoming more comfortable in her own skin as time passes.

Along with her growing understanding of her cultural racial identity, another area where Sarah had made significant strides was with her self-esteem. Given Sarah’s

academic achievements and her projection of self-assuredness when I met her, it surprised me to hear that she had struggled with self-esteem for much of her life. As an adult, much of her struggle with self-confidence and self-esteem centered around the appearance of her eyes to others. As a result of her nystagmus, Sarah's eyes can have uncontrolled movements, and she worried that other people would be focused on her eyes rather than her, especially during the interviews that are part of her work as a counselor. After realizing that most of the time her clients did not notice her eye movements as much as she thought they did, Sarah started to understand that much of her struggle was internal to her, and that she had to "check herself" and realize that she could either be her own worst enemy or make her disability something that propelled her forward. For Sarah, this meant a change of perspective with regard to her disability, and starting to see it more as an asset that made her interesting and unique, rather than as a deficiency that held her back.

Overall, Sarah had found the experience of graduate school to be empowering for her and she said, "when I first came into the program I was a totally different person than I am now... for my Master's and now leaving with Ph. D. I feel like I'm a lot more self-sufficient." Sarah explained that when she started the program she lived on campus, in part so that she would not impose too much of a burden on her mother (with her need for transportation) but also because she was afraid that she would not be able to do well in school if she did not live on campus. However, by the end of her program she described herself as a lot more independent and she told me that she never thought when she started her program that someday she would be applying for faculty jobs in places as far away as Seattle, New York, Maryland and even Dubai:

Before I wouldn't have done that, I would have been scared, but now I'm like you know with all the things I have done in this program I can do anything. It's just that I may have to do it in a different way, but I can do it.

I was happy to find out through her major professor that Sarah had in fact accepted a position as a faculty member at a university in Dubai. Although I am sure the move to another country will be an adjustment for Sarah and her family, I am confident that she will do well in her new job. Throughout this research project, Sarah served as a role model to me and seeing how dedicated she was motivated me to keep going and complete this dissertation. Her determination and work ethic inspired me, and I'm happy to count her as a friend I will stay in touch with despite the distance that now separates us.

Creative Synthesis

In keeping with the methodology of heuristic research, I have allowed the following poem to emerge from my own experience of working with the data. Much of this poem came to me one morning while I was in a half-awake and half-asleep state. It was a weekday morning and I had just woken up before the alarm. As I lay there in this half-asleep, half awake state, I started to think about the many times in my life where I have had to navigate boundaries, first as an immigrant coming to this country as a child, then as I started to lose my eyesight. The following poem aims to capture those experiences, and those of my fellow co-researchers, as we learn to live between and betwixt the worlds of the sighted and the blind.

In addition to the poem, I have composed a photo (figure 12) that visually explores the ideas presented in the poem. As I have continued to lose more of my

eyesight, photography has remained an important creative outlet for me. To me it is not only a means of self-expression, but also a way to make a political statement. My hope is that when people see me holding a camera in public, it forces them to challenge pre-conceived ideas they may have about people with visual disabilities and what we are capable of doing with the right technology and supports.

Entre/Between



Figure 12. Self-portrait.

Neither here nor there
Neither blind nor sighted
I see you, but not all of you
You see me, but not all of me

Ni aquí, ni allá
The islands, the city, the country
Español, Spanglish, English
Y hoy, ¿quién soy?
Hay, ¿quién sabe?

So I learn to live in between
In and out of the shadows
And as the light turns to dark
And the darkness comes to life
I've learned to just dance
Just dance in those shadows
Tap, tap, tap
Tap, tap, tap
Tap, tap, tap

Chapter Five:

Discussion

The purpose of this heuristic research study was to describe and explain the graduate school experiences of a selected group of graduate students who have visual disabilities in order to help me better understand my own experiences and identity as a graduate student with a visual disability. In addition to helping me understand my lived experience better, I also chose to pursue this research with the goal of providing insights that will be helpful to not only other students in a similar situation but also faculty and staff who work to support those students in their pursuit of a graduate education. In addressing these dual purposes, the following exploratory questions guided this study:

1. How do I, as a student with a visual disability, perceive and describe my social and academic experiences in graduate school?
2. How do other graduate students who have visual disabilities perceive and describe their social and academic experiences in graduate school?
3. What barriers and challenges do we as graduate students with visual disabilities encounter in graduate school?
4. What factors empower us as students with visual disabilities to achieve success in graduate school?

In chapter four, I focused primarily on questions 2-4 as I presented the data I collected from a series of three interviews with each of the three purposefully selected co-

researchers, related documents they shared with me, interview notes, and my reflections in a researcher reflective journal. I immersed myself in each co-researcher's data for some time and when I thought I had reached a natural stopping point where I had a holistic understanding of their data I prepared an individual depiction of each co-researcher's experiences as a graduate student with a visual disability. This individual depiction aimed at providing each student with a voice, and thus included extensive verbatim excerpts from the interview transcripts. After I had verification from the co-researchers that the individual depictions accurately and comprehensively represented their experiences as graduate students with visual disabilities, I entered into another period of immersion with all of the individual depictions, my researcher reflective journal and other notes. I then sought to develop a group depiction that included me as another participant and represented our shared experiences as graduate students with visual disabilities. In keeping with heuristic research methods, I followed this group depiction with the creation of an exemplary portrait of one of the co-researchers.

In selecting that co-researcher for the portrait, I sought to bring the study back to the autobiographic frame of reference that led me to pursue this research in the first place. I tried to do this by selecting the co-researcher whose experience had the most in common with my own. This participant turned out to be Sarah, the only co-researcher who like me was not only a doctoral student, but also a person of color with the experience of growing up across different cultures. I concluded chapter four with a creative synthesis, in the form of a poem and a photo, that captures my best understanding of my experiences as a graduate student with a visual disability who has lived in between and betwixt the worlds of the blind and the sighted. In this chapter, I

continue my exploration of the impact of this research on my self-understanding as a person with a disability, then turn to the social implications of the research and suggest some directions for future research in this area of study.

Impact on the Researcher

Writing as process. As I conducted this research study I kept a researcher reflective journal to help me think about the impact of this research on my own life as a person with a visual disability. This researcher reflexive journal was valuable tool for helping me put into words some of the feelings and thoughts I had as I conducted the study. I also found it to be a helpful analytical tool. Van Manen (1990) stated that writing is the method of what he called human science research, because it helps to externalize what has been internal as we put our thoughts down on paper. He added that to do justice to the fullness and ambiguity of our experiences also requires re-writing, a going back and forth in which we look at life experience at various levels of questioning. To incorporate these ideas into my research, I followed the advice of one of my committee members who suggested that I plan to write for at least two hours each day. This routine was different from the way I had written in the past, where I would go for long periods without writing and then have a corresponding period of intense, focused writing. However, as I continued to practice my writing habit, it became a regular part of my daily life. Even on days when not many words flowed onto the page, I found that sitting down to write moved me into the reflective stance that is needed for this kind of in-depth, personal research. Many of the thoughts that had their genesis during these writing sessions would end up coming back into my consciousness at a later time in a more developed form. Thus, I found that regular writing and re-writing in my researcher

reflexive journal, which I maintained as a file on my computer, was a helpful tool for working through the personal issues I wanted to explore through this research study.

Revisiting the past. As valuable as my research journal was for helping me explore my own experiences with visual disability, it was a question from one my students that finally got through all of my defenses and really pushed me to think about what my disability means to me. The class I have taught as a graduate student focuses on narrative and exceptionality and throughout each semester I have tried to bring in a number of guest speakers to share their experiences living with a disability. I have continued to bring in these speakers because students tell me in the course evaluations and in their journals that these presentations have had a significant impact on their understanding of disability. One of those speakers was a friend of mine who used to be a soldier and who suffered serious injuries, including the loss of his vision, as a result of a rocket attack during the war in Iraq. He spoke candidly with the students about his experiences, including the dark moments during his recovery when he had become addicted to pain killers and the long road back to recovery from his many injuries.

Shortly after the presentation, as we debriefed and engaged in some discussion, one of the students asked me a question that caught me by surprise. “Mr. Perez, what has been the darkest time you have experienced with your disability?” he asked. Nobody had asked me such a pointed question before, and I must admit that it caught me off guard. As I started to answer the question I found myself unable to speak as I could feel a number of emotions come to the surface. I had to take a deep breath and ask the student if I could get back to him in a few minutes, hoping that would give me a few minutes to collect

myself before providing an answer. The class discussion continued as usual, then once I had gathered myself and built up the courage, I finally started to answer the question.

The most difficult time I have experienced was shortly after I had started my Master's degree here at [current university]. I had just found out the previous year that I had retinitis pigmentosa, the condition that was causing me to slowly lose my vision. Finding out that I had RP had influenced my decision to return to school, since it was likely that I would not be able to continue doing job as the condition progressed and my vision loss got worse. Well, shortly after my wife at the time and I moved to Florida for school, the marriage fell apart and my wife moved out of our apartment with my daughter, who was just four years old at the time. The end of my marriage plunged me into a prolonged depression and my darkest moment came when I found myself sitting in the middle of an empty apartment wondering about my reason for living. That was the darkest time of my life. I felt like I had nothing left to live for, and as I considered my options I am grateful that I had my daughter, even if we would no longer live together.

Thinking about her is the reason I'm here with you today.

Now it was the students' turn to be caught off guard. I don't think they expected such an honest response, and frankly neither did I. After a brief moment of silence we moved on to the next topic on our schedule for the night, but the question and my response stayed with me over the following days. A few days later I had that "aha" moment that often occurs with heuristic study. I was taking a shower and out of nowhere I just started crying. I couldn't understand where this was coming from, but I just went with it. I felt a release of emotion, as if a weight had finally been lifted from my

shoulders. Once I had an opportunity to reflect on it in my journal I began to understand how I had associated my disability with loss as a result of the experiences I had lived through during my divorce.

Whenever I began to think about my disability and its personal meaning, I also thought about losing my family. I realized that I had never had an opportunity to grieve that loss. Despite my depression following the breakup of my marriage, I had to pick up the pieces and keep going with my schoolwork and other responsibilities. I did receive therapy at the time, but I did not feel that either of the two therapists I saw had the level of empathy with my experience that I needed at the time, and I discontinued the therapy after just a few visits and tried to move on with my life. I moved from one assignment to the next until I had finally completed my coursework for both the Master's and the doctorate.

Aside from my therapists, my bout with depression is not an experience I have ever discussed with anybody else. At first I was not sure if I would include it in this dissertation due to the public nature of this document. However, after much reflection on the matter I decided that I had a responsibility to share both the darker aspects of my experience as well as its more positive ones. If just one student out there in a similar situation reads this and learns that it is possible to overcome whatever challenges he or she is facing in order to enjoy a better life, then I think it will have been worth it to take the personal risk and put myself in such a vulnerable position in this document.

I knew going into this study that it would force me to revisit experiences I would rather avoid, but I feel that paying attention to the darker aspects of my experience was something I needed to do to further my growth as both a scholar with an interest in

disabilities studies and as person who lives with a disability. As a result of doing this research, I feel that I have experienced a catharsis that has allowed me to break through the hold past negative experiences had on my life. While I may have arrived at a similar stage in my personal development even if I had not chosen to pursue this research, I believe that the conversations I had with my participants during our interviews paved the way for me to start to finally open up about my disability at a deeper level. Seeing the way in which they shared their life experiences with me in such an honest way encouraged me to be more transparent to both others and myself when it comes to my life experience and my feelings about my disability.

My position within the disability community. Along with helping me reach a point where I had the courage to examine the meaning of my disability in a more honest way, this research study has allowed me to explore my position within the disability community as a person who lives between two different worlds, those of the sighted and the blind. At around the same time that I was conducting the last of the interviews for this study, I had the opportunity to be a guest speaker for a event hosted by the Foundation Fighting Blindness (FFB), an organization that promotes medical research on vision loss. I was invited to the event in my role as an Apple Distinguished Educator, so that I could share some of the new technologies that are available to people with vision loss who use iPads and other mobile devices. The presentation went well, but I was most excited by the people I met as a result of attending the event. On my return home, I remember mentioning to my class the next time we met that “I had finally found my people.” By this I meant that I had finally met people who were at about the same point of their journey with vision loss because they were not completely blind but like me still had

some functional vision. Along with the people I met at the event, I was introduced to a number of groups on Facebook where I started to communicate with others who have a similar experience. I enjoyed this correspondence and found it to be a great source of helpful information on how to live with vision loss.

Over the next few months, I attended other FFB events in my home city, and even invited Michael to come with me to two of them. One of these was an information session with a medical doctor who explained the latest advances in retina research, the other a walk to raise awareness and funds for vision loss research. While I greatly enjoyed the positive energy I felt at some of these events and how welcoming the people I met were, something was just not quite right for me. Much of the talk at these events focused on “finding a cure” and “ending vision loss.” I didn’t know why these terms bothered me so much until I came across an excerpt from a speech by Norman Kunc, a disability rights advocate who has cerebral palsy. In the film *Including Samuel*, which I showed to my class, Kunc states that if there were a pill that could instantly “cure” him of his disability he is not so sure he would take it, because his disability is such an integral part of who he is that taking it away would call into question his identity as a person. As he put it, “we are the product of our history.” By this I don’t think he means that our past determines our future, but rather that our experiences all have played a role in shaping who we are as people. Kunc’s message resonated with me because it put into words the discomfort I felt whenever I heard people say that they wanted to “cure” me of my disability. After living with retinitis pigmentosa for more than a decade, this disability is an important and integral part of my identity. Kunc’s words helped me realize just how far I have come in terms of accepting my disability.

Reframing my liminal status as a person with a disability. In gaining a better acceptance of my disability, I was helped by listening to the different ways in which some of the other participants in this study found ways to reframe their disabilities into a positive aspect of their lives. For Sarah, this meant thinking about her disability during times of success instead of only during times of crisis. It also meant acknowledging that her disability could be an asset rather than a deficiency, something that helped her stand out from other doctoral students and made other people pay attention to her and her work. As Sarah said, our disability is something that makes us interesting and unique. One example is my work as an Apple Distinguished Educator, which often calls for me to travel to different cities to do presentations on how technology can have a positive impact on the lives of people with disabilities. As a speaker, I have been told that I come across as being authentic and sincere in what I say, and the reason for that is that I often mention my own experiences during my presentations. While other speakers can talk about the tools and how they could be utilized to improve access, I often speak about how I use them myself to help me do the things that I want to do, whether that be doing my academic work or just taking a photo (one of my favorite hobbies).

Part of accepting my identity as a person with a visual disability has also been accepting my status as a liminal being, one who lives in the boundaries between different identities. I must admit that at the beginning of this study I was hoping that there would be some kind of resolution for me at the end of this study, that I would somehow be clearer on where I stood with regard to my place along the continuum of visual disability. If there has been a big change, it has been in how I approach this issue of identity. I no longer feel the need to have a resolution to my undefined status, but instead see my

ability to cross boundaries as a personal strength that has allowed me to make the most of some of the experiences that I have had in my life. One example of this was when I first came to this country as a child. I had to negotiate boundaries on a daily basis between the traditional culture and Spanish language of my Dominican family, and the popular culture and English language of my school. A few years later, I again negotiated boundaries between the culture of the boarding school in suburban Philadelphia I attended on a scholarship, and that of my relatives and friends back home in New York City. Over the course of this research, I started to think about those experiences more, and to consider the similarities that they have with the kind of boundary crossing that I engage in today. Examining these other life experiences I have had has made me appreciate the resilience and determination that it took to navigate the many obstacles that were placed in front of me as I strove for a better life for myself in this country through education. I plan to continue to focus on those traits as a source of strength to allow me to navigate any obstacles I may encounter once I graduate with my doctorate and pursue employment. I still see myself as a work a progress when it comes to my identity, but at least I am more comfortable in my own skin than I was at the beginning of this study.

Disability and boundary crossing. One area I still struggle with is with the intersection of my disability with my cultural background. The concept of disability is not well understood or accepted within my Dominican family, and this often makes it difficult for me to communicate with my parents and other relatives about my experiences with vision loss. Although I know they are all well intentioned in their concern for my well being, I am frequently offended by the paternalistic attitude I sense

from them. The conversations are also made difficult by the fact that I have made few visits back home since I started graduate school, and my relatives do not really get to see how I manage to live with my disability on a daily basis. Someday I hope that we can come to a better mutual understanding, and this could be another focus for my advocacy efforts, but for now it is another kind of boundary crossing I will need to continue to perform. I just have to remind myself that I have done it successfully before, when I came to this country and when I went away to boarding school, and can do it again in the future.

I see my ability to perform boundary crossing not only as a personal asset that has helped me adapt to a number of different situations over the course of my life, but also as an opportunity to improve communication between people with diverse perspectives in the blind community. When it comes to vision loss, I have experienced firsthand that sometimes the groups that represent people with visual disabilities do not communicate or work well with each other. As a member of several of these organizations, I hope that I can encourage them to include the unique perspectives of people like me in their future outreach efforts. Toward this end, I will continue to attend the meetings of the Foundation Fighting Blindness and encourage them to focus not only on the medical research, but also on outreach that involves people with vision loss sharing strategies and tools (including technology) that have allowed them to be successful in their approach to day-to-day life with vision loss. I was encouraged to see an FFB member lead a presentation on the impact of physical activity in her life at a recent meeting I attended, and I hope to do a similar presentation in the future that focuses on how technology has impacted my life in a positive way. My hope is that presentations like these will not only

provide practical advice to others who are in a similar situation, but also continue to build a network of people with visual disabilities we can turn to for support and advice.

I also plan to continue to be active with the National Federation of the Blind and other national advocacy groups for the blind community in the U.S. While these groups do great work in the policy arena to promote greater rights for Americans who are blind, I have not always felt included when I attended their meetings. The focus at these meetings was primarily on the concerns of those who are completely blind, and while I understand that this is these groups' primary constituency, the blind community continues to become more diverse. In addition to those who have been blind from birth, the blind community also now includes many soldiers who are returning from war with eye injuries, as well as older Americans who are dealing with vision loss from chronic illnesses such as diabetes. In many cases these injuries or illnesses lead to complete vision loss, but there is usually a period when the person with the injury or illness either still has some functional vision and/or has to emotionally cope with the loss they have just experienced. I will continue to advocate for organizations such as the NFB to be more inclusive of all people who live with vision loss, not just those who are completely blind.

Becoming an advocate. I believe doing this research has made me a better advocate by allowing me to address some of the inner tensions that in the past made it difficult for me to speak about my own experiences in public. Recently, I addressed an audience of about one thousand people and shared how technology has allowed me to continue to do my work as a graduate student with a visual disability. Doing such a presentation would have been unthinkable for me just a few years ago. Not only would I have had the natural nervousness that comes from presenting to such a large group, but I

would have probably not been able to even get through the presentation without being overcome by my emotions. For this presentation, I believe I was able to find just the right tone. Yes, I did find myself tearing up at times, especially toward the end, but I was able to keep my composure while also speaking with authenticity about my experiences. In the days following the event, I heard from many of the attendees that my presentation had a significant impact on them.

As I sat on the plane on my way back from the presentation, I could not help but think about how far I had come in my own personal growth over the last couple of years. I looked back with pride at the courage that it had taken me to decide to go forward with this research knowing that it would force me to revisit difficult experiences from my life. I was also thankful for the other co-researchers whose example encouraged me to look at my disability with a newfound honesty that has allowed me to move forward in my life while at the same time acknowledging the rich life experience that has shaped and will continue to shape my identity as a person with a visual disability living in between and betwixt the worlds of the blind and the sighted.

Key Findings

Along with allowing me to further explore my identity as a person with a visual disability, I chose to pursue this line of research with the goal of providing insight to not only future graduate students with visual disabilities but also practitioners who can impact the lives of those students. This includes not only faculty, but also staff in disability service offices, advisors and other university personnel who are responsible for supporting these students to make sure they have a successful academic and social

experience in graduate school. In that spirit, I present the following key findings that emerged from my analysis of the interview transcripts and other data from this study.

Empowering Factors

Personal characteristics of the students. Some of the personal characteristics Galdi (2007) cited in her study of graduate students with visual disabilities were important to my co-researchers' success in graduate school. This included their perseverance and resilience in the face of the barriers they encountered in graduate school. Maria described herself as "just stubborn and hardheaded and independent," and she added "that's me, it's like when I make my mind up to do something, it's going to get done." This determination and resilience helped Maria continue with her studies even after the complete loss of her eyesight as a result of a serious eye injury. Similarly, Sarah said that "someone telling me that I can't do something, it's always made me want to do it more." Michael also focused on persistence with the metaphor he shared with me, where he is swimming across the ocean and just has to "keep swimming" until he accomplishes his goals. I too recognize this drive to achieve in myself (some would call it stubbornness) as one of the factors that has kept me going throughout the long journey of doctoral studies. When there have been setbacks (like having a paper I submitted to a journal be rejected, or not receiving the grade I expected on an assignment), it has made me want to work harder to prove my abilities. While at times it may have resulted in us placing a lot of pressure on ourselves, I believe our ability to persist in the face of challenges and turn negative experiences into a source of motivation was a key contributor to our success as graduate students with visual disabilities.

Along with their persistence and resilience, my co-researchers also showed the kind of resourcefulness Galdi (2007) cited as an important personal characteristic for success in graduate school if you are a student with a visual disability. For example, Sarah had found ways to acquire accessible educational materials by contacting publishers directly and relying on her dual role as a student and instructor to secure more accessible digital copies of her books. Likewise, Michael had developed his own system for preparing to deliver the presentations that caused him so much anxiety when he started his program.

Along with the personal characteristics of persistence, resilience and resourcefulness exhibited by my co-researchers, the idea of “reframing” in relation to their disabilities was an important empowering factor for them. This idea of reframing the disability into a positive was best captured by Sarah when she said she often found she had to “check herself.” By this she meant she had learned to reframe how she viewed her disability as an asset rather than as something that held her back. In Michael’s case, his professors and advisors encouraged him to view his disability as an asset by emphasizing the unique perspective he brought to the program. This idea of reframing was one of the most valuable takeaways for me from this research. As I interacted with my co-researchers over time, their persistence, resourcefulness and ability to reframe the challenges they faced into a source of motivation continued to inspire me in my own quest to complete my doctorate.

Supportive relationships. Confirming what Galdi (2007) reported in her research, the three participants in this study discussed a number of supportive relationships that were important to their success as graduate students with visual

disabilities. These included relationships not only with close family members such as parents and spouses, but also with major professors and other staff within the students' departments. Michael compared the support network around him to a "support boat" when he used the metaphor of swimming across the ocean to describe what his journey through graduate school felt like to him. His wife not only provided his transportation to and from school, but she also helped him type many of his papers early on in his Master's program and continued to help him with his challenges accessing the Blackboard content management system. Within his program, two important relationships were those with his program's coordinator and with a professor who encouraged him to be more bold and to not hide his disability.

For Sarah, her mother not only provided most of her transportation, but also pushed Sarah to strive for excellence in everything she did. Her major professor also held Sarah to a high standard while at the same time addressing her needs as a person with a visual disability in small but important ways, such as by attending conference presentations with her. In Maria's case, her husband "took over the household" after her injury and allowed her to focus on her schoolwork so that she could complete her program on time. The support she received from a faculty member and her internship supervisor, both of whom had experience with disability, was also important to Maria. The internship supervisor helped Maria with learning how to use the JAWS software on her computer, and the faculty member maintained ongoing communication with Maria to see if she needed assistance with school projects and other aspects of her studies. However, in both cases what Maria valued most in the relationship was working with someone who understood some of the barriers and challenges faced by someone with a

disability. This suggests that pairing graduate students with visual disabilities with mentors who themselves have disabilities (or experience with disability) could be a good way to make sure these students feel supported as they pursue their graduate education.

My own experience has been somewhat different from my co-researchers when it comes to the role of my family in my experience as a graduate student. Although I know they are proud of my accomplishments, my parents and relatives have watched mostly from a distance as I have pursued first my Master's degree and then my doctorate. My experience is unique in that I left home at the age of sixteen to attend a boarding school and have been on my own since. For the most part, my parents have not been too closely involved with my educational pursuits since that time. At the beginning of my graduate school experience, I also went through a divorce. Thus, for much of the time I have been in graduate school, I have been living alone. By living close to school, I have been able to work around the issue of transportation. My unique experience notwithstanding, the importance of supportive relationships from family members and key people within the student's program emerged as the most consistent theme throughout the study. The other participants emphatically agreed that these supportive relationships were key to allowing them to achieve success in graduate school.

Barriers and Challenges

Access to instructional materials. The inaccessibility of instructional materials is a factor that both Galdi (2007) and Joshi (2006) reported as one of the key barriers for graduate students with disabilities. This includes not only access to printed materials but also access to online classes and library resources for research. In this study, access to instructional materials was a significant barrier for Maria and Michael, but not so much

for Sarah and I. Maria experienced difficulty getting her textbooks scanned on time for the beginning of her courses. She also noted that when some of her professors scanned documents to make them available online through the course management system, these documents were not accessible to her with the JAWS screen reader. The reason for this lack of accessibility was that her professors often did not know how to properly scan the documents with the option for adding Optical Character Recognition (OCR) to the text. As a result, each page of the documents was scanned as an image that could not be described by Maria's screen reader. The only solution for her was to print out the documents and re-scan them properly to make them accessible to her screen reader. This extra step took up a significant amount of time for Maria that she could have spent actually learning the material. Maria had a similar problem with access to the content in PDF documents she needed to do her research through the library.

Along with the accessibility of PDF documents, the accessibility of the online course management system was another concern for Maria, the one participant with the most experience with online courses. Despite the fact that Maria was an experienced user of the JAWS screen reader, she encountered difficulty with the online quizzes that were required in one of her online courses. In that case, the professor found a workaround that allowed Maria to complete the quizzes offline, but Maria did not feel that she had an equivalent educational experience to that of her sighted classmates. For example, she did not receive the same immediate feedback her sighted classmates received when they took the quiz online, and according to Maria this prevented her from accurately discerning her understanding of the material covered in the course.

For Michael, the issue of access had two components to it. One was his lagging technology skills, which sometimes limited his ability to use the content management system or conduct online research without assistance from his wife or a friend. The other was the way in which content was designed in a way that made it incompatible with his screen reader, an issue that was also reported by Maria. This was especially a problem for some of the specialized applications that are used in his field, and which Michael would need to know well for his career in higher education.

Sarah and I, on the other hand, encountered fewer access problems in relation to instructional materials. This was most likely due to the fact that as doctoral students we were experienced students who had over time come up with ways to get around the access challenges we had encountered. This was the case when Sarah found a way to use her status as a graduate student instructor to acquire digital versions of the textbooks directly from the publisher. Both of us are also proficient with the built-in technologies of our Apple devices, including the built-in magnification feature. Our level of vision loss is also not as pronounced as Michael's or Maria's. Thus, the issue of access needs to be considered not only in the context of the student's level of vision loss, but also in the context of their ability to use new technologies to overcome access challenges. In this study, access challenges had more of an impact for the students who had more advanced vision loss and those who relied on screen readers for access, but less of an impact for those of us who had less advanced vision loss or relied on technologies such as magnification. The length of time that we had been in graduate school, which was significantly longer for the two of us who were doctoral students, also played a role in our ability to navigate access challenges related to instructional materials.

Social isolation. The graduate students who participated in this study described the social alienation they felt in a number of different ways: Michael referred to it as feeling like “a fifth wheel” in his cohort, Sarah described it as “walking alone”, and Maria said her relationships with her peers were “severed” after her injury and complete loss of her vision. Likewise, if I had to use a word to describe my own experience as a graduate student, it would be “lonely.” With each of us, there was one trusted peer that we relied on not only for academic support but also for our most significant interpersonal interactions. Outside of that trusted individual, there was not much interaction with the rest of our cohort members and other peers.

A number of factors contributed to our feelings of social isolation. For those of us who lived a significant distance away from the university, access to transportation appears to have played a role in contributing to our perceived social isolation. According to Nichols and Quaye (2009), the social engagement of students with disabilities may be hampered by inadequate transportation and long commute times that may prevent them from participating in out-of-class activities and joining student organizations. Among the participants in this study, only Michael and I were active participants in the social life of our university, primarily by joining student organizations. I lived within walking distance of the university, and Michael only had a short commute.

However, it was not just the practical issue of transportation that worked to limit our social engagement at our university. Another factor was the difficulty some of us, especially those of us with less visible disabilities, had with discussing our disabilities openly with others. For Michael, the disclosure of his disability to his peers was something he avoided because he already felt he was different from them because of his

age and status as a non-traditional student. He did not want to highlight his difference further by introducing his disability into the mix. Similarly, Sarah did not initially want to disclose her disability because she did not want people to treat her differently because of it. The issue of disclosure was not as important to Maria and I because we have more visible indicators of our disability (in my case a white cane and in hers a guide dog) that make it more difficult for us to hide that aspect of our identities.

As Nichols and Quaye (2009) note, as students with disabilities we must overcome our own internal attitudes about our disabilities before meaningful social connections with our peers can be established. When we are uncomfortable or anxious about the disclosure of our disabilities, we may avoid social situations where the topic is likely to come up in conversation, thus limiting our interactions with peers and our opportunities to develop meaningful social relationships with them. This issue of social isolation not only has implications for the quality of life we experience as graduate students, but also for our ability to do our best academic work. A great example of this was when Michael took initiative to reach out to some of his classmates to participate in a study group for his comprehensive exam. According to Michael, the collaboration with peers he had rarely interacted with up to that point was helpful in filling in some of the gaps he had in his preparation for the exam. Such opportunities for collaboration should not occur toward the end of our graduate programs, but should be the rule throughout our graduate school experiences.

The role of institutional support

The level of interaction with the disability services office varied among the participants in this study. The Master's students were more likely to rely on the office's

services, while the interaction was more limited among the doctoral students. Michael received a letter of accommodation from the disability services office that permitted him to record lectures and to bring his CCTV to class. Aside from receiving the letter of accommodation, however, his relationship with the office of disability services was limited. He attributed his decision to limit the relationship to his struggle with accepting his disability and his desire to appear as independent as possible. Maria, on the other hand, interacted with the disability services a lot more, but the nature of that interaction was not always positive. According to Maria, her interaction with the disability services office was strained by a disagreement over how the office would handle e-mail communication with her, as well as by the delays she encountered with the scanning of her textbooks. What would seem like a small issue to others, the inappropriate petting of her guide dog by disability services staff, also left a lasting impression on Maria that influenced her perception of the office and its staff in a negative way.

For Sarah and I, the two doctoral students, our interactions with the disability services office became more limited as we progressed in graduate school. Sarah said she relied on some of the services offered by the disability services office as a Master's student, but as a doctoral student she knew her professors much better and instead worked with them on a case-by-case basis to find accommodations that addressed her needs. Throughout my Master's program I too received a letter of accommodation, and early on in my doctoral program the disability services staff scanned one of my textbooks into a PDF document I received on a CD. However, as I progressed in my program and my courses were based more around independent research, the accommodations did not really address my needs, and I stopped registering with the office at the beginning of each

semester. Like Sarah, I worked with individual faculty members to address whatever needs I had in their courses. In this way, we both found ways to get what we needed to successfully do our best work as graduate students, even when the provided accommodations did not address our specific needs.

Implications for Practice

Need for improved accessibility. As an assistive technology professional, I strongly believe in the potential of emerging technologies for having a positive impact in the lives of people with disabilities. I have witnessed firsthand how these technologies can empower individuals with disabilities by providing them with access to information that would not have been possible just a few years ago. However, there is another side to the gains in accessibility we have experienced in recent years. It is easy to mistakenly assume that students with disabilities no longer encounter significant accessibility problems just because the devices themselves now include more accessibility features. The reality is that the accessibility features of newer devices can only work to their full potential when the content students need to access with them is also accessible. Based on the data I reviewed for this study, this appears to be an area where more work needs to be done to improve access.

The accessibility of digital materials such as PDF documents will become more important as colleges and universities continue their transition to the online world. According to the Campus Computing Project's 2010 Managing Online Education Survey, 91% of the 183 surveyed two- and four-year colleges reported an increase in online enrollment the previous three years (2007-2010) and 96% expected an increase over the following three years (2011-2013) (Campus Computing Project, 2010). For students with

disabilities, online education can provide a number of advantages when it is provided in an accessible manner. For example, it can lessen the impact of limited transportation options by allowing these students to take most of their coursework from home. However, for online education to reach its full potential for students with disabilities, including those with visual disabilities, a more coordinated effort needs to be undertaken to ensure professors and other staff are following accessibility best practices. The same Campus Computing Project survey found that many of the surveyed institutions had no formal policies or procedures to assure that their online courses and programs are compliant with legal mandates such as the Americans with Disabilities Act. Almost a fifth (17%) of the respondents reported having no institutional policy or procedure for ADA compliance at all, and only one in six of the survey respondents (16 percent) indicated that their institution had a central office that examines each course for ADA compliance. When there was a policy in place, ADA compliance for online courses resided with either with the academic department (24%) or with individual faculty members (34%).

It has been my experience that most faculty are well-intentioned and would like to find a way to properly accommodate the needs of all their students. There have only been a few cases where I have heard from other students with disabilities that a faculty member actually refused to provide a requested accommodation. The problem is that many faculty members do not know how to provide an appropriate accommodation when it comes to digital content and online learning environments. Training in accessibility practices for online content was probably not provided as part of their preparation to teach in higher education (especially for tenured faculty that have been teaching for a

longer period of time), and it is not always provided as part of the professional development opportunities available for current faculty. Improving the accessibility of digital materials and online learning environments will require a more coordinated effort involving not only the office of student disability services, but also the faculty support infrastructure many universities have created to promote the transition to online learning. As a graduate teaching assistant, I was able to attend an event where staff from the office of student disability services and the group in charge of faculty professional development at my university sat side by side and discussed accessibility challenges and possible solutions. This is a positive step toward facilitating the exchange of valuable information on accessibility best practices and techniques that will have an impact on the academic lives of students with disabilities, but the conversation should not be limited to these infrequent events. Rather, there should be an infrastructure in place that facilitates ongoing collaboration around a common goal of academic success for all students.

Rethinking the accommodations process. Students with disabilities themselves could play a valuable role in helping faculty develop their awareness of accessibility barriers and their knowledge of possible solutions. A great opportunity for starting a meaningful collaboration in this area exists at the beginning of each semester, when the student discusses the need for an accommodation with his or her professor. My own experience has been that the faculty member will read the boiler plate statement from the university included in the syllabus, the student will present a letter of accommodation at the end of the first class, the faculty member will sign it, and that will be the end of the conversation. The accommodation letter will also usually suggest general accommodations that do not always address the specific needs of the student for a given

course. For example, the letter of accommodation I received from the office of student disabilities services stated that I should receive all materials in large print because I have low vision. However, large print makes reading more difficult for someone with a disability like mine that affects peripheral vision. In that case, the letter of accommodation actually introduced an additional barrier for me.

It would be much better if faculty were instead encouraged to meet individually with students with disabilities to discuss needed accommodations, like one of Michael's professors did. At that point, the faculty member would have an opportunity to ask more in-depth questions about the student's specific needs than would be possible at the end of class when many other students also have questions about the course and time is limited. This would also allow the student to discuss his or her disability and specific needs in a more private setting. The emotional impact of making the request on the student should not be underestimated. Many students may still not yet be at a place where they feel comfortable discussing the disability with others. Moving the discussion to a setting where the student may feel more comfortable could result in a more open exchange between the faculty and the student. This was the case with Michael. When a faculty member asked him to visit with her in her office after the first class, the two were able to work through Michael's reluctance to bring his CCTV to class.

My thoughts on the role of the accommodation letter were also shaped by a conversation I had with Maria's husband, who is himself blind and an advocate for the blind community. As he stated, the letter of accommodation in its current form actually takes the power away from the student and places it on the document itself, and by extension on the office of disability studies. While such letters of accommodation are

necessary to remind faculty of the important legal responsibilities they have for providing access to students, they could be worded in such a way that it promotes the individual student's ability to advocate for him or herself. Thus, the letter could be written in a way that makes it a more flexible document by presenting some broad responsibilities of each party and then encouraging both the student and the individual faculty member to work together to resolve the specific accessibility issues that arise in a given course. Worded in such a way, the document would not only address the specific needs of the student, but also promote the kind of collaboration that would offer the faculty member an opportunity to learn more about both specific disabilities and the accessibility techniques needed to address the needs of the students who have them.

As part of a rethinking of accommodations, an effort should also be made to take into consideration the unique and diverse needs of graduate students. Many of the accommodations provided by the office of disability services, such as extra time for testing, do not necessarily apply to graduate students in more advanced courses that focus on independent research and rely on projects and papers as opposed to tests for assessment. In this study, there was a difference in the level of interaction with the disability services office between the Master's level students (Michael and Maria) and those pursuing doctorates (Sarah and I). Whereas Maria relied on the disability services office to scan her textbooks, and Michael took advantage of accommodations such as extra time for testing and being allowed to record lectures and bring his CCTV to class, Sarah and I made little use of the disability services office as doctorate students. Much of our work as doctoral students involved reading journal articles that professors often make available through the university's content management system, or conducting research

that involved library databases and other online resources. In both cases, we would benefit more from a more coordinated effort to educate faculty and library staff on how to make these kinds of materials we need to do our research more accessible. Such an effort should include a number of different stakeholders, with the office of disability services and the ADA coordinator taking the lead, but working closely with information services, the library, and individual departments to ensure broader accessibility in the entire university's digital infrastructure.

Promoting social engagement. As the one student who was pursuing a degree in student affairs, Michael had some excellent suggestions for how to improve the social engagement and integration of graduate students with visual disabilities at their universities. One of these was for universities to make an effort to retain their students with visual disabilities when they decide to continue their education. I agree with Michael that it helps when the student remains at the same university for the Master's or doctoral degree. The student would not only already know the campus well, but also be more likely to already have developed a number of supportive relationships with faculty and staff. In this study, Maria was the only participant who was enrolled at a different university from the one where she received her previous degree. All of us who were at the same university for our Master's or doctoral degrees stated that it was helpful in allowing us to make a smooth transition to our new academic programs. Just knowing where things were located on campus helped reduce the anxiety some of us felt when we first arrived at our university, and lessening this anxiety with mobility and orientation can be an important first step toward making us feel more comfortable with the campus so that we are more willing to participate in its social life.

As Michael suggested, if it is not possible to attend the same university (the desired degree may not be offered), the student should attend one of the orientation programs offered at his or her new university. As part of the admissions process, the university should undertake efforts to ensure students with visual disabilities know these programs are available to them, and encourage them to participate wherever possible. These programs can not only help familiarize the student with his or her new environment, but they can also provide opportunities for the student who has the visual disability to develop meaningful relationships with non-disabled peers in an environment that is free of the academic pressures encountered during the academic year.

In addition to orientation programs, the university should also support the creation of student organizations started by students with disabilities themselves. At our university, Michael has taken a leadership role of working with the disability services office to create a new student group that meets on a regular basis to not only educate the university community about disability related topics but also to provide a forum where students with disabilities can come together to get to know and support each other. For most of my time as a graduate student at my current university, I was the only person with a visual disability I knew. I wish it had not taken my pursuit of this research, toward the end of my time in graduate school, to finally meet other students who were in a similar situation to mine. Through my conversations with my co-researchers in this study, I have learned a number of tips that have made my life as a person with a visual disability better. An example was when Maria told me about a bus route I did not know existed, one that now allows me to get somewhere I want to travel to independently. The support we as graduate students with visual disabilities can offer each other is valuable, and the

university should do more to make sure we have the resources and support we need to come together to share that advice with each other.

Delimitations and Recommendations for Future Research

As Stake (1995) has stated, case study research is not sampling research, and “the real business of case study is particularization, not generalization” (Stake, 1995, 8). Thus, the aim of this research was not to describe and explain the experiences of graduate students with visual disabilities as a population, but rather to examine the experiences of a selected group of graduate students with visual disabilities within a given context. Based on my interpretation of the information the student participants provided, it is up to the reader to decide if the findings and conclusions presented in this document are applicable to his or her own context. To help the reader with this determination, I provide some additional information in this section about the setting where this research took place and the participants.

Institutional culture. The university where the student participants pursued their degrees is a large public university located in the outskirts of a major urban area of the southeastern United States. The university has an enrollment of approximately 41,000 students, and it has a strong commuter culture because the majority of students live off campus. The experiences of a selected group of graduate students with visual disabilities may differ at a smaller university or college with a strong residential focus. In that setting, a lack of access to transportation may not be a significant barrier to social engagement if most of the students live on campus and can more easily participate in social activities as a result. The same could be said of a university or college located in another part of the U.S. where public transportation is more readily available (such as by

subway or light rail rather than just by bus or taxi). As part of a larger team of researchers, I could conduct a study that compares the experiences of students at different types of institutions, including both smaller residential colleges and larger commuter universities. This study could provide valuable insights for helping graduate students with visual disabilities better determine which setting would be best for accommodating their needs. A similar comparative study could examine regional differences in the experiences of graduate students with visual disabilities. Again, the insights gained from such a comparison may help graduate students with visual disabilities better determine the best place to pursue their graduate degrees.

Non-traditional status of co-researchers. While the student participants were a diverse group with regard to age, racial identification, and the type of degree (Master's level or doctoral), it should be noted that all of us were non-traditional students. A group of younger students entering graduate school immediately or soon after completing their undergraduate degrees may report having a different experience from this study's participants. Such students, who are considered part of the millennial generation, may have more familiarity with technology than the students I interviewed for this research. While this does not necessarily mean that the younger students would be more proficient with assistive technology, having a level of comfort with technology could make it easier for these students to develop said proficiency in order to overcome barriers to accessibility presented by the move to digital materials and online education. Since none of the participants in this study were of traditional age, it was not possible for me to verify this assumption.

Focus on social sciences. In addition to our non-traditional age, almost all of the student participants in this study were pursuing degrees in the field of education. The one exception was Maria, who was pursuing a Master's degree in social work. The experiences of graduate students with visual disabilities may differ in fields such as engineering or the sciences, where there is a more of an emphasis on the visual representation of information. Graduate students with visual disabilities in those fields may encounter additional accessibility barriers related to the use of inaccessible diagrams, charts and other images that are essential to the understanding of course content. A study that looks at the differences between the different fields of study for graduate students with visual disabilities could provide valuable insights to help these students better plan their career paths.

Focus on successful students. This study also does not include the perspectives of students with visual disabilities who dropped out of their graduate programs. At the start of this research I hoped to include some students with this experience as participants because I thought they could provide valuable information related to the barriers that kept them from completing their degrees. However, finding these students was made difficult by the fact that many of them may no longer be connected to the support infrastructure I relied on for recruiting the participants for this study (such as the disability services office at my university and the local agency that provides assistance to students with visual disabilities). Given more time, I might be able to find at least one student with this experience through other informal networks (including through social media channels). With the small window I had to complete the data collection for this dissertation, I was simply not able to locate such a student. However, I still think the experiences of students

with visual disabilities who have dropped out from a graduate program needs to be represented in the literature, as those students are even less visible than the students I interviewed for this research study. With more time, I would try to find even one student with a visual disability who has had the experience of dropping out from graduate school, and complete an in-depth portrait of that student's experience. I believe such a study would provide valuable information for helping future students successfully complete their graduate degrees.

Summary and Conclusion

The students I interviewed for this study reported a number of barriers they encountered in graduate school. Despite the fact that current technologies available to us continue to add accessibility features, those of us with the most significant vision loss still face accessibility challenges due to the way in which digital materials such as PDF documents are improperly scanned without the optical character recognition needed by screen reader software. This lack of accessibility also extends to the content management systems used to deliver content in the online courses that are becoming increasingly popular in higher education. Online education could level the playing field for some students with visual disabilities by eliminating barriers related to transportation, an issue that was significant to some of the students in this study who did not live near the university. However, for the full potential of online education to be realized for students with visual disabilities, the adoption of online education needs to be carefully orchestrated to ensure faculty and staff have the training they need in accessibility best practices for online education. As with other digital materials, the accessibility of electronic library resources needed for research was another significant barrier for those

of us who relied on a screen reader. Thus, building up the accessibility of the university's digital infrastructure should involve a number of institutional stakeholders, including information technology and library services.

Overall, a lack of accessible instructional materials can limit the usefulness of assistive technologies even for those who are proficient in their use. When content is formatted to work well with those technologies, on the other hand, students can use their screen reader software and other assistive technologies to their full potential. Students with disabilities themselves can play a meaningful role in educating faculty about their disabilities and the needed solutions to accessibility barriers, but only if the way accommodations are provided is rethought to encourage closer collaboration between the two of them. Faculty can facilitate this collaboration by meeting with students outside of class time to discuss the student's needs in a more private setting where the student would be more comfortable discussing the disability. Such a practice would not only improve communication regarding the needed accommodations, but also encourage students to develop the self-advocacy skills many may be lacking but will need once they graduate and move on to the workplace.

Despite the accessibility barriers they encountered, the students who participated in this study were highly successful. At the time of writing, all of them had graduated from their programs and either secured employment or gone into business for themselves. According to the students themselves, the most significant factor in their success was the support they received from family members, close friends, and mentors within their programs. Family members not only helped with transportation, but also provided moral support and showed their understanding of the time demands and pressures the graduate

students were under. Close friends often had to step in to help the students with the accessibility challenges they faced, and mentors (such as major professors or advisors) communicated high expectations and encouraged the students to not hide their disabilities.

In contrast to the meaningful relationships they had with faculty and other staff, a consistent theme among the students I interviewed was the social isolation from their peers they experienced. While practical concerns such as a lack of access to transportation and time constraints played a role in the students' ability to participate in social activities with their peers, so did the students' difficulty opening up about their disabilities to others. This was often the case because the students themselves did not always feel comfortable enough with their disabilities to discuss them openly with others. I can understand this reluctance to discuss one's disability because it is an issue that I too struggled with throughout my time in graduate school. It was the primary reason I decided to pursue this heuristic research study, with its focus on the self and the meaning of one's own lived experience.

Sela-Smith (2002) has described heuristic research as a "surrendering," a leap into the unknown that requires the researcher to set aside the skills of controlled, objective observation in order to embrace the subjective experience that occurs within the "the last frontier" of the self, where our inner-most thoughts, feelings and even dreams reside. With this heuristic study, I decided to take that leap, uncertain of what I would learn about myself as I looked inward and explored my thoughts and feelings about my experiences as a person with a visual disability. However, I have not been alone in my journey of self-discovery. Along the way, I have "borrowed" from the experiences of my

co-researchers who have visual disabilities in order to help me better understand my own personal experience with vision loss. In that way, my co-researchers' experiences have served as a mirror to help me re-examine not only my past experiences but also my current status as a person with a significant visual disability who is neither blind nor sighted, but instead lives in between and betwixt.

Aside from the generosity they showed me by sharing their time to participate in the interviews, I sincerely appreciated the comradery, empathy and validation I experienced during my interaction with my co-researchers. As we conversed about our shared experience, their openness and honesty provided the encouragement I needed to help me continue my search for self-understanding with a similar focus on transparency and authenticity. It was this desire to be authentic that guided me to share some of the darker aspects of my experience as a graduate student who has a visual disability, including my experience with severe depression as a Master's student. At first I was reluctant to include that part of my experience in this public document, but it did not feel right to ask my co-researchers to be transparent with me if I could not be completely transparent with myself. I also felt that sharing that side of my experience could be helpful to someone else who is experiencing depression while dealing with the more difficult aspects of being a graduate student and having a disability. I don't think I could have opened up again to that painful experience had it not been by the empowerment I felt from working with a group of peers who know what it is like to experience vision loss while facing the pressures of graduate school.

My co-researchers also empowered me to think about my disability in a different light than I had before, by helping me "reframe" it into an asset rather than always

considering it a burden. Even Michael, who so often used the word burden during our interviews, shared a metaphor for how he views his life that I continue to go back to whenever I face a setback in my work or home life. Like Michael said, I just have to keep swimming, knowing that I now have a much bigger support network (a “support boat” as he put it) of people who share my experience than I did when I started this research. Despite the confidence I have gained from doing this research, I am still by all means a work in progress. My vision loss is unpredictable, and it could take a turn for the worse at any moment, especially as I get older. However, as I alluded to in my creative synthesis, I have also become more comfortable living in this state of uncertainty and ambiguity that comes with living with partial sight.

Whereas in the past I felt like I was alone in my experience of vision loss, I now feel that I am part of a small but tight-knit community of peers I can call on whenever I have a question or need emotional support, and I am confident that the other participants feel the same way about me. Even today, months after data collection has ended, I continue to stay in touch with the other participants and we have become good friends. This is a key difference between this kind of research and more traditional forms of inquiry. The relationships we developed during the interviews continue to this day, and that was one of the goals of this research: creating strong bonds between students with disabilities so that we become a support network for each other and are empowered to educate others about our experiences and advocate not only for ourselves but for those who will come after us.

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Appendix A

Letter Advertising Study

To Whom It May Concern:

I am a doctoral student in the Department of Special Education at the University of South Florida. I am pursuing my dissertation research on the experiences of graduate students with visual disabilities. I am looking for graduate students with visual disabilities who have completed at least one semester of graduate study. Your participation will consist of three face to face interviews that will last approximately one hour each. Each interview will be tape recorded and I will provide you with an opportunity to review the transcripts to ensure accuracy. In order to help me get a better understanding of your experiences as a student with a visual disability, I will also ask you to keep a reflective journal of your experiences for the duration of the study, and to share any relevant documents (letters, email exchanges, etc.) that might shed some light on your experiences. Any information you provide will be used for educational purposes only, and I will take precautions to ensure your privacy and confidentiality.

Participation in this study will be an excellent opportunity to share your graduate school experiences and help future graduate students with visual disabilities acquire knowledge of the factors that can empower them to achieve success in graduate school. Should you be interested in participating in this study, please contact me by phone at (813) 390-6153 or by email at lfperez@mail.usf.edu.

Sincerely,

Luis F. Perez

Appendix B

Informed Consent Form

(adapted from Janesick, 2004)

Form to be sent to participants:

Affirmation of Intent

This is to affirm that I am conducting this study for educational purposes, that no harm will come to you, and that all information will be treated with confidentiality and anonymity. You may withdraw from the study at any time, and you will receive a copy of the final report for your review. You may also see the data and anything I write at any time during this study.

Signed: _____

Form to be completed by participants:

I, _____ agree to participate in this study with _____. I understand that the information collected during this study will be used for educational purposes, and I can withdraw from the study at any time. By signing this document, I affirm that I understand the intent of this study.

Signed: _____

Date: _____

Appendix C
Demographic Questionnaire

1. Age: _____
2. Gender: Male _____ Female _____
3. Racial/Ethnic Identity: _____
4. Marital Status: _____
5. Employment Status: _____
6. If you are employed, are you employed full time or part time?

7. Degree Program _____
8. Number of Semesters Completed in Current Program _____
9. Grade Point Average (e.g., 3.0) _____
10. Were you enrolled in another graduate program? If so, can you provide a brief description?

11. What university did you attend as an undergraduate?

12. What was your undergraduate major?

13. What was your undergraduate GPA? _____

Appendix D

Initial Interview Protocol

1. Can you tell me how it was that you came to be in graduate school?
 - a. Possible follow-up question (PFQ): What were your reasons for pursuing graduate study?
 - b. PFQ: How did you decide on your current program of study?
 - c. PFQ: What was the admissions process like for you?
2. How would you describe your experiences in your graduate school courses?
 - a. PFQ: What have your experiences been like with faculty?
 - b. PFQ: What have your experiences been like with other students?
 - c. PFQ: If you use them, what have your experiences been like with support services at the university?
 - d. PDQ: Can you describe what a typical week is like for you?
3. How would you describe your involvement in the social life of your university?
 - a. PFQ: What has influenced your level of involvement in social activities at the university?
 - b. PFQ: What do you consider your most important social relationships at the university?
Can you describe how you developed these relationships?
 - c. PFQ: What do these relationships mean to you?
4. What are some challenges you have faced while enrolled in graduate school?
 - a. PFQ: What did you do in response to those challenges?
 - b. PFQ: Who were some key people that helped you with those challenges? How did you come to know them?

- c. PFQ: What personal characteristics do you think helped you in dealing with those challenges?
5. When have you felt most empowered in graduate school?
- a. PFQ: What has been your greatest accomplishment in graduate school? Can you describe how that felt?
 - b. What personal characteristics do you think contributed to that achievement?
6. What does being a graduate student with a visual disability mean to you?
- a. PFQ: What does your disability mean to you at this stage of your life?
 - b. PFQ: What aspects of your experience as a graduate student do you feel have been influenced by your disability?
 - c. PFQ: What do you think has been a defining moment in relation to your experience in graduate school?
7. If you could talk to someone who has a visual disability and is considering graduate school, what advice would you give to them?
- a. PFQ: What do you wish you had known before you decided to enroll in graduate school?
 - b. PFQ: What would you do differently in relation to your graduate school experience?
8. Where do you see yourself after you complete your degree?
- a. PFQ: What motivates you to keep going with your studies?
 - b. PFQ: What is your top career goal?
 - c. PFQ: How do you think your graduate school experience has prepared you to pursue that goal?
9. Is there anything else you think I should know that has not been asked?

Appendix E

Peer Reviewer Form

(Adapted from Janesick, 2004)

I, _____ have served as a peer reviewer for “The Perspectives of Graduate Students with Visual Disabilities: A Heuristic Case Study” by Luis Perez. In this role, I have reviewed transcripts and engaged in discussions about emerging issues with the researcher.

Signed: _____

About the Author

Luis Felipe Pérez has devoted his career to the empowerment of those who are on the margins of society. Prior to pursuing a career in education, he was on the staff of the Mexico-U.S. Border Program and the Immigrant and Refugee Rights Project of the American Friends Service Committee (AFSC), a humanitarian service organization. At the AFSC, he supported projects that advocated for the rights of immigrants and refugees and for better working conditions along the Mexico-U.S. Border. After becoming interested in technology as a personal hobby, he decided to combine this interest with his passion for education by working as a technical specialist for a large school district and later by pursuing a Masters of Education in Instructional Technology at the University of South Florida. As a graduate student, he has developed several websites to enhance the technology skills of teachers and promote greater accessibility of the curriculum to students with disabilities. Luis earned a Bachelor of Arts degree in Political Science from Haverford College. In 2009, Apple recognized him as an Apple Distinguished Educator.