

Growing Up: Disability and Cultural Dynamics in an Egyptian/American Family  
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**Abstract:** This paper explores my personal narrative as a young adult woman in my mid-twenties with a visual disability. I describe my experiences and how disability generally is perceived in the Egyptian culture, in particular within the Egyptian Coptic Orthodox Christian community in the United States. The aim of this paper is to illuminate the impact of comments, gestures and overall treatment from this community's people on its members with disabilities. The actions of close family members throughout various rites of passage at different stages of life is another central theme of this paper, for it highlights the impact of acceptance, overprotection, exposure, and independence on the daily life experiences of a person with a disability. I discuss how my values and assumptions as a person with a disability can sometimes conflict and other times coincide with those of my immediate, extended and religious families. While this paper explores the narrative of one individual, it has the potential to challenge people's stereotypes and behaviors which may subsequently impact the lives of people with disabilities. As human beings, people with disabilities are all a part of various "families" whether religious, biological, or the (dis)ability-related communities. Overall, this paper explores my personal narrative, given the interaction of multiple components of identity—gender, race, age, religion and disability.

**Keywords:** Visual Disability, Egyptian Families, Personal Narrative

### The Foundations

My mother and father were born in Cairo, Egypt. Both of my parents immigrated to the United States in 1969 to pursue engineering degrees. In Los Angeles, both of my parents attended Saint Mark's Coptic Orthodox Church. They met, fell in love, and were married in 1974. By 1976, they had their first daughter and their second child, a son, in 1980. In 1985, my mother became pregnant with her third child, and they and my siblings had no idea just how drastically their lives were about to change.

Initially, my mother's third pregnancy was not any different from the first two. However, as an older expectant mother, her physician urged her to undergo an amniocentesis to detect any genetic or developmental anomalies. Many parents use the results to help inform their decision whether to proceed or to terminate a pregnancy. Resulting from my mother's personal and religious convictions, she never would have agreed to terminate a pregnancy. She believes that every baby has a right to live and a purpose in life. In Egyptian society, medical doctors occupy a venerated position, and are often called "the wise ones." Thus, my mother did not press her physician as to the potential dangers in such a procedure. For her, questioning a medical professional's actions or even asking for an explanation of their treatment plan was unacceptable.

During the amniocentesis, the doctor unknowingly punctured my mother's amniotic sac, causing her water to break. Upon inquiring about the leaking, the doctor informed her that it would eventually stop. After that, my mother continued with her daily routine: driving her children to and from school, helping them with homework and preparing dinner for her family. All the while, her water was still leaking. For over a week, she continued to call the doctor, and

his nurse kept assuring her that it would stop. After all her “pestering,” the doctor agreed to visit her at home. At the home visit, the doctor concluded that the baby no longer was viable and for the sake of my mother’s health, it had to be aborted. However, the doctor was not willing to do the procedure himself as the pregnancy, by then at approximately 23 weeks – was beyond his “comfort zone” for performing abortions. He contacted another doctor, and the abortion was scheduled for the following Monday morning.

Throughout the night before the scheduled abortion, my mother was having contractions and before she and my father could make it to the hospital, the baby’s head had already crowned. After arriving at St. John’s Hospital, my mother’s intuition and her faith led her to believe that her baby was alive, and as such, she pleaded with her doctor to allow them to go to Santa Monica Hospital, where there is a Neonatal Intensive Care Unit (NICU). The doctor relented and sent my parents to Santa Monica Hospital.

On May 27, 1986, while the operating room was still being prepared for the abortion, I came out crying. I was born severely premature and weighting only about one pound, three ounces. Since my parents were told I would survive only a few days, our priest was summoned, and he baptized me right in my incubator. I spent the first five months of life in the NICU. My parents and siblings visited me in the hospital every day. My six-year old brother would urge me, “rough tough, come home!” During my hospital stay, I was given an excess of oxygen, which further exacerbated my physical disability.

As a result of my prematurity and subsequent complications, I ended up going home with a heart monitor and a diagnosis of a visual disability called Retinopathy of Prematurity (ROP). ROP affects premature babies. It is commonly diagnosed in babies who are born more than 12 weeks early. ROP occurs when blood vessels in an infant's retina develop abnormally. In a typical situation, blood vessels grow providing blood to the retina while a fetus is developing inside the womb. This growth usually happens a few weeks before the fetus is born. However, when an infant is born prematurely, the blood vessels of the retina have not yet fully developed. As a result, the vessels may develop atypically after birth(National Eye Institute, 2008).

Without hesitation, my mother quit her job to take care of me. I was connected to a heart monitor for about a year. Due to the responsibility of possibly having to resuscitate me in the event of an emergency, my grandparents were uncomfortable helping to care for me, so I became my mother’s full-time job.

Over the next decade, secondary conditions developed, including nystagmus, involuntary movement of the eye, cataracts, cloudiness of the lens, retinal detachment, separation of the retina from its underlying tissue, and glaucoma, an increase in eye pressure (Glossary of Eye Terminology, 2007). We went to numerous visits to various specialists from all over the country and I underwent approximately ten surgeries. I visited with world-renowned retina specialists and became one of the first patients to receive certain novel treatments for that time, such as cryotherapy. Cryotherapy is the process of repeatedly placing a cold device on the outside of the eye to freeze through the surface to the retina, destroying the part without blood vessels (Casey Eye Institute). During this period my parents went through an intensive medical education, but

thankfully received unbounded support from family members, church members, friends, medical professions, and special education teachers.

### Forming My Identity

Dajani (2001) discusses that many people with disabilities have multiple identities and do not only view themselves as their impairment and their disability may have more than one meaning (as cited in Johnstone, 2004, Complex Identities section, para. 1). Furthermore, Wade (1994), reflects that disability does not solely bring one “pride” or “scorn” but rather, it is both a source of “empowerment” as well as “pain.” (as cited in Johnstone, 2004, Complex Identities section, para. 1) The stories highlighted within this narrative are embedded within the multiple facets of my identity beyond solely my visual impairment. The stories that I recount as I discuss my identity formation highlight times of success, achievements and struggles which encompass both “empowerment” and “pain.”

### Religious Family

My parents raised my siblings and me in the Christian Coptic Orthodox Church. “Copts,” as they are known, are the native Christians of Egypt; their beliefs follow the apostolic teachings handed down by Saint Mark the Evangelist, the first Pope of the Coptic Church founded in Alexandria during the first century A.D. As one hears about “Little Italy” and “Little Tokyo,” the Coptic Christian community in Los Angeles could easily be referred to as “Little Egypt,” the only difference being that the community is united through the church. The culture endures in the preparation of Egyptian style cuisine, speaking Arabic at home, expecting their children to live with them until marriage, demanding respect for elders, and putting a strong emphasis on obtaining higher education. Children have a strong family support system, financial support until marriage, friends and peers who are also the children of first generation immigrants, and who simultaneously go through the same experiences while living in America, and a church support system with Sunday school teachers, spiritual advisors and priests. On the other hand, children feel that they are treated different than their American peers; they accuse their parents of not understanding American culture and feel unable to communicate with or relate to their parents. Fortunately for me, my parents were educated in private English and French schools in Egypt, which prepared them to embrace life in America. Although my parents may have had an easier transition because of their educational backgrounds, they were ill prepared both emotionally and in identifying resources.

### Cultural Dialectics

Reflecting on how my accomplishments and my quality of life are closely tied to the access to resources, support and education I have received throughout my upbringing in the U.S., has made me wonder how the lives of people with disabilities, especially those with visual disabilities are similar or different in Egypt. As discussed in Ashoka Arab World (2010), people who are blind in Egypt have no access to information, knowledge, services or employment and are ostracized from society and thought of as “lesser than”. Additionally, within the group of marginalized individuals, those who are blind appear to be the most marginalized group, rather than being included, due to their need for specialists, technology and special materials and can be

seen as a microcosm of groups that are excluded. Further, in Egyptian society, those viewed as “other” are “stigmatized – hidden, unemployed, isolated and alienated . . .” (Ashoka Arab World, 2010).

Furthermore, the popular mentality among Egyptians is that people who have disabilities cannot be successful and live fulfilling, productive and independent lives. Males born blind within Coptic families are assigned to work in the churches as Coptic hymn instructors to the deacons. If the men are born into a Muslim family, they are employed by the mosques to chant through megaphones during the Muslim hours of prayer. According to Ibrahim (1932), Muslims who are blind customarily earn their living by reciting the Koran, from memory, in private houses, in stores, and in the streets. Additionally, the Copts who are blind chant in the church which does not enable them to earn enough money to secure a comfortable lifestyle (Ibrahim, 1932).

Females who are blind are uniformly shut away in their families’ homes to protect them from humiliation and public disdain. Many who are born into poor families end up beggars in the streets. Al-Shamahi (2010) mentions that people with disabilities in the Arab world, whether they have a physical impairment, such as blindness, or a mental disability, or something else, tend to be invisible to the rest of society. Regardless of an increase in the understanding, disability is still often viewed as a source of shame for a family, as if they have done something wrong, and are cursed as a result. Furthermore, he discusses that the poor are seen as a financial burden. Thus, there are a multitude of people with disabilities who are beggars, in order to make a living. He elaborates that these individuals are not even referred to by their names, but rather by their disability. There is a lack of public awareness about disability, including the rights, causes, treatments and individuals’ potential as well as a severe lack of accessibility, in terms of the physical environment (Al-Shamahi, 2010).

Some see scriptural justification in these practices, that is to say that disabilities are caused by someone’s “fault” or “sin.” This is evident in the biblical New Testament story of the man born blind as people asked Jesus, “Rabbi, who sinned, this man or his parents, that he was born blind?” (John 9:1) They are something to be hidden and individuals with disabilities and their families are pitied. As Charlton (1998) explains, “The impression of culture on beliefs and mythology, traditions and rituals, institutions and doctrines, has individual and social implications . . . The beliefs, ideas, and values of society at large not only reflect the dominant culture, they help to produce it” (Charlton, 1998, p. 51). I have been forced to manage my own challenges with regards to formulating my identity, within a disability “family.”

### Disability Family

When I arrived, a child with a disability, my parents had no idea where to turn. Fortunately, my ophthalmologist suggested enrolling me in the Blind Children’s Center that offers special education, support and training to children with visual impairment and blindness, who are newborn to school age, and their families. The name of the institution, including the word blind and its connotation, was an emotional deterrent for my mother. She was not ready to accept the severity of my disability. Only after much encouragement from my ophthalmologist was my mother willing to at least visit the school. Once she visited the Center, she saw how the

children were cared for and the variety of developmental tools and techniques at their disposal. Following my enrollment, I was able to excel beyond anyone's expectations. The support from the Center was necessary but not sufficient to propel me to educational success. The support that I received from my family, the church, and my schooling lifted me throughout my life. After attending the Blind Children's Center for about two-and-a-half years, I transitioned to mainstreamed education.

Attending the Blind Children's Center was a path to a new life. It was a door that led my family and me to a comfortable place where we felt a sense of belonging. We were not subjected to stares and pity. My mother and grandmother were treated as part of the Center's "family." They regularly volunteered by answering telephone calls and assisting administrative staff members with sending out mailings. This was the beginning of an educational path to a new world and abundant knowledge of available resources for people with visual disabilities, and ultimately to a new disability culture that shaped my life. It was an introduction to a culture that empowered my family and me to strive to reach life goals and strengthened us to be able to face any societal barriers or challenges along the way. As Charlton (1998) reflects, the cultural realm of our lives gives us our bearings.

Goodley (2001) discusses that stories are not solely subjective current accounts of situations, they additionally highlight social backgrounds. Furthermore, Bertaux-Wiame (1981), discusses that, "... Stories allow readers to listen beyond the words of narrators and to tap into the speech of their social culture" (as cited in Goodley, 2001, p. 216). As an example of stories that formed my disability identity, owing to my mother's exposure to Western perspectives and approaches in dealing with disabilities, she did not let me miss out on any school activities. At Easter time, during my preschool's egg hunt event, drawing on our experiences from the Blind Children's Center, my mother arranged for Easter eggs that beeped so that I could participate with my classmates. My teacher was so impressed and inspired that she decided to teach the other children to use their sense of hearing. The rest of the class were all blindfolded and experienced the egg hunt without sight.

Similarly, in first grade, when my school sponsored a Jump Rope for Heart fundraiser, my grandmother spent hours teaching me to listen to the rope hitting the concrete and to jump at the right moment. Not only did I learn to jump rope but I excelled at it and was able to participate in the fundraiser.

### Biological Family

I was expected not only to keep up with my classmates, but with my siblings as well. Family tradition called for piano lessons, and I would be no different. Initially skeptic that a girl with a visual disability could play the piano, my mother prevailed upon my teacher to use handwritten sheet music in large print. Similarly, my sister taught me how to ice skate and secured special permission from the rink to teach me when it was closed to the public, so that I would not get hurt or bump into other skaters. In an effort to develop my social skills and help me to converse with my peers about popular culture, my sister took me to movies and described every detail on the screen. Shakespeare (1996) discusses that identity is about feeling a sense of membership within a community as well as acknowledging similarities and differences between

you and the other members. Further, Weeks (1990) explains that it provides a “sense of personal location, the stable core to your individuality” (as cited in Shakespeare, 1996, p. 98).

All of my parents’ siblings and parents, with the exception of two of my father’s siblings, eventually also immigrated to Southern California. This allowed us children to grow up with our extended family nearby, enjoying holidays and vacations together. Throughout my childhood my immediate and extended family and I spent many vacations in Santa Barbara, California. One of the favored activities for all my cousins was to go bike riding around the lake. My uncle was determined to enable me to share in this experience. He bought me a bicycle and attached training wheels. Then, he, my brother and cousins would ride around me, protecting me and giving me verbal directions. Experiencing the simple thrill of riding a bike was only possible because of my family’s support. Similarly, my aunt spent hours teaching me to swim with my head above water, due to my doctor’s orders to avoid exposing my eyes to water pressure. At the time, I did not value their efforts, but as an adult, I look back and realize the significance of being exposed to these various opportunities and of the resources that made these sometimes costly opportunities possible.

As I grew older and my peers moved on from ice skating and jump roping to skiing, my family still did not give up. My mother researched adapted sports organizations for people with disabilities. She came across the Mammoth Mountain Disabled Sports Eastern Sierra office which provides ski guides for people with disabilities. Since this discovery, every year I attend a church youth group ski trip to Mammoth. My ability to participate in skiing has made me the “talk of the town” among my church peers.

### Personal Tribulations

Hidden in these stories, however, are also personal struggles that I had to overcome. Personal struggles which deeply touched me and impacted my beliefs and value system, struggles that raised a greater question of what these incidents reveal about the social, educational and societal realities that people with visual disabilities face on a daily basis, struggles which gave me the determination to pursue both teaching and social work degrees in an attempt to educate, serve and empower others.

During my elementary school years, having to be mainstreamed for lack of resource rooms for students with visual impairment in the neighborhood schools, I was the only student with a visual disability in the school, surrounded by classmates from affluent families. I had a strong fear of being excluded and I desperately wanted to belong. I would hide my cane in my backpack in an attempt to not look different. This resulted in daily bumps, bruises, and dangerous falls. I will never forget how the physical education (P.E.) coach made me sit on the bench during every P.E. class period in an attempt to protect me from danger. Little did he know the emotional damage he was inflicting on me, as a child who simply wanted to play like everyone else. Another example was how I ended up failing Spanish class rather than having to stand out of the class as different, by informing the teacher that I cannot see what she was pointing to while verbally naming different objects in the classroom in Spanish. Later in life, as a young adult using a mobility aid, when I meet people for the first time or walk into a room, I want people to see me for the person that I am, not by the symbol that instantaneously signifies

my impairment and subsequently places me in the category of “other.” In this same vein, when building new relationships it is a constant question of whether people are being genuine or giving me unwanted sympathy and pity. Goffman’s (1963) words express these sentiments as he explains that “. . . a discrepancy may exist between an individual’s virtual and actual identity. This discrepancy, when known about or apparent, spoils . . . social identity; it has the effect of cutting [her] . . . off from society and from [her]self so that [s]he stands a discredited person facing an unaccepting world” (p. 19).

### Overcoming Habits

Throughout my childhood, I exhibited an extreme unwillingness to participate in activities that resulted in dirtying my hands. I vehemently refused to finger paint, play in the sand or with play-dough, bake or eat with my hands. Even today, I have not been able to completely overcome this tendency. Compounding my disability was my fear of animals, including dogs, both because I believed they were “dirty” and because of the potential for rapid movement. Despite the fact that our family had a dog growing up and because of my pre-disposition, I did not seriously entertain the possibility of applying for a guide dog to help me transition to the dorms during my junior year in college. Due to my lack of night vision and depth perception, agreeing to get a guide dog was the condition my parents placed on allowing me to move into the dorms. Again, it was my mother who led the way, surreptitiously researching and filling out an initial application to a dog guide school on my behalf. I reluctantly agreed and even surprised myself when I finally overcame my fear of dogs and graduated from dog guide training school with my yellow Labrador guide dog, Sundance, who would become my eyes, my constant companion, and my dear friend. Sundance empowered me with a new sense of independence and self-confidence. Not only did Sundance allow me to live in the dorms during my last two years of college, she also enabled me to travel independently and move half-way across the country from my family to pursue graduate education. I moved to Illinois in 2008 and obtained a Master’s of Science in Education specializing in teaching individuals with visual impairment and blindness at Northern Illinois University.

### Breaking Away

I have culminated my second graduate degree, a Master’s of Arts degree in clinical social work from the University of Chicago’s School of Social Service Administration. With the help of Sundance, I have been able to travel independently throughout Chicago using public transportation. On the other hand, during home visits on holidays and school breaks, despite their best intentions, to this day, some of my family members still try to coddle me with various daily living tasks, such as offering to cut my food, serving me a plate, pouring me a beverage, and taking care of Sundance. As an adult and as a professional in the field of visual impairment, I now know better and am able to advocate for myself in these situations. As a child, I did not mind and enjoyed being the center of attention and having the special treatment. The negative impact of the coddling and overprotection became pronounced when I moved to Illinois to pursue my first master’s degree. I could no longer take my dirty laundry home, or call my mother for a home cooked meal. Reality set in that I had to do it on my own. This was accompanied by a period of helplessness, withdrawal and depression. Seeking advice from God, my close friends and professionals, I got through these feelings and started to take matters into

my own hands. I realized that I had to direct my attention away from negative feelings and focus on the immediate tasks at hand. I made many mistakes: burning food and burning myself while cooking. Today, while I still make mistakes, with time and practice life is becoming easier. I have to admit that I still have a lot to learn, especially when it comes to the kitchen. Frozen food, deliveries and eating out are tempting but not very healthy and cost-effective. With my passion for cooking and baking, I still have a long way to go.

My identity as a person with a disability, especially as a young adult breaking away from my tight knit protective family has been a process. Giddens (1991) proposes that self-identity is neither an individual's specific trait nor a combination of traits. Rather, it is the individual's sense of self reflexively understood in terms of their biography (as cited in Shakespeare, 1998).

### Pockets of Resistance

Outside the protection and domain of my immediate and extended family throughout my life, I cannot deny that I continuously meet challenges. When Sundance was first introduced to my church community, there was significant resistance to the presence of a dog in a holy place. This stems from the fact that the majority of the congregation is of Egyptian descent and is influenced by the Muslim belief in Egypt and other places that dogs are impure and defile one's purity. Also, as far as I know, it is rare to come across a dog guide in Egypt and it is prohibited in churches. It took a long time to combat this resistance among the regular attendees. However, when I am back home visiting family and attending our church, I encounter the same resistance from visitors and new comers. Additionally, new immigrants who are unfamiliar with the proper etiquette towards people with disabilities, tend to stare, attempt to help me unnecessarily and pity me. As Charlton (1998), discusses, "Beliefs and attitudes about disability are individually experienced but socially constituted. They are . . . pejorative . . . paternalistic . . . often sadistic and hypocritical" (p. 51). Paradoxically, people with disabilities often face pity, sympathy, and stares, even though the person who cannot see or is using a wheelchair for mobility may be a happy, well-adjusted person. As Wendell (2006), states, people with disabilities share many forms of social oppression including staring. People feel pity not only towards the person with a disability but also towards their family, considering it shameful. In one instance, an Egyptian couple who immigrated recently was having a friendly conversation asking my mother for advice. Once they discovered that she has a child with a visual disability, their demeanor changed, no longer giving eye contact, and lowering their tone of voice. Without saying a word their body language expressed a sense of pity and sympathy. The conversation ended and they no longer sought out her advice. My mother had to change the direction of the conversation in an attempt to indirectly comfort them to show them that she is not in need of their sympathy. While I have highlighted the misinformed beliefs of some members of the Egyptian community, it is important to note that I have also met roadblocks and misinformed individuals outside the church and Egyptian communities. For instance, while at the University of Chicago, I have been denied service at a local Pockets restaurant due to the presence of my guide dog. Similarly, taxi cab drivers often bypass me once they see Sundance. Even in the local Catholic Church that I sometimes attend on campus, I overhear parishioners commenting to one another about me and Sundance.

Morrison and Finkelstein (1992) discuss that:



“Challenging stereotypes, building solidarity, recounting new stories, are all about developing a disability culture. These processes are also about new options for disability identity: To encourage the growth of a disability culture is no less than to begin the radical task of transforming ourselves from passive and dependent beings into active and creative agents for social change” (as cited in Shakespeare, 1998, p. 22).

These small glimpses into my life illustrate the transcendence and impact of acceptance, overprotection, exposure, and independence across various components of my identity including gender, race, age, religion, and disability. My disability identity has shaped me into the three interchangeable facets Cook (2001) (as cited in Johnstone, 2004) notes, the “tolerant person” who exudes patience with others because of my own experiences, the “survivor” or the “supercrip” (Shapiro, 1993, as cited in Johnstone, 2004) and the “sensitive person” who has a heightened awareness of oppression due to my first hand experiences of discrimination. My journey and its stories have shaped me into a young-adult with a passion and a dedication to become an agent for education and change within the world of visual disabilities and beyond.

### My Vision

My hope in sharing the stories of my life as a child and as a young-woman with a visual impairment is to identify some of the struggles people with visual disabilities and their families encounter in the education system and society at large. It is beyond mere self-reflection, but rather an effort to reveal the reality of life with a disability, through supporting the work of Disability Studies scholars; I hope my stories help others recognize and embrace human diversity.

While I am one young-adult woman with a visual disability, it is my vision that my life experiences and accomplishments can be illuminating through my exploration and the interconnection of my membership within various “families” and various facets of my identity - gender, race, age, religion and disability. Johnstone (2004) notes that identity is present in both personal and societal realms. Further, he postulates that identity is “. . . most empowering when it is self-described and defined as an individualized experience. When individualized experiences are asserted, communities of common experience grow” (Johnstone, 2004). Accepting and embracing my physical disability as a young-adult Egyptian Coptic Orthodox Christian woman, born and raised in the United States, has been a journey and continues to be a process of personal growth, gaining greater independence, and continuously educating others on a daily basis. Finally, Wendell (2006) explores that, “Our real human bodies are exceedingly diverse-in size, shape, color, texture, structure, function, range and habits of movement, and development-and they are constantly changing.” However, the author notes that we do not take this fact into account, but rather we “idealize the human body” (Wendell, 2006, p. 112). Cultural views of physical ideals of what is acceptable perpetuate within both Egyptian and American societies despite the existence of diversity, as Wendell discusses. I urge my fellow members of the disability “family” that we must never forget that as the title of Charlton’s (1998) book suggests, in life there is “Nothing About Us Without Us.”

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