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Editorial:

Whatever Happened to Mary Ingalls?
Megan A. Conway, Ph.D.
RDS Managing Editor

Since this issue features a forum on the family, I figured I could easily write an editorial focused on my own family experiences. But then I realized that many of my editorials focus on my family. After all, my family is the most important thing in my life. Who wants to read another editorial about the exploits of my eight-year-old? So instead I am going to focus on another family, then admittedly a family who comes to us because of my daughter's recent interest in the Little House on the Prairie books and TV series, but another family all the same. They are the Ingalls family, and most importantly, Mary Ingalls, the blind sister of the book and American TV show's main protagonist, Laura Ingalls.

For those of you unfamiliar with the American classic saga of the Ingalls family, their journey by covered wagon in the 1870's from the state of Wisconsin, through Kansas, Minnesota and finally into South Dakota, is told rather charmingly in the children's series, *The Little House Books,* by Laura Ingalls Wilder, who wrote the fictionalized story of her family's true journey when she was an older adult in the 1940's and 50's. I devoured these books as a child, and even lived their stories of pioneer hardship, family love and adventure in play with my friends. In the 1970's Michael Landon directed and starred in the American TV series, *Little House on the Prairie*, which was a big hit for family television and ran for nine seasons. The TV series diverges from the books in countless ways, but the primary themes of family and hardship remain, with the appearance of family characters from the books including Laura, her "Pa" and "Ma", and her three sisters; Mary, Carrie and Grace.

In both real-life, the book and the TV series, Mary becomes blind as a teenager, due to a then-unidentified illness that for many years was thought to be Scarlet Fever but which more recently is thought to have been Meningitis. In the book, and presumably in real life, blindness is for Mary the end of all expectations that she will realize her hopes of becoming a teacher or having a family. Laura's descriptions of Mary in the *Little House* books are of someone who suffers her blindness without complaint, who at first spends days upon end in a rocking chair in the corner, but who gradually learns to contribute to household chores and childcare.

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Indeed, as told in the *Little House* books, according to the website XXX although Mary does have the opportunity to attend a school for the blind in Ohio where she is educated and learns vocational and housekeeping skills, she lives with her parents or sisters for her entire life and never has a family of her own. Her primary vocations include involvement in church life with her mother, and making fly masks for horses to help make ends meet after her father dies.

As a child, I never noticed the sad plight of Mary, other than to sympathize with her blindness in a general way, without ever connecting it to my own blindness or noticing any difference between her sheltered life and my life of "mainstream" schools, wandering the

neighborhoods of San Francisco with friends, and dreaming of a career as a movie star (or lawyer if that didn't work out). As an adult, Mary's situation seems to me to be dreary and representative of the constraints that disability has placed on people of the past, and unfortunately, on people of the present as well. Why could not Mary have had a family of her own, pursued a career as a teacher, even if "only" as a teacher of others who were blind?

Apparently the creators of the *Little House on the Prairie* TV series thought the same. In the concluding episode of Season Three, Mary is slowly going blind. I am not sure about in real-life, but in the books Mary's blindness came on much more quickly. Apparently there is more drama to be squeezed out of the gradual, torturous loss of sight, with plenty of time for denial and, of course, tears (we counted no less than seven bouts of tears in the one-hour episode, from each of Mary, Pa, Ma, Laura, friends and neighbors).

Forum: Global Families

Introduction: Writing the Global Family, International Perspectives on Disability Studies and
Family Narratives
Janet Sauer
University of Colorado, Colorado Springs &
Philip M. Ferguson
Chapman University

We live in the Golden Age of the memoir. Everyone has a story to tell, and a growing
number are finding their way to publication. The disability memoir has certainly been a part of
this growth. It is refreshing to note how many of these recent narrative accounts of living with a
disability have been written from what might be broadly termed a "disability studies perspective"
taking on a more critical, socio-cultural orientation than the traditional 'inspiration in the face of
personal tragedy' motif. The list of such accounts is growing (a very short and incomplete list
would include works by Anne Finger (2006), Simi Linton (2006), Harriet McBryde Johnson
(2005), Eli Clare (1999), Rod Michalko (1998), and Stephen Kuusisto (1998). Beyond the
personal memoir, there has been a similar explosion of memoirs written by family members of
individuals with disabilities (parents, siblings, and children). However, unlike the personal
memoir, relatively few of these "family narratives" have adopted a clear disability studies
perspective. There are, of course, important exceptions: Lennard Davis' (1999; 2000) personal
and socio-cultural examination of *normalcy* as a child of deaf parents; Michael Berubé's (1996)
powerful account of discovering the history of a label as he engaged with the reality of his son's
Down syndrome; or Ralph Savarese's (2007) distinct but equally powerful accounts of
fatherhood, adoption, and the meaning of neurodiversity.

We also aspire to live in a Global Age for disability studies. Of course, there is no area of
academic study that should not be in such a "global age." We are long past the time where
assumptions, hidden or explicit, that "West is Best" and "White is Right" can go unchallenged.
Still it is important to recognize that it is families everywhere, from the Global South as well as
the North, whose voices about the experience of disability must be heard in greater number. If
disability is unavoidably cultural, then our search for family voices must also reflect the
international – and intra-national – diversity that contributes to that cultural context. As Goodley
puts it, the literature emerging from "global disability studies" must be "pan-national" in
perspective as much as "cross-disciplinary" (Goodley, 2011, p. 1). Yet, here as well, the
burgeoning literature of personal and family narratives has remained predominantly white and
western in origin and perspective. Even the selections that follow might be said to show a
somewhat "westernized" overall tone. A truly global disability studies remains as much
aspiration as reality. It is this personal and socio-cultural negotiation with the (re)interpretations
of disability from various family perspectives that we focus on in this special issue of the *Review
of Disability Studies*(RDS).

In our call for proposals for this special issue, we sought a global perspective
representing a variety of cultures and traditions. The response was overwhelming, making the
selection difficult, but we hope representative of ways in which gender, race, class, disability and
culture intersect with family systems. While a unifying theme is the combination of the personal

with the scholarly using a disability studies orientation, we organized the manuscripts into two parts: the first group of articles places special emphasis on narratives where disability is located *within* a family context. This emic perspective includes primarily autoethnographic work of mothers, daughters, sons and "the othered sister." The second group of articles consists of studies conducted by disability studies researchers *about* family systems, thus providing more of an etic (outside the family looking in) perspective. We are the first to admit that this emic/etic distinction is not a clean separation, but it provides a useful way to think about singular experiences as opposed to socially organized structures. As Mark Sherry (2008) points out, "disability is always a sexed, gendered, racialized, ethnicized, and classed experience…[that] operates within a framework of multilayered and complex patterns of inequity and identities" (p. 75). Considering all of the articles together, we think this collection of family narratives and narratives on family provides intersectional sites for critique of the ways in which history, geography, culture, gender and religion mix with the disabled experience.

The first set of articles includes narratives written from the direct personal perspective. Um and Won's account, written by a South Korean daughter and her mother who has a visual impairment, draws upon Toni Morrison's approach of reconstructing past realities to interrogate their memories. They include partial transcriptions from distanced conversations to construct a dialogue in order to illustrate their interrogation process. This unusual form for presenting their experiences and analysis responds to disability studies scholars who argue for the importance of using experimental qualitative designs: "Diverse ways of writing reports can meaningfully convey ideas about social situations and contexts" (Brantlinger, Klingner, & Richardson, 2005, p. 104). The authors acknowledge how their process of reflexivity was accompanied by tension as they became increasingly aware of their different positionalities within the experience.

Youssef, a young adult woman with a visual disability describes how her Egyptian Coptic Orthodox Christian community plays a role in her emerging identity. This personal narrative provides "insider knowledge" on ways in which religious and cultural traditions traverse the globe in an immigrant family. Her story illustrates the role of mothers as advocates indicative of the privileged parents Ong-Dean (2009) describes in his socio-cultural analysis of the special education system in the United States. Acknowledging the less than straightforward negotiation of a disabled identity, Youssef describes both her achievements and struggles that led her to a sense of empowerment as well as pain. When she moves away from her protective family to attend university, Youssef shares some of her own trepidation as she endures discrimination in her daily life. She explains how these experiences informed her career decisions "to become an agent for education and change."

Jones writes about being the 'othered' sister, noting that the "biases toward individuals with disabilities do not occur in a vacuum affecting only those with a disability." Like Um and Youssef, Jones uses the reflective process of autoethnography to situate her family's story within the public sphere. Jones discloses "family secrets" that were created in response to "the public stare, segregation and isolation" she and her family experienced having a member with an intellectual disability. She describes her process of understanding growing up with -- and the subsequent loss of -- her brother who died nearly three decades ago. Jones' story emphasizes the importance of hearing the lived experience and the lasting impact society has on these families. In reference to Garland-Thompson (2006), Jones suggests her essay "is meant to be

generative…toward social change in perception…unmasking and reimagining disability 'not only for people with disabilities but for everyone' (p. 259)."

In an American mother's search for an "Inclusive Oz", Sauer describes how these social perceptions and disability constructs are revealed in what Gee (2005) calls people's "storylines" or "habits of conversation." By documenting and analyzing the discourse of the people her family encounters when they move across the country, Sauer shows how her son *becomes disabled* when confronting a new set of social and cultural constructs reminiscent of Mercer's (1973) classic study of the "6-hour-a-day retarded child." While highlighting the increasingly mobile world in which we live, Sauer calls for a more thorough examination of socio-cultural influences on family's experiences, with particular attention on the power of economic and cultural capital.

We conclude the first part with an Iranian journalist's (Goodrich) description of a family's experience over a thirty year period, beginning in 1980 when their son, Mohsen, was born with cerebral palsy in a city under attack by Saddam-Hossein's army. Goodrich explains how she first met Mohsen H. Taha at the newspaper office when the young man offered his writing samples to the journalist in an effort to seek employment as a contributing author to their journal. Taha's voice begins the piece where he writes, "The tragedy happens in a society who treats persons with disability like unhumans. Our life tragedy is made by our society, not by our disability…" Goodrich honors Taha's voice throughout the manuscript, but she also gives voice to Taha's mother, father, sister, and brother including many quotes taken from years of interview transcripts. Their mixed experiences include feelings of "shame" reflected in some of the other stories in this issue and so they are not wholly owned by those in so-called less developed countries. These shared human experiences are meant to provide readers with a chance to reflect upon our own storylines and the roles we may play in the lives of disabled people and their families.

In the second grouping of manuscripts we see the influence of historical and political legacies on disability experiences for British Pakistani families and American immigrant mothers from Japan, the Philippines, and the Dominican Republic, as well as for a group of Ecuadoran men with physical disabilities who come together to play basketball. Extended families in both the genetic sense and in the social structural sense are shown to play an important role in providing support for families. Goodley, Runswick-Cole, and Mahmoud, employ the complicated notion of diaspora as it plays out in the lives of three British Pakistani families. The authors use the voices of their participants to explore the often liminal status of these families as they negotiate their place within multiple communities while seeking the best for their disabled children. The second article, by Wilgus, Valle, and Ware, continues this exploration of the immigrant experience by recounting the stories of three mothers living in New York City with their disabled children. Coming from three different backgrounds – Japanese, Dominican, and Filipina – these mothers tell stories that are both similar and different. As with the British Pakistani families, these mothers also reported a life of complicated interactions with the educational and social institutions of the dominant society. The authors describe a process through which disability, race, class, gender and other signifiers of identity were used to create a kind of cultural calculus that gave different results to each family. What was common was the influence of this social

formula, or algorithm of access, by which intricate formal and informal bureaucracies drew upon multiple factors to shape the lives of these mothers and children.

The following article, by Rattray, reminds us that the very notion of "family" itself is mutable and contextualized. Using the concept of "segunda familia" or second family, Rattray examines how the identities of wheelchair athletes in Ecuador were importantly shaped by the close, familial relationships that they formed with the other members of their team. In these extended, second families, his participants came to embody lives that identified as disabled and proud, strong in both their individual achievements and their collective sense of purpose.

It is our hope that these family narratives offer a contribution to the authentic voice of the disability experience in today's societies. This is an effort to privilege the voices of the lived experience of disabled people and their families from a variety of 'locations' both geographic and metaphoric. We acknowledge the risks involved for some of the families as they made the personal public and appreciate what in some instances involved emotional upheaval in the telling. The topography of these stories offers an opportunity to examine the intersection of societal structures that impact disabled people and their families. For instance, material and cultural capital played an important part in the opportunities and choices afforded to the Sauer family as they relocated across the country, while it could be argued a lack thereof restricted Taha's choices.

As is often true with story-telling of any kind, these narratives leave readers with as many questions as answers. As researchers, our first responsibility is to "ensure that these stories are valued and gathered and told in ways that are culturally respectful, recognizing the potential the stories have to bring about social change" (Stienstra, 2012, p. 386). One of the ways we hope to fulfill that responsibility is to let the stories mainly speak for themselves. The questions they raise should prompt us to continue to listen, not rush to answer. In that spirit, we end by mentioning some of the more provocative questions that we take away from the stories that follow:

- How have family experiences with disability changed over time?
- How do the functional implications of specific impairments shape the family experience of disability?
- How does the location of a disability within a family system (i.e. who is the person with the disability label – father, mother, brother, sister, son, daughter) shape the experience?
- How relevant and helpful is a disability studies lens to understanding family experiences in developing countries?
- How do race and culture intersect with family systems to shape the meaning of disability?

In raising these and other questions, the authors help remind us that even within the global context there are at least a few common places to begin the quest for answers. Not only is disability a universalizing context, both in concept and in experience, but so is family. It is at the intersection of both within a global perspective that further voices must be heard; further questions must be sought.

Philip Ferguson is a Professor in the College of Educational Studies at Chapman University in Orange County, California. His research focuses on family/professional interactions and

supports, social policy and the history of disability, as well as qualitative research methods in disability studies and education.

Janet Sauer prepares teachers to work with and learn from people with disabilities and their family members. She taught children in Botswana, Africa, on the Navajo Reservation, in Boston, Ohio and Iowa. Her research interests focus on examining positive relationships in inclusive contexts, the nature of creativity as access to literacy, and interdisciplinary collaboration. Sauer's advocacy efforts for the inclusion of students with disabilities in community and educational contexts have also led her to explore co-constructions in portraiture research methodology.

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FORUM:

Memories and Re-Memories of My Mom's Eye Bandage: Trans-Relation Among the Norms,
Otherness, and Resistance
Sujung Um
Teachers College, Columbia University and
Jong Lye Won
Korea National College of Rehabilitation and Welfare

Abstract: A mother and daughter from South Korea construct re-memories about the mother's visual impairment. The paper uses the concept of re-memory that Toni Morrison uses in her novel, *Beloved:* the act of revisiting a memory in order to reconstruct "past realities." The aim is not to "tell" the story of what it means to live as a person with a visual impairment while being a single mother and working as a special educator in Korean society, or what it means to live as the daughter of that person. There is no attempt to claim an authoritative version of "our stories." Instead the goal is to recognize our own social construction and cultural conditioning through re-reading our shared memories. Conceiving ourselves as sites for cultural critique and social change, the presentation will interrogate the ways in which mother and daughter have been constituted by historically, socially, and culturally specific discourses. The presentation will interrogate the ways in which our memories and experiences are enmeshed in a web of ableism, classism, sexism, and ageism. Finally, the paper will discuss what ethical work mother and daughter may/can do on themselves as educational researchers and teacher educators.

Disability has been reduced to an "object" of discovery, learning, and practice. Non-disabled researchers have strived to establish systematic knowledge about disability. Through the authorial knowledge, disability has been *created* as a biological and psychological reality, which is fixed and explorable. James Charlton's (1998) book entitled, *Nothing About Us Without Us*, reveals the positioning of people with disabilities in the process of knowledge production. However, with the current debating surrounding the ethical and political questions of ethnographical representation of "the researched" (Britzman, 1995; Fine, 1994; Denzin & Lincoln, 2000; Miller, 2005), the conventional way of inquiring about disability has been reconsidered (Couser, 2005). With recognition of costs and limits of ethnographic representation of disability, increased attention has been paid to the genre of autobiography, autoethnography, and memoir authored by those who are subjected to the category (Biklen, 2005; Biklen & Burke, 2006; Blackburn, 1999; Mooney, 2007; Mukhopadhyay; 2000). Yet, the stories of individuals with disabilities are often read as if they portray transparent and generalizable "reality" of their experiences. Questioning the modernistic notion of a fully conscious, rational, and coherent story teller, in this article, we produce family narratives about a visual impairment that one of us, Jong Lye, "has."

We – Sujung, a doctoral student who studies teacher education from a disability studies perspective in the United States and her mother, Jong Lye, who is a professor of early childhood special education in South Korea – interrogate our own memories around the visual impairment. We do not aim to "tell" our stories of what it means to live as a person with visual impairment while being a single mother and working as a special educator in Korean society or what it means to live as a daughter of that person. We do not attempt to claim an authoritative and

completed version of "our stories." Instead, our goal is to recognize our own social construction and cultural conditioning through de-familiarizing and de-naturalizing our own memories. Specifically, we question why the absence of Jong Lye's right eye has deprived her from the opportunity to give an account of herself, why she has been coerced to normalize herself even when the norms demonstrate its arbitrariness, and why she has actively produced ableist discourses to resist it. Conceiving ourselves as sites for cultural critique, we seek to interrogate the ways in which our experiences have been formed by historically, socially, and culturally specific discourses.

It is important to note that we have encountered tensions while reconstructing new meanings of our memories. The tensions come from the irreconcilable struggle between the voices of Sujung who has experienced her mother's disability as a witness and Jong Lye who has been dealing daily with material and ideological effects of her disability; between Sujung's epistemological stance implicated by Disability Studies and Postcolonial Studies and Jong Lye's one shaped by constructivism and a conflicting blend of special education and Disability Studies; between our lived experiences and their transformation into written texts; and between our original transcript written in Korean and its translated English version. Therefore, our autobiographical narrative should be read as conditional, contradictory, partial, and in tension. Based on our lengthy and emotionally driven conversation, we craft the script in a dialogue format and organize it around the three themes: production of otherness through fixity, ubiquitous and yet arbitrary norms, and paradox of agency. Each section begins with Sujung's vignette of her memory and follows with our conversation about it.

Production of Otherness Through Fixity

A small bandage has covered Umma's right eye for as long as I can remember. I believe that she started to wear the bandage to avoid the unwelcomed attention that an absence of one eye brought. I still do not know whether she was born without the eye or lost it by an accident when she was young. I have never asked about her impairment because seeing her "difference" has been taboo in my family. When I was growing up in Seoul, Korea, most of my friends and their parents went to a public bathhouse every weekend. Taking their kids to a public bath was a weekend routine of most Korean families in 1980s and in the early 1990s, when hot water systems were regarded as something luxurious. Whenever Umma took my younger sister and me to a public bathhouse, she was interrogated about whether her right eye under the bandage was infectious. She used to respond to them by explaining that she injured her eye in an accident. She would not forget to add that she would be okay soon. That has been the way that I have also learned to satisfy other people's interest, curiosity, or concern.

SJU: Umma, I don't know where and how to start our conversation because we have never talked about your eye. Why haven't we talked about it?

JLW: Maybe I never wanted to have conversations about my eye? It has been something that gives me some sort of pain whenever I have to dredge up the issue.

SJU: I think I know what you mean… But, let me ask why it has to give you the pain.

JLW: My right eye is something I have strived to hide so that nobody could see it. I was born without my right eye. I have a crooked nose probably because the eye was not formed. The right side of my nose went up a little bit. Ever since I was young, I have been something that other people stare at. I was, and am still, sick of being looked at in disgust, pity, or even curiosity.

SJU: I'm amazed by how the simple act of looking can be a tool of violence against you.

JLW: It also worked as an efficient technique that taught me how strange, different, and abnormal I was, and still am. Any time people looked at me in "that way" they were pivotal in constructing the way I saw myself. When I was a little girl, I would play with my image…I would place a mirror next to the image of my face so that my left side, my good side, would be reflected up…this would make a perfect face for me to see. My perfect face—I thought I was beautiful.

SJU: I cannot find any words to describe how shocked and disturbed I am by this story. Since you were young, you've been learning what is normal and abnormal and which category you belong?

JLW: That is right. When I was in 7th grade, I started to wear an eye bandage. I do not exactly remember where I got the idea. But most likely, I was looking for a tool that could help me start over in relationships when I would meet new friends and teachers in middle school. I truly enjoyed the fact that I could decide whether or not to disclose my disability… although, I did not open it up in most cases. With a small eye bandage, I avoided being labeled as disabled as soon as they saw me.

SJU: Why have you strived to liberate yourself from the category of disability?

JLW: I did not want to allow the label to explain what or who I was and am. I felt that I was fixed as something undesirable, pitiful, or monstrous by a simple stranger's look.

SJU: You did not want to be associated with stereotype of disabilities. According to Bhabha (1994), the stereotype is an "arrested and fetishistic mode of representation" (p. 109) in the field of identification that always *fails* to account of someone. The strategy of the stereotype has been central in creating "the disabled" as a fixed social reality. You've resisted the ableist discourses that attempt to lock you in the rigid category.

JLW: You're right. I have tried to avoid being defined by and with the essentialized label. I did not want to be one of the objects sitting in a glass case at a museum and being explained with a small label and a short description.

SJU: I find it interesting that disability has been regarded as an object which people can establish complete knowledge about even though there has always been anxiety over the unfamiliar and ambivalent category. For what purpose and for whose benefits have the category been being mummified?

JLW: I don't have the answer to the question, but one thing I can tell you is that the determinist and essentialist stance plays a vital role in "othering" people who do not conform to hegemonic cultural and social norms.

SJU: I agree. If we put it in other words, it is a vital component of privileging those fulfilling the norms. Going back to your metaphorical statement, I could read the way in which epistemic violence (Spivak, 1987) was exercised against you by positioning you as a knowable object, not a knowing subject.

JLW: I haven't framed my experiences in that way, but I thought it was unfair that I would be explained with the label of disability while other "normal" people would be the author of the account for themselves. Maybe I have used the eye bandage to have the authority to define myself, although; it also has been a survival tool, which has allowed me to live in the ableist society.

SJU: Your eye bandage has such complex meanings… So, using the eye bandage as an instrument to control your body and identity, you have resisted to the epistemic violence. Would you explain what it means to use it as a survival tool?

JLW: With the eye bandage, I have been able to use the identity strategy of passing to gain inclusion into the ableist spaces around me. Many people think I am temporarily sick or injured rather than permanently disabled. I've learned that the way of interpretation allows me to be less alienated. With the simple devise, I could manipulate people's interpretation of my difference and break free of the constraints imposed by the "abnormality."

SJU: With the eye bandage, you seem to have been able to transgress the limits imposed on you to create a little space where you can be partially empowered and temporarily liberated. Yet, why have you been culturally and socially coerced to seek a way of "normalizing" yourself even when your normalization tool, the eye bandage, is a reminder of your "failure" to meet the expectation of normality?

Ubiquitous and Yet Arbitrary Norms

I had believed that people could see much more clearly from their right eye than from their left one like they could use their right hand more easily for chopsticks. One day, in third grade I realized that it was only me who could barely see from my left eye. In Korea, once a year, students from third grade take a physical checkup to measure their height, weight, eyesight, and hearing. On that physical checkup day my teacher called my Umma to share the unfortunate news that my left eye sight could not even be measured since I could not read any letter on the board. The next day, Umma took an early leave from her school and came to my classroom to pick me up to go to see an eye doctor. We spent almost half of the day in the hospital to figure out what was wrong with my left eye. My eyes were tested over and over with a number of different machines. After endless tests and a long wait, my name was called, and a nurse took us to the doctor's office. The doctor told Umma that my left eye was amblyopic and kindly explained what it meant. Umma looked ready to cry. As soon as we came home, Umma started crying bitterly as if she wanted to be compensated for holding up her tears on the way. I felt

terribly sorry for Umma. Maybe it was because I remembered she mentioned how much she was relieved when I was born with two eyes.

JLW: When your dad wanted to marry me, your grandma disapproved at first. The only reason was that I had a disability. She feared that a disabling condition might be passed on to a child. I was worried about it as well. When you were born, the first thing I did was to check your eyes. You had two, beautiful eyes. I cannot forget the feeling of profound relief. But, when I was informed that your left eye did not function well, I had a strong feeling that I could not describe. Complete sorrow and guilt... I suspected your eye abnormality was caused by me even though I never knew if my condition was genetic.

SJU: Wow… you've been dealing with various cultural expectations and norms as a woman, as a mother, and as a person with disability. Although it is painful to know that my dear grandma was part of the descriminatory discourse, it is not surprising to me that she as a shi-uh-muh-ni [mother-in-law] had the clearly set expectation on your role as myuh-nu-ri [daughter-in-law]: bearing "healthy" children with preference for a son, who can carry on the family line. The clear cultural expectation that having children *is* a natural and inevitable part of being a myuh-nu-ri seems to rob you of your rights over your own body.

JLW: What was more interesting to me was that no one regarded my disability as a reason that the cultural norm needed to be reconsidered. At that time, I was working in a special education school for students with intellectual disabilities. A main concern of the teachers and the families was how to "protect" our middle and high school female students from becoming pregnant. One of the underlying assumptions was that they should not be mothers since they would not able to take care of their child. Disabled women in many societies, including ours, often encounter pressures not to be a mother. Korean government currently allows abortion if the person or her partner has genetic mental or physical disabilities under article 14 of The Maternal and Child Health Act (2010). Interestingly, I wasn't persuaded not to have a baby despite your grandma's concern about the genetic possibility of my disability.

SJU: Ableism creates a fundamental paradox of the discourse of reproduction and motherhood. Why do you think that you were not discouraged from being a mother?

JLW: Probably, I was assumed to have the ability to fulfill the cultural expectation of motherhood especially since I was a teacher, which is considered a nurturing and caring job. It also resulted from your grandma's firm belief that it was my responsibility pass on the family line, especially because your dad was the eldest son. The complex interplay of sexism and ableism, which are grounded in blending of traditional cultural beliefs shaped by Confucianism and Western ideologies, shaped my experience of having you.

SJU: This story clearly shows that we are caught up in a realm of social norms. Our subjectivity and our experiences are socially and culturally constituted through the norms intertwined with relations of power. Remembering the day that I realized the "abnormality" of my left eye, I have been hunted by a question: why have I *not* been constituted as "the disabled"? I use only one eye to see the world, and so do you. Yet, I cannot recall any memories of

battling with the ways that other people look at me, resisting the stigma associated with my "abnormality", and being tortured with the paradox of having to accept marginalized status along with the pressure to demonstrate normality.

JLW: It is an interesting point, but it also brings me relief as your mom. You would be diagnosed as a class-6 visual impairment according to the Disability Rating Scale of Ministry of Health and Welfare in Korea (2003) that defines class-1 as the severest and class-6 as the mildest. I am categorized as a class-5 visual impairment.

SJU: Our impairments do not seem much different based on the "severity" according to the Korean government's definition. Why has my amblyopic eye colored my life experiences radically differently than yours have done?

JLW: It probably lies in the invisibility of the "issue" of your eye. The absence of one of my eyes surprises, fears, disgusts, or saddens other people because it does not fit in their frame of reference; however, your eye does not challenge their idea of what normal eyes look like.

SJU: That is exactly what I am intrigued by. What governs the politics of (in)visibility? Why is your non-existent eye visible while my amblyopic eye remains invisible?

JLW: I believe the notion of normality plays out in a relation to the politics of (in)visibility. The socially and culturally constructed concept of normality, which defines who has disabilities in a "common-sensual" way, has been taken-for-granted. Thus, people do not even know that the standards they often use to sort differences from sameness, ability from disability, and normality from abnormality are something that can be questioned. Our vision seems to be subjected to the hegemonic power.

SJU: The concept of normalcy leads people to assume that the categories of "the disabled" and "the abled" are mutually exclusive. But, my way of being is disrupted by *and* disrupts the assumption. I am conceived as non-disabled in my day-to-day contexts and, simultaneously, as disabled in Korean legal and policy contexts. I am positioned both as one of "the able-bodied" citizens who conforms the hegemonic cultural norms and as a person with disability who would need extra resources and supports from the Korean government. I am located in-between the presumed mutually exclusive subject categories. Isn't my body one of a number of examples revealing the ambivalence of the categories and the arbitrariness of notion of normalcy? Is my case not an exception of the borderline condition but the nature of the concept of normalcy? What ethical work we may/can/should do to disrupt the ableist discourses that constantly defend the boundaries and attempt to define what belongs within the realm and what does not?

Paradox of Agency

Umma has always been a smart and strong woman. Her mom, my grandma, used to say how she was exceptionally smart compared to her siblings and other kids. I was always proud of introducing Umma to my friends because she was a career woman who had earned advanced degrees unlike most of my friends' Ummas. Overhearing her conversation with her coworkers, I

also knew that her outstanding competency at work was admired and valued by other people. While she has always been my pride and my hero, I was often suffocated by her overemphasis on ability and smartness. To speak more correctly, I was frustrated whenever I encountered her normalized yardstick measuring someone's ability and smartness. She wanted me to get along with those who get good grades at school. She was unhappy about my boyfriend who did not attend a top-ranked college. While struggling with her overemphasis on ability and her unfair standards, I cannot deny that I have been privileged by her tendencies. When I received admission from a prestigious university in the U.S., Umma did not hesitate to allow me to accept it and to use our limited family resources to pay the awfully expensive tuition. She thought that not only would the college polish my talent, but its diploma would also serve as an indicator of my smartness, like a small warranty label guarantees quality of the product.

SJU: Umma, where do you think your strong emphasis on being intelligent and smart came from?

JLW: I don't know exactly, but I think it came from my family background, my social location, and who I am as a person. When I was young, my family was not affluent, actually poor. My parents migrated to Seoul from a rural area, whishing to establish your grandpa's tailor business in the big city. But, settling in the new area was not easy. They raised six kids with the limited resources, and they had to plan how to use the money for their children's education. Your grandpa decided to support his eldest son and me to receive college education. His rationale was that his eldest son would need the college education to lead the household, while I would need it to compensate for my disability and to live independently.

SJU: What did you think of his rationale?

JLW: I agreed with his idea that education was the instrument that would help me survive as a disabled woman with low socioeconomic status in the society. In the 1960s and 1970s, it was not the norm that women entered into the job market. Most women would become housewives and be supported by their husband. However, nobody in my family including myself thought I would get married due to my disability. Accordingly, I had to be prepared to have a job to support myself. The available jobs for women at that time were secretary, nutritionist, nurse, and teacher. I decided to become a teacher and therefore needed a higher degree.

SJU: Educating yourself was not a choice for you but an actual survival tool in the social context. Then, where do you locate your standard of smartness that I've always battled with as your daughter?

JLW: In school, I was a "model" student who got good grades and was adored and valued by teachers. Through my schooling experiences, I learned that my ways of thinking and learning were understood as smart. In addition, I've been growing and living in this society that decides people's smartness and their value based on what college, high/middle school, and even elementary school they graduate from. Wouldn't it be strange if I was not "contaminated" by what I have been seeing and learning?

SJU: I agree, Umma. We cannot be dependent on ourselves; we are always subject to the contexts in which we are located in nonlinear, unpredictable, and messy ways. While watching, experiencing, and living with you as your daughter, being "smart" seems like a driving force of your life. Umma, what does your "smartness" mean to you as a person with a disability who lives in this ableist society?

JLW: If my bandage is a "shield" that protects me from being "othered," my smartness is my "weapon" that challenges others' doubts about my ability associated with my "abnormal" appearance. While wearing the eye bandage, I could never get rid of the feeling of defeat. I sometimes see myself as a coward who is hiding behind the eye bandage, rejecting to "talk back" to the oppressive world. However, with my smartness, I could more actively challenge the ableist assumptions that other people might have about me. I could gain the respect of others and prove my worth. When I started my teaching job in the 1970s, the workplace operated in a male-centered way even though women were more numerous. Most female teachers easily gave up competing with their male colleagues for promotion. I was different. I would compete. I enjoyed having my intellect and capacities recognized. My smartness has not been merely a tool that offset my disability. Rather, it has been the foundation of my self-esteem. Yet, I am also aware of the paradox of my challenging ableism by (re)producing ableist discourses on smartness.

SJU: I would like to discuss the paradox. Your conceptualization of smartness, which has proven your value, might be the foundation of justification of other's worthlessness. Doesn't this paradox expose the nature of agency in subordination? You could interrupt the presumed fixed relationship between the label of disability and its connotation by demonstrating how capable and smart you are. As you make the label somewhat enigmatic or even inappropriate to explain who you are, you could question the discriminatory knowledge on disability. However, like you mentioned, while justifying your way of being, you might have been actively engaged in reproduction of cultural hegemony. Leonardo and Broderick (2011) conceptualize "smartness" as systems of ideology that operates simultaneously to privilege some people and to marginalize others in both material and ideological ways. Hasn't your way of resistance disrupted *and* constructed the mythical category of disability?

JLW: If I look at someone very closely and deeply, I often see what I have never noticed in the person. If I turn the interrogative gaze into myself, I notice "the problem" that I've strived to contest within myself. I am finding myself as the oppressor through the interrogation of myself as the oppressed.

SJU: Why does it remind me of Mamdani's book title, which brings me deep sadness, When Victims Become Killers? Your example complicates the conceptual opposition of the oppressor/the oppressed and reveals their complex relation. It seems that the categories do not exclude each other but rather blur with each other. Why have you had to turn yourself into a producer of ableist discourses in order to be free from it?

Discussion

Through this autobiographical writing, we inserted ourselves into our past and "re-experienced" it although we acknowledge that the past is not something to which we can simply "return." We did not aim to merely unearth what we had not been aware of; rather, we sought to construct new meanings of our experiences. As we revisit and interrogate our memories, we could read the partial "finger prints" of social and cultural conditions left on our "personal" experiences. In this section, we want to discuss what we have learned and what implication our leaning has for social researchers committed to production of counter-narratives in order to "create vision and imagination for what could be" (Weiss, Fine, Wessen, & Wong, 2000, p. 56).

First of all, through the interrogation of our memories, we have learned that Jong Lye has not been constituted as "the disabled" by her physical difference. Her "disability" status has been *created* through her daily experiences, which are formulated in the cultural contexts where her difference is conceived as "abnormal." Her "disabled self" is anchored firmly in the micropolitics of normalcy. The oppressive representation of her visual impairment in her day-to-day contexts must not be read as the reflection of the pre-given biological traits. Instead, through a frame governed by the concept of normalcy, social and cultural signs are arbitrarily but systematically constructed to signify her difference (Bhabha, 1994). It appears that the hegemonic cultural power asserts the fixity of the signs whenever she attempts to disrupt the ableist conceptualization of her difference. We do not claim our story as universal, but a number of people labeled with disabilities struggle with the deterministic and essentialized signs attached to their differences. To disrupt the process of overly determining them with cultural signs, we need to move beyond recognizing images of disability as positive or negative. As researchers, we must produce knowledge that enables us to understand the mechanism of disability subjectification. We must question the very frame through which "the other" is born although it also threatens our own existence (Butler, 2006).

Secondly, we, the researchers, have been haunted by the social and cultural norms. Yet, once we acknowledge how the norms are ubiquitous and yet arbitrary, we become able to see ourselves as liminal beings standing at the intersection of self/other, normal/abnormal, and abled/disabled. I, Sujung, find myself being characterized as "able-bodied" in my daily life while being labeled with class-6 visual impairment in the legal and policy contexts. I, Jong Lye, become more aware of the ways in which my "partial" presence of "the normal" is produced by normalizing strategies. By covering the absence of my right eye with a small bandage, I become "almost the same [as the able-bodied], but not quite" (Bhabha, 1994, p. 127). I, Jong Lye, am also able to cross the boundary of "the normal" partially and temporarily by demonstrating my "smartness" in a normalized sense.

Most people, like us, are framed with various types and degrees of privilege and discrimination simultaneously given by the ambiguous and arbitrary norms. It is important to acknowledge our liminal ways of being because it allows a new form of solidarity for social change to emerge. If we acknowledge our liminality, "Not Self and Other but the otherness of the self" (Bhabha, 1994, p. 63), the social change comes from neither one group's abandonment of privilege nor the other group's liberation from oppression. Instead, it is derived from everyone's active engagement in creative intervention for oneself as an oppressed and oppressive being. The social change also requires our collective efforts to challenge our cultural normative expectations

and re-inscribe social imagination. What we need as researchers is to develop analytic frameworks that enable us to recognize and understand the "in-between" spaces that have potential to revise meanings of the normal and the abnormal.

Lastly, we could acknowledge the complexity of agency through closely scrutinizing our memories. Jong Lye has rejected becoming a pure victim of the hegemonic culture. She has exercised her agency by negotiating the arbitrary concept of normalcy. She could transgress the limits that she encounters through demonstration of her normality. Yet, her act of normalizing herself also reveals that she is clearly marked by the hegemonic cultural power even when she resists it. Our example confirms Bhabha's (1994) assertion that not only are we constituted by the intersection of various power networks, but we also (re)constitute it simultaneously. He argues that agency is characterized by the tension between people as a priori of their national history and the people as its product. The techniques that Jong Lye has adopted to exercise her agency in her daily contexts challenge our pessimistic understanding or utopian vision of agency. As researchers, we might have put too much emphasis on how change agents work against the system while paying less attention to how they work against and within the system. Thus, we might not fully understand the complex and paradoxical ways in which one, who is not necessarily engaged in an oppositional act with political intention, constantly questions, disrupts, and reinscribes the ableist discourses on a daily basis. We need a more nuanced and complex analysis of agency that will stop dismissing hope for change as a too idealistic faith.

We, Sujung and Jong Lye, hope the narrative we produce here is not understood as a device that makes our personal stories public. We hope that our readers have been engaged in the process of reexamining our memories in the social and cultural contexts with us. While we realize that our work of de-naturalizing our taken-for-granted memories is partial and incomplete, we wish to create a tiny "crack" in the "canonical" discourse of disability.

Su Jung Um is a doctoral candidate at Teachers College, Columbia University. She is a former teacher who has served as a classroom teacher in an Elementary School in Seoul, South Korea. She earned a Master's Degree in Curriculum and Teacher Education at Stanford University. She is currently teaching at Woosuk University in Jeonju, South Korea. Her research interests include understanding inclusive and exclusive schooling practices from postcolonial studies and preparing pre-service teachers for democratic education.

Jong Lye Won is a professor in the Department of Care & Education for Young Children with Disabilities at Korea National College of Welfare. She is a consultant, author, advocate, and scholar who works with teachers and families to provide supports for young children with disabilities. She is a former special educator who has worked with students labeled as having an intellectual disability and emotional disturbance. Her research interests are full inclusion, teacher education, and positive behavior support.

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Growing Up: Disability and Cultural Dynamics in an Egyptian/American Family
Christine-Marie Youssef, M.S. Ed, A.M., LSW

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 Childrens 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."

Christine-Marie Youssef, M.S. Ed, A.M., LSW is an educator and a licensed social worker passionate about supporting and educating individuals with visual disabilities. She has a Master's of Science in Education specializing in teaching individuals with visual impairment and blindness and in Vision Rehabilitation Therapy from Northern Illinois University. She obtained a Masters of Arts in clinical social work from the University of Chicago's School of Social Service Administration. She is moving to the Seattle area with her guide dog, Sundance, to begin a position in the Vision Rehabilitation department at SightConnection, a nonprofit, which serves individuals with visual disabilities.

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The 'Othered' Sister: Family Secrets, Relationships, and Society
Melissa M. Jones, Ph.D.
Northern Kentucky University

Abstract: Through auto-ethnography, the intersection between family culture and a hegemonic culture of normalcy is explored. One sister's investigation of disability, as manifested through shared family secrets, acts of resistance against the public stare, segregation and isolation, and notions of incompetence, unveil evidence of historical oppressive practices.

I will never forget the phone call that came in the middle of a cold night back in February of 1984. On the other end of the line I could hear my mother's hollow words, "Tom's gone." Seared in my brain is the memory of confusion, wondering where my brother could have disappeared to. He did not drive, he had never gone off on his own before, and it was three o'clock in the morning. Where would he be? Patiently, my mother repeated, "He's gone, Missy. Tom died."

At that moment, the world slipped away from me. A chasm had been opened and I was being swallowed inside it. Up until that point, life had seemed so certain, but suddenly nothing made sense. I thought if I could only understand what had happened, then perhaps the pieces would fit together again. The scene that played out repeatedly in my head, as clear as if I had been there, provided no comfort to me. My mother on the phone with the life squad, my father sitting on the edge of the bed holding my brother's hand, his last look, his last breath. How the medical staff worked diligently to resuscitate him. In the end, Tom was still gone.

I have told this story, and written it, and rewritten it, countless times over the years, along with others that mark my life. Our stories of lived experiences signify our uniqueness and individuality, and the telling of these stories says something about our sense of self and how and where we fit in the world. Hidden in these stories, however, are also our connections with others. Sometimes they are only fragile filaments connecting us, but some connections act like heavy braided ropes. Regardless of the strength, these connections bind us with others. The ties developed through my stories are with other families who experience disability in a very intimate way because my brother - my big brother - was born with a disability.

Families that include someone with a disability are often resituated in the margins of society, set slightly askew from other families due to the unfamiliar and unknown. Wanting to avoid the voyeuristic nature of the abled, truths of family life are secreted away, like the practices of an underground society. One may know of them, or hear rumors and myths about them, but never truly understand what goes on in these families. Relatives who are compelled to hide the realities of family life may do so in response to the disabling social processes which contribute to misunderstandings of diversity in perceived ability.

Having a brother with an obvious ability difference, I know that bias toward individuals with disabilities does not occur in a vacuum affecting only those with a disability. The impact felt by family members is also very real. As private experiences can provide insight in to public

issues (Bullough & Pinegar, 2001), investigating my history as a sister of someone with a disability through a Disability Studies lens may offer hints into the historic, systemic exclusion (both social and physical) of individuals with disabilities that continues today. In reality, my history, just as the history of others, is a legitimate representation of a socio-historical moment in time (Bullough & Gitlin, 1995), and is investigated with this focus.

Weaving Connections Between Self and History: Finding Threads Through Auto-Ethnography

Over the years, I have intermittently engaged in journaling about my life growing up in a family where disability was part of our everyday reality. In reflection, I noticed during each opportunity I had to either write or provide an oral history about my life, I consistently told the same stories, over and over again. What was the significance of these stories? Why did they touch me so deeply, and what impact did each have on my current beliefs and value system? An even greater question was what these stories might reveal about the social and political realities families confront everyday. Studying the spaces between the self and history, or what Bullough and Pinegar refer to as the "arena of practice" (2001, p. 15), became in integral aspect of this reflective process, as I sought connections between our family's history and the public sphere. Like Wendell (2006), I was not satisfied with simply describing my family experiences, but strove to better understand them, dissecting and viewing them through a wide angle lens, investigating the intersection between society, identity, and representation, ultimately learning from these experiences.

As I began my quest, the old journals I had written were gathered, reflected upon, and analyzed. As I re-read the stories, I not only noted the repetition of stories, but also common phrasing and word choices. I tried to find what was lying beneath the stories by sifting through them, breaking each apart and looking for similarities across them including tone and emotion, as well as identifying what Mezirow (1997) referred to as any "transformative learning" (p. 5) incidents among them. The common elements were grouped in to themes, and then investigated through a Disability Studies lens, looking for connections to the social and political ideologies that permeated my family's life.

A Tapestry Undone

The process of auto-ethnography was an unraveling of sorts, as I slowly, and sometimes painfully took apart, stitch by stitch, the fabric that had enveloped our lives, investigating the strength, texture, color, and even worn-out nature of each thread. There were times when I contested and even resisted what was materializing before me, a necessary phase of the auto-ethnographic process (Hamilton, Smith & Worthington, 2008).   Understanding I hold legitimate knowledge as a sibling of someone with a disability, I juxtaposed the personal against the social and political representations of my experiences, recognizing the precarious balance that sometimes exists between biography and history (Bullough & Pinegar, 2001). Duarte (2007) suggested that auto-ethnographers situate themselves within context of a culture, group, or subgroup in order to compare experiences. For my purposes, I situated my stories alongside those of scholars in Disability Studies as a means for analysis, searching for shared epiphanies among us.

My story is a single thread in the tapestry that makes up the experience of disability across multiple people, recognizing that each of us "is a victim, vehicle, and ultimately a resolution of a culture's dilemmas" (Bullough & Gitlin, 1995, p. 25). Through intense reflection, my hope was to analyze my responses to life events as a sibling of someone who was perceived as having a moderate to severe intellectual difference, to better understand the struggles families encounter in schools and society today related to inclusive practices, perhaps offering a fresh perspective on some established "truths". The result was an unveiling of the connection between family secrets and peer responses to disability and difference, the public stare, segregation and isolation, and the negative connotations of mental retardation juxtaposed to a brother with competence and value.

The Meaning Behind the Stories Family Secrets at the Heart of Family Culture

Using Societal Thermometers

I learned the value of secrecy in my elementary years when a close friend stopped coming over to play. I had mistakenly confided in her about my brother hitting me during a moment of frustration. After that conversation, her parents would not allow her to return to my house, requiring us to play at her house alone. This one experience set the course of secrecy for me, not that I had anything to hide, but I learned early on that others may make judgments about my family or me due to inaccurate perceptions and accepted societal notions about disability. LeCompte (1993) talked about silencing as an act imposed on one by another, when people are "deprived of voice without their consent" (p. 10). For siblings, it is not that we lack the ability to speak for ourselves or share our stories, but when we do share our stories, we are often ostracized. This results in a deprivation of voice.

As a consequence, I did not announce to my friends that I had a brother with a disability, just as I never announced anything about my sisters, and I invited only a select few to my home. If friends visited, I watched with curiosity to see how each would react to our family makeup. My friends were my societal thermometers, testing the temperature of our cultural climate. How they responded to my family provided information to me about what others actually understood about disability. These early experiments were not intentional, but useful all the same, with my friends acting as signposts of understanding and awareness.

Solidarity in Silence

My two sisters, engaged in similar experiments as we united to protect our family from cruelties that spawned from ignorance and lack of experience. Our complicity in these experiments did not evolve out of an organized collusion but through an underground consciousness of shared experiences. We harbored the same unspoken fears, witnessed the same struggles, endured the same screams and cries, shared the same joys and triumphs, and were repeat victims of the same prejudices. We never actually talked about our collective experiences. The unspoken awareness that we each coveted our family story was enough to bind us together as a tight knit family unit, despite our personal differences. The history we shared forged our family culture, and as Charlton explained, "it is within the realm we call culture that we get our

bearings in life" (2000, p. 51). Our sense of personal and familial identity was intricately woven by our mutual family experiences.

Silence Bred Isolation

Although my sisters and I had a sense of solidarity through our experiences, my parents' experiences were born in isolation, as they made decisions with only each other to lean on, determining the appropriate avenues for solving problem issues and supporting my brother's continuous development and learning. There were no clubs, support groups, nor collective knowing from which to draw strength. At the heart of their isolation was the secrecy that cloaked many family experiences of disability.

In one neighborhood in which we lived, my parents befriended another family, resulting in children playing at each other's homes and our parents enjoying casual dinners together. Over time, my parents learned this family also had a child with a disability, who they had institutionalized at a young age. Although this couple knew my parents' situation with my brother, they had chosen silence and avoidance over conversation and dialogue. Their silence speaks volumes about the fear and shame that pervaded our society in the 1960's.

Today, many families have access to support groups, where families who live with similar circumstances can learn from and lean on one another, finding solace in camaraderie. The satisfaction, however, is short lived when we recognize the impenetrable barrier that continues to exist between families who live with disability and those who do not. This void, eroded by silence and secrecy, remains difficult to cross and contributes to the ongoing marginalization of family members.

The Public Stare and Acts of Resistance

Shared Experiences

Although there exists multiple dimensions of disability, making each person's experience unique, people with disabilities do share some forms of social oppression (Wendell, 2006), such as the public stare, or "the look." I was reminded about the look recently when in Denver co-presenting at a conference with a college student with Down syndrome and his mother. The focus of our presentation was on creating inclusive campus communities. While dining with this family, I became painfully aware of the stares of others, causing memories of the stares from my own childhood to wash over me. I was reminded of the resentment I had felt as a child toward those who demonstrated their curiosity, fear, concern, disgust, sympathy, or empathy in public ways, and I was confronted with the reality that even with all the work done in the field of inclusive education and inclusive communities over the past several decades, not much had actually changed.

The fact remains, individuals with disabilities and their families are often subjected to the public stare. It is one of the burdens of disability exposing "individuals to inspection, interrogation, interpretation, and violation of privacy" (Couser, 2006, p. 400). Wendell (2006) contended that the stares are born out of fear, ignited by perceptions of suffering, and that this

fear runs deep within our culture. Yet, my brother, just as the young man I was presenting with, did not suffer from anything. He had a good quality of life with a loving family, gainful employment, interests that were supported, talents that were capitalized. He contributed to his family and the community in meaningful ways, and yet, his presence continued to be responded to with reticence, caution, avoidance, and curiosity:

> "When we make people 'Other,' we group them together as the objects of *our* experience instead of regarding them as fellow *subjects* of experience with whom we might identify. If you are 'Other' to me, I see you primarily as symbolic of something else – usually, but not always, something I reject and fear and that I project on you" (Wendell, 2006, p. 251).

Perpetuating Oppression

The fear exuded by others was oppressive to my family and to me. What we considered normal was shunned outside the family circle, exemplified through a simple stare. My parents adopted cultural scripts of sorts, providing rehearsed answers to fend off inquisitions, but my sisters and I demonstrated our own acts of resistance by staring back, enough to make the curiosity seeker uncomfortable and turn away. We wanted onlookers (rubber-neckers, lookie-loos) to know what it felt like, responding to our oppression by oppressing others, being complicit in the preservation of oppressive practices. The 'othered' space of the margins is a space of resistance (Fine, 1994) not acquiescence. As a family, we found ourselves in the position to fight back at times, lashing out at those who threatened or questioned our balanced family dynamics.

In a study I did with teenage girls who had been identified as having an emotional disturbance, I noted their acts of resistance against the societal, organizational, and interpersonal forms of power to which they were subjected (Jones, 2004). I explained how this form of power over another is devastating because it acts to perpetuate the marginalization and oppression of others, similar to Willis' (1977) *lads*. Years later, as I reflect on my personal history, I am just now beginning to recognize my own oppressive responses to the oppression I was feeling as a child because of perceptions others had of my brother's disability, and question the connection these have to the personal and professional choices I make today.

Raised Consciousness

For me, the history of societal marginalization seeps deeply in my skin and penetrates my being, as my family confronted injustices both in solitude and in a sisterhood of solidarity. Whether threatening not to join the neighborhood game of kick-the-can unless our brother could play too, or making others uncomfortable through our own version of the public stare, the intent was the same – to stop the behavior that was causing us discomfort, and to cause discomfort in others. Charlton (2000) spent ten years studying about and with individuals with disabilities who became disability rights activists. Through countless interviews, he noted how each respondent shared anecdotes of experiences that spurred the replacement of a "false consciousness of self-pity and helplessness with the raised consciousness of dignity, anger, and empowerment" (Charlton, 2000, p.16). This evolution of identity does not seem to be just a reality for

individuals with disabilities, but also perhaps for those fortunate enough to be around them such as peers and family members. At least this was the case for us. Hall (1991) noted that history influences our sense of self, and that our identities are partly generated through the relationship one has with an Other. "Only when there is an Other can you know who you are" (Hall, 1991, p.16). The cultural responses to which we were subjected seeded our rebellious reactions. It was our way to show pride and demonstrate value for what we held dear, negating the derogatory and demeaning views imposed by others through self-righteous indignation and action.

The Message Behind Segregation and Isolation

Historical Testaments to Injustice

The picture is of a small class of students, huddled together on the front steps of a school building, each squinting in the sun for the benefit of the photographer. Bookended by two teachers, the tiny band of students remains frozen in black, white, and shades of gray. This is a snapshot of historical significance because it is a snapshot of segregation and exclusion. The photograph hangs framed on the wall of my office, a testament to my family history, struggles, and beliefs, and acts as a reminder of why I make the professional and personal choices I do. It is why I feel I always have to fight for, explain, or support something, and ignites my passion for confronting practices of exclusion and ignorance, because seated on the front steps of the school among this band of isolated students, is my big brother.

The school is segregated. My sisters and I never shared the same teachers as my brother, did not learn the same subject matter, and did not cover the same curriculum. We did not share the experience of participating in school or community sports, theatre, music or art. This picture signifies a historical practice that occurred in my lifetime, when children with moderate to severe disabilities were exempt from a public education.

In the 1960s and early 1970s, compulsory schooling was only for those who could learn the three R's. The message sent by the exemption status was that children with more significant disabilities were not worthy of public dollars, and that it would be a waste of anyone's time to try to educate them. A perfect example occurred when we were living in California for a few months before my father's transfer to Connecticut.

History Repeats Itself, Even in One Lifetime

I hold an indelible memory of my brother perched on a boulder at the end of our driveway waiting for us each day as we got off the school bus. Since we did not intend to stay in California long, it was easier for my parents to have my brother stay home during that time then it was for them to tackle the arduous task of finding a school that would accept him. When we moved to Connecticut in the mid sixties, and then eventually to Ohio in the early seventies, the scene was continuously repeated like a bad re-run, as my brother stood by the window and watched his sisters go off to school, college and jobs, living independently and away from home, and having opportunities that were not afforded to him.

On this last move, the school district in which my mom enrolled us recommended a sheltered workshop in another county for my brother, who was sixteen at the time. The workshop, a dismal place with insufficient work for the "clients," employed managers with limited experience. When my brother, who was only able to speak a few words, refused to go, my mother, through some investigation on her own learned that when no work was available, clients had to sit at tables with their heads down. She simply stopped taking him to the workshop, and to my knowledge, no one from the school system or workshop setting ever came looking for my brother or ask for his return. Thus was the end to his formal education.

The educational inclusion of individuals with intellectual disabilities has been confronted with strong resistance over the last century. In her historical account, Winzer (2002) described the blatant fear of the "feeble-minded," with eugenics advocates arguing for the institutionalization and sterilization of children with mental retardation, keeping students with significant disabilities out of public schools. Even with the push for increased educational opportunities for children with disabilities, "schools made it clear that they did not want trainables" (Winzer, 2002, p. 330), with institutions remaining the obvious option.

Although federal compulsory education laws were eventually enacted, multiple state rulings supported the continued exemption of students with more severe disabilities from attendance in public schools (Yell, Rogers, & Rogers, 1998). As recently as 1969, state courts "upheld legislation that excluded students whom school officials judged would not benefit from public education or who might be disruptive to other students" (p. 220), adopting the "all children except those" policies prevalent of the time. Progress was slow and hardly notable.

Responses to Difference

With the signing of P.L. 94-142, the Education for All Handicapped Children Act of 1975, children with disabilities were all at once guaranteed the right to an education. While too late for my brother who had quit the sheltered workshop around 1973, this law was intended to open doors for others. Although this law and subsequent reauthorizations, mandated compulsory education for all children, there continues to be a segment of the school-age population that often remains ostracized and segregated from the public school environment through the use of segregated classrooms and separate schools. When I ask the preservice teachers and teachers in my classes where the students with moderate to severe intellectual disabilities are educated in their districts, I often receive the response, "We don't have them in our school."

As Sapon-Shevin explains, "Exclusion is not about difference; it is about our responses to difference" (2001, p.26). Entrenched in the minds of many of my current graduate students who support the learning of students with intellectual disabilities, is the perceived need to segregate their students. Instead of recognizing what benefit students might gain from interacting with others who do not have disabilities, educators continue to focus on the differences among students as primary considerations related to inclusion. Constricted notions of ability and learning potential mask a student's value to a community, with society failing to recognize that learning is limitless regardless of perceived ability. While the use of terms such as "idiotic", "imbecile" and "moron" are frowned upon in contemporary society, what society understands about the abilities and competence of individuals with intellectual disabilities remains stagnant,

with any budding awareness derived out of politically correct responses and not a true valuing of difference.

We need to raise our cultural consciousness to unveil the hidden assumptions about individuals with intellectual disabilities that foster exclusion. If we can rupture these tightly held beliefs, then we may be able to move beyond seeing disability as a "condition people have, but instead a social negation serving powerful ideological commitments and political aims" (Connor, Gabel, Gallagher, & Morton, 2008, p. 441). In contrast to segregation, inclusive classrooms can create the space in which students learn to take a stance against oppression, recognizing their own agency and power to make substantive changes (Sapon-Shevin, 1999), leaving a legacy of equality in their wake.

Notions of Incompetence

The Creation of Artificial Identities

In 1954, doctors told my parents my brother would never roll over, never crawl, and never walk. They were told to institutionalize him before they became too attached, because watching him suffer would only break their hearts. In this instance of medical sympathy, disability became synonymous with incompetence. Through conceptualized notions generated by those deemed abled and competent (Charlton, 2000), a social stigma prevailed over reality, creating an artificial identity for my brother and an undesirable (if not unfathomable) fate for my parents. Ferri (2008) called for a challenge of "reductionist understandings of disability" (p. 499) such as these, unpacking notions of incompetence and disability, providing competing frameworks through which others can view ability as a means for changing the disability paradigm in the United States.

I witnessed these competing frameworks every day growing up, as I was constantly reminded of not only my brother's abilities and interests, but also of his character. He was honest, loyal, nurturing, independent, curious, mechanical, industrious, and musical, among other things, hardly the terms traditionally used to describe someone with an intellectual disability. As his sister, I resisted the notion of him being defined by his limitations because those did not seem to be the prevailing characteristics of his being. What was so difficult to witness and continually confront was the myopic view others had of him, focusing only on the areas in which he might need support instead of what he could meaningfully offer in return.

Competence Versus Incompetence

Competence, as defined by Jenkins (1999), is "the capacity or potential for adequate functioning-in-context as a socialised human" (p. 1). If competence represents a socialized humanity, then incompetence must refer to a lack of humanity. The characteristics differentiating competence and incompetence are constructs that are contextually varied across era, setting, and culture (Jenkins, 1999), generating a composite of human variation to colonize people in to homogenous groups that are not homogeneous at all. Our cultural conceptions and interpretations of [in]competence, personhood and identity, profoundly affect the way in which people ultimately come to understand, relate to and treat people with an intellectual disability

(Edgerton, 1993). It will require a careful deconstruction of these cultural practices in order to eradicate them.

The idea of incompetence in disability proliferates from the accepted notions of normal. As Davis (2006a) contended, "The 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 3). What is considered an allowable human variation of universal traits is produced by a "hegemony of normalcy" (Davis, 2006a, p. 4), with concepts of normal and the abnormal continuously reinforced in public ways. Within each society, variations exist as to what constitutes normal, but "at what point does this variation become disability?" (Wendell, 2006, p. 245). While much of the Disability Studies literature focuses on concepts of an idealized body, as a society we also idealize a concept of intelligence that inhibits our ability to embrace and value intellectual diversity.

Challenging Paradigms.

Throughout my life, I never felt the sense of loss some parents describe when they learn their child has a disability, probably because I never envisioned my brother as broken or less than. The loss I felt was only in his death. This belief in parity among siblings became fully apparent to me during his funeral, when someone commented that at least Tom would not be disabled in heaven. I remember thinking, "Why not?" There was nothing wrong with him in the first place. If there was a God, would she/he have to change Tom before permitting his entrance through the pearly gates? I recognized then, in a state of awakening, that something was inherently wrong with this form of reasoning offered by a sympathetic friend.

Disability is "itself an unstable category" (Davis, 2006b, p. 237), revealing the absurdity of corralling individuals with disabilities in to artificial groups. Labeling individuals with intellectual disabilities as incompetent and less than is an arbitrary categorization of heterogeneous people, creating false subjectivities. Instead of sharing these patterns of thought we need to shatter them, moving away from degenerative toward regenerative beliefs about ability.

From Pathology to Equality: Moving Beyond Difference

Advocating for Social Change

This essay was meant to be generative, moving beyond self-reflection toward a social change in perception, doing what Garland-Thompson (2006) suggests, unmasking and reimaging disability "not only for people with disabilities but for everyone" (p. 259). In our family, we were all subjects of care and oppression, as well as givers of care and oppression, creating a balance across birth order, gender roles, and perceived ability. Disability was not as apparent within the confines of our home as it was outside the walls of our house, supporting the perspective of disability as a social phenomenon, congruent to the perspective of Disability Studies scholars and activists (Conner, Gabel, Gallagher, & Morton, 2008; Gable & Danforth, 2008; Simmons, Blackmore & Bayliss, 2008; & Terzi, 2004).

Family Cultures of Disability

While I remain unclear about the parameters of a disability culture, per se, as Brown (2002) contended, I am fairly certain there exists family cultures of disability. Although my parents practiced inclusion in our family before the term was ever coined, the world around us taught us about separation, perceived inferiority, and exclusion. My parents quietly fought the fight as they diligently demonstrated to us all that each person deserves to be loved, to be included, and to be a part of something. Through their actions, they also taught us that each person deserves the opportunity to have a dream and to follow that dream, creating an environment in which their children could all find success.

Learning to Think Differently

Whether oppression comes from an Other as Russell (1994) promoted, or promulgated within systems of structures, as Charlton (2000) described, the end result is the same. Disability remains a fundamental aspect of human diversity and is an "inescapable element of human existence and experience" (Couser, 2006, p. 399), not to be ignored, isolated, or devalued. Helping others to recognize this fact is a painfully slow process, with awareness secreted among small pockets of informed and self-determined individuals. What we need is what Eiesland referred to as "cultural resymbolization" (1994, p. 98), producing counter images that alter the way we think about and imagine disability in order for radical social changes to unfold.

I disagree with Wendell's (2006) call to abandon the term *differently abled*. In fact, I think it is how we should describe all of us, as we are each differently abled from each other, with variations of strength, talent, gifts, and interests. The error is in using the term only to describe individuals with perceived disabilities as we, as a society, continue to try to create pathology for our human variations. Acknowledging these variations instead of fearing them is an important step to a progressive cultural consciousness that recognizes and finds comfort in the fact that we are simply different… and simply the same.

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What's Behind the Curtain? A Family's Search for an Inclusive Oz
Janet S. Sauer
University of Colorado

Abstract: Families are moving at ever increasing numbers. Relocating a family is challenging under any circumstance, but transitioning a child with a disability between schools, especially to new states or countries can be particularly difficult. When families seek full inclusion, the situation becomes more complex. This paper describes one American family's journey through the moving process and how that process brought to the surface ways in which disability is socially and culturally constructed. Despite federal legislation in some countries regarding special education and the involvement of families, practices differ geographically, sometimes significantly, when determining eligibility, communicating with parents, and discussing how support services will be provided. The author - a parent, educational researcher, and instructor of pre-service teachers – asks questions throughout the family's relocation and examines people's "storylines" or habits of conversation (Gee, 1999) to get at underlying assumptions. Related research and implications for improving educational practices are discussed.

Keywords: disability, narrative, special education

Seeking an Inclusive Land of Oz

While sitting at my kitchen table in rural Iowa, a Midwestern American state, I phoned one of the schools on my list. "What's your child's IQ[1]?" asked the special education teacher on the other end of the phone. She continued, "If he's below 70, we have a great Life Skills program[2]…" I was researching schools in a different state within commuter distance of where I was soon to begin my new job, trying to find an inclusive community where my two sons would be welcomed. When I first asked the Middle School teacher about their special education services for my eleven-year old, she sought his diagnosis, but I did not answer her question, instead choosing to explain "Iowa is a non-categorical state," meaning the label from the American Psychological Association's diagnostic manual was not included in my son's Individual Education Plan document. "Okay, but what is his disabling condition?" she asked, to which I responded, "He has difficulty with expressive communication. It's hard to understand his speech and because of his fine motor delays, he has trouble writing so we're working on typing…" She did not appear to be interested in hearing the details of my son's educational support needs. Instead, she persisted in asking for a label, something which I felt she would use to categorize him and strip away his individual human qualities. I was trying to figure out from the phone conversation what my son's educational experience might be in her school. I was seeking something similar to what we had in a rural farming community school where there were no Life Skills programs because there were too few children with disabilities to justify any "clustering" of those with similar diagnostic labels, or because the small town neighborhood school did not fall victim to external, top-down programming structures that some other districts, even those not more than an hour's drive away, seemed to embrace.

In the end, I gave the teacher an answer close to what she wanted: "Trisomy 21," I told her, choosing to emphasize the medical diagnosis in lieu of the more commonly used term "Down syndrome" in a weak effort to disrupt the typical discourse around students with this

label who are often referred to as "Down's kids" implying they are the children of Langdon Down, the British physician who first described what he called "Mongolian idiocy." I ignored the teacher's subsequent reiteration of the question about IQ score, not because I did not know the answer, but because I wanted to share what I thought was relevant: "He's been fully included throughout his schooling. I have current curriculum-based assessment results, work samples illustrating how teachers adapted lessons for him this year in 5th grade, and results from standardized testing. He loves to read and enjoys school, especially his friends." Rather than engaging in this conversation with me, she said, "When you come, we'll begin by testing him and determining his IQ." I thanked her for her time, hung up the phone, and crossed out the school's name on my list. I felt as though she, and many others with whom I talked on the phone, could not share the vision my family had of a successfully inclusive schooling experience for our son. I wondered if this teacher thought I was unrealistic, that I was like the disillusioned girl named Dorothy from the American children's novel The Wonderful Wizard of Oz (Baum, 1900) who was swept away from the comforts of her rural Kansas life in a tornado, and who became lost in a land of poppies and faced many barriers to find the Wizard who would return her home. Although I was not disillusioned, it seemed as though I was lost in a list of schools in an unfamiliar state seeking some kind of Inclusive Land of Oz, but instead of finding the humane Tin Man, the courageous Lion, or the insightful Scarecrow, I was running into Wicked Witches who stood in my way.

Through a combination of auto-ethnography (Ellis & Bochner, 2003) and narrative (Connelly & Clandinin, 2006), I tell the story of our family's move across the United States using the classic tale of the Wizard of Oz as metaphor. This blurring of lines between researcher and "subject" is intentional in auto-ethnographic work, offering a resistance to jargon and instead presents a narrative of daily interactions (Ellis & Bochner, 2003). In the Baum (1900) story, Dorothy was in a foreign land in search of a way back home just as we sought a place we could call "home" in an unfamiliar context. I found the prospect of thinking critically about and reflecting upon our decisions as they related to other research might be valuable to others who work with families on the move or who themselves might be moving. As such, it was useful to use narrative methodology "to adopt a particular view of experience as phenomenon under study" (Connelly & Clandinin, 2006, p. 375) and to analyze my personal experience through a social-cultural lens (Ellis & Bochner, 2003).

Families are moving at ever increasing numbers and many of these families include a child with a disability (Center for Global Development, 2010; McLachlan, 2008). In a British study of families moving internationally, McLachlan (2008) described significant disruptions to families that had been previously unreported. She emphasizes the importance of schools and families working together to mitigate the stress children experience. Relocating a family can be a challenge under any circumstance, and my husband and I were especially concerned about how we could support our children through the transition. We moved from the upper Midwest to the American West, from a rural community to a city. At the time, we had an 11 year old with an Individualized Education Program (IEP) and a 9 year old who qualified for a Gifted and Talented Program; we sought an inclusive community for both of them. By this we meant more than a placement option in the "least restrictive environment," but rather a philosophical understanding of the naturally occurring diversity within our humanity where interdependence is valued and

impairments or disabilities are not stigmatized. We sought a community where neither child would be segregated but both would be welcomed as equal individual members.

As educators my husband and I knew services differed, sometimes significantly, between states and districts (Carlson, Brauen, Klein, Schroll, Willing, & Westat, 2002; Kluth, Biklen, English-Sand, & Smukler, 2007). We also knew interpretations of the Least Restrictive Environment (LRE) principle of the Individuals with Disabilities Education Act (IDEA) differed by category classification (Beratan, 2006; Downing, 2008; Grove & Fisher, 1999; U.S. Department of Education, 2006; Smith, 2010). We also found a paucity of research about the impact of moving on families that included a child with a disability with only a guide by the National Dissemination Center for Children with Disabilities and a few studies that I discuss in the following section. General information about transitioning students with disabilities tend to focus on young children as they enter public schooling and young adults' transition from the public schools to post-secondary school or employment. So, we anticipated a lengthy road ahead of us as we set out to find an inclusive school and community.

Two months following the relocation, our efforts to find an inclusive school were largely successful, not the land of inclusive Oz, but a fairly good "fit," that captured what Hansen describes as positive spaces of respect, acceptance, and support (2005, p. 34). This paper describes some of what we thought were preventative actions we took that seem to have made a significant positive impact for both of our children, and how the process of moving highlighted the social and cultural construction of disability. In a way similar to what Dorothy found when she looked behind the Wizard's curtain, we found some troubling realities based in human fear and prejudice. Like Dorothy who "dared to question the Great and Powerful Oz," we took extra time to more closely examine several schools' practices and underlying philosophies, to look "behind the curtain" of how schools purport inclusive mission statements, but who might otherwise practice socially isolating acts under the guise of special education.

I must acknowledge that my education, social class, and White ethnicity afforded me a more powerful opportunity to question school personnel than other families who might not have this social or financial capital at their disposal. In fact, I found the role of privilege in the special education process disturbing and consequently examined this issue in a separate paper (Sauer & Albanesi, 2012). Therefore, I understand the limitations of this narrative because of that privilege and I do not want to suggest that the choices my family had are the same as others and should not be used by the system as a weapon upon families with perhaps fewer choices. Such capital in fact has been argued to work against systemic change in what is for many discriminatory (see Skrtic & McCall, 2011). In any case, regardless of our cultural capital, there were some things we did not do as well as we might have and I share these insights as well.

Home in Kansas, No Iowa – Clarifying Vision and Understanding Rights

The birth of our first child set in motion a frequent challenge to our inclusive beliefs that we had always espoused, that education and the pursuit of happiness for all is a civil rights issue. Over the years my husband and I engaged in many discussions about our vision and priorities for our children. We became increasingly informed about the importance of legal rights and knew that relocating our family would involve researching legal precedence in the place where we

planned to move. In their guide, *Moving to a New Location,* the National Dissemination Center for Children with Disabilities (NICHCY, 2009) advises parents to begin by familiarizing themselves with federal legislation. Before our son was born I was a practicing special education teacher and therefore familiar with the principles of Public Law 94-142, better known as the Individuals with Disabilities Education Act (IDEA).   Since his birth and the confirmation of an extra twenty-first chromosome from a blood test, I (re)entered the world of special education, but this time from the parent perspective.

My husband and I felt the medical model that seemed to permeate most of the early childhood intervention programs conflicted with our inclination to approach our son as a complete person and include him in all aspects of family life. Despite his successes, we repeatedly we found ourselves having to defend our son's inclusive education referring to the process of negotiation as "the fragility of inclusion" (Sauer, 2007). We referred to and exercised our rights to direct involvement in our son's Individualized Education Program (IEP) and although on occasion we involved parent advocates, we never exercised our Due Process Rights (though we felt empowered knowing we could). So, we knew our rights and we knew we wanted an inclusive educational community. In an effort to find the best "fit" and minimize surprises, it seemed important to learn as much about prospective schools options as possible, to help in making the decision of where to move more specifically.

<center>The Cyclone Hits! Chaos and Questioning</center>

In spite of our professional knowledge and sense of certainty about what we sought, we felt unsettled emotionally. Was the move a selfish ploy to advance my career? What would be the unintended consequences? Despite the frustration we had on occasion with our Iowa lives, would we ever find the same comfort that came with familiarity and local understanding (Kliewer & Biklen, 2007)? After I was offered the new position out of state, my husband and I entered into a discussion about the possible negative consequences of moving for our children. We found little written about this topic regarding families including a child with a disability other than the NICHCY piece and a national study about twelve families who moved in search of a more inclusive school for their children (Kluth, Biklen, English-Sand, & Smukler, 2007). The NICHCY paper begins:

> Moving to a new location disrupts your life! For any family this can be a time of chaos. There is the adventure of newness but also a maddening confusion. Everything and everyone is certainly somewhere, but where? You have to find new grocery stores, new roads, new schools and new doctors. You have to unpack and reorganize your home and your daily routine. You have to make new friends, meet new neighbors and establish new systems of support and help. For a family with a child who has special needs, the confusion can be particularly stressful. (NICHCY, 2009)

The NICHCY paper goes on to outline a series of "To Dos" to make the IEP, assessments and medical files current, and to research the particular state's structures, entitlement procedures, and differences in local school practices, but it does little to address the social-emotional aspects to moving for families.

On the other hand, Kluth and her colleagues (2007) conducted in-depth interviews with families who moved and thus, in addition to the logistical and financial challenges, their article described many of the families' feelings of guilt, frustration, and disappointment throughout the relocation process. Although these researchers purposefully excluded families like ours who were moving for professional reasons in their study, we found the issues parents described personally relevant. For instance, they refer to parents' anticipating the inevitable "price to pay" for moving that could have negative implications for siblings as well. When we first told our children about our possible move, our younger son explicitly stated that he did not want to move and he proceeded to cry, a cry that would resurface unexpectedly and repeatedly throughout the move. Families described "finding inclusion was different than finding a place; it was more an idea than a location" (Kluth et al., 2007, p. 52). We agree with this sentiment and feel that inclusion is a belief and moral value about accepting the range of human experiences. Our search for an inclusive community was one where we wanted *both* of our children to feel welcome and benefit from an engaging education. We sought a community where coming from a different place was not stigmatizing – something my husband and I had always felt as adults in our rural Midwestern town since we moved there from another state 13 years prior – and one where our older son's differences would not be devalued and our younger son would not be made to feel embarrassment of his brother's disability such as the experiences reported by other siblings (Meyer, 2005). With both boys showing interest and talents in the arts, we also hoped to find a place where they might have a greater range of artistic instructional opportunities.

Our eldest son was soon to turn 12 years old and he had genuine reciprocal friendships with classmates with whom he had socialized since childhood in school, soccer and the local library's reading and music groups. Would a new community and school be as accepting? Would he make new friends? These of course are questions many parents ask themselves, but we were also familiar with research that showed the additional barriers that existed for students with disabilities in the attitudes and resulting practices of teachers and students without disabilities (Hansen, 2005; Palmer, 2002; Siperstein, Parker, Bardon, & Widaman, 2007). Additionally, our boys were close in age and the older son, the more social of the two, had always been there supporting his younger brother - yes, the one with the so-called disability was often the one leading the way in social contexts. The move, however, would mean they would no longer be in the same school, not because of the disability, but because of their chronological ages. We learned that the area where we were going had adopted the middle school philosophy[3] and since the boys would be entering into grades 6th and 5th respectively, they would not be attending the same school. Furthermore, the move would mean an overall financial hardship on our family, undoubtedly something that would add to family tensions.

Though we kept all of these concerns in mind, we opted to focus on the positive aspects of the move. First, the children would have greater exposure to culturally diverse people and experiences in a city than they had in the rural community of 200, mostly farming families, where they were born and raised. In Iowa our combined daily commutes to and from work totaled 120 miles and moving meant we could live closer to work and save both time and money. Ready access to a city provided both children with greater opportunities for employment when they came of age and public transportation would be available should either of them not get driver's licenses.

We learned to take stock in what we knew and felt. We were comfortable researching specific legal protections or court cases involving families and schools in the communities where we considered relocating. But we found we needed more time to assess and discuss our family members' feelings and to clarify our priorities. These sometimes awkward conversations seemed to provide us with greater clarity regarding our family's values about justice and equality.

Follow the Yellow Brick Road

Immediately upon deciding to move, we began researching schools located close to my new place of employment. Ours was not a literal road like the one of yellow bricks that led Dorothy through forests and deadly poppy fields, but a metaphoric one representing similar challenges along a journey. To get a general sense of educational options in the area, we used the internet to explore school districts' homepages, reading their strategic plans, school board minutes, and current newsletters. One district provided the results of a recent survey they had conducted on parents' experiences with their schools' IEP processes. We also read local newspapers where we learned there was an impending redistricting plan. Additionally, both boys explored school websites alongside us, asking questions about the school's lunch options and schedules. Their questions and perspectives expanded our original set of research questions and it brought them into the act in a meaningful way. Our younger son's question, "Is it normal to bring your lunch from home?" led us to further discussions about 'What is normal?' and reaffirmed our family unit as a team, something more important, we insisted, than being accepted by others. This initial research phase provided us with information about the huge variability in the sizes of schools, teacher to pupil ratio, achievement results and the general financial state of education in the region. While sometimes people will also examine real estate to get an idea of "preferred schools" based upon the socio-economic status of the local families, it is more difficult to use numbers to understand the underlying beliefs that drive daily school practices.

Having worked in schools for nearly twenty years, teaching, supervising student teachers, collaborating with teachers, and conducting research, I knew that a school's outward appearance as viewed through their mission or official statements does not always accurately reflect the inner workings, beliefs, or daily decisions of a school. How could we find out what was being done in schools every day? How did the teachers, the other adults in the schools, and the children talk about or engage with diversity issues? We wanted to know what the daily interactions might be like, but we did not have the opportunity to visit the schools, and even if we did, would the people giving us a tour speak freely and wouldn't the teachers and children be "on their best behavior" for the visitors? From my professional background knowledge about discourse analysis, I had become sensitive to the way in which language, whether written, spoken, or expressed non-verbally, serves "to support human affiliation within cultures, social groups, and institutions" (Gee, 2005, p.1). In other words, although this was a lived experience and not a study, we began to reflect upon the words people used to describe their schools, students, and communities to see if they might reveal underlying assumptions and beliefs. For example, I began the piece quoting the teacher who asked for my son's IQ score, a clear indication that she thought this number was the most important information she needed to make decisions about what my son needed in order to learn despite extensive literature questioning the validity of these scores and their supposed predictive qualities concerning intelligence

(Borthwick, 1996; Donnellan, 1999; Gardner, 1983; Gould, 1981; Plucker, 2003). On the other hand, when school websites touted the virtue of the people who worked in the schools and echoed the use of the word "relationships" as symbolizing their communities, they reflected a different, more inclusive discourse.

Looking "Behind the Curtain"

In the children's story, after a long and terrible journey the young girl, Dorothy, is finally given an audience with the Wonderful Wizard of Oz. When the Wizard does not agree to fulfill her request to be sent home, Dorothy's dog pulls aside a large curtain behind which is a little old "common" man, who she discovers had no magical powers at all. In our journey we used the phone and email to contact educational administrators directly asking both general questions (e.g. "Tell me about your school") and specific questions about their special education services (e.g. "How do you educate your students who might need special education support?"). In our effort to find the inclusive "fit" we sought, we needed to look more closely, to look *behind the curtain,* to listen more deeply and think about the meaning behind the words. We were looking for an inclusive philosophy to be actualized through action; we sought specific examples of inclusive practices that reflected inclusive beliefs. The opening scene provides an example of one conversation where once I provided the teacher with our son's diagnosis, we quickly learned he would be tracked based on his results of a battery of intelligence tests given to him by a complete stranger immediately upon moving to a new state and home. By contrast, a special education administrator in another district began by asking about our son's achievements, his skills with various academic and social demands. After conversing at length, I told the administrator about the previous district's request for an immediate IQ test to which she responded dismissively, "Oh, we don't do that anymore." Her response suggested a more closely aligned philosophy to ours.

Administrators can significantly influence a school's culture, but occasionally they move on and schools return to entrenched practices. Sometimes the support staff, who are less likely to leave their positions, more accurately reflect a school's culture. Therefore, we frequently engaged administrative assistants in conversations which informed our developing pictures of various schools. For weeks we continued making phone calls and exchanging emails with school personnel in an effort to narrow our search. We also identified parent support groups such as the "Parent to Parent" organizations (P2P) and advocates via the internet and sought their input. One advocate described her experience with a local district this way: "They are pretty good. I don't get lots of complaints about them." In hindsight it is interesting to realize we had not engaged one general education teacher in our research; we think one reason was their general inaccessibility, or they need not be further "burdened" by potential parents, or that we, too, had engaged in what Gee (1999) refers to as "storylines" or habits of conversation. Regardless of the reason, the irony did not escape us, that they are the very people whose philosophies about and practices with educating their students with disabilities are exactly the people who can have the greatest direct impact on our children's education (Interstate New Teacher Assessment and Support Consortium, 2001).

We engaged in two facets of research. The first was practical and meant updating the current IEP and seeking advice and involvement from the originating home school. The second

involved examining the underlying meaning behind what people said. In our relationships with all of the players back at the originating home and while developing relationships with people in the various possible future home sites, we found it valuable to ask probing questions of as many people as we could and carefully consider *how* they engaged us. Also, we sought out specific examples to support claims made about the procedures and practices of school support teams. Although we felt we had gathered a great deal of information from a distance, we knew we would need to make a trip and walk the halls and neighborhoods of the prospective schools in order to get a better sense of each school community.

The Reconnaissance Trip: A Split in the Road

With a copy of our son's new IEP and a folder of his work samples in hand, we went out West. We had scheduled appointments to visit two school districts which we felt best met our priorities for inclusive school communities and affordable housing, based upon the information we had collected thus far. From afar the two districts were similar, providing housing that was within close proximity to the schools and that offered our family small enough schools and neighborhoods that it would not be such a dramatic change from our rural Iowa community. The school principals and other personnel were all friendly on the phones and willing to meet with us and give us tours. They indicated it was the last week of the school calendar so we should not expect typical school days. I reminded them that both my husband and I had been school teachers and would not be surprised to find disturbed routines.

The obvious differences between the two districts were how they had chosen to structure the schooling for their 6-8th graders. In what I will hereafter refer to as District A, they had a Junior High (JH) for grades 7-8, because, as one principal put it, "The students need to be prepared for High School." "We are not a Middle School," she clarified, distinguishing her district from District B. Their newly-built JH was impressive but equally imposing I thought as I entered the large, modern, entranceway. It drew students from several elementary schools, three of which I visited. We visited schools by day and houses by night. In the "off time," we examined the district maps we had received from the realtor trying to match the houses we had visited with their respective schools. District B had chosen the Middle School model where grades 6-8th were educated in one building; they drew their students from three small elementary schools. There were houses in both districts we could afford and which offered comparable advantages, so the decision essentially came down to the schools.

In addition to meeting principals, for the greater part of a week we engaged janitorial and office staff, teachers, parents dropping off and picking up their children, and the children themselves. We took note of the location and support service structures for the enrichment and special education programs. We were disappointed to see separate "resource" classrooms for students in both schools and to learn the state used categories to determine eligibility for special education. Both schools touted teaching all children but there were subtle ways in which we began to see markedly different foci between the two districts. Though both districts reported similar achievement data, our conversations with people in District A repeatedly focused on students' standardized test scores, whereas our conversations with people in District B centered on relationships. With a laugh one principal from District A shared how a parent of a kindergartener already had pegged his daughter as a future graduate of the prestigious Yale

University, suggesting a tone of presumed class privilege. Her comment was one of many in which we became concerned about what seemed like an inordinate pressure on students' test performance. Our younger son, whose standardized scores qualified him for the Gifted and Talented Program, had expressed heightened anxiety regarding any tests. We shared this concern with the elementary principal in District A, who then assured us she was familiar with students like our son and she gave us her home phone number offering to let our son talk with her on the phone before the move. We were comforted somewhat by her comments but we wondered how the atmosphere might negatively impact both of our boys.

The principal from District A interacted kindly with the children who lined up in the hall, but it was nothing like the enthusiastic greeting a principal in District B received from the children who hugged him and begged him to listen to their stories they had written about their community. The principal from District B had said, "We welcome *all* kinds of kids here," emphasizing "all" with his tone of voice. Furthermore, we observed a powerful spontaneous interaction between the Special Education Director in District B and a student who used an augmentative alternative communication device which suggested to us that students with significant disabilities were included in the natural hallway discourse of the Middle School. The reconnaissance trip reminded us of the importance of doing our logistical homework and reevaluating the underlying meaning behind what and how support services for students with disabilities are enacted. In hindsight, it's become abundantly clear that we benefitted from our cultural and economic privileges in this process and the inequities weighed on my conscience creating a tension between advocating for my son and the possibility that my efforts inadvertently contributed to the perpetuation of systemic discrimination against families of color or those with less capital (Sauer & Albanesi, 2012).

Not Quite the Inclusive Land of Oz but a New Home

Upon returning to Iowa, we discussed our decision to move to District B. The children gathered their friends' addresses, emails, and phone numbers during a going-away party put on by their teachers. School ended and we decided before the actual move, we would camp near our new neighborhood, and visit the schools there. The camping trip helped demystify the changes ahead and provided our family with time to reaffirm our interdependency and, with fewer distractions, the reasons behind our decision to move.

Despite all of our best efforts, once we moved, the children still exhibited some anxiety about starting at a new school asking us a series of questions about when their Iowa friends would visit and they sought assurances that we could move back to Iowa if we did not come to like it. "We haven't sold our Iowa house anyway, so we can just move back, right?" queried our younger son. In the end, however, our children seem rooted in a shared value regarding inclusion. When the new elementary school offered him "GATE" (for the Gifted and Talented) services in a pull-out model, our younger son scowled and said he would prefer to stay in the general education classroom. And during a day in honor of Martin Luther King, Jr. when this son witnessed his older brother's social exclusion during an activity, he immediately brought it to our attention noting the irony of the situation.

The new Middle School held a welcome dinner for the students and their families the Friday before school was to start where they had intended to pass out the schedules but with a new principal these were not yet complete. Therefore our eldest son, thought to have significant intellectual disabilities, began his first day in his new school without knowing where to go first. "Don't worry, none of the 6th graders will know where to go," one teacher assured me. Needless to say I *did* worry but our son insisted he wanted to enter the school on his own. Pointing to the car as he climbed out of the back seat, he said "you stay." He managed the change and adapted to the more complex schedule where he had seven class periods in different classrooms with different teachers.

One of our most poignant affirmations that we had made a good decision in choosing District B was when our elder son spontaneously said, "I like this school better." We think one reason for his happiness was the welcoming attitude from one of the general education teachers who told us, "I feel it's a great privilege for me to have (son's name) in my class this year." Her prior personal experiences with people with disabilities proved to be a comfort for her and she agreed to help identify possible budding peer friendships for our son using the Circle of Friends (Falvey, Forest, Pearpoint, & Rosenberg, 1994). However, I would be remiss if I did not acknowledge that conflicting interpretations of assessments and approaches to decision-making occurred with the new educational team, making it difficult at times for developing trusting relationships. What we found resonated with other researchers who suggest shared understanding and trusting relationships are often localized and temporary in the sense that each time new teachers became involved we needed to start anew, renegotiating power and local understanding (Kliewer & Biklen, 2007). Local understanding, according to Kliewer and Biklen (2007) holds that an individual's membership, regardless of impairment, is unquestioned in responsive and respectful contexts. The importance of this local understanding became increasingly apparent during our times of change in personnel as well as environment.

Conclusion

Moving a family that includes a child with a disability proved challenging in many ways, and although we cannot call the new school and community The Land of (Inclusive) Oz, our family seems to be making the adjustments for a good ideological 'fit.' Nearly three decades have passed since Hamre-Nietupski and Nietupski (1981) developed a detailed list of suggestions for the "integral involvement" of students considered to have significant disabilities when they were moved from segregated schools to their neighborhood schools. In current literature, there is much written about transitioning students from early childhood special education programs to regular elementary schools and from high schools to work, but little is written about moving a family that includes a child with a disability, particularly articles that invoke questions about why there are such stark differences in the ways in which students with disabilities and their families are supported in their search for inclusive schooling experiences. This paper attempts to encourage the discussion about what Kliewer and Biklen (1996) describe as examining "how we come to understand what those differences mean" (p. 91). The process our family went through seemed to illustrate what the United Nations Convention on the Rights of Persons with Disabilities (2007) describes as the disabling impact resulting from attitudinal barriers. It was similar in many ways to Mercer's (1973) study about children who were successfully included in their families and communities and only "retarded" [sic] during their time spent in schools. For

our son it seemed, the implications for where he went to school would mean whether or not he was to be understood as an equal member in the school community, or forever an outsider. In other words, this experience for us illustrated how disability was socially constructed by the people and their practices in educational contexts.

Although every American public school must provide parents with information outlining their rights and states offer parent resource centers or support groups, these are insufficient in addressing the complex needs of students with disabilities and their IEP team especially in light of the numbers of families relocating to different parts of the country and abroad (McLachlan, 2008). As parents of children considered atypical, we found little guidance or ready systems of support. We relied upon our knowledge and experience gained from our professions as educators and as privileged parents within the American educational system to ask important questions, to seek out information, and to negotiate inclusion. This story leads one to ask questions about the role of privilege in the process of advocacy. What about families who are moving between countries that speak languages and have cultures that differ from those where they are relocating to? What disadvantages drive decisions for families that jeopardize their children's access to inclusive schooling? It would be helpful for researchers to examine the experiences of parents who have no or little educational background or "training" in special education, and the experiences and opportunities for teachers in the field to expand their knowledge and examine their practices in helping to support their students with disabilities and their families in their relocation process.

Although personal cultural interpretations of disability experiences from around the world increasingly appear in the literature, only recently have we begun to consider these types of questions regarding the movement of families with children with disabilities and the social and cultural intersections from a disability studies framework. One example is a special issue of *Disability Studies Quarterly* that included a collection of manuscripts resulting from a disability rights workshop in Kenya in 2007. Ressa's (2009) transcribed interview, for instance, provides insight into the complexities involved when lived experiences of disability are examined through a social-historical and political lens. Other more recent articles published in the *Review of Disability Studies: An International Journal* have also illustrated issues involved when families move. One example is described in a study about wheelchair users in Sweden (Krantz, Edberg, & Persson, 2011) regarding the required change of assistive devices when someone moves between municipalities. A more nuanced example in the same issue examines discrimination against women from within the disability movement in Ghana (Naami & Hayashi, 2011). According to the Migration Information Source (Terrazas, 2009), "The number of African immigrants in the United States grew 40-fold between 1960 and 2007, from 35,355 to 1.4 million. Most of this growth has taken place since 1990 and includes many women who tend to be the parent in charge of their children's education. As people increasingly cross geographic and social borders, it becomes important for us to continue to examine how mobility highlights the ways in which those with impairment become disabled upon confronting changes in social-cultural constructs.

[1] Intelligence quotients (IQ) are readily used in American special education as objective and stable measures of a child's level of understanding, with a score 95-110 being considered "average." IQ cutoff scores have been used to determine whether or not and the degree to which a child is mentally retarded [sic] (Kliewer & Biklen, 1996).

[2] According to one U.S. school district website, "Life Skills" means "Mental Disability;" These terms are presented as synonymous and defined as "Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects an individual's educational performance. In practice, "Life Skills" is used to describe an educational curricular program where students are taught skills determined necessary for functioning in daily life such as window-washing or cooking.
[3] The Association for Middle Level Education, which includes members worldwide, ascribes to a philosophy focusing on the unique characteristics and behaviors of young adolescents 10 to 14 years of age.

Janet Sauer prepares teachers to work with and learn from people with disabilities and their family members. She taught children in Botswana, Africa, on the Navajo Reservation, in Boston, Ohio and Iowa. Her research interests focus on examining positive relationships in inclusive contexts, the nature of creativity as access to literacy, and interdisciplinary collaboration. Sauer's advocacy efforts for the inclusion of students with disabilities in community and educational contexts have also led her to explore co-constructions in portraiture research methodology. She can reached at jsauer@uccs.edu.

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A Family Narration of Disability Experience in Iran
Negin H. Goodrich
Purdue University, Calumet

Abstract: Focusing on Mohsen Hosseini Taha, a person with cerebral palsy, and his family, this research explores the social and mental consequences of having a member with physical disability on a typical Iranian family. The oral narratives used in this research have been collected in a series of in-depth interviews with Mohsen, his parents, and his only sister, in 4 sessions or 10 hours of face-to-face interviews. The analysis of the interviews addresses several questions: How was Mohsen's disability initially diagnosed and what were his parents' first reactions? What have been the social obstacles facing Mohsen's family's efforts to practice a routine life within Iranian society? How has Mohsen's disability affected his family's life socially and mentally throughout the years? Finally, how well do core concepts of Western disability studies apply within a typical non-western family? The real names of the participants have been used with their permission.

Keywords: disability, family, Iran

"…And the tragedy begins with his/her gradual isolation from the society. The tragedy begins when a person with disability transfers to a machine with no rights to have fun, to love, and to live like the other individuals. The tragedy happens in a society who treats persons with disability like unhumans. Our life tragedy is made by our society, not by our disability…"
 -Mohsen H. Taha

In the Family's Words

There is no exact number of people with disabilities living in Iran; however, according to the latest report of the State Welfare Organization of Iran (October 2012), about 10% of the total population has disabilities that would yield an estimated number of 7,500,000 individuals. By considering the families who have at least one member with disabilities, the number of Iranians who are dealing with disabilities, directly or indirectly, increases up to 25,000,000 individuals (State Welfare Organization of Iran, 2012).

Mohsen Hosseini Taha was born ironically in 1981, the International Year of Disabled Persons, in Tehran-Iran, and was diagnosed with cerebral palsy at the age of three. For more than thirty years the Tahas, a middle class family living in Karaj (near Tehran, the capital), have been dealing with the disability of their son, Mohsen. I remember the first day I met Mohsen waiting for me early in the morning at the newspaper office. I could barely understand what he tried to say until he decided to write down what he wanted. I could eventually read the nearly illegible but impressive handwriting of a young boy with a severe physical disability who wished to collaborate with the disability page of *Ettela'at* newspaper. He had brought samples of his writings which sounded strong enough to hear immediately a "yes" respond from me, but I had to check first with my boss before giving him any promises.

A week later, Mohsen started working for the disability page of *Ettela'at* newspaper under my supervision. For Mohsen, this was the dawn of his entry into the realm of the Iranian

media professionally; he started working for other newspapers as well. Mohsen and his family soon became a part of my articles on the disability experience in Iran. As a journalist dedicating her career mostly to disability issues, I have published several interviews with the Taha family in *Ettela'at* newspaper, and have combined and translated them into English for this article. The interview sessions have provided over 10 hours of narrative data from which to explore the Tahas' perspective.

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An exploration of the Tahas' views shows how at least one Iranian family has experienced a disability, suffering not primarily from their child's disability, but from the way their society has treated them for having a disabled child in the first place. Their experience also shows how attitudes in many traditional societies may not distinguish physical and intellectual disabilities, with both groups being denied their basic human rights. Finally, the Tahas' experience provides an opportunity to analyze how familiar concepts of Western disability studies (e.g., the contrast between social and medical models of impairment and disability) can be observed in practice within the family context of a developing country such as Iran (International Monetary Fund, 2012).

Mrs. Taha (Mohsen's mother): "It was actually during the Iraq-Iran war when I was taken to a hospital, after hours of delay, to deliver my baby. At that time, most of the ambulances were either sent to the borders or at the service of the air-attacks' victims in Tehran and other cities. So, our son, Mohsen, was born with hours of delay. As an infant in his early weeks, he showed no signs of disability; yet, I remember, from his early months he could not grab his toys or crawl. Since my husband and I had raised another child (our three-year-old daughter, Mahbubeh), we were experienced enough to find out that our son's growth did not look natural. Then we started taking Mohsen to different doctors; most of them assured us that our baby was healthy and we, "the very young parents," should not be so "sensitive" to our son's "naturally-delayed" reactions."

"Mohsen was 3; his naturally delayed reactions had not vanished, but rather were aggravated with time. Eventually, a doctor diagnosed that our son was born with cerebral palsy, a physical disability that affects body movement. It was so shocking for us, because we had no disability background in our families, and expected to have a healthy child… So shocking, disappointing, and unbelievable... Our first questions were: "how to tell the truth to our families, to our parents, to our siblings, and especially to our three-year-old daughter. What would be their reactions to Mohsen's disability? Would they accept it? Would they love Mohsen?""

"It took several months to admit our son's disability. We started gathering medical information, and found out that Mohsen needed medical interventions, such as physiotherapy and speech therapy, to help his movement limitations, but we were not able to do them permanently, not only because of the expensive bills we had to pay for each session of therapies, but also because of Mohsen's resistance. The more he grew up, the more he disliked therapies that imposed too much pain on his thin bones and stiff muscles. Every session of physiotherapy ended up with his screaming and begging to stop those torturous therapies."

Mr. Taha (Mohsen's father): "For four years after Mohsen's birth, I was an under-graduate student and simultaneously, an employee. I had to manage my time, from early in the

morning till the evening, to go to work first and then to school. So, I could not allocate much time to my family, especially to my kids. I recall most of the nights when I was back home; they were in bed before I could even give them a goodnight kiss. After graduating in 1985 as a History major, I found more time for my family, and started taking my 4-year-old son to physio and speech therapy. As my wife mentioned, we had to dedicate a big budget for Mohsen's rehabilitation while the Iraq-Iran war (1980 - 1988) had affected Iranian families economically, and the situation was typically worse for families, like us, who had a person with disability in need of special care and therapies. We had to struggle not only to survive a ruinous war, but also to take the best care of our children."

Mrs. Taha: "Shortly after Mohsen was diagnosed with cerebral palsy, we decided to publicize it. As I said before, it seemed so difficult to us… It was like revealing an unpleasant secret… I think we were so fortunate that our families could understand the situation. They accepted Mohsen kindly and even encouraged us to do whatever he needed to get better. Like us, they were also hopeful that by the help of therapies, our son would find his ability to walk without braces and to speak more clearly."

"From the first years, it was obvious that our biggest problem was located outside of our family, with the people in the streets, even with some friends, relatives and neighbors. Most of them used to show us different unfriendly faces reflecting their unpleasant feelings, from absolute empathy to hatred; from over emotional expressions to cursing us for having a disabled child. Some people in the streets even put coins in the hands of my son as if he was a beggar. To them, disability equated with begging. Some people thanked God 'for being healthy, and not being like this poor handicapped boy' when they passed by Mohsen. It is still the same… We are getting used to these reactions."

Mahbubeh (Mohsen's sister): "Though I was only three years old when Mohsen was born, I could understand that my little brother needed my help. I started acting like an older sister to him from my early years. In fact, I became mature so early and too quickly… He obviously had attracted our parents' total care and attention, but rather than being jealous, I could understand Mohsen's situation. He was, and still is, the loveliest person in my life whom I used to take good care of. I knew how to play with Mohsen, how to feed him, how to teach him to pronounce words… Mohsen could not utter words clearly, and it was so heart-breaking for me. This made me to try to help him more."

"I think Mohsen brought a kind of unity to our family. After his birth, we had got one big common goal: to improve Mohsen's quality of life. My brother also brought us the necessity of a new attitude. In traditional societies, like Iran, disability is attached with grief and shame for the individual and his/her family. But our parents taught us how to practice thinking the opposite of the mainstream… to think the way that seems right, not the way that the society tried to dictate to us… I think we would never be non-mainstream if Mohsen were not disabled. Well, I cannot deny our social difficulties, our pain to see segregation, inequalities, denials and ignorance that all people with disabilities receive in our traditional society, but it was only one face of the disability coin; its other face was the unity, love, intimacy, and new attitude that Mohsen gifted us."

Mr. Taha: "At the age of 7, Mohsen's physical disability was obvious throughout his body and speech. His cerebral palsy impeded his walking easily or playing like the other kids. He could not talk clearly either; however, his IQ was above the average. Anybody who knew Mohsen would agree that he was more mature and smarter than his age."

"In 1988, there were a handful of special schools for the students with disabilities in Tehran. At that time, nobody could even imagine that a child with physical disability was able to attend regular schools and find a place among non-disabled students. So, our decision to register Mohsen in a regular school was an unusual one; a brave action that predictably led to objections or resistance from those who were attached to the traditional understanding of 'dis'ability."

"I recall the first obstacle was presented by the Education Ministry experts who asked us to prove our son's 'mental health and ability.' After taking a set of time-consuming examinations and passing the IQ tests successfully, Mohsen could receive The Special Education Organization experts' approval to be registered in a regular school. But the next hurdle was made by the principals of regular schools who were resistant to accept a student with physical disability. Even though they had talked to our son in person and had seen The Special Education Organization's reports on his mental abilities, they still rejected Mohsen. Eventually, the principal of Yaaser elementary school admitted him."

"Mohsen will never forget the first day that he entered the school. All of the students and the teachers were just staring at him; the kind of looking that, of course, was/is familiar to us. His teacher who knew that Mohsen had passed different tests, decided to give him an exam about elementary pre-school concepts to make sure that 'this disabled student' was qualified to stay at a regular school. After Mohsen passed that exam with a high grade, he received applause from his teachers and classmates who were incredulous at the abilities of a 'stammering staggering boy'."

Mrs. Taha: "At the start of every educational year, Mohsen had to encounter the same problems in order to interact with the others at the school. Usually, it took several months for the students and teachers to know Mohsen and to get convinced that he was a smart boy with high potential to get brilliant grades, although his special needs were not fully met. For example, one of Mohsen's problems was with the spelling exam in which his performance was so slow. Mohsen's handwriting was also so illegible that teachers could not read to grade. Given the absence of an educational assistant for a student with that kind of disability, I had to accompany my son to his classes, to reiterate the teacher's spelling words for him and to translate Mohsen's scribbles for his teachers. Sometimes, I even begged Mohsen's teachers to allocate him more time so that he could finish his answer sheet. Whenever Mohsen could receive his special support, he would make the highest scores among his classmates."

"I was not only my son's educational assistant in his classes, but also his only pal at the school, 'cause most of the students were reluctant to befriend him. Making fun of him for his physical differences, there were also boys who never stopped bullying Mohsen. Even a gang of unruly boys had named my son 'Michael Jackson' for his 'dance-like movements'… Very heart-wrenching for a mom to witness all of those harsh behaviors that a society can show to her defenseless child (Mrs. Taha starts weeping)… In such a merciless environment, my son needed

to be guarded by someone, and I was there for him. I have to mention that there were also few boys at school kind enough to take Mohsen's hand to the class and to smile at him. They liked Mohsen and helped him sometimes, but were too young to endure Mohsen's slowness."

"On the other hand, since Mohsen had rejected using a wheelchair, I was so worried about his daily journey to school that I used to accompany him on most days. On the way to school, we could hear some people mumbling, 'why do you take this cripple kid to school? Let him stay at home! Do not suffer yourself for such a handicapped child! Does he need to go to school at all? Just take him to an institution and leave him there!' For all of us in the family, such merciless comments were more heartbreaking than Mohsen's physical disability. They thought that Mohsen was intellectually disabled and could not understand anything. Even if he was intellectually disabled, his dignity as a human being should not be spoiled like that."

Mr. Taha: "For several years, we possessed no home and had to move to new places every other year. Changing locations did affect the whole family. We had to restart adjusting with the new environment and the new neighbors who had got the same traditional attitude towards disability. For example, before starting of a new academic year, I found another regular school nearby our house to register my son. After talking to the school principal and showing him Mohsen's brilliant grades in the previous regular schools, the principal decided to admit such a student with physical disability. Since Mohsen was not present at the registration day, the principal had no idea about the extent of his disability."

"The first day that Mohsen arrived at school, the guard blocked his way, shouting, 'Get out of here! No beggars at school!' Mohsen tried to explain that he was also a student, but the man pulled his sleeve and kicked him off the school property. The next day, Mohsen and I went straight to the principal's office. He was surprised by seeing Mohsen and said if he had known that Mohsen was 'so disabled like that', he would never have admitted him!"

"Year after year, we had to encounter the same social problems. I think Mohsen is the only Iranian person with severe cerebral palsy who has been able to enter and endure the regular schools from 1988, when the idea of educational inclusion has not even been suggested in Iran. Mohsen finished high school successfully and got his diploma while many people, even the educated ones, still believed that he had to study in special schools rather than the regular one."

Mahbubeh: "My brother has been gifted with special abilities, such as writing stories and poems. When he was a 7th grade student, he asked a handful of the nice boys at his school to help him to write down his creative writings. He named his small group as 'The Futurists'. I also used to re-write his scribbling notes from the day that he learned how to write. I enjoyed his poems and stories, and was sure that he would have a bright future if he would follow his talent, and if the society would let him show himself."

Mr. Taha: "In Iran, it is literally difficult to enter university after high school. The applicants must pass a very difficult exam in which only 25 percent of 2 million students will be admitted. Mohsen successfully passed that exam and was admitted in Persian Language and Literature at Allame Tabatabaee University, which is one the best public schools in the country. The first day that he entered the school, the guard shouted, 'Hey boy, where are you going? Get

out of here!' Mohsen had a very hard time to convince that man. You see… repeating stories at every single step of improvement."

"All these have happened to my family since 1981. Over those decades, the society was not as informed as today, and disability NGOs had not started working on disability rights yet. We had to fight with a society that knew nothing about the rights of individuals with disability. Though we have been supporting Mohsen from different aspects, he has done his best to be able to stand on his own feet. There exist cultural difficulties, especially in a traditional society like Iran. I think Iranian families who have one or more members with disabilities encounter the problems that have been already solved in the developed countries, because in those countries disability rights have been systematically formulated and require the least intervention by families. Families with a disabled child in a developing country like Iran suffer too much, 'cause they must carry the load that should be borne by a regular system of disability rights. For example, The *Comprehensive Law to Protect Disability Rights* that was enacted in 2004 by the Iran Islamic Parliament has no 'implication guarantee' yet [consequence for violations]; and therefore, could not fully remove discrimination based on disability. Consequently, the families still have to compensate for the legislative and administrative inefficiency.

Mrs. Taha: "We have gone through difficulties for more than 30 years… Sometimes, we have thought that God has had certain reasons for creating Mohsen like this, and therefore, we must admit it with open hearts. We have practiced thinking positively, to focus on Mohsen's abilities, to wash off the negative feelings that an ignorant uninformed society has presented us constantly… We have tried to treat Mohsen's disability much differently than the traditional attitude... My husband and I, now, feel exhausted from life-long fighting with society… They made us sick… We are both under medication, not because of our son's disability, but because of what people have done to us intentionally or unintentionally …. Of course, we have also had understanding companions in our long journey: some of our friends, our relatives, Mohsen's teachers… They have always been with us… They encouraged us not to give up, and we thank them all."

The Nature and Source of Family Reaction to Disability

Jaeger and Bowman (2005) listed social reactions to disability as marginalizing, ignoring, stereotyping, misidentification, and discomfort, common reactions which occur frequently in Iranian society as well. Persons with disabilities in Iran suffer from being traditionally ignored, undermined, misunderstood, marginalized, and pitied. Most family narratives of disability in developing societies such as Iran signify that the moral, medical and religious perspectives of disability are vehemently prevalent. Moral models outline disability as a shame to both disabled individuals and their families (Goodley, 2011). Accordingly, traditional perceptions of disability in Iranian society force most of the families, especially in the small towns, to hide their disabled member(s) at homes to shield the embarrassment.

The medical model is also a prevalent approach to disability in Iran, delineating disability as a problem located within the body or mind of individuals that should be fixed (Goodley, 2011). From this point of view, Mohsen has a physical and/or mental problem that needs to be healed either by professionals or through miracles. Jaeger and Bowman (2005) referred to the

significant role of religious beliefs, such as miracles, in the public perception and attitudes toward persons with disabilities. Therefore, in addition to moral and medical perspectives, a religious point of view is also common, inviting the true believers to show pity to the poor and disabled members of the community. In fact, following the "miracle" perspective, it seems that the "charity" point of view is a prevalent social reaction to disability in Iran. Hence, Mohsen and his family frequently encounter people in the streets who wish to "help" Mohsen by putting coins in his hand.

Numerous Iranian families with a disabled member argue that they suffer not only from witnessing how their loved one has to encounter the social ignorance, insult, denial, and segregation, but also from feeling deeply humiliated by the mainstream for having a disability in the family (Hosseini, 2008). Ferguson (2001) described the significance of social context in shaping personal reactions, as well as the "nature" and the "source" of family response to disability. According to a number of Iranian family narratives (Hosseini, 2008), the nature of their reaction to the disability of their loved one consists of different feelings of grief, failure, "shame" and "depression" that Browns (2001) referred to as the negative attitudes of families toward disability. Although there is no official record of the number of Iranian families who prefer to "hide" (Ingstad, 2001) their children/members with disabilities, some stories on mistreating disabled members in and out of their families are often released by the media.

Mohsen's family members have delineated their difficulties over 30 years. Like many parents facing the reality of disability, Mr. and Mrs. Taha have gone through different stages; from anger to acceptance, from absolute disappointment to expecting the promise of a new day; contrary feelings that Ingstad (2001) referred to as "problem" and "hope" for disabled individuals and their families in developing countries.

During the first years of discovering Mohsen's disability, his parents could hardly admit it. Instead they were expecting a "miracle" to happen and "cure" their son. Awaiting a miracle to happen is a common reaction among persons with disability and their families in Iran. It is actually a religious term that lies primarily in Islamic beliefs. Most of the Muslims believe that miracles are likely to happen in the lives of the true believers, especially at times of distress. In the Quran, there are stories of Prophet Jesus' miracles in healing blind people and reviving the dead (The Quran: The House of 'Imran: 49). This religious perspective seems to act as a contextual source (Ferguson, 2001) of individuals' and families' reactions to disability.

The Tahas have also been living with a permanent stress not only because having a member with disability is a stressful event (Ferguson, 2001), but also mainly because of the negative reactions of the mainstream, the lack of social information about disabilities, and the absence of environmental facilities that accelerate the social participation of disabled people. Imagine parents who have to let their son with severe cerebral palsy to go to school by himself. Their stress increases as the son puts the first step out of the house, because of sidewalks full of humps, busy streets with no pedestrian bridges, ignorant citizens, and some ill-willed persons' intentions to abuse a disabled boy.

There is seemingly a meaningful relationship between environmental facilities and the extent of stress experienced by individuals with disability and their families. Fatemeh Bozorgnia

(1938-2002), an Iranian disability advocate who lived with the after-effects of Polio for more than six decades, referred to her "better feelings" of "less fear" and "less stress" while residing temporarily in the United States in comparison with her disability experience in Iran. She claimed that the social environment in a developed country like the States has been so increasingly accessible for persons with disabilities that they feel more comfortable and less stressed that those in less accessible countries (Bozorgnia, 2011). She also indicated that even her family could benefit indirectly from those facilities, since there was no need to accompany their disabled relative in a well-equipped safe environment. Actually, most of Iranian individuals with disabilities believe that adequate environmental facilities will increase the feelings of independence, dignity, protection, safeness, and security in both the person and their families (Hosseini, 2008).

There are few Iranian families who, like the Tahas, go beyond the mainstream stereotypes and clichés in reaction to the disability of their relatives (Hosseini, 2008). In other words, Mohsen's family represents a small number of Iranian middle-class families who, despite hindering social reactions, have been able to shape their own response to disability. According to the social model of disability (Altman, 2001), social barriers reduce opportunities to take part in social life; however, the Tahas refused to let limited societal facilities impede Mohsen's communal activities.

Neely-Barnes and Graff (2001) referred to a handful of inquiries on the consequences of being the sibling of a person with disability. They noted that those studies have found both negative and positive impacts like wrath, unhappiness, jealousy, as well as family intimacy and personal improvement. Mahbubeh emphasized that Mohsen's disability brought unity to the family. Although the disability of a child is reported numerous times as one of the main reasons for divorces and collapse of families in Iran, as mentioned earlier, it is likely that disability also increases closeness and intimacy in families, like the Tahas, who have had strong bonds (Havens, 2005). On the other hand, sibling jealousy of the child with a disability who is viewed as receiving more parental services (Havens, 2005) has not apparently happened in the Taha family, according to Mohsen's sister, who instead has voluntarily helped her parents to improve Mohsen's life.

Patterns to Adapt to the Stress

Ferguson (2001) has referred to the possibility of adaptation to stress within the disabled individual and their families. It seems that some Iranians have found certain patterns to adapt to the stress, as well as to their other negative feelings. According to the narratives of a number of Iranian persons with physical disabilities and their families (Hosseini, 2008), religious beliefs have assisted them in harnessing the anger and stress of having a child with a disability. Linguistically, "Islam" means "submission to God's will without any objection," and a true Muslim must practice that kind of absolute obedience in every aspect of her/his life. In addition, according to Islamic beliefs, there are undiscovered and unknown reasons for any mundane event that only God is aware of. A Muslim who trusts God truly, never questions Him for the reasons. Disability is an event that could happen in anybody's life for a reason, and a true believer should not only submit to God's will for creating an individual with disability, but also should not inquire of Him about the reasons. This attitude seems to assist in the positive acceptance of the

reality of disability, and to cope with the negative consequences of what Ferguson (2001) called "internal and external influences."

Besides the religious attitude toward disability, "positivity" seems to be another pattern to adapt to stress in the Taha Family, as well as in a number of other Iranians with disabilities and their families. As they described, the Tahas have practiced focusing on Mohsen's abilities, defining his personality by his individuality rather than his disabled body, and teaching Mohsen to see himself as perfect as a non-disabled individual. Mohsen's parents found out, eventually, that changing their own minds was much easier than changing a context as big as a society.

Finally, they talked about the role of close friends and relatives in improving their strength. Though the number of understanding persons is not too big in comparison with the number of mainstream people, even that small number seems so effective. Those people, like a compassionate teacher, a sympathetic friend, and a friendly neighbor, have been encouraging Mohsen and his family to pursue their goals diligently.

Practicing the Academic Concepts of Disability

Since the pillars of disability studies are built upon Anglo-Saxon culture and history, this field of study is almost unknown in some developing countries like Iran. However, a number of concepts and theories of this academic field are permanently practiced by disabled individuals and their families in developing societies. For instance, confronting the mainstream reactions to disability, both disabled individuals and their families, such as the Tahas, are consistently encountering the "moral" and "medical" attitudes towards disability; and by practicing how to adjust positively to those traditional reactions, they seem constantly to be responding in accordance with the "social" model.

Permanent practicing of at least three models of disability in the daily lives of disabled individuals and their families, such as the Tahas, suggests that some of the concepts and theories of Western disability studies are applicable within non-Western contexts. In other words, the individual and family narratives of disability from different geographical origins seem to share common spotlights, as Ingstad (2001) documented similar disability reports from developing countries. For instance, most of the Taha family friends and neighbors believed that Mohsen's parents should not take their "handicapped" son to school and had to keep (imprison) him in the house or in an institution (moral and medical attitudes). Yet Mr. and Mrs. Taha refused to play the traditional role of ashamed parents. Rather, by taking Mohsen to a regular school and exposing him to the eyes of the public, they tried to advance the goals of the disability rights movement, i.e. the right to get out of the house, and to eliminate the social barriers preventing their son from participating fully in society (social model).

Negin H. Goodrich is a journalist, author and disability researcher from Iran, living in the United States since 2010. As a journalist and a (previous) PhD candidate in Communication, she has devoted more than 15 years of her professional and academic activities to disability issues. Attending three Paralympic games: Athens 2004, Beijing 2008 and London 2012, she has written two books and tens of articles on the event. Negin has been a visiting scholar at the Center for Global Studies at Purdue University, Calumet from 2010 to 2012. She is now working on a book

(in Farsi language) to introduce Disability Studies to her native country, where, as she claims, there is little awareness on this growing subject.

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Disablism and Diaspora: British Pakistani Families and Disabled Children

Dan Goodley, PhD

University of Sheffield &

Katherine Runswick-Cole and Uzma Mahmoud

Manchester Metropolitan University

Abstract: This paper explores the intersections of diaspora, disability and family. Drawing on qualitative interviews with the parents of three British Pakistani families we draw out three lines of enquiry. The first, *disability and disavowal in Pakistan*, explores parents' relationship with 'home' and how this is complicated by the presence of disablism. The second, *disability and the fight for care in Britain*, explores the ways in which British Asian families are grounded not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain. The third, *disability and diaspora - from isolation to ensembled caringscapes*, examines the limits and possibilities offered through diaspora. One key affirmative element of this is the support of an extended family, which brings with it, the chance to look to the future with hope and possibility.

Introduction

This paper explores the accounts of three British Pakistani families who include a disabled child. Their accounts intersect a number of key concepts. Our first consideration is **diaspora**. The families represented in this paper merge important cultural, familial and subjective elements of Britain and Pakistani. By recognising that both nations boast complex forms of multiculturalism the mixing of these cultures resonates with the postcolonial concepts of cultural hybridisation (the mixing of cultures and heritage) and diaspora (the geopolitical spread of groups of displaced and in some cases exiled people, see Grech, 2011 for an excellent discussion of these concepts). Brah (1996) characterizes diasporic identities as those that cut across and displace national boundaries, creating new forms of belonging and challenging the fixing of identities in relation to place. As Anthias (1998) observes: the etymological basis of diaspora relates to the Greek word for 'scattering of seeds'. Dwyer (2000, p. 483) argues that while cultural theories of diaspora have celebrated 'cultures of hybridity' found particularly in music, sport or fashion, there has been a tendency to ignore the everyday, mundane and, therefore, complex negotiations of diasporic identities. British Pakistani families, following Dwyer (2000, p. 475), can be readily assigned membership of the 'new diasporas' created by postcolonial migrations. The concept of diaspora:

enables an unraveling of the nexus between (and relative significance of) place(s) of 'origin' and place(s) of 'settlement' and allows us to comprehend how the identities of second- and third generation British Asians are subject to both global and local, or, … 'glocal', influences. (Burdsey, 2006, p 23)

This raises questions about how people live in a culture of hybridity and how they articulate diasporic identities that cut across fixed notions of belonging. Diaspora is thus often used to describe 'groups of displaced and exiled people who feel they possess a shared ethnicity, culture, (imagined) community and traditions but at the same time, have a relationship, whether

real or imagined, to a perceived homeland' (Mavroudi, 2007, p. 469). The heuristic potential of the concept of diaspora is therefore as a descriptive typological tool and as a social condition and societal process (Anthias, 1998, p. 557).

> The postmodern versions of diaspora … denote a condition rather than being descriptive of a group. Not only is the condition one structured through the trajectory of movement but it is one which seeps into the very fabric of the modern (or postmodern) condition itself. This condition is put into play through the experience of being from one place and of another … Here the issues around the destabilizing effect of transition and movement of the individuals' cultural certainties may be explored and the ontological and epistemological effects researched. (Anthias, 1998, p. 565)

In considering the experiences of these families we need to be mindful of how we theorize their identities. Any exploration of family life evokes considerations of the kinds of social theories that we draw upon. We are guided by the great Stuart Hall, (2003,p. 222) here who argued that:

> Identity is not as transparent or unproblematic as we think. Perhaps instead of thinking of identity as an already accomplished fact, … we should think, instead, of identity as a 'production', which is never complete, always in process, and always constituted within, not outside, representation.

Diasporic identities are 'those which are constantly producing and reproducing themselves anew, through transformation and difference'. (Hall, 2003, p. 235). Hall's concern 'has been to reconstruct an approach to cultural identity and 'race' which avoids the pitfalls of essentialism and reductionism' (Anthias, 1998, p. 560). Like Hall, we do not consider identities to be fixed in time and place. Instead, we understand identities as constantly evolving and changing as a consequence of a host of relational, cultural, political and material factors. Bhabha's (1985) work on hybrids emerged out of writing about postcolonial contexts. He suggested that it is best to understand the postcolonial subject as a subject who fuses pre/present/post colonial practices through 'mimicry, hybridity and sly civility' (Bhabha, 1994, p. 21). Following Goodley (2011), the Indianized gospel, a British-born Pakistani identity, the glocalization of a South East Asian youth each exemplify, in their own way, the appropriation and imitation of colonial *and* traditional cultural practices (see also Spivak, 1985, p. 253). The postcolonial subject is always hybridised. For Sherry (2007, p. 19), Bhabha's (1994) model of hybridization 'stresses those in-between moments that initiate new sites of identity, new collaborations and new conflicts of one's identity'. 'The hybrid draws attention to the weaving away, making sense of, experimenting nature of human subjectivity and relationships' (Goodley, 2011, p. xx). We adopt this dynamic constructionist view of identity in relation not only to diasporic identities of the British Pakistani families but also, crucially, in relation to our second area of consideration, *disability*. Just as critical race and postcolonial theories have historicized and politicized 'race' and ethnicity – moving it from a fixed, pathological and essentialist position – critical disability studies scholars have also recast disability as a socio-political phenomenon (see Goodley, 2011 for a contemporary overview of the field). Following Dwyer (2000, p. 483), we seek to provide new ways of theorizing disability and identity that recognize differences and avoid essentialism. To this we could add the avoidance of cultural determinism

which overplays national context and fails to capture the cultural hybridity of British Pakistani mothers and their families. Similarly, from a critical disability studies perspective, by advancing a socio-cultural model of disability then we seek to challenge a lapsing back into traditional pathological notions of impairment. How impairments are understood, responded to and treated depends hugely on their cultural location. The word 'disability' hints at something missing either fiscally, physically, mentally or legally (Davis, 1995, p. xiii). Disability affects us all, transcending class, nation and wealth (Goodley, 2011). Critical disability studies respond to the emergence of impairment in society and dominant socio-cultural responses. Thomas (2007, p. 73) provides a definition of *disablism,* as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being'. This is helpful because it permits disablism to sit alongside other forms of oppression including hetero/sexism and racism. And because disablism is a fundamentally environmental response to impairment then, just like diasporas, it is prone to shift, mutate and change according to a multitude of external factors. The dynamic nature of diaspora and disability interact with a third concept; the ***family***. In recent years there has been a plethora of research, particularly in Western Europe and North America, about disabled children and their families that have tended to emphasise the experiences of white, middle class, Global North families (e.g. Kittay, 1998a, 1998b, 2002; Traustadóttir, 1991, 1999; McKie et al, 2002; Watson et al, 2002; McKeever and Miller, 2004; Hughes et al, 2002; McLaughlin *et al*, 2008). We know from this work that families, as a whole, experience disablism (hence the term disabled families). Parents have to fight for basic services, support, and recognition of their children as valued members of society. These families face more socioeconomic hardship than non-disabled families. Communities fail to support them by including their children in day-to-day activities, ranging from education to leisure, and mothers are often pushed to take the lead role in care for their children. We aim to explore in this paper what this research has failed to uncover: how the phenomena of diaspora, disability and family intersect in the accounts of three British Pakistani families who boast a disabled child.

There are currently approximately 1.2 million British citizens who were either born in Pakistan or whose ancestors came from there (Nabassi, 2010). Here we want to think carefully about the hybridisation of local and global meanings. In considering the global place of the families, we seek not to fall into the trap identified by Rattansi (2004, p. 614) where 'sociological analyses have been wont to smuggle in unacknowledged normative considerations … on the basis of simplistic and common-sensical assumptions about 'human nature' and 'group dynamics'. In similar ways to Lloyd (2000) we want to explore the ways in which the parents we interviewed criss-crossed and renegotiated material and imaginary boundaries between countries and cultures in caring for their disabled children. Moreover, following Anthias (1998), we explore these diaspora by paying more attention to 'intersectionality', in this case, across disability, family and diaspora.

Methodology

This paper draws on a number of accounts of disabled children and their parents collected as part of a project funded by the Economic and Social Research Council[1] Does every child matter, Post-Blair: Interconnections of disabled childhoods'. Our over-arching aim was to ask what life is like for disabled children/young people in contemporary British society. The research was

carried out over a period of 32 months from September, 2008 – May, 2011 and had the following empirical phases included:

(i) Pilot Study – to explore approaches to interviewing and ethnography;
(ii) Narrative inquiry – retrospective interviews with 6 parents of disabled children aged 14 + to reflect on their experiences with their disabled children;
(iii) Children's accounts: Interviews with two groups of children: 4-11 and 12-16yrs old;
(iv) Focus group interviews with professionals;
(v) Longitudinal narrative case studies of 7 parents with disabled children (ages ranging from 4 – 16);
(vi) Growing up – 50 days of ethnography of children's social worlds.

Our participants included disabled children aged 4-16, their parents/carers and professionals who work with disabled children, including teachers, third sector workers, health workers and social workers. Children had a range of impairment labels including autism, cerebral palsy, developmental disability, Down's syndrome, achondroplasia, profound and multiple learning disability and epilepsy.

Despite contacting nearly 40 organisations supporting children and parents, we originally failed to recruit any families from a British Minority Ethnic background. We were very lucky to be able to work with Uzma, one of the authors of this paper, and a Pakistani international postgraduate student, to contact families. We eventually found three families who were happy to participate. Uzma and Katherine interviewed the families once in the family home. At times Uzma acted as both interpreter and interviewer and at other times, in the same interview, participants spoke in English. It is beyond the scope of this paper to speculate on why we were initially unable to recruit diverse families to the study, despite our attempts to contact a myriad of organisations. However, it is important to acknowledge that 'minority' families are often excluded from the research process and that their engagements with disabling society often remain untold. Furthermore, we feel it important to acknowledge the white positionalities of Dan and Katherine and follow Burdsey's (2006, p. 12) stance that:

> 'it is essential for white researchers in the field of ethnic and racial studies to examine not simply how hegemonic 'whiteness' and notions of white privilege permeate the structures and institutions in our areas of research, we must also examine how these issues enter and affect the research process'.

One key reflexive point for us was not to homogenise nor essentialise families in terms of their presumed cultural capital. We know from Anthias (1998), amongst others, that the concept of ethnicity fails to be articulated in the relation to whiteness though always rears its head in the company of diaspora. Our work with Uzma and the families detailed below has revealed the ways in which much disability studies research on children and families – like a lot of social science – remains broadly Eurocentric and ignores political, cultural and social factors associated with ethnicity, culture and globalisation (see Wakeling, 2007 for a broader discussion). We hope to address this lacuna both empirically and theoretically through reading the accounts of a few British Pakistani families:

The Families

Saira is a second generation British Pakistani. She lives in a borough in a city in the North of England with a high proportion of British Pakistani residents. She lives in a semi-detached house on a quiet cul-de-sac. Saira is in her early forties and has four daughters aged from eight to fifteen. She is married but her husband is currently a resident in Pakistan because of visa difficulties. Saira and her children have British passports, but her husband does not. Saira's extended family all live in Pakistan. She told us she has one friend in England who lives around the corner, but who is currently on an extended visit to Pakistan, and does not know the other families on her street. Saira works part-time at the local primary school as a multi-lingual teaching assistant. Two of Saira's daughters are disabled. Asiya is 12 and has the label of ADHD and challenging behaviour and Aamira, who is 15, has the label of severe learning difficulties. Asiya attends a local mainstream secondary school and Aamira attends a local special school. The family lived in Pakistan for a while when Aamira was younger.

Yusef is a second generation British Pakistani. Shanaz, Yusef's wife, was born in Pakistan and came to England after their arranged marriage eleven years ago. Yusef and Shanaz live in a city in the West Midlands of England. They live in a borough with a high proportion of British Pakistani residents. They live in a small terraced house, which has recently been extended to provide a ground floor bedroom for their disabled daughter. They are both in their late twenties and have two children: Habiba who is 9 and has the label of profound and multiple learning disabilities and Fatima, her little sister, who is 2. Habiba attends special school. Shanaz and Yusef are very happy with the education Habiba receives there. Shanaz's family are in Pakistan, but Yusef's parents, brothers and sisters all live nearby and are very supportive of the family. Both Yusef and Shanaz care full-time for their daughter. Yusef gave up his job shortly after their daughter was born.

Mysha is second generation British Pakistani, her husband Asif came to Britain some time after their arranged marriage. They live in a small terraced house in a town in the South East of England in an area with a high proportion of British Pakistani residents. Mysha and Asif are in their early forties. They have three children, but only Farhan lives with them, two older children have left home. Farhan is sixteen and has the label of learning difficulties. Asif has his own business and Mysha has no paid work outside of the home. Mysha's mother also lives with the family. She is the main cook in the family, however, there are no other members of the extended family nearby to help care for Farhan.

Our sample size could be viewed as too small to allow us to tease out any recurring themes of relevance to many other British Pakistani families with disabled children. In defence we are able to mine a rich seam of disability studies research that have attended to the rich qualities of a few lives to tell us much about social, cultural and political conditions faced by disabled people and their families (Bogdan and Taylor, 1976, 1982; Humphreys et al, 1987, Groce, 1992, p. 175). While our sample is not big enough for wide analysis of a population we believe that it is narrow and deep enough to tell us much about living as a family with a disabled child.

Analysis

We all define ourselves, at least in part, by where we are from. Yet this was not a straightforward process of identification for the parents in our study (see Valentine and Sporton, 2009: 741 for a similar discussion). Saira (and her daughters) were geographically separated from her husband. Other families exhibited less direct forms of distinction: as they had to juggle distinct cultural and welfare contexts of Britain and Pakistan. These tensions were further magnified by the presence of a disabled child as families fought for the rights of their children. Where you are from, of course, is complicated by a hybrid identity. Following Valentine and Sporton (2009) we understand identity not just to be about commonality or belonging; but also to be defined by difference. The discourse around disabled children utlilized and promulgated by families reflected the differential aspects of being British (born or based) Pakistani. We follow Valentine and Sporton's (2009) interest in the multiple, shifting and sometimes contradictory ways that individuals both identify and dis-identify with other groups; and with their fluctuating emotional investment in different subject positions. We do not uncover essentialist interpretations of ethnicity and culture – differentially related to Britain and Pakistan – but instead are drawn to the complex ways in which location, culture and disability intersect.

Disability and Disavowal in Pakistan

Parental interviews led us into discussions of Pakistan. Alongside the more practical discussions such as, in the case of Saira, the difficulties associated with her husband being away from the family home, Pakistan appeared to be framed as an 'imagined community' (Anderson, 1991). Burdsey (2006, p. 17) explains this in terms of forming 'a symbolic link with the subcontinent, enabling the celebration of tradition and feelings of belonging with the nation from which they or their forebears migrated'. For Clarke (2009, p. 229), Anderson's (1991) work allows us to consider the ways in which communities are constructed through a variety of symbolic forms (from marking borders to flags, from everyday ceremonies to the little linguistic ways in which a common identity is assumed). Having a disabled child, however, added a further layer of complexity to this imagined community:

> Shanaz: I was listening yesterday … to the radio and there's a family in Pakistan there that's got three blind children and … it's a terrible country and families are brought to that position that they don't want anything to happen to their kids so they keep them in the house and all three children they were blind and mum and dad had to go to work to feed them and that.

Saira had a similar experience, as noted here.

> Saira: Yeah, because of Aamira we can't go there because … in Pakistan it's different… these are special needs children and I think even for normal children… if you are very, very rich then it's alright. He's [my husband] saying you have to come home. I keep saying 'How can I come home, my daughters, they don't want to go and what will happen with Aamira and she just staying there and sitting and nothing to do' … Her behaviour is very, very terrible in Pakistan … she will not go to school, she will just sit down, because when I came in this country before she used to go to school and there are no any special need school just mainstream school … here they realised that she's special need ... In Pakistan they didn't realise that she is special needs and then she didn't listen to the

teachers. They [the teachers] really badly, really badly beat her he used to beat her very badly … she came home with bruises all over her legs…

Both families had a similar and dramatic experience with their children's experience in Pakistan, the nation with which they have a symbolic link.

According to Dwyer (2000, p. 483) metaphors of 'home' remain significant in diasporic discourse. All of the parents we spoke to had strong ties to Pakistan. Such metaphors of home are also gendered, and thus women are reconnected to Pakistan both symbolically, as guardians of familial cultural values, and, sometimes in practice, through ties of intermarriage (Dwyer, 2000). For Shanaz the 'home' of Pakistan is imagined as exclusionary and disablist in terms of the reactions to her daughter. Her account supports the findings of Dwyer (2000, p. 483) in her study of young British Pakistani women. She found that while some individuals enjoyed greater freedoms when visiting Pakistan, the majority found the expectations of normative gender roles in rural Pakistan more restrictive than their lives in Britain. For Dwyer (2000, p. 477) diasporic identifications are always configured through gender because women occupy a symbolic place, sometimes as the guardian of family honor and integrity. Identities are shaped by familial expectations of 'appropriate femininities', which ensure that the behaviour and attire of young women are strictly monitored. These practices are upheld through patriarchal discourses, often given new emphasis within the diaspora context, which define young women as guardians of religious and cultural integrity. We found similar expectations of 'appropriate femininities' in our accounts but these were complicated – or cripped (McRuer, 2006) – by the presence of disability.

> Saira: Because of her [Aamira's] condition because of her religion I want her to settle and everything like normal [arranged marriage]. When she is a nineteen or twenty, I'm trying to go to Pakistan and you know do everything normal like normal daughters. I'm trying to find partners … I am thinking because I don't have any boy and y'know my husband lives in Pakistan so it's really hard for me if … if she's stayed with me all the time, I do work at the school and I want to do more work, not just for two hours …

Hence while Saira has powerful emotional investments in the traditions of arranged marriage there is a risk of disinvestment because of her daughter's impairment. In this sense then we could argue that the embodied realities of disability (Edwards and Imrie, 2005) framed familial perspectives on Pakistan in particular ways.

> Yusef: I'm glad that she's born here … Pakistan is a nice country. They could make it even nicer if they did some things different. Because [in England] she has like problems going to the toilet some of the time and in Pakistan she had *no* problem, as soon as we come back to England we had to give her the medicine…

> Shanaz: She had constipation here from the medicine that they give to us and… we never used it in Pakistan, because .. the heat is good for her [in Pakistan]

> Uzma: There are some other problems that you don't have [in England]?

Yusef: I used to take the wheelchair out there [Pakistan] and I'd have the whole village following me thinking 'What's this?'

Here Pakistan is imagined as a community with varying responses to disability. For some, Pakistan was a place associated with difficult talk about their disabled children:

Uzma: And what about Pakistan society as compared here?

Shanaz: [in Urdu]

Uzma: Can you explain in English? Because, uh … she's saying very good things.

Yusef: What she's trying to say is ...uh... in Pakistan, people do talk especially the elders. They say, 'What's the reason they have a disabled child?' 'Why?' or 'I feel sorry for her'. They don't y'know look at how beautiful she is, y'know there are people that are in the world with worse conditions. But you can't stop people from talking you can't, so, I just let them talk and I just say 'Thank you very much' You can argue as well but arguing just makes things worse. Families talk, you can't stop them.

Whereas Valentine and Sporton (2009) found that different diasporic histories of mobility infected people's self-identifications, as in this case of British Somalian young people, we found evidence for the impact of different histories of disablism on the identities of our participants. Specifically, we can view the accounts of our families as histories of psychoemotional disablism (Thomas, 1999; Reeve, 2008): which refers to the in/direct responses of (non-disabled) others (such as staring, ignorance, voyeurism) which threaten to engender negative emotions in disabled people. Families face a further layer of dis-identification with Pakistan: associated with the cultural disavowal of their *disabled* children in which children are subjected to contradictory responses of fear and fascination. This might explain why not all diasporas sustain an ideology of 'return' to an imagined community (Burdsey, 2006, p. 23).

We want to be clear here that neither our families – nor we – are suggesting that disability is disavowed only in Pakistan. As we shall we see below; Britain offers more than enough of its own examples of disablism. Instead, what we are suggesting is that a diasporic relationship with Pakistan is influenced by the disabling processes around children that shift families perspectives on the imagined community. Hence, as with Anthias (1998: 557), a reliance on a notion of 'deterritorialised ethnicity which references the primordial bonds of homeland' – whether imagined or not – is problematised by disability. As Valentine and Sporton (2009, p. 748):

While as individuals our identities might be multiple and fluid, within the spaces within which we [imagine we] live and move, power operates in systematic ways to generate hegemonic cultures and spatial orderings that define who can claim a particular identity, where, and who cannot, who is in place and who is out of place.

This question of who can claim an identity is apposite for our families. We know that disabled people are denied opportunities to claim a valued identity and are very often placed in spatial positions of 'outsider' or 'stranger'. Bauman (1997, p. 14) argues that not everyone is

welcome in the postmodern sphere of fluidity and consumerism; new strangers are created, 'flawed consumers' who are 'objects out of place' (see also Hughes, 2002). Feelings of home and belonging are increasingly being seen as affected by the processes of migration, globalization and we can now add disability (Mavroudi, 2007, p. 472).

Hardt and Negri (2000, 2004) describe migration and nomadic forms of labour as possible forms of resistance to strict national requirements around employment status. The migrant worker, they suggest, moves across national boundaries and stretches concept of work from something done in the same country as one resides to forms of work that permit flows of capital from one country to another. Yet, they also acknowledge that nomadic forms of work create difficulties and tensions for workers and their families. The absence of a father (due to being denied a visa to live and work in the UK) made day-to-day living difficult for Saira and her children. The lack of support from neighbours and friends conspicuous by their absence and the challenge of seeing two daughters off to mainstream school while meeting the needs of her disabled daughter pushed Saira near the edge:

> Saira: It's really hard, I need my husband … nobody can help like my husband … Everyone is in Pakistan. Just me and my children are here. They say, if you want to live with your husband you should go to Pakistan, but why should I go to Pakistan? Because my children, they don't want to go, they erm…
>
> Uzma: They born here?
>
> Saira: We have British passport, and everything. And my youngest daughter was crying and I asked 'Why you cry?' 'I want my Daddy now, I want my Dad now.' I said 'I can't give you your Dad now' so she y'know … I said if you want to stay with your dad you can stay you live with him. She said, no, I want you and him, Mum and Dad together.

Not only does literature on diaspora risk romanticizing the hidden referent of home and point of origin (in our case Pakistan) it also fails to apprehend the differentiated forms of transnational movement and settlement that occur as a consequence of diaspora (Anthias, 1998) and, in Saira's case, complicated by disability.

<div align="center">Disability and the fight for care in Britain</div>

Diasporic British Asian families are grounded 'not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain and beyond, with increasing reference to globally mediated spheres' (Burdey, 2006, p. 23). Unsurprisingly, caring emerges as a key social sphere for families of disabled children. Kittay (1999b, p. 205) views parents, especially mothers, as being nested in sets of reciprocal relations and obligations. Watson *et al* (2004, p. 333) note that caring work is often assumed and silently demanded from mothers and women more generally. Most meet these demands, embracing them in an active fashion, as demonstrations of their femininity and presumed social and economic roles.

Attending to care is an important part of recognizing labour outside of the normative material paid sense of the word. Across cultures wives and mothers are ideologically and practically associated with unpaid care-giving often in the home. The various positions that

parents, occupy from day to day, perhaps hour to hour, highlight Traustadóttir's (1991) concept of the extended caring role of parents. On the one hand, caring can be extremely hard, tiring work that limits parents in pursuing other roles and activities. On the other hand, caring can provide for more opportunities than normally associated with the traditional parenting role (Pratesi and Runswick-Cole, forthcoming). We are reminded here of Kagan et al's (1998) call to find ways of valuing the caring work of parents. After all, we know from previous research that parents occupy 'positions of 'reserve army' care provider or 'para—professional' in health and social care through being almost single-handedly responsible for performing skills such as physiotherapy, suctioning, urinary catheterizations, administering medicine, spoon or tube feeding, lifting and positioning' (McKeever & Miller, 2004, p. 1188). Following Hardt and Negri (2000, 2004) we can consider parenting and care as key elements of what they term immaterial labour. These forms of labour are traditionally banished from malestream notions of meaningful labour – such as service work, care and support – are revisioned as some of the most significant forms of labour of contemporary societies. The immaterial labour of mothers and fathers translated into a growing knowledge about, and response to, the needs of their disabled children. This ranged from communication to medication:

> Mysha: He can understand us but he cannot speak at all. He can understand a word. We said 'Eat?' he said 'Yes' but he took me to kitchen, and ran some water. I say 'Want to go to sleep?' and he understands that and I say 'I'm going for walk, you come with me?' and he understands that… They've [school] been teaching him to sign haven't they? Because he talked about signing, and they were they were, all the information was about managing his behaviour and trying to stop him from throwing things or whatever and what they did to manage his behaviour.
> … so he's taking medicine. And, erm controlled drugs like, y'know? Liquid and capsules, he cannot swallow but we give him the bottle just erm y'know capsule broken up and erm putting them on spoon in bottle and erm then he'll take controlled drugs fine, we give him controlled drugs but then he's calm…

This knowledge extended to the extent that parents' convictions were so strong that they refuted diagnostic suggestions:

> Yusef: erm… before she was born the doctor says… they gave us the choice if she want an abortion and they did say that they could see that the baby was going to have some problems but we said no.
>
> Katherine: Did you feel under any pressure?
>
> Shanaz: Uh… not really.
>
> Katherine: Did you feel like they just gave you the information and they gave you a choice?
>
> Yusef: They were saying it could be linked to family first cousins but I said no. My mum and dad were first cousins and in four generations this is the first disabled child in my family so, I don't understand. I don't like being accused, it can happen to anybody. So…

it's alright. I suppose but… they didn't let me… they didn't let me into the room they go you look too young! [laughter] you can't be the daddy.

In some cases parents were called on to manage medicalisation.

Mysha: because medicine we gave to him there, there is no medicine over here because these are special medicines, only these medicines available in Arab country y'know?

This growing knowledge of medicalisation and diagnosis mirrors the findings of McLaughlin *et al* (2008) who found that in a number of cases parents were, seemingly, more up to date about their child's care needs than many of the professionals. One consultant they interviewed happily admitted that parents would often turn up to appointments with 'state-of-the-art' knowledge about treatment and prognosis that the consultant was yet to hear about. McLaughlin *et al* (2008) inform us that parents are active participants in diagnosis. They often seek a label for their child and participate in their own diagnostic processes. Diagnosis is often not an immediate one off event, even if there is evidence that the child is developing or acting differently, defining the source involves a significant amount of medical uncertainty. Medical diagnosis in young children is a comparative process, made against developmental markers, which define both the normal and the distance from it (McConachie, 1995). Often there are mixed messages, generating ambiguity, from different medical practitioners (McLaughlin 2008 *et al*). Confusion, anxiety and concern are common emotions for parents during the stage of diagnosis and these emotions are heightened for parents whose first language is not English.

Katherine: When Farhan started at school, did they give you a diagnosis? Did they give a name to what he has?

Mysha: Erm…

Uzma: She wants to ask, what exactly problem he has? Did they give you that this particular problem he has?

Mysha: No, he had a bad problem of telling me the area y'know? Other thing is err he is err not learning quickly you have to spend a lot of time with him. (.) Other thing is (.)

Katherine: So they didn't give you any particular diagnosis?

Mysha: No, no, no only that he cannot speak. Otherwise (.) so they scan him, whole body almost and said he was normal.

Of course parents find getting a diagnosis helpful. But seeking a name – particularly when it as vague and seemingly pathological as in the case of the vague diagnosis above – may disturb parents' relationship with their children (McLaughlin, 2005; Goodley & Tregaskis, 2006).

For Anthias (1998) a key issue associated with gendering diaspora involves asking to what extent the experiences of diasporic women capture some of the cultural and structural shifts

in relation to their 'labour' which might produce emancipatory and liberating experiences. We could argue that the mothers in our three case studies are empowered in terms of their skills and knowledge precisely because, like other mothers of disabled children, they have to take on the extended role of parenting a disabled child. However, as Anthias (1999) warns, we need to be careful not to romanticise these accounts and remain attuned to entrenched systems of subordination. Indeed, supporting the findings of McLaughlin *et al* (2008), parents (and particularly mothers) of disabled children risk being drawn into disempowering systems of professional governance and surveillance:

> Saira: I was at home, making dinner … and the children were upstairs fighting each other. Asiya was doing her homework and Aamira was messing around with her stuff and Asiya pushed Aamira and she fell down. I didn't know. The next morning she said 'Look Mum, look!'. I asked her 'What happened?'. And she was laughing and she said 'I'll go to school and I will tell my teacher Mum hit me!'I said she's just joking. I was at work and I received a call from the deputy headteacher. I couldn't receive the call and they didn't have my mobile number and he left a message. I couldn't listen to the message because I was working. When I listened to the message at half past three the school was closed. I couldn't call back. So I thought, it's alright, I'll give the call tomorrow morning. Then when Aamira came at 3.45 and at 4.00 social services came they said 'the school called us because you hit your daughter'. I was really shocked because I didn't hit my daughter. So the lady said 'we have to speak with you alone and we have to speak with your daughter alone'. They spoke to me and then they called Aamria she said 'No! I don't want to come with you alone, I want my mum.' Y'know the lady noticed she's really attached with me … They asked 'What happened?' and I said 'I don't know what happened, because I asked her in the morning and she didn't tell me what happened' so she said 'You have to know about it, what happened' I said 'It's just in the night time I was making the dinner' she asked me 'Did you go anywhere and leave them alone' I said 'No, I didn't go anywhere'. So the lady came from social security she said 'Oh I know [professionals who work with your families] and I will ask them as well about you and we are going at the moment and we have to go to the doctor to find out what happened and everything because Police are involved now in this matter and the Police will come in the school tomorrow.' Then I had to go to Deputy Head and I explained everything and I asked Asiya, 'Asiya please tell me what happened', then Asiya told me in the night time, 'I pushed her because she was messing around in my homework and I was telling her again and again, go away, go away, and she was not listening. I was sitting on my bed because they share a room, and because I was sitting on my bed but she was messing around with my homework and I didn't really push hard I just push her like this and she fell down'. It's only a small bruise, that lady y'know came again making an appointment to the Doctor. When I went to the Doctor, the Doctor knows me very well, she said, this young lady makes up stories. Y'know, her mum can't hit her, I know.

Raghuram (2009, p. 175) argues that diasporic research can at times be so accustomed to thinking that stories of migration are always stories of arrival, from 'there' to 'here', that we rarely stop to think that the UK is also the site of departure and of circulation. We were reminded of the circulating practices of power associated with the care of disabled children undertaken by families in the context of the British welfare system.

Disability and Diaspora: From Isolation to Ensembled 'Caringscapes'

The concept of diaspora is useful because it helps us to understand how people can have continuing attachments to places – or scapes – which cannot be explained if we think of populations as static and territorially bound in nations (Raghuram, 2009: 183). For Anthias (1998) any use of the concept of diaspora should capture some of the trajectories of migration and settlement that then lead to a reconfiguration of ethnic solidarities. A diasporic space is created when it transgresses the boundaries of ethnicity and nationalism (Anthias, 1998, p. 566). We could argue that the articulations presented above are symptomatic of a hybridised identity (offered through the diaspora) which permit critiques of cultural responses to disability and challenges to service provision. The families that we spoke to illuminated some of the ways in which their diasporic positionings left them feeling isolated or, in contrast, supported by ensembled relationships. For Anthias (1998, p. 564) the diaspora is constituted as much in difference and division as it is in commonality and solidarity. One can feel an acute dual sense of loneliness and camaraderie. Like many other parents of disabled children, parents spoke of the difficulties of parenting a disabled child. Mysha's son struggled to sleep at night, which kept her awake, and she complained that he was difficult to control and 'discipline'.

However, as others have suggested (e.g. McLaughlin *et al*, 2008), these difficulties of parenting should not be attributed to the 'burden' of a child's impairment. Instead, and in line with a critical disability studies perspective, we need to excavate the social and relational support enjoyed by families and its impact upon their capacity to care. For example, Saira spoke about the barriers she experienced in accessing health, social care and education when she had to make a 3 hour round trip to pick up medicines from the hospital which her local GP was unable to prescribe. Hughes *et al* (2005) propose that the feminization of care in a phallocentric culture makes participants in the caring relationship – regardless of gender identity – necessarily subordinate. Saira's account would, perhaps, indicate subordination. Saira told us of the lack of friendships and community support 'I don't have so many friends, just one friend and she knows my children' complicated further by the fact that her husband was refused a visa. On the other side of the diaspora experience were those times when support, care and love was provided to the disabled child (and their parents) by their extended families.

> Katherine: Do you get (um) some families get support from people coming to help in the home. Do you have any help in the home or do you just look after Habiba yourselves?

> Yusef: No my family does it all the time

> Shanaz: She comes back from school to Grandma's house… She plays with Grandma she plays with Grandad when he comes home at half six and then my brothers come and probably play with him if not my sister if she comes back from University she puts her music on. Her Grandma begs us 'Leave her here, leave her here for the weekend, leave her here!'… we're ever so blessed.

This description resonates with Hughes *et al's* (2005, p. 266) notion of care as a 'gift' redolent with positive properties such as 'generosity, trust, confidence, love, commitment, delight and esteem'. How these gifts are offered will, of course, be influenced by social class,

economic and cultural capital. As Anthias (1998) reminds us: the diaspora is a heterogenous phenomenon marked by class, gender and, in our case, disability. Contemporary western parents are often expected by others to play a pivotal role in enhancing their children's 'futurity': their anticipated value, productivity and well-being as adult citizens (McKeever & Miller, 2004). Similarly all parents imagine what the future will hold for their children. 'These ideas will be influenced by dominant narratives associated with the trajectory of the 'proper family'. The introduction of disability into a family shatters the 'presumed certainty of such possible futures' (McLaughlin and Goodley, 2008, p. 329). It would seem, though, that the presence of an extended family may provide some hope and positivity for the future:

> Katherine: Is it okay for me to ask about the future, when Habiba grows up, what do you think will happen for her? Do you think that she will still live with you?

> Yusef: Yes, then my brothers will look after her.

> Katherine: You're very lucky to have that, very, very lucky.

> Yusef: If there's a problem then my sister will definitely take her. If something does happen to us two, and if worse comes to worst then her grandparents, they'd love to take her.

> Katherine: So there'll always be a family member who'll look after her? Yusef: Yeah.

The potential offerings of the extended family captured in this account contrasted markedly with the isolated experiences of many white British families that we have worked with. Drawing on the work of McKie *et al* (2002) and Watson *et al* (2004) we could conceptualise the contributions of the extended family in terms of 'caringscapes'. This concept acknowledges the complex and diverse ways in which people deal with the day-to-day challenges of organizing and conducting caring work. Following Watson *et al* (2004) it incorporates the spatial and temporal into an analytical framework that reflects ideas of landscape or terrain. Thus, some of the time people try to realize particular aims and goals by actively selecting their paths through this terrain. But caring pathways can be restricted by the availability of caring resources, income or services or routinized through well-trodden conventional, invariably gendered, pathways. In contrast to the limited caringscapes associated with the isolated mothers and families described above, Yusef and Shanaz depict an ensembled caringscape that boasts interdependency. At their best, caringscapes 'shift in response to the influences of others or changes in mobility, communication, and the institutional organizations which confront individuals' (Watson et al, 2004, p. 341). According to Crozier and Davies (2006), British South Asian parents have been variously accused of having too high expectations of their children or not being interested at all. In contrast, they show, parents demonstrate huge parental involvement in their children's lives and that this involvement resides not simply in the hands of the parents but within the wider family. Similarly, we would suggest that there may well be similar opportunities for ensembled support in the wider British Pakistani diaspora. What this points to is a further need to critique diaspora. For Anthias (1998) this involves considering the ways in which men and women are inserted into the social relations of the country of origin. A case unit of analysis for Anthias (1998) is the family and other institutions and discursive formations in the reproduction and

dynamic transformations of central facets of culture. Yusef and Shanaz's extended support capture the productive possibilities for enhancing caringscape through the diasporic family.

Conclusion

Diaspora may be seen as dynamic,'on the move' and multiple but also subject to power relations, tensions, disconnections and the specific, situated processes that enable (or force) the constructions of shared (and often politicised) notions of belonging, identity and community (Mavroudi, 2007, p. 472)

We aimed to explore in this paper the intersecting nature of diaspora, disability and family intersect. Drawing on qualitative interviews with the parents of three British Pakistani families we drew out three lines of enquiry. The first, *disability and disavowal in Pakistan*, explores parents' relationship with 'home' and how this is complicated by the presence of disablism. We suggested that previous literature on diaspora risked romanticizing the hidden referent of 'home' and 'point of origin' (in our case Pakistan) and had failed to apprehend how diaspora is complicated by disablism. We make a plea, therefore, for researchers of diaspora to include socio-cultural theories of disability in their analyses. The second, *disability and the fight for care in Britain*, explored the ways in which British Asian families are grounded not only in the cultures and traditions of their parents and the Asian subcontinent, but also in the social practices of Britain. We focused on their engagement with services and professionals. We conclude that service evaluation and critiques of professional practice must be sensitive to the diasporic identities of their clients. The third, *disability and diaspora - from isolation to ensembled caringscapes*, examined the limits and possibilities offered through diaspora. One key affirmative element of this is the support of an extended family brings with it the chance to look to the future with hope and possibility. In illuminating the affirmative impacts of extended families on the care of disabled children we hope to extend understandings of caringspaces that view cultural diversity in terms of possibility. Following Raghuram (2009) the families accounts remind us of the diasporic potential for translocalism: simultaneous attachment to the places one might have left and the places one moves into. Translocalism emphasises the many activities that families engage in to maintain these relations across space.

Dan Goodley is Professor of Disability Studies and Education at the University of Sheffield. He is interested in engaging with the dual processes of ableism and disablism and recent texts including 'Disability Studies: An interdisciplinary introduction' (Sage, 2011).

Dr Katherine Runswick-Cole is Research Fellow in Disability Studies and Psychology in the Research Institute of Health and Social Change at Manchester Metropolitan University, UK. Her research focuses on the lives of disabled children and their families. Katherine writes from a Critical Disability Studies perspective and has published extensively in the field.

Uzma Mahanoud has an Msc in Psychology and Disability Studies from Manchester Metropolitan University.

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Endnotes

[1] (RES – 062-23-1138) (see project website: http://post-blair.posterous.com/)

Algorithms of Access: Immigrant Mothers Negotiating Educational Resources and Services for
their Children

Gay Wilgus and Jan W. Valle
City College CUNY &
Linda Ware
State University of New York at Geneseo

Abstract: This article draws upon the narratives of immigrant mothers (e.g., Japanese, Dominican, Filipina) of children with disabilities who reside in New York City. Common to each mother's narrative is a description of her ongoing negotiation between cultural meanings of disability and the American conceptualization of disability and its institutionalized response to disability. In considering these narratives through a disability studies lens, we identify ways in which race, class, culture, and language impact immigrant mothers' access to disability resources and services for themselves and their children.

Introduction

The back roads between Santa Fe and Taos, New Mexico, lead to the sparsely populated town of Chimayo, home to *El Santuario de Nuestro Senor de Esquipulas.* This Southwestern spiritual center is nestled in the foothills of the Sangre de Cristo Mountains and serves as the destination for the largest annual religious pilgrimage in the United States. Each year during the *Semana Santa* (Holy Week) pilgrims trek along the winding path traveling on knees, walking, limping, or wheeling along in wheelchairs in the performance of a ritual that dates back centuries. Popular legend holds that the sacred ground in Chimayo offers healing—*milagoros* (miracles)—to those in need.

On a recent daylong excursion to Taos, I (Linda) drove with my good friend, Ria, in deep discussion about our disabled sons who continue to face obstacles posed by the helping systems purportedly designed to advance their right to be in the world. We considered a stop in Chimayo to offer prayers although neither of us is particularly religious nor prone to pilgrimage. Still, at this stage of parenting, we would welcome miracles that could guarantee educational and social access for our sons whose diagnoses—cerebral palsy (Justin) and autism and cerebral palsy (Andres)—present on their bodies in deliberate ways. With parental encouragement and support, both live beyond the threshold for independence as assessed by educational and service-based agencies. Justin, nearly twenty years older than Andres, is a power wheelchair user who lives independently in an accessible apartment in Albuquerque. Andres is completing his last year of high school and lives at home with his mother. After the school district recommended homeschooling as Andres' only educational option, Ria left her position as a mediator to become her son's full-time classroom aide, thereby ensuring his legally entitled access to public education.

We are, as mothers, well-versed in the legal history of rights for disabled people and often swap parenting episodes about our sons that range from the mundane to the miraculous, informed by our particular knowledge about disability as a site of societal oppression compounded by race, class, gender and geography. The ableist landscape that disability scholars theorize is our lived cartography. Few parents would debate the value of advancing a political

interpretation of disability and yet throughout society "proper" the "ideology of ability remains largely unquestioned" (Siebers, 2008, p. 81). As American-born middle class parents who possess the cultural capital that might otherwise advantage us in our advocacy efforts (Ong-Dean, 2009; Hale, 2010)—it is significant that we have always experienced—and *continue* to experience—societal and institutional obstacles to access that are formidable, unyielding and overwhelming. Access may be a hard-won right, but it is a right that has proven illusive in context.

Algorithms of Access

The challenges to access described above are not specific to the life stories of these two particular mothers, but rather reflect persistent issues documented within the literature shortly after the passage of The Education of All Handicapped Children Act, 1975—known now as The Individuals with Disabilities Education Improvement Act or I.D.E.I.A.—(Lipsky, 1985; 1989; Sonnenschein, 1981; Hoff, Fenton, Yoshida, & Kaufman, 1978) until the present (Hale, 2011; Valle, 2009; Kalanypur & Harry, 1999; Ware, 1999; 2003; 2004). Although I.D.E.I.A. guarantees educational access for children with disabilities, we argue that the degree to which *federal* legislation is realized within the lives of families is dependent upon a complex algorithm of factors within the *local* context.

If we look to civil rights legislation as a point of comparison, the Civil Rights Act of 1964 guaranteed equal rights for African Americans; however, no federal law could ensure swift attitudinal shifts among individuals at the local level where implementation of the law was to occur. (Indeed, the enactment of "affirmative action" policies, for example, functioned as a strategy to aid in local compliance.) Likewise, the Education for All Handicapped Children Act (1975) guaranteed access to a "free and appropriate public education" for children with disabilities, but could not ensure attitudinal shifts about disability at the local level where implementation was to occur. Whereas *racism* was acknowledged as a significant issue to address in the implementation of equal rights for African Americans, it is worth noting that no comparable acknowledgement was made in regard to *ableism* as a significant issue to address in the implementation of a "free and appropriate public education" for children with disabilities. The long-standing supposition has been that school professionals designated at the local level to implement special education law do so without bias—an assumption that reflects the assumed objectivity of the medical model upon which special education is grounded. Moreover, it has been largely understood that parents of children with disabilities are a monolithic group with whom school professionals interact without influence from their own belief systems regarding race/ethnicity, language, culture, gender, social class, and ability.

In this paper, we present narratives told by two mothers of children with disabilities who immigrated to New York City as adults (from Japan and the Philippines, respectively) and a third mother (whose parents emigrated to New York City from the Dominican Republic) who lives in the predominantly Dominican neighborhood of Washington Heights/Inwood where she was raised. The mothers were identified by direct sampling. We traveled to the interviewees' homes or a place convenient for them to reach to conduct semi-structured interviews. Interview questions centered, broadly, on the details of parents' past experiences in finding out about and

gaining access (or not) to services for their children with disabilities. Each interview lasted from 2-3 hours.

The interview data was transcribed separately by each interviewer, then, working together, the authors aggregated the transcribed data. Next we coded data within interviews according to the following categories: Interviewee personal background; child's diagnosis; history of services and education for child with disability; interviewee report of her treatment by service personnel; interviewee report of her treatment by school personnel; treatment by other parents.

In our analysis, we propose that (1) race, class, culture, and language can impact mothers' access to disability resources for themselves and their children, (2) cultural stereotypes may influence interactions between school professionals and parents, and (3) the type and severity of disability matters in negotiating educational access. We argue that the complex interactions among these multiple factors disrupt the assumption of an objective context (where race/ethnicity, culture, gender, language, social class, and beliefs about disability are irrelevant) and create "algorithms of access" that influence negotiations between parents and school professionals.

Mother Narratives: Portraits of Access

We begin by contextualizing our discussion within the "narrative portraits" of three mothers of different non-dominant cultural groups in the United States: Takako, a Japanese immigrant, whose son's visual disability has been present since late infancy; Maria, a first-generation Dominican, whose son was identified as having a learning disability during his school years; and Agnes, a Filipina immigrant, whose daughter has Down syndrome.

Takako: "His teachers have been so eager to help!"

Takako, who emigrated to the United States from Japan approximately 20 years ago, is a wardrobe manager for both a ballet and an opera company. Her son's father, from whom she is recently divorced, is Italian. Their now 16 year old son, Matteo, was diagnosed at the age of ten months with retinoblastoma—the most common eye cancer of childhood.

In relating her son's medical history during the interview, Takako maintained a calm, focused, and even tone—reflective of the single-minded, steady focus on her son that she described in managing his initial diagnosis and treatment. Following Matteo's successful treatment, Takako concentrated on finding optimal educational opportunities for her son. She began engaging him in various educational activities, working from the assumption that he had the same abilities as any other child.

At the age of three, Matteo was evaluated for early intervention services by the child development center he attended. The results of this evaluation suggested that Matteo was "behind"; however, Takako did not agree with the assessment, asserting that his performance was most likely affected by the unfamiliar context and people involved in the test administration. She reflected, "I was not ready to admit that he was different." In fact, Takako sought to enroll

Matteo in a private, five day Pre-K program for typically developing children, in lieu of continuing one-on-one services from the Jewish Guild for the Blind." After all," Takako recalled, "he had learned to ride a bicycle!" She described the director as "very welcoming" and amenable to the idea of having Matteo in her program. Takako recalled, "She really wanted to work with him"—yet, it is worth noting, that Matteo was permitted only to attend one day per week unlike his able-bodied peers who attended Monday through Friday.

Takako went on to describe Matteo's educational experiences in public school (elementary, middle school, high school) as largely positive. She noted that Matteo has always had the assistance of vision therapists who not only worked with his classroom teachers, but also functioned in an advocacy role for the family. These therapists have followed Matteo for years and maintain a strong relationship with him and his mother.

By Takako's account, teachers at all of the schools "have been so eager to help." It is worth considering, however, that the nature of Matteo's disability, his ability to compensate for his disability, and the assistance he receives from vision therapists work together to create a context in which little is actually required of classroom teachers to include him. In fact, Takako retracted somewhat from her original stance by revealing later in the interview that films shown in the classroom, for example, are somewhat inaccessible to Matteo because he "doesn't expect to be able to see it, but only to hear what is going on." (In other words, it seems that Matteo's willingness to compensate—instead of asking for modifications, such as having someone describe the visual aspect of what he is hearing—relieves teachers from having to think ahead about how to accommodate his disability-related needs within the classroom.) Moreover, Takako admitted that Matteo engages in a lot of guesswork in class and wonders if his teachers know how much energy he expends on "passing" (i.e., faking it) in order to blend into the classroom like his able-bodied peers.

Over the years, Matteo's efforts in the classroom have been noticed and rewarded. Takako proudly noted that her son was *asked* to be one of the first students at a new and progressive middle school and then again at a new inquiry-based college preparatory public school that infuses technology and arts throughout the curriculum. He is successfully integrated at this school as the only student with a diagnostic label of "visual impairment."

Maria: "Am I in a precinct?"

Maria, a New York City Teaching Fellow, is completing her master's degree in bilingual special education. Born in the United States to parents who emigrated from the Dominican Republic, Maria was raised speaking both Spanish and English. She currently resides in the Dominican neighborhood of Washington Heights/Inwood where she grew up and attended public school. She lives with her 18 year-old son, Carlos, who was identified as having a learning disability in first grade and dropped out of school at the age of 16. As a New York City Teaching Fellow, Maria teaches high school in a self-contained special education class for students with learning disabilities. Thus, she has the dual perspective that comes with being a mother of a child who received special education services *and* a special education teacher in the public schools.

Maria was largely unaware that Carlos had any learning issues until his Catholic school kindergarten teacher called her in for a meeting. She recalled her bewilderment at the suggestion that "something was wrong" with her child—after all, she could name many things that Carlos did very well at home—as well as the anger she felt toward the teacher who concluded the meeting by stating, "You gotta get your kid to a psychologist." Maria brushed off the incident, thinking that the teacher simply did not like her or her child.

Maria enrolled Carlos in a public first grade where he had difficulty learning to read. He repeated first grade with a teacher Maria described as "very loving and so nice." This teacher explained that Carlos seemed to have "wires that were not connecting" and suggested that Maria take him for eye training in an effort to remediate his reading skills. A subsequent psycho-educational evaluation deemed Carlos eligible to receive resource services as a "learning disabled student."

After a year in general education with resource services, Maria enrolled Carlos in another public elementary school known for being child-centered. She explained, "He did okay there. He was a really good public speaker, but continued to struggle with reading. He had good relationships with adults in the school." She recalled these years as a time when Carlos seemed socially competent and engaged in school.

Maria's countenance and tone notably shifted as she began to talk about Carlos' transition to middle school—a period fraught with difficulties. He attended a neighborhood middle school for only a few months. Maria described the "Puerto Rican principal" at this school as "the *nastiest* person who ever talked about my son." She recounted how this principal took her into her office and said, "I'm going to show you *evidence*!!" She pulled out one of Carlos's notebooks and kept repeating, "He is doing *nothing*. Nothing!" Maria recalled thinking, "Am I in a precinct? You are talking to me like my son has been *charged* with something!!" She was determined not to cry in front of the principal, but when she left the office she "cried like a baby." She recalled, "It was *horrible*. Horrible! That was the beginning of the end…I had nobody to talk to. I kept thinking—'What am I going to do? What am I going to do with my kid?' The assistant principal was Dominican and she did help me because I was feeling like my son was a *criminal."* Maria decided to withdraw her son and re-enroll him at another public middle school; however, his experience at the next school was troubled, as well. Carlos dropped out of high school as soon as he could. Maria hopes that VESID (Vocational and Educational Services for Individuals with Disabilities) will help her son get training and a job.

During the interview, Maria was quick to point out how much Dominican parents want their children to be educated. She became teary talking about how she feels when she overhears teachers talking about "how *those* parents don't care" about their children. She said, "When kids drop out of school, Dominican parents just cry and cry. When these parents come to me as a professional, I wish I had the magic answer. Parents just don't know what to do when their kids are failing in school...I know a lot has to do with how the kid is being *treated* in school. Think about what happens to a kid when all he hears from teachers is that he is not going to *be* anything in life!"

Reflecting upon her years advocating for Carlos within the public school system, Maria remarked, "People see me…as a young, single, uneducated mom. The fact that I am getting my second master's is my secret thing. I speak like everyone speaks and I am proud of it. School people sized me up. I could tell by the way that they spoke to me. White mothers are treated differently. If a White child has a learning disability, it's real. That's something we need to work with. If it is a Latino or Black child, it's just that they are *bad kids*."

Agnes: "I talked to the mothers at Riverside Park."

Agnes, who emigrated from the Philippines to the United States in 1991, met and married her Irish American husband a few years after her arrival. Although they had decided "for financial reasons" not to have children, Agnes became pregnant at age 39. Their now 15 year old daughter, Katie was diagnosed *in utero* with Down syndrome. Agnes recalled how she anguished over telling her husband; however, he reassured her that "it doesn't matter, we will have the child no matter what."

Throughout the interview, Agnes repeatedly referenced her ongoing search for information, services, and appropriate educational settings for her daughter. Given that Katie's disability was known at birth, Agnes recalled receiving information from the hospital about support groups for parents of children with Down syndrome. Later on, information about early intervention services came to Agnes through her husband who visited their city councilwoman's office in search of assistance for Katie. As a result of this fact-finding mission, Katie began receiving early intervention services (e.g., speech/language, occupational and physical therapies) three times a week.

Unlike her husband who sought out information from organizations, Agnes relied instead upon neighborhood playgrounds as her source of knowledge. While Katie engaged in play, Agnes sought out mothers of children with (visible) disabilities to talk to about services and educational opportunities. For example, when she reached the decision that Katie should go to preschool "to be with other kids," Agnes consulted "the mothers in Riverside Park" who recommended "the best school" (albeit with a waiting list)—a private inclusive family center with a commitment to educating children with and without disabilities. She eventually enrolled Katie in this preschool—and true to the assessment of the "mothers in Riverside Park"—had a very positive experience.

Agnes recalled that finding a kindergarten for Katie was not nearly so easy. The administration at the neighborhood elementary school informed her that they "did not have services" for Katie, so she would have to attend an elementary school out of the neighborhood that did have services. In light of this news, Agnes turned to a "playground mom" of twins—one with Down syndrome and the other without. She advised Agnes not to send Katie to the suggested alternative school, but rather to a well-known "good school" for meeting the educational needs of students with disabilities. Agnes explained: "We were initially denied access to [the good school.] They told us they couldn't take her and they put her at [the other school] which is further away." Unhappy with this situation, Agnes returned to the trusted staff at Katie's preschool who directed them to a lawyer who succeeded in securing access for Katie at the desired school.

Although Katie was included in a general education kindergarten for two years, Agnes moved her in first grade to a self-contained special education setting because of the lower student-teacher ratio. She recalled that this class had "some [students] in wheelchairs, other ones with Down, and others with disabilities that you can't tell." Throughout Katie's elementary school years, Agnes remained satisfied. She told us, "I am very happy about the teachers…yes, very happy. There is no problem there."

Reflecting upon Katie's upcoming high school years, Agnes shared that she and her husband have already begun thinking about possible options. "My husband started to talk about going somewhere else…but later on he decided to stay here because the services here can be easily reached." In considering the possibilities for Katie's secondary education, Agnes returned to her old friend from the playground who had given her advice about elementary schools. She recommended the largest private, inclusive educational organization for children with special needs in New York City where her own adolescent daughter with Down syndrome attends. Agnes seemed unsure about this school as an option for Katie: "Yeah, but I don't know. My husband doesn't like…that she would go on the bus…he wants to take her to school and pick her up from school." With a look of worry on her face, Agnes then mentioned that they just found out that they have to apply for guardianship when Katie turns 18. The realization of the unending quest for information and resources into the foreseeable future appeared to weigh heavily on Agnes.

Discussion

In order to make sense of the "narrative portraits" presented above, it is relevant to first consider the larger cultural context within which interactions between school professionals and parents take place (Ware, 1994; 1999; 2003; Valle, 2010). The idea that negotiations occur within a hermetically sealed environment free from cultural influence is at best naïve. All of us receive cultural messages through multiple sources—media (print, television, social), national histories, families, shared community experiences, to name a few. We need only look to recent news stories for examples of cultural stereotyping. Of late, Jeremy Lin, the surprise savior for the New York Knicks, has appeared regularly in both national and international headlines. It is of interest that journalists rarely refer to Lin's prowess on the basketball court without also identifying him as Harvard-educated and Chinese. Serving to distinguish Lin from the typical (and stereotyped) professional basketball player, these descriptors perpetuate a dominant white racist framing of Asian Americans as belonging to (1) "the model minority" (a point we take up in greater depth in the following section) and (2) one large homogeneous Asian heritage. (Lin is, in fact, Taiwanese-American.) Moreover, racist images continue to appear in connection with Lin's news coverage, such as the CBS airing of a fan's sign featuring Lin's face over a broken fortune cookie with the words "The Knicks Good Fortune" and a USA Today cartoon (February 23, 2012) that refers to Lin as "Moo Goo Guy Slam." It is noteworthy that language mocking at the expense of Asian Americans is not uncommon in the United States and is "usually linked to societal discrimination against the racialized 'others'"(Chou & Feagin, 2008, p. 11).

We do not mean to imply that school professionals may be more susceptible to these kinds of cultural messages than anyone else nor that members of non-dominant cultural groups

have no stereotypes of their own about dominant cultural groups or one another. Rather, we argue that it is important to *acknowledge* how cultural understandings can influence the supposedly objective process of negotiation between professionals and parents under IDEIA—as we see within the narratives of Takako, Agnes, and Maria.

Cultural Stereotyping: Ignorance to Racism

In *The Myth of the Model Minority,* Chou and Feagin (2008) assert that a racial hierarchy exists in the United States predicated on a "white-to-black continuum of status and privilege with whites at the highly privileged end, blacks at the unprivileged end, and other racial groups typically placed by whites somewhere in between." According to the authors, the American public perceives Asian Americans as a "model minority"—an (imposed) identity most often associated with strong educational values, academic excellence, and high college enrollment. Chou and Feagin suggest that the stereotype of a "model minority" is problematic on a number of levels:

> First, it groups all Asian national cultures together…Second, assuming that people of Asian descent are culturally inclined to value education tends to be linked for whites to the argument that certain other racial or ethnic groups are culturally devoid of such a value…A third weakness of the typical "Asian culture" argument is that it ignores the very substantial and continuing negative impacts that white hostility and discrimination have had on Asian Americans (2008, p. 106).

Nonetheless, it is worth considering, the possible influence that a "model minority" stereotype may have upon the interactions with school professionals that Takako and Agnes describe.

Takako, quiet, poised and self-restrained, fits the stereotype many Americans hold about the Japanese; yet, there is no passivity or deference in the relentless way she pursues educational access for her son. She describes school professionals as "very welcoming" and "so eager to help" with Matteo's integration into general education settings—the kind of overall positive experience that is missing from much of the literature about parents and professionals. It is possible that Takako's ethnicity contributes favorably to her interactions with school professionals. Given that the "model minority" stereotype constructs Asian Americans as valuing education above most other cultural groups, it seems likely that Takako possesses the advantage of being perceived as highly committed to the education of her child.

It is also worth considering America's admiration of Japan's excellence in business and technology—as if it were the site of "some sort of external oriental wisdom, inaccessible to western experience…far across the seas like a rare and forbidden spice (Montgomery, 1992, p. 276). As a Japanese American, it could be that Takako is seen as someone to be respected for her intelligence and ingenuity. For example, it is of interest that Takako does not report being admonished by any professional to "be realistic" about expectations for her child—as many other mothers of children with disabilities report. Furthermore, it is possible that Matteo's Asian heritage contributes to a favorable perception of his potential for academic success.

Agnes, a Filipina American, is also subject to the "model minority" stereotype that homogenizes diverse Asian and Pacific Islander groups. With the exception of having had to hire a lawyer to gain access into a desired elementary school, Agnes is likewise positive about her experiences with school professionals. It is worth considering how much influence that the cultural characterization of Filipinos as hardworking, honest, and honorable people might have upon the willingness of school professionals to engage with Agnes—the origins of which can be traced back to the Philippine government's construction and promotion of a positive image for Filipino migrant laborers (Guevarra, 2009). It is noteworthy that Agnes searches out other mothers of children with disabilities rather than professionals, thereby minimizing her experiences of negotiation. Her choice to seek out mothers in informal spaces (rather than professionals in organized spaces) could be reflective of Agnes' challenges in speaking and understanding English and/or a cultural deference to authority. Recently, a Filipina student remarked to one of the authors, "Yes, we are taught to *always* respect authority. We are taught not to cause a disturbance, not to cause conflict or argue. We are taught to be very quiet…." (private conversation at the student teacher orientation, January 25, 2012). Indeed, it is Agnes' husband who exercises his white male privilege to engage professionals "to get things done" for their daughter.

Dominicans, on the other hand, historically have not been the beneficiaries of "positive" stereotypes of the kind imposed upon Asian Americans of late. In a graduate class about racial and ethnic identity formation in young children, for example, my (Gay's) students were asked to anonymously report the ethnic group with which they primarily identified. Given a list of all ethnic groups reported by the class, each student was then asked to write descriptions which jumped to mind upon reading the name of each group. All lists were submitted anonymously in an effort to achieve authenticity—the kind that, one student revealed, in a move of unabashed honesty, by writing next to the category Dominican—"loud, driving flashy cars, drug-dealers, playing loud music, welfare queens."

As stated previously, all of us, school professionals included, are exposed to cultural stereotypes that circulate through a variety of sources (e.g., print media, television, film, music, family and community, social media, personal experience)—yet we are most certainly not always aware of the origins of such cultural framings nor the difference between fact and stereotype. For example, the origin of the "welfare queen" stereotype can be traced to the collapse of the manufacturing industry in the 1990s that left "tens of thousands of Dominican workers" unemployed, creating "economic distress… particularly among Dominican women" (Hernandez & Rivera-Batiz, 2000, p. 44). In the workplace, Dominican women report having to contend with cultural stereotyping as the "mamasita" —a negative image akin to the jezebel stereotype of African American women "…[that is] part of the race-gender-sexual exoticization and 'symbolic taint' of the urban ghetto and its inhabitants" (Lopez, 2003, p. 186). Moreover, the New York City police department notably made national headlines when dozens of police officers posted inflammatory remarks on Facebook about West Indian parade-goers (including Dominicans) —describing them "animals" and "savages" (New York Times, December 11, 2011).

Guarnizo's (1994) observation that Dominicans tend to live, work and socialize with other Dominicans offers at least a partial explanation as to how these stereotypes are galvanized and perpetuated. Goris-Rosario (1994) further explains,

> …Dominicans who work outside their community are no more integrated into the larger New York City community than those who work among Dominicans. Dominicans working outside their ethnic enclaves, although more likely to have non-Latino employers and supervisors and to speak English in their workplaces, work primarily around other Latinas/os with whom they speak Spanish and sustain ethno-racial norms….Thus they are able to sustain and reproduce pre-immigration ethno-racial identities (p. 186).

Taken together, these factors make for a scenario in which there is little or no opportunity for majority groups to intermingle and socialize with Dominicans first-hand, presenting few opportunities for dispelling and dismantling stereotypical images of Dominicans.

Thus, the stereotypes described above may, in part, account for the unsavory nature of Maria's experiences with other-than-Dominican personnel. Her description of being made to feel "like a criminal….in a precinct" reflect s Collins' (1990) assertion of the ways pejorative images and stereotypes of Dominican and other Latina women "justify the exploitation of women who are deemed racially inferior" (p. 18) Maria also related how a White male special education colleague regularly communicates contempt for Dominican special education students by being "nasty to the kids" under the guise of "being funny". She painfully described how these students experience his remarks as harassing and wistfully mused, "This story represents a lot of the stuff I've seen…a person's position in the world *does* matter. There *is* bias against these [Dominican] kids. I am a self-contained special education teacher. And I can tell you that these kids are *great*…It has nothing to do with good and bad kids. It is how they are *treated.*"

Ableist Attitudes and Negotiating Access

In much the same way that cultural stereotyping circulates within American society, so do ableist notions of disability. If we contrast the low visibility of people with disabilities in all aspects of society to the glut of disability *representations* within our culture (e.g., film, novels, children's literature, television, animation, history, humor, language, print media), it seems likely that the majority of non-disabled people *think* they understand what it means to be disabled based upon representations of disability rather than first-hand accounts or actual relationships with people who have disabilities (Valle & Connor, 2010; Slee, 2004; Ware, 2001). Again, we do not mean to imply that school professionals are more prone to misconceptions about people with disabilities than anyone else; however, we do believe that they are not immune to misconceptions simply because special education is *thought* to be an "objective and scientific" process.

In keeping with I.D.E.I.A. procedures, a student's eligibility for special education services is determined by the administration of a psycho-educational evaluation. If results indicate that a student meets the criteria for one (or more) of the 13 categories of disability served under I.D.E.I.A., school professionals and parents meet to determine "the least restrictive

environment" (LRE)—a continuum of settings ranging from full inclusion to residential placement—in which to best meet the student's educational and social needs. However, we contend that LRE negotiations are based less upon the individual manifestation of characteristics delineated within each of the 13 categories of disability and more upon the *perception* of those disabilities as being more or less appropriate for the general education setting.

Ableist attitudes can—and do—contribute to negotiations about LRE. What happens in negotiations directly reflects how professionals and parents *understand* disability. We challenge the assumption that school professionals necessarily operate objectively —immune to cultural messages about disability—and assert instead that access has less to do with the principle of LRE and more to do with how much a disability requires able-bodied people to *understand* and *do*. If we return to the narratives told by Takako, Agnes, and Maria, it appears that school professionals perceive students with disabilities as follows: 1) *delicately disabled*—students whose disabilities present in ways that non-disabled people easily acknowledge and grasp (e.g., visual and auditory impairments) and, depending upon where their disabilities fall along the continuum of mild to severe, can sometimes "pass" among the non-disabled; 2) *deliberately disabled*—students who are unable to "pass" as non-disabled ever because they move through the world marked as deliberate with every breath they take (e.g., physical disabilities, Down syndrome, autism); and 3) *defiantly disabled*—students who defy the rules of "appropriate behavior" because their needs conflict with the "normal" presentation we expect and are willing to accommodate (e.g., ADHD, learning disabilities, behavioral challenges).

Takako's son, Matteo, clearly reflects the *delicately disabled.* Takako's ability to negotiate access to general education for her son is enhanced by the fact that his particular disability is not only easily understood, but also generates empathic responses from others given its origins in childhood cancer. Moreover, it is significant that 1) Matteo's low-incidence visual disability entitled him to vision therapists who have assisted his teachers and effectively advocated for him and his mother with continuity over the years, and 2) he is oftentimes able to "pass" in academic situations and compensates on his own. Taken together, these factors position Matteo as a model student for an inclusive setting—primarily because he requires little of his teachers and his "inclusion" undoubtedly leaves everyone feeling good about a successful integration of a "visually impaired student." Thus, it is unsurprising that Takako concludes, "His teachers have been so eager to help."

With a diagnosis of Down syndrome, Katie, the daughter of Agnes, could be considered *deliberately disabled.* Her embodiment marks her in the world as qualitatively different from non-disabled people, precluding any chance of "passing" among them. Agnes, like Takako, is not in a position of debating the presence of disability in her child; however, the agreed-upon acknowledgement of Katie's deliberate disability comes with traditional ableist notions about competence. At one point in the interview, Agnes refers to Katie as "having an IQ of 75"—a "truth" that she accepts without critique. In seeking access for her daughter, Agnes seeks advice from other mothers (whose children are "like" hers by virtue of *their* deliberate disabilities). Other than negotiating access to "a good elementary school" closer to home for Katie, Agnes does not talk about negotiating with school professionals about access at any other time. She appears accepting of (and uncritical about) Katie's lack of access to general education beyond kindergarten. She focuses instead upon the capacity of a smaller segregated setting to provide

"more attention" for her daughter rather than considering the least restrictive environment in which to provide her with an appropriate education. It is of interest that Agnes seems to regard Katie's *deliberate disability* as more of a family issue that *she* must solve rather than an issue of educational access.

Of the three mothers, Maria is the one who reports substantial and ongoing difficulties negotiating educational access for her child. As a student labeled as having a "learning disability", Carlos is perceived as *defiantly disabled.* Given that his educational needs do not conform to traditional expectations of schooling, Carlos' success depends upon his teacher's willingness to "do something" to provide access to the general education curriculum. Unlike the disabilities of Matteo and Katie that are unequivocally acknowledged, the manifestation of Carlos' learning disability is subject to interpretation by school professionals—leaving Carlos highly vulnerable to the consequences of their unexamined ableist attitudes about competence. Maria describes how the significance of Carlos' *defiant disability* shifts depending upon the school context, *who* is perceiving Carlos' difficulties, and to *what* his difficulties are attributed. Thus, Maria's account of her ability to negotiate access for her son is rife with challenges—and ends with Carlos dropping out of a school inhospitable to meeting his educational needs.

Further Considerations

We hope that readers will recognize that this article is the first in what promises to be further exploration of the nuances in each of the portraits of access we presented. Due to the limits of space we have restricted our discussion to only a handful of the themes we will continue to explore. For example, given the unique positions that culture affords when intersecting with disability how might our analysis inform the systems that shape the lives of students and their families? Can cultural competency impact the xenophobia at play in the face of the credentialing process that casts parents as a monolithic group—to be managed by professionals who are not exempt from misconceptions about culture and the families they serve? We also acknowledge that presenting our typology poses the risk of simple categorization, or the blunting of the existing 13 categories. What we aim to tease out over time is not so much who belongs within our categories, but rather, to show how society unconsciously construes those distinctions on first sight. Our typology provides a tool for educators to utilize in unpacking their understanding of ableism in schools and society. As Maria wistfully noted, "It has nothing to do with good and bad kids. It is how they are treated." We fully intend to wrestle with the degree to which federal legislation is or is not realized within the complexity of cultural contexts we view as algorithms of access.

Conclusion

In this article we explored specific mechanisms, practices and elements which actively prevent working-class, immigrant families whose first language is other than English from having the same access to services for children with disabilities as do their middle and upper middle class, non-immigrant counterparts. The narratives we presented point to institutionalized stereotyping of ethnic/cultural groups by public school personnel—a fact that immigrant mothers believe to be influenced by the ethnic/cultural background of educators. Within this collection of narratives, we revealed how the *type* of disability significantly influences the nature of

professional response that immigrant mothers and their children with disabilities can expect to receive. Our research contributes to the growing literature on the ways that disability complicates motherhood, and further we consider the ways that race/ethnicity, culture, gender, language and social class imprint that experience. We believe that much remains to be mined by exploring the tensions, gaps and complexities that mothers experience as they seek access to educational provision for their disabled children.

Gay Wilgus is an assistant professor in the Graduate Program in Early Childhood Education at the City College of New York, CUNY. Her current research centers on the experiences of mothers from immigrant backgrounds as they seek services and schooling for their children with disabilities in New York City. She is the editor of *Knowledge, Pedagogy and Postmulticulturalism: shifting the locus of learning in urban teacher education* (Palgrave, 2013).

Jan Valle is an associate professor in the Department of Teaching, Learning, and Culture at The City College of New York. Her research interests include inclusive education, parents and families of children with disabilities, disability studies in education, and disability and theatre arts. She is the author of What Mothers Say About Special Education: From the 1960s to the Present (2009) and Rethinking Disability: A Disability Studies Approach to Inclusive Practices (2011).

Linda Ware is an Associate Professor of Education at the State University of New York in Geneseo, NY. She has authored numerous publications on educational inclusion and the implementation of humanities-based disability studies in education informed by her teaching in urban, suburban, and now, rural educational settings. She consults with universities in the implementation of institutional change to support disability studies in higher education.

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Wheelchair Basketball Teams as "Second Families" in Highland Ecuador
Nicholas Rattray
University of Arizona

Abstract: This paper examines the concept of second families as social networks that complement primary families as forms of social support and identify formation. Based on analysis of narratives of three wheelchair basketball players, I argue that second families play a crucial role the performance of masculinity and personal development for physically disabled men.

Introduction

If you arrived around dusk on a weeknight at the *Coliseo Jefferson Perez,* an indoor sports area in the Ecuadorian city of Cuenca, you might find a group of wheelchair basketball players warming up. Most of these athletes drive their own cars to the stadium parking lot. They lift themselves out of the front seat, maneuver around to the back of the vehicle and get into their wheelchairs. Most players have two chairs: their everyday chair and one adapted to play sports. To enter into the arena, the athletes traverse a heavy wooden ramp laid over the stairs that leads to the court level. Like any athletes, they engage in elaborate preparatory rituals. Some players painstakingly wrap their hands in white athletic tape yet most play with their well-calloused, bare hands. Others warm up by practicing turns, stops, and accelerations. The athletes in Cuenca range in age from early twenties to approaching fifty. Each player has varying levels of ability to push their chairs, dribble and shoot the basketball, and execute offensive and defensive plays.

For many of these Ecuadorian men, playing wheelchair basketball has been a crucial way of making sense of the experience of living with a physical disability. I met several members of the wheelchair basketball team in 2008 during fieldwork with disabled communities in highland Cuenca. Norberto, an artisan in his thirties who made folk art for the tourist trade, reported than joining the basketball team helped him recover from an injury suffered after falling from the second story of a building. For Francisco, learning to play basketball encouraged him to seek out formal employment in Cuenca. After being injured in mining accident, through the help of his family Francisco recovered and secured a job in a factory. While most of the men found themselves playing basketball after debilitating injuries, some like Enrique had congenital disabilities. Born with shortened legs and no feet, he panhandled by day and transported himself using a skateboard.

In this paper, I analyze how adaptive sports like wheelchair basketball have helped to reconfigure the subjectivities of disabled men. Examining "subjects" implies a specific emphasis on how people define themselves through social encounters, conscious use of their body, and in relation to wider cultural forces (Biehl, Good, & Kleinman, 2007, p. 9). I argue that the basketball arena represents a place where they can redefine their masculinity, maintain an active lifestyle, and acquire social capital. Drawing from the embodied narratives of wheelchair users in highland Ecuador,[2] I explore how joining the basketball team has transformed their relationships to their primary families and reshaped their masculinities as fathers, sons, and providers. In

addition to challenging prevailing stereotypes about masculinity and disability, I argue that for these men, playing wheelchair basketball connects them to an important social network that they call their *segunda familia* (second family). S*egunda familias* (also called *segunda casas* or second homes) play an important role in identity construction and social relations that complement natal relationships. I refer to primary families as units comprised of natal and extended kin relationships.

The individuals that I have highlighted are drawn from a broader set of data collected with disabled athletes in Cuenca. I had numerous conversations with these men in addition to recorded and transcribed interviews. In reflecting on the meanings and social status of disabled men, these men narrated ideas ranging from their family roles as providers to surmounting many of the challenges facing disabled Ecuadorians. One common theme discussed was that playing wheelchair sports disrupts cultural expectations that are often attached to individuals with physical disabilities. As in other parts of the world, in Ecuador disability is commonly viewed as a tragic loss, a solely medical condition, and in static terms. The athletes I met in Cuenca disrupt popular notions of disability by demanding access to public spaces, whether through playing in local sports facilities or eating at restaurants. In doing so, they project disability identity as a source of pride, and as a normative, ordinary existence. Furthermore, they epitomize new social roles embodied by disabled athletes -- capable workers, mobile citizens, breadwinners, competitive athletes.

My analysis of the narratives of Ecuadorian wheelchair athletes brings together a disability studies framework that emphasizes the social and cultural construction of bodily differences within the context of limited economic resources, a virtual absence of the state, and significant social hierarchies. Anthropologists recognize that ethnographic research can shape new "public narratives" around disability (Rapp & Ginsburg, 2001), and some emphasize the diverse strategies of survival for those who lives are undervalued by society (Biehl & Moran-Thomas, 2009, p. 281). In the case of wheelchair athletes and many other disabled Ecuadorians, the impetus to join new groups is not necessarily based on similar physiological impairments. Disabled Ecuadorians have turned to groups as a source of support and social capital due to the absence of effective rehabilitation and medical services, limited employment opportunities, and the difficulties of managing impairment among natal households. They come together because they share the public identity of living with a visible disability and the technological usage of wheelchairs. In other words, what is shared is corporeal rather than biological. While disabled Ecuadorians continue to face persistent social exclusion, I demonstrate how these athletes have collectively shaped local perceptions of disability through their actions.

Disability and Embodied Narratives

Analytical categories like "disability" or "family" depend on historical, political, and geographic contexts. Anthropologists in particular have focused on the narrative analysis of chronic illness and disability to draw attention to wider cultural practices connecting health, illness and the body (Das & Das, 2007; Frank, 2000; Ingstad & Whyte, 1995, 2007; Mattingly & Garro, 2000). Those taking a comparative approach have focused on how meanings of disability are contingent on broader cultural systems of bodily and behavioral differences (Davis, 2000; Shuttleworth, 2004). While the first wave of disability studies was heavily influenced by a distinction between the

causes (biological anomalies) and consequences of impairments (disability), there has been wider acknowledgement that the social aspects of disability can never be separated from corporeal concerns (Shuttleworth & Kasnitz, 2004; Tremain, 2002) and issues of embodied differences (Titchkosky, 2003, pp. 23-24).

In Ecuador, up until the 1990s', the state had little involvement in the lives of families with disabled individuals (Cazar Flores, Molina Yépez, & Moreno Pramatárova, 2005; CONADIS, 2006)[3] even though developing countries like Ecuador, actually produce impairments at a higher rate due to poverty and lack of social capital (Grech, 2008; Staples, 2011, p. 548). The relative absence of the state created the conditions for the emergence of new social groups. My analysis examines how constructions of gender and performance play a key role in understanding how bodily differences intersect with the cultural meanings of families and ancillary social networks (Das & Addlakha, 2001). As in other parts of Latin America, these stories illustrate how disabled men are subject to gendered expectations around virility, earning a livelihood, and heading households (Gutmann, 1997; Pribilsky, 2007). In particular, "embodied narratives" (Hyden & Antelius, 2011) offer a framework for understanding how disability is performed and enacted beyond what is said through interviews or social interaction. Thus, I analyze how these wheelchair athletes moved, reflected on their own gestures and movements, and viewed their teammates. For athletes who have had to learn new ways of using their body, theories of performance and gender construction are particular useful (Smith & Sparkes, 2005). Disability studies scholars have suggested that narrative approaches to understanding disability have been supplemented by accounts written by parents of children with disabilities, which overlap and diverge in meaningful ways from first-person accounts (P. Ferguson & Asch, 1989, p. 111). I extend disability studies scholarship by honing in on the public and embodied aspects of disability narratives.

The Interplay of Primary and Secondary Families in Highland Ecuador

Stigma, shame, and pity are important themes that have been historically associated with visible impairment and chronic illnesses in Ecuador. Disabled Ecuadorians has often been described as *escondido* (hidden) and *abandonado* (abandoned) (Torres Dávila, 2004). As in other parts of Latin America, many disabled individuals spend the majority of their life at home (Aptekar 1983). The presence of a person with an impairment often generates discomfort for people because a person's disability is linked to the idea that they are contaminated or abnormal (Goffman 1963); as such, disabled individuals may be "regarded as objects of sociological danger and treated with avoidance or fear" (Scheer and Groce 1988: 32). Many informants described that their physical impairment had been perceived as something that makes them permanently ill or contagious. Disability has been associated with shame in part because it has been thought to be a tragedy, deserving of pity or charity. The circulation of negative discourses around disability discourages Ecuadorian families with disabled members from being publicly involved in community life (Miranda-Galarza, 2009).

Through interviewing and playing with wheelchair athletes in Cuenca, I came to understand how they attempt to collectively dispel many of these popular cultural assumptions about disability. In 2008, I conducted twelve continuous months of ethnographic fieldwork, primarily with members of two nonprofit community organizations with the objective of

understanding issues of citizenship, accessibility, and disability in highland Ecuador (Rattray, 2012). I collected qualitative data through participant-observation and semi-structured interviews with thirty disabled individuals. I would like to note that my positionality undoubtedly shaping the research findings. My status as an American male researcher of European descent helped me approach these organizations as foreigners often receive favorable receptions in Cuenca. Since I do not identify as a person with a disability, it was important to establish credibility. Explaining my experience working as a personal attendant and conducting research on accessibility and disability (Rattray 2007) helped me establish rapport. Interviews I conducted with Enrique, Francisco, and Norberto were between 45-90 minutes. These interviews were recorded and transcribed, and were supplemented by field notes.

Midway through my fieldwork, I was invited to watch a basketball practice. When I first arrived, I took pictures and assisted preparing the players court for practice. They immediately invited me to mount a wheelchair and play since they were short one player. Overcoming my initial hesitation – playing seemed to violate my assumption that able-bodied people did not play – I ended up participating on several occasions. The team has a weekly schedule of practices. While the practices consisted mostly of "pick-up" style scrimmages, several players have represented the regional team in intra-national competitions. About half the players are on the Azuay Province team and compete in national competitions.

My interviews with the players covered a wide range of topics that began with sports but included disability rights, accessibility, migration, and even the normally taboo topic of sexual relations among disabled people (Earle, 1999; Shuttleworth, 2001). During interviews, I discovered that many players referred to the team as their "second family." The team provided a critical outlet for men struggling to earn a living and form social bonds outside of their natal families. Many players felt that participating generated feelings of belonging, comfort, and confidence, and often cited *compañerismo* (friendship) as most important aspect of their involvement. Second families play an important role in the meaning of masculinity in the primary families as I show in the following discussion of the three players with which I began: Norberto, Enrique, and Francisco.

Embodied Masculinities among Wheelchair Athletes

Garland-Thomson (2007) suggests that stories of disabled athletes can offer counter-narratives to "personal tragedy" or "pity" themes in popular discourse. In analyzing how male athletes make meaning of their roles on the US Wheelchair Rugby portrayed in the film Murderball (Shapiro & Rubin, 2005), Garland Thomson calls our attention to the "ultra-masculinity" performed by men with ideal bodies for the sport, with a storyline that "disability can provide a meaningful life in which ones thrives rather than languishes" (Garland-Thomson 2007: 115). While such storylines can be misleading in that they offer simplistic explanations for what constitutes a meaningful life, most of the basketball players subscribed to the idea that playing sports enabled them to challenge the expectations of people around them. From the limited sample from which I drew from of approximately seventy-five research participants, a much higher proportion of athletes than non-athletes drove cars, were employed, and had a spouse or children. Without suggesting a causal link, it is important to note than many athletes emphasized that central importance that sports had played in their success Most drove

themselves to the arena and engaged in either formal or informal employment, which stands in contrast to the eighty percent of disabled Ecuadorians estimated to be unemployed (Cazar Flores, et al., 2005).

Transformations in the meaning of family were apparent in my discussion with Norberto, the artisan whose family lives on the outskirts of Cuenca. He described his family as *campesinos*, whose main livelihood is agricultural production. I came to know Norberto first through his participation in a local disability advocacy organization. Norberto later invited me to wheelchair basketball practice, encouraged me to interview the players, and typically gave me a ride to and from the arena. Norberto's story indicates the importance that sports can play in performing masculinity, including the expected duties of raising children, providing income, and transporting members of the household.

Norberto's narrative shifted from feelings of dependency after his accident to loss and normalization, a trend that was common to many individuals with disabilities I spoke with in Cuenca. Norberto's life objectives shifted in response to an injury he experienced when he fell from the second story of a building when he was 21. His girlfriend, who was pregnant at the time of the accident, could not handle the dual pressure of caring for a baby and a paraplegic partner, so they split up. With a subdued voice, Norberto said that when his daughter was born, he felt as though he had been "stabbed," since he was unable to start a family. Subsequently, he realized that it was "nobody's fault." After his injury he went through a period of transition that included mourning and depression, followed by healing. Norberto realized he would need to make use of available adaptive technologies in order to live a full life. After an unsuccessful trip to Quito where government agency staff treated him as if he had a mental, not physical impairment, Norberto ceased trying to secure benefits from the state. Instead, he used money sent from his brother working abroad in the United States to adapt his truck so that he could drive with just his hands. Norberto eventually accepted his new state of being, explaining that his life post-injury was "no worse than before, just different."

In terms of recovery, Norberto claimed that playing wheelchair basketball has been the most important factor. "What I'm trying to tell you, Nico," he explained, "is that it has been the best rehabilitation I found in my life, you know? To see friends, play basketball, even the pressure I feel to attend practice is the best rehab, really the only therapy." Wheelchair basketball helped him more than either psychological approaches or traditional physical rehabilitation. "The therapy that has been best for me, by far, has been basketball and it has given me the desire to live." He credits basketball with improving his physical range of motion and muscle strength, but prizes it most for improving his mental outlook on life. By 2008, Norberto was working at home crafting wooden figurines to be sold in the tourist market and was planning the construction of a home with zero-grade entrances, wide bathroom doors, and a generally open architecture that would make using a wheelchair much easier. His new house represents the culmination of his vision for self-care: accessible design, family-oriented, and mostly self-sufficient. Norberto had fulfilled much of what was expected of him as an Ecuadorian man. Although he was supported in part by US dollars sent home by his brother, he also had a paying job, a wife and children, (McKee, 1980). He had "run the household" since his brother has migrated to the United States (*El Otro Lado*).[4] His suffering has not been seen as an individual issue, and has instead been managed and ameliorated by the household as a whole (c.f. Staples, 2011).

Strategic Embodiments

Enrique, an Afro-Ecuadorian man in his mid-thirties, found that joining the wheelchair basketball team created new opportunities for social networking and support. Compared to other basketball players, Enrique took a less common route to providing for his family: he panhandled each day from eight in the morning to four in the afternoon on a busy street corner in Cuenca. Enrique's narrative demonstrates how flexible forms of embodiment offer avenues for participating in primary and secondary families. After a few months in Cuenca, I initiated a friendly relationship that involved casual chatting as he solicited money on the street. Enrique often greeted me by saying, "Hey, amigo, how have you been?" in a heavy, sing-song accent common in this part of Ecuador, vigorously shaking my hand.

Enrique was a recognized fixture in Cuenca's downtown area, known to sit on a skateboard and solicit money from cars and pedestrians at a busy intersection. My acquaintances suggested that Enrique's presence was unique due to his outgoing personality in a city known for reserved, formal social conventions. Enrique was both without feet and had dark skin, which made him stand out in a city with very few Afro-Ecuadorians (less than 3% of residents). As Enrique pushes himself along the narrow sidewalks and intersections with thickly gloved hands, he transgresses deep-rooted physical and social barriers that shape daily life for most Ecuadorians with disabilities. I have argued that beyond the impropriety of begging from street, Enrique's display of a highly visible impairment defies a local norm in Cuenca where disability is encouraged to hidden (Rattray, in press).

I had mistakenly assumed that Enrique used a skateboard because he could not afford a wheelchair, in part since he had explained his marginal income. Enrique also assumed that in my research, I was solely working formal disability advocacy organized. Thus, when we both arrived at a wheelchair basketball practice one day, we were both a little bit surprised. I had no idea that Enrique also played on the team, and Enrique told me that he found it strange that I had tracked down the basketball players. Enrique clearly stood out as one of the best basketball players on the team and was extremely adept in his wheelchair.

After a few practices with the team, I sat down with Enrique one evening to ask him more questions about his experience, his background, and how he makes a living. Enrique, 37, and was born in the Esmeraldas province, on the Ecuadorian coast. Most of his extended family lives in Quito, but he had lived in Cuenca for twelve years. His wife lives in Guayaquil, where his daughter attends school. The money Enrique earns begging helps pay for his wife and daughter's housing expenses, which total $12.60 each month for their cane house. Enrique's situation differs from many of his fellow wheelchair basketball players for a number of reasons. One key difference is that Enrique was born with his disability, and thus did not need rehabilitation. Accordingly, he learned from a young age how to navigate through life with a highly visible impairment. Enrique told me that using a skateboard (*patineta*) allows him to go places easier, interact with people in cars, and makes it possible to navigate damaged sidewalks. Enrique depicted his life as a "*lucha diaria,*" or a daily struggle. "It's not easy to get out of bed each day not knowing how much I will earn," he said in describing how uncertainty clouds his life. While panhandling has enabled him to support his family in the absence of government benefits or

other outside assistance, the necessity of begging all day presents an unending challenge. He dreams of owning a small store somewhere close to his wife and daughter in Guayaquil and completing a wood roof for their cane house.

Enrique had never used a wheelchair before he joined the basketball team. He described how he first joined the team:

> When I was first invited to play, I knew nothing about basketball, didn't know anyone and really I had never hung out with other disabled people. But when I got here, I was amazed to see them play, how much fun they were having, and it was such a great experience. I thought 'If they can, then I can too.' When I first tried, I fell about 50 times, and stayed away for a while but now I am part of the team.

Playing basketball had been a revelation in terms of the way Enrique envisions his social life. The most important aspect of the team has been forging close friendships with other players. A few years earlier, he finished in first place in Ecuador's Paralympic swimming competition and third place in wheelchair track, but was unable to travel to the South American championships due to lack of funds. Enrique pointed out that because other athletes had connections (*palancas*) or benefactors (*padrinos*) that he lacked, they were able to finance their travel in ways he could not.

Another difference between Enrique and his peers is his social status. Unable to procure steady work, he has panhandled on the street throughout his adult life. Enrique's roots in the coastal province of Esmeraldas and his African heritage differ from the other players, most of who identify as Mestizos from different parts of southern Ecuador. Even though he is a cherished member of the wheelchair basketball team, Enrique adopts a different presentation of self in the street that helps him make a living in the competitive informal system of street begging in Cuenca. His shiny, blue, high performance wheelchair would likely make him seem less needy in the street. To make a living in the street on a skateboard, he has learned to alter his role from athlete to street beggar through shifting his mode of transport, self-presentation, and attitude.

Enrique's story was one among several instances I documented where the absence of job opportunities or support from the state, many disabled men seek a wide range of tactics for providing for their family. While the only one who panhandled, others sold lottery tickets, candies, or other items in the informal economy to make ends meet. Although Enrique was not originally from Cuenca, he had been able to find a niche making a living in the street that has enabled him connect with his family members across Ecuador. The wheelchair basketball team is a social network that offers a safety net and a means for Enrique to maintain meaningful friendships in the context of a life preoccupied with daily survival.

Rehabituation and Disability Identity

Learning to play basketball offered individuals like Enrique and Norberto new opportunities to join a community and redefine how they think about themselves. I suggest that disabled identity is enacted through the cultural training that takes place through embodied practices, or what Manderson terms "rehabituation" (2011, p. 96). In contrast to rehabilitation,

rehabituation focuses holistically on how one's *habitus* (Bourdieu, 1977; Mauss, 1973) must be newly constituted following an accident, injury or other bodily disruption as well as the incompleteness and extended duration of recovery.

Many of the Ecuadorian basketball players reported that basketball transformed the way they thought. Many embodied the "maverick" mentality described in *Murderball*, and were able to translate assertive attitudes into other arenas of their lives. These athletes explained asserting their right to patronize bars and restaurants, access services, and apply for jobs with pride. They narrated instances where they intentionally transgressed boundaries of space or social conventions in order to claim their rights.

Many of the transformations necessary to inhabit maverick subjectivities were inculcated gradually over a period of years. I suggest that these athletes have adapted to a new sense of normality in part by learning new ways of their bodies through a combination of adaptive technology and corporeal retraining. Although a few athletes I met had congenital disabilities, the majority had suffered some type of accident. The arduous process of rehabituation necessary to learn how to efficiently and quickly locomote with a wheelchair was sped up by wheelchair basketball and provided a foundation of motor and social skills necessary to live an independent life as a disabled adult in Cuenca. Even those with congenital disabilities like Enrique acquired new habits and mentalities associated with being a wheelchair athlete.

The role played by primary and secondary families in rehabituation was most clear in the narrative of Francisco, a low-key younger member of the basketball team. While his natal family played a key role in his initial recovery, the basketball team became his most important social network. Francisco's journey from working in a mine to playing basketball and being employed at a local factory helps illustrate how recovery from injury took place without public assistance**.**

Over beer and plantain chips, Francisco and I spoke about how he came to live in Cuenca and play wheelchair basketball. Francisco was unmarried, 30, and was from the countryside but had lived in Cuenca for several years. Francisco was working as a miner in a rural province of coastal Ecuador when an accident occurred. His team was drilling for a vein of gold with a massive drill when a large slab of rock fell from the roof. They later told him that over two and half tons had crushed his legs. After riding for two hours on a mattress in the back of a pickup truck, Francisco found himself alone and dealing with various doctors. "They came and the doctors told me that the operation was dangerous – not dangerous but that they couldn't guarantee anything – I may or may be able to walk again." From that point on, Francisco felt ashamed and depressed, and did not want to tell his family. After a few days, the doctors forced him to call his aunt. The doctors in a nearby town told them that they could perform an operation for thirty million *sucres* (around USD $8500 at the time) just for the operation, and since his extended family lived in Cuenca, two weeks later they brought him to a clinic. The doctors in Cuenca gave him a more realistic assessment:

They said that I would never walk again and that I would have to search for work in a wheelchair. That was the last straw – imagine that you can't take care of yourself but instead have to spend your life depending on others. It killed me to hear this, I literally wanted to die for about three or four months while I was disappointed and confused about what I should do. But,

with the considerable help of my family and my brother, little by little I was able to overcome until now where I am today. I am as I am, thanks to the Lord, things have been alright and that which I wanted, I have had. I didn't want to know anything, I wanted to disappear for a year – well, the first three months were the worst, but then I began to adapt because it was a whole new way of living, totally different to depend on the wheelchair, depend on others. I spent each and every day for while learning how to move again.

Francisco's response to a debilitating injury involved shock and despair, but eventually he developed a sense of acceptance and a new set of life expectations. As in many narratives from those who acquire disabilities, there is a trajectory that starts with life before the accident, a period of liminality that includes the fear of an existence consisting of dependence on others, and a resolution that entails a transformed sense of self (Antelius, 2009; Murphy, 1987). Following his move to Cuenca, Francisco gradually created what he considers to be an independent life. Francisco described joining the wheelchair basketball team as the "best form of therapy," and credited it with helping him recover physically and psychologically from his injury, much like Norberto.

Following Francisco's injury, he was considered disposable and unemployable. The financial burden of medical operations and recovery was borne by his family, not the state or the mining company. Yet Francisco was one of the few disabled people I met with formal employment. He had worked for the six prior years as a skilled laborer in a factory making parts for refrigerators, from seven in the morning to six at night. Hired as part of the firm's compliance with a recent law that requires any business with over twenty-five employees to have at least one disabled employee, Francisco felt fortunate to have a steady job. Although he admitted feeling like a token worker employed to fit a quota and avoid a tax liability, he felt relieved to be working again and living a more or less independent life. In prior eras, he probably would not have worked again, and perhaps would be permanently a "non-productive body" (Mitchell & Snyder, 2010, p. 184), with a body unfit for formal employment. One important lesson to draw from Francisco's experience rests on how his participation in a collective group of athletes has broken norms about acceptable behavior at a local factory where his employers have been forced to reconsider inaccessible aspects of their workplace alongside stereotypes about the capabilities of wheelchair users.

Francisco's process of rehabituation took several years. When he moved from the country-side to Cuenca, he was able to advance socially because he was able to avail himself of more medical services, social supports, more accessible physical environments, and more open attitudes toward disability. More than most athletes, Francisco's connection to his natal family had diminished since the period in which he had intensive medical care and recovery. In recent years, the basketball team served as his key site for social support and connections. While he aspires to start a new family of his own, his more immediate goals center on saving money from his factory job so that he can try to compete in national competitions for the wheelchair basketball team.

Narrating Families through Disabled Athletes

Carefully interpreted stories about disability as embedded within families and social networks can reveal insights into contemporary cultural practices (P. M. Ferguson, 2002, p. 129). Second families, like the one formed by the wheelchair basketball team, play a crucial role in the lives of the disabled men I met in Ecuador and their collective stories illustrate how the experience of playing wheelchair basketball has helped these athletes conceive of themselves as capable, active men. Thus, transformations taking place through involvement with second families has reshaped their role within their primary families. While I have focused here on athletics, other narratives of second homes or families were prevalent among individuals associated with community-based organizations in Cuenca.

As I witnessed while riding in Norberto's truck as he gave Enrique a late-night ride home, the team has also brought together people who otherwise may never have met and become friends. The team builds on a mostly unspoken set of common experiences around living with a disability to cultivate the personal development of its members. Participation in wheelchair sports provides a crucial site to negotiate the tensions between shame associated with bodily difference and the gendered enactment of familial roles. The narratives of Norberto, Francisco, and Enrique, show the limitations in approaching disability experiences from the perspective of individualized perspectives that emphasize rehabilitation or biomedical models.

Disabled athletes help us think about subjectivities that may have been difficult to imagine in prior eras. I have shown how disabled men have challenged received assumptions about their abilities to care for their family and earn a living. However, I have also argued against simply reducing the activities of wheelchair athletes as promoting counter-narratives against orthodox ideologies about disability. Men like those discussed in this article engage in complex strategies that enable them to both transgress and fulfill roles expected of them as Ecuadorian fathers, husbands, brothers, and sons. Sports have enabled new ways to negotiate the substantial cultural, spatial, and economic barriers facing these individuals.

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End Notes

[1] I conducted twelve months of in-depth, ethnographic fieldwork in the city of Cuenca in 2008, with shorter trips in 2006 and 2010. Of the approximately fifty research participants, interviews were audio-taped and transcribed with thirty disabled individuals among three groups: a regional association of people with disabilities, an organization of visually impaired individuals, and wheelchair athletes.

[2] People with disabilities make up roughly one in eight Ecuadorians (Cazar Flores, et al., 2005). Of these 1.6 million citizens, forty percent have severe impairments. Only one in ten people with disabilities receives any type of support from institutions, public or private, in Ecuador (Cazar Flores, et al., 2005). Government reports also indicate that half of all people with disabilities fall into the bottom two income quintiles, meaning that they survive on less than thirty dollars per month. These statistics underscore the limited economic resources available to households with disabled family members.

[3] It is common in the Azuay-Cañari region for households to have at least one family member in the United States or Spain. It is estimated that one in three households have at least one family member abroad (Borrero Vega & Vega Ugalde, 1995). Remittances often help make up higher cost of having a disabled or aging family member.

BOOK & MEDIA REVIEWS:

Book Review

Title: *The Problem Body, Projecting Disability on Film*

Editors: Sally Chivers and Nicole Markotic

Publisher: Columbus, OH: Ohio State University Press, 2010.

Hardcover: ISBN: 13978-0-8142-1124-3

Cost: $69.95**;** 239 pages (inclusive of index)
 (may find less expensive copy at online booksellers):
(Also available in electronic form as PDF file): $9.95
The electronic version also makes it accessible to readers with disabilities who may use their
own text-to-speech technologies or require large font size for viewing.

Reviewer: Raphael Raphael, Ph.D.

     The Problem Body considers projections of the body with disabilities in film, examining both the ways that disability is 'projected' on film, as well as what viewers 'project' onto these images of disability. Through a wide variety of essays, covering different genres and time periods, *The Problem Body* illustrates some ways these imaginary images may become important 'real' parts of discourses of disability in culture.

     The essays also show how, in the charged space of cinema, disability intersects with other markers of identity, including race, gender and sexuality, as well as nationalism. Examining King Vidor's celebrated *The Big Parade* (1925), Timothy Bernard shows how disability and masculinity connect in post-war American cultural politics. Michael Davidson adds consideration of the slipperiness of disability in film, how sometimes disability can stand in for other "social panics" (he focuses on sliding identification with homosexuality in the film noir).

   This *dis-ease* with the connection of sexuality and disability is also at the heart of Eunjung Kim's investigation of intersections between prostitution and rehabilitation. On one hand, Kim suggests this connection acknowledges the sexuality of people with disability (a truth many films deny); at the same time it aligns uncomfortably close with a medicalization of the sexuality of people with disabilities, as hired sexual services often seek to 'cure' disability.

     This interrogation of the presence of the medical model in films is key to the essays in *The Problem Body*. Dawne McChance suggests Francois Truffaut's *Wild Child* (1969*)* offers a powerful example; the famed director places himself in the central role as doctor, illustrating ways cinema participates in the medical model as he (and the film) interrogates a disabled child for proof of humanness. Similarly, Johnson Cheu suggests *Wait Until Dark* (1967) dehumanizes 'blind' women and perpetuates stereotypes of disability. Likewise, looking at *Whose Life is it Anyway* (1981*)*, Paul Darke catalogs ways the film's medical model of disability dehumanizes its central disabled character, presenting disability as a fate worse than death.

As this pervasiveness of the medical model is largely invisible to many viewers, Robert McRuer investigates the gap between universal acclaim for *Million Dollar Baby* (2004) and its equally unambiguous condemnation by disability rights communities disgusted by yet another film equating disability with a fate worth than death. He also places the film in tension with the radically different experience of disability suggested by *Murderball* (2005). Examining the film adaptation of Margaret Edson's *Wit* (2001), Heath Diehl suggests that the only films that can really begin to come close to authentically conveying the personal experience of physical pain are films that admit that it is impossible to do so.

Examining the pervasiveness of the medical model in shaping narratives about the experience of disability, David Mitchell and Sharon Snyder suggest much of this is a function of genre, as many genres rely on disability to buttress the fiction of the "normal" body. They suggest 'New Disability Documentary Cinema' offers a powerful alternative space to express counter-narratives of disability. In doing so, though, the authors overlook the many ways audiences (both disabled and non-disabled) create their own unique meanings in their viewing experiences of any film.

Anne Finger's coda to the book hints at this unpredictable power of audiences with her "ficto-critical" reading of film's relationship with disability. Her provocative essay is about how a viewer with disabilities experiences the film *Mata Hari* (1931). It suggests ways a film's *meaning* can change depending on the audiences watching. It is this plasticity of film—a flexibility for the most part not addressed by most of this collection's essays—that allows film to offer such powerful experiences to so many very different audiences.

The Problem Body is an important contribution to the field and is highly recommended to students and scholars interested in the ways disability and the medium of film have intersected. While wide-reaching, it could be enriched by greater attention to the ambivalence of this relationship. For the most part, the essays assume static, passive audiences who digest films' ready-made *meanings*. This valuable collection points to the need for even further exploration into how disability has figured in the many unique ways viewers create *their own* unpredictable meanings with film.

A short glossary of films mentioned in review:

The Big Parade (1925) - Successful silent film in which an idle rich young man is transformed by his experiences of the horrors of war. The film was groundbreaking for its depiction of a soldier who becomes an amputee.

Wild Child (1969*)* -The film by famous French New Wave director Francois Truffaut tells the story of young man found living in the wild in the late 18th century who gradually becomes successfully socialized.

Wait Until Dark (1967) - Thriller in which a young woman who lost her sight in a car accident (Audrey Hepburn) battles criminals who break into her home.

Whose Life is it Anyway? (1981*)* - Richard Dreyfuss plays a sculptor who becomes quadriplegic and argues for his right to end his own life.

*Million Dollar Bab*y (2004) - Clint Eastwood's sports drama in which he plays a gruff boxing trainer who helps an amateur boxer (Hilary Swank) achieve her dream of being a professional. When she becomes quadriplegic from an injury in the ring, he helps her take her own life.

Murderball (2005) - This acclaimed documentary film is about quadriplegic athletes who play wheelchair rugby.

Wit (2001) - The film, adaptation of the Pulitzer Prize winning film of the same name, centers on an English professor and her experience coming to terms with metastatic Stage IV ovarian cancer.

Mata Hari (1931) - Greta Garbo stars in this loose adaptation of the life of the famed exotic dancer Mata Hari who was executed for espionage in World War I.

Raphael Raphael, Ph.D., is a film and media scholar/producer whose work appears in Modern Language Association's *Teaching Film* and is a contributor to *The Encyclopedia of American Disability History*. His most recent work includes *Transnational Stardom*: *International Film and Popular Culture* (Palgrave-Macmillan, 2013). He serves as technology faculty for American Community Schools, Athens and lectures for the Center on Disability Studies at the University of Hawaiʻi at Mānoa. He will be co-editing a special issue of RDS on disability and popular culture in Summer 2014 (with Holly Manaseri).

Book Review

Title: *The Silvering Screen: Old Age and Disability in Cinema*

Author: Sally Chivers

Publisher: Toronto: University of Toronto Press, 2011

Paper: ISBN: 978-0-8020-1104-7

Cost: $24.95 from the publisher, 240 pages

Reviewer: Amanda T. McLaughlin

Western society often looks to media for guidance, vulnerable to its overt anti-aging message that personal value is based on youthfulness and to buy products that perpetuate it. Westerners are left with a sense of emptiness and worthlessness at the sight of graying hair and wrinkling skin. Western media displays a grossly skewed, though endlessly enticing idea of beauty. Celebrities are used as a point of reference and comparison, leaving those exposed to their seeming perfection feeling less than adequate.

In *The Silvering Screen*, Sally Chivers tackles this subject, showing Hollywood's unfair representation of older characters, especially women over the age of 60. This book aims to highlight the realities of how the film industry unfairly portrays characters of a certain age, and does so under the lens of a disability focus, asking the difficult question of where the older population belongs in a society. Are they relegated to feeble, helpless, sickly, mentally inferior wastrels that must be a burden until they finally die? Chivers' assessment of many films, from the fifties to the present, illustrates how again and again we relegate the post-60 demographic to a less than desirable position in society. Our elderly population, according to films like *Sunset Boulevard* (1950), where the heroine would rather shut herself off from the world than face the reality of aging in the film industry, is all but worthless. If we solely turned to film for our sense of direction, for our social and personal cues, we would entirely dismiss people of a certain age, and without guilt.

Chivers eloquently elaborates on the notion that the ideas presented in such films contribute to the mounting fear western society has of aging and the cultural and economic implications of our demographic shift that the aging population is causing. Chivers asks the reader to consider venturing further, to align this attitude towards the aging with that of people with disabilities. She boldly addresses the idea that because certain disabilities can arise as one ages, such as Alzheimer's, as in the film, *Iris* (2001*)*, these films offer an interesting parallel that indicates the truth of how our society views those with disabilities. It has become accepted behavior, according to the films provided, to dismiss the aging, to ignore them because they cannot be as readily and actively participatory. When you apply this same viewpoint to those with disabilities, of all ages, the reality is harsh and unforgiving. If Hollywood portrays a person with a physical or cognitive disability, whether due to aging or otherwise, as inferior, we are in danger of passively accepting this attitude and it becoming the norm.

Chivers asks the reader to see this view of the aging population as misguided, encouraging a thoughtful analysis of the characters and stories that entertain us. She offers these compelling issues within the framework of cultural gerontology, which views aging and old age as a social construct rather than biologically fixed.

Chivers' insightful examination of film over the last half century and its influence over Western society's view of aging and disability is an attentive, important, and necessary one. This book is a crucial read for those in film studies, cultural studies, and disability studies, pushing a focus towards what it means to age in a society that dismisses its aging population and is so willing to portray them as narrow and weak in film.

Amanda T. McLaughlin is an assistant editor for the *Review of Disability Studies* at the University of Hawaii, Manoa. She holds a Bachelor's Degree in Media Communications with an emphasis in Film. You may contact her at amandat2@hawaii.edu.

Book Review

Title: *Perfect Chaos: A Daughter's Journey to Survive Bipolar, a Mother's Struggle to Save Her*

Authors: Linea Johnson and Cinda Johnson

Publisher: New York: St. Martin's Griffin 2012.

ISBN #s: Hardcover: 9780312581824; Trade Paperback: 9781250023254; Ebook: 9781429948883

Cost: Hardcover, $24,99; Trade Paperback, $15.99; ebook: $9.99.

Reviewer: Charmaine Crockett

In *Perfect Chaos*, a searing testament to the unrelenting darkness of mental illness, that casts shadows and confusion in one American family, Linea Johnson confided in her journal, "I now don't even care enough to hurt myself (p.111)."

Hundreds of millions of people experience mental illness. In the US alone, 55.7 million people experience mental health challenges in a given year while one in 17 Americans suffer from a mental health illness. This is the story of the Johnson family, an unflinching look at the chaos within, the singularity of pain and how a community of family members, friends and professionals support a young woman through her illness.

Stories instruct us, becoming roadmaps for those who struggle through illness or who know someone with an illness. This non-traditional memoir, told in the voices of a mother and daughter, breaks open a wall of silence of a middle class American family, who by all appearances, were privileged, well-educated and talented but whose lives were thrown off course by the emotional turbulence of teenage daughter Linea.

Readers become an intimate partner of Linea and Cinda Johnson's journey. Even those unfamiliar with bipolar illness, are likely to identify with the inner demons of self-destruction where the lust for escape becomes overpowering, inevitable at times. Linea, a talented young music major at Columbia College in Chicago drank, drugged and cut herself when she was not in classes. These days and weeks of darkness, penned with clarity by a gifted young writer who eloquently describes her spiraling descent into depression, are contrasted by a mother's voice of love and dedication to save her daughter from hell. Cinda carries her own grief like a well-worn backpack, shedding her own silence on a brother's apparent suicide while utilizing all her personal and professional resources to keep Linea safe and free from pain.

Armed with a cadre of family and community support, both Linea and Cinda appreciate their luck even in the midst of personal and familial chaos. While in the hospital Linea solemnly notes that while she had friends and family, most patients had no visitors. Feelings of unimaginable loneliness and despair are difficult enough - having no friends or limited access to health care push people over the edge. While these women focus on their own story, at moments

they contemplate the fate of millions of people who do not have access to resources, services and human support.

The Johnsons' story reads like an archetype of the hero's journey where ordeal, near death and rebirth is followed by a resurrection and return home. The return home for Linea is this: her illness does not define her, nor does it navigate her choices in life. What gives this memoir the fullness of hope and coming full circle from an unwelcome adventure, is the relentless courage of mother and daughter. Call this writer an idealist but the book's ultimate strength lies in the resiliency of the human spirit, the ability to manage and transcend depression and emerge as a leader and advocate for positive social change for persons with mental health challenges. While Linea' illness led her to blackouts in alleys, death wishes, hospital stays and electroconvulsive therapy (ECT), her courage to live is an inspiration for thousands of young people. Parent and community advocates will likewise be inspired and guided by a deep understanding of the complexities of a young person.

Mental Health stigma continues to permeate our society, creating barriers towards accessible and equitable services and resources. *Perfect Chaos* challenges those stigmas, and is a welcome addition to enriching the intersection between disability studies, mental health and literature.

Charmaine Crockett is special projects coordinator at the Center on Disability Studies, University of Hawaii and has a rich and varied background in international human rights, finance and the arts.

Book review

Title: *Lovers Lame*

Author: Robert Rudney

Publisher: Port Charlotte, FL: Booklocker.com, 2012

Paperback: ISBN: 978-1-61434-962-4

Cost: Paperback: $29.95**,** 270 pages; E-book: $8.99

Reviewer: Steven E. Brown, Ph.D.

I first learned about this book in an email from the author. He indicated he wanted to put stories about love, sexuality, and disabilities, as well as social issues in a novel, instead of another article. I have read many tales about disability over the years, but few novels and even fewer captivating ones. *Lovers Lame* achieves something unexpected. I would use it in an introductory class to disability issues and disability studies.

Lovers Lame is the story of hemiplegic David Levin, who at the beginning of the novel is employed and looking for love. Despite affairs, one in particular which is the focal point of the story, he is constantly searching for his one true love. The object of his desire for most of the book clearly tells him not to expect that to be her, but he does not want to listen. Along the way he become unemployed, hooks up with a volunteer group focused on helping people with disabilities looking for jobs via networking, and finds himself unexpectedly applying for Social Security Disability Insurance.

Will he find a job by the end of the novel? Will he find true love? Those are answers for those who read the book.

Longtime disability advocates may see aspects of themselves in this story, but will not find it surprising. Those who are fairly new to advocacy or disability issues may find *Lovers Lame* a smooth way to ease into and discuss a variety of life choices (or lack of choices) that impact many individuals with disabilities.

Steven E. Brown, Ph.D. is Professor of Disability Studies and *Review of Disability Studies* Media Reviews Editor at the Center on Disability Studies, University of Hawaii. He can be contacted at sebrown@hawaii.edu.

DISABILITY STUDIES DISSERTATION ABSTRACTS

Disability Studies Dissertation Abstracts

Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at http://www.hsls.pitt.edu/guides/histmed/dissertations/

Disability in the Methodist tradition: An exploratory study analyzing the understanding of and response to the disabilit rights movement by the General Conference of the UMC (1968-2004) Pridmore, John Eric. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- New Jersey: Drew University; 2010. Publication Number: 3420022.

Global ethnography with disabled refugees: Combining individual narratives with systems & policy analysis Mirza, Mansha Parven Qamar Husain. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- Illinois: University of Illinois at Chicago, Health Sciences Center, School of Public Health; 2010. Publication Number: 3417523.

Canadian public discourse around issues of inadmissibility for potential immigrants with diseases and/or disabilities 1902-2002 Capurri, Valentina. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. Canada: York University; 2010. Publication Number: NR64897.

The effects of the Americans with Disabilities Act on the health coverage and post-secondary education of people with disabilities Honeycutt, Todd C. ProQuest Dissertations & Theses 2011. [Ph.D. Dissertation]. United States- New Jersey: Rutgers, The State University of New Jersey and University of Medicine and Dentistry of New Jersey; 2010. Publication Number: 3418767.

On the other side of hyperactivity: An anthropology of ADHD Goodwin, Marc Andrew. ProQuest Dissertations & Theses 2011. [Ph.D. Dissertation]. United States- California: The University of California, Berkeley; 2010. Publication Number: 3413376.

Tongueless: Representation of the mentally disabled and the novel Cline, Brent Walter ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- Michigan: Western Michigan University; 2010. Publication Number: 3424850.

Degeneration nation: The body, medicine, and the culture of biofuturity in American literature, 1883-1928 Stuckey, Michelle Ann. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- California: University of California, San Diego; 2010. Publication Number: 3426445.

Constructing a disabled identity: The influence of impairment, social factors and reflected appraisals Ridolfo, Heather. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation].

United States- Maryland: University of Maryland, College Park; 2010. Publication Number: 3426291.

Andi's story: An oral history of a woman labeled learning disabled Polo, Maude Ann. ProQuest Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- New York: Teachers College, Columbia University; 2010. Publication Number: 3436220.

 Cultural interpretation of disability: Perspectives on home-school partnerships Cantor, Laurelyn Hope Morry. Dissertations & Theses 2010. [Ph.D. Dissertation]. Canada: University of Manitoba; 2010. Publication Number: NR64271.

 Including preschool age students with disabilities: Perceptions and beliefs of community-based early childhood providers Bond, Christine. Dissertations & Theses 2010. [Ph.D. Dissertation]. United States- Florida: University of Florida; 2010. Publication Number: 3416657.

Community-based theater and persons with psychiatric disabilities: An investigation of individual and group development, social activism, and community integration Faigin, David A. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Ohio: Bowling Green State University; 2010. Publication Number: 3417188.

An analysis of Haitian parents' perceptions of their children with disabilities Gregoire, Josee. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Florida: Florida International University; 2010. Publication Number: 3470219.

Deaf community mobilization in Uruguay Lockwood, Elizabeth. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Illinois: University of Illinois at Chicago; 2010. Publication Number: 3417527.

Creativity and the schizophrenia spectrum unveiled: The similarities and the differences Michalica, Kerri. Dissertations & Theses 2010.[Ph.D. Dissertation]. Canada- Brock University; 2010. Publication Number: NR64560.

Cripping the workspace: Performing physically disabled professional identity in personal narrative Scott, Julie-Ann. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Maine: The University of Maine; 2010. Publication Number: 3415488.

Effects of social story interventions on preschool age children with and without disabilities More, Cori Michelle. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States-Nevada: University of Nevada, Las Vegas; 2010. Publication Number: 3412390.

Under the cover: Disability and children's literature Karambatsos, Sofia. Dissertations & Theses 2010.[Ph.D. Dissertation]. Canada: York University; 2010. Publication Number: NR64914.

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Material witnesses: A feminist disability theory of testimonial voices Schriempf, Alexa. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Pennsylvania: The Pennsylvania State University; 2010. Publication Number: 3420280.

The impact of the physical environment on the social integration of individuals with disabilities in community Christensen, Keith M. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Utah: Utah State University; 2010. Publication Number: 3419189.

Toward a disability studies oriented framework for social justice leadership in education McKinney, Sarah A. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Wisconsin: The University of Wisconsin – Madison; 2010. Publication Number: 3424250.

"First we crawled, then we walked, now we want to run": An examination of the transition processes used by inclusive camps Tucker, Teresa W. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- South Carolina: Clemson University; 2010. Publication Number: 3419301.

We are the same but different: Navigating African American and Deaf cultural identities Clark, Heather D. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Washington: University of Washington; 2010. Publication Number: 3421743.

The impact of unemployment on women with physical disabilities in Tamale, Ghana Naami, Augustina. Dissertations & Theses 2010.[Ph.D. Dissertation]. United States- Utah: The University of Utah; 2010. Publication Number: 3428490.

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The mission of the Center on Disability Studies (CDS), at the University of Hawai'i at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawaiʻi, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.