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Disability and Identity

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Disability and Identity

*A Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Master of Liberal Studies*

by

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April 2004

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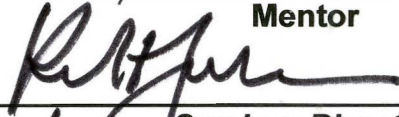
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Disability and Identity

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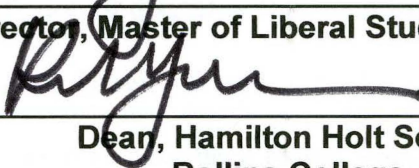
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“Throughout history, disability has been seen through varying lenses. Aside from the often sentimentalized mythology of disability stars, whatever history exists has not come from the marginalized disabled themselves but from able-bodied observers, anthropologists colonizing an exotic land” (p. 160). –Andrew Potok

All human beings are temporarily able-bodied, at the most. The stories of disabled people get told by others: by myths and fears, stereotypes and prejudices, and sometimes, by the realities of daily life as seen by friends, family, and caretakers. Potok (2002) establishes the idea that disability, until very recently, suffered under the gaze of those who do not occupy the territory. However, people with disabilities have existed from the beginning of time and our collective history carries weight. In addition to the category of disability, we also occupy a range of ethnicities, classes, religions, and viewpoints. We answer to many titles: writer, artist, filmmaker, intellectual, activist, feminist, radical, man, woman, gay, lesbian, heterosexual, bisexual, and a range of categories in-between. We desire life and love. We work to obtain equal access to the world. In order to move beyond our category of physical distinction, we must reclaim our voices and tell our stories. We must not gloss over the pain or the bittersweet realities of our lives. Instead, we must tell the truth and identify the meanings created by the culture at large.

Pursuing a Masters in Liberal Studies allowed me to examine the development of thought over time through the core courses and their utilization of “great books.” Western culture’s perception of disability follows a similar evolution to the development of society. Just as the early Greek’s feared, subjugated, and worshipped women in their culture, people with disabilities have been feared, subjugated, and honored. The work of Hellenistic artists dared to examine the more taboo and macabre subjects of human life; disability often falls into this category.

Modern and post-modern perspectives of disability help people with disabilities to embrace their identity and use it as a tool for transformation, in a similar manner to members of feminist and queer communities. Disability itself questions ideas of the body, consciousness, and many other aspects of human life. By integrating ideas relating to feminism, queer theory, and disability we can stretch the intellectual imagination and expand our notion of binary concepts of normal/abnormal, masculine/feminine, and able/disabled. The perspectives of disability theory, feminist theory, and queer theory complement one another in their emphasis on the personal and the cultural. All three theoretical standpoints acknowledge how cultural forces influence our experiences as individuals. Ableism contributes to the segregation of people with disabilities from “regular” schools, sexism keeps women out of certain jobs, and homophobia reinforces heterosexual relationships as the norm.

Examining my own life and the lives of others in marginalized or oppressed groups reveals that identity exists as an ongoing, meaning-making process rather than a fixed state of being. I feel “more” disabled in some contexts than others. I also find myself pushing boundaries regarding gender and sexuality.

In this paper, I use disability theory, feminist theory, and queer theory to describe and evaluate my personal identity. My reflections and experiences demonstrate how social construction determines our interpretation of gender, sexuality, and the body. I also explore how people with disabilities work to reframe the culture and how current multicultural scholars isolate or ignore experiences of disability. My analysis offers a particular worldview centered on the formation of identity, cultural interpretations of (dis)ability, organized resistance, structural oppression, language, and sexuality. A series

of episodic retellings emphasize shifting patterns of thought as I step forward and back from the meaning of disability in my own life. The purpose of this text is to offer a view of three identities that help define me as a person and a scholar. I hope this work provokes inquiry, questioning, compassion, and understanding. This serves not as an ending, but a beginning of study, contemplation, and reflection.

In order to guide the reader through a complex combination of theory and personal experience, I offer a brief synopsis of the things to come with a brief summation of each chapter.

Chapter 1 establishes my search for reflections of my identities in the larger culture. I describe my search for recognition in a culture that glorifies the “able” bodied and explore why difference must be explored from multiple contexts.

Chapter 2 describes the methodology I chose for this project and how it reflects the nature of the perspectives I utilize. It explores the difficulties and rewards of autoethnographic work.

Chapter 3 describes the process of identity formation. Since this project views disability as a construct, I must determine which forces create and perpetuate our identity as human beings. I also explore ideas related to the management of multiple identities.

Chapter 4 examines models of disability and the implications of these models for disability scholars and the world at large. I offer my reflections and interpretation of the meaning of disability in my own life.

Chapter 5 explores the process of turning to disability. Instead of keeping disability issues at bay or beneath the surface, I examine how many people with

disabilities, including myself, choose to “come out” as disabled and integrate disability as a key form of their personal identity.

Chapter 6 looks at the ways people with disabilities choose to respond to pervasive negative forces, including the structural and the cultural. This chapter also forges connections between disability and the mobilization of other oppressed groups.

Chapter 7 emphasizes the importance of language and other forms of recognition for people with disabilities. This chapter recognizes the ongoing debate over choosing labels and the implications of language and identity.

Chapter 8 describes disability across the lifespan. I outline the theoretical issues occurring at different life stages and recount specific personal experiences relating to my life and my identity.

Chapter 9 enters the terrain of disability and sexuality, a major source of pain and oppression for all people living with a disability. I link ideas related to disability and sexuality to concepts encountered in queer theory and feminist theory.

My conclusion delineates the place of disability within the multicultural arena. I summarize the arguments of multicultural and feminist scholars and note areas where disability does and does not receive adequate coverage. I emphasize the need for continual coverage and research in the area of disability studies because of the profound influence it exerts on my own and others' lives.

CHAPTER 1: RADICAL FEMINIST WITH A DISABILITY SEEKS SAME

In a short story entitled "Street Haunting," Virginia Woolf (1984) reflects on her travels throughout London and her prowl for the perfect pencil. I engage in a similar quest, only mine occurs in bookstores across central Florida, where I have spent twenty-two years of my life thus far. I start by flipping through the bargain books, and occasionally come across titles that relate to my present pursuits in academia. One excellent find: Anderson and Collins (1995) *Race, Class, and Gender: An Anthology*. Then I wander over to women's studies and gay and lesbian studies. Fellow scholars, allies, and friends exchange shy glances and knowing smiles as we scan the titles and skim passages. No matter how many feminist anthologies I own, I can't seem to get enough. I flip through the pages and occasionally see fragments of my own experiences within them: flirtation with self-mutilation, sexual assault and date rape, confusion regarding sexuality, eating disorders, and occasionally, a rare glimpse into disability. It is always a brief foray, never too detailed or complicated, but a slight nod to the fact that women with disabilities exist.

After my sojourn ends, I begin my usual quest to find a disability studies section. Usually the search is futile, but I find two disability studies sections during separate hunts: a couple of books on a shelf at Borders and a whole shelf at an independent bookstore in the Mission District of San Francisco. I also find an anthology of writing and artwork by queer youth. I remain completely absorbed on my flight home, racing through the words and pictures trying to find a closer view of my own experiences. Jackpot, I find her! Or more specifically, I find a BYAAFWWCP, a Bisexual Youth Activist Advocate Writer With Cerebral Palsy, modeled on the writer's view of "queer

affinity for acronyms.” Without even beginning to devour her essay, I run a mental checklist to see if we occupy the same categories. Bisexual: check. Youth Activist: check. (Although I’m about to leave the youth category behind as the recent celebration of my 26th birthday indicates.) Writer: check. With Cerebral Palsy: check. (I smile at her use of “with” to emphasize the fact that we are people despite and before our disabilities). The merging of my favorite schools of theory: feminist theory, queer theory, disability theory, and multicultural theory: check. Although this paper does not specifically use multicultural theory as a “lens,” it maintains a natural presence in this work through the articles and authors I reference, the general nature of all of these “schools” of theory, and my own knowledge of multicultural issues.

I need a viewpoint, a structure, something that will allow the center to hold. I need a technique in which I, the writer, pull from my experiences, pull from my theoretical and cultural knowledge, and try to find the larger meaning behind being female, having a disability, and existing on a perpetual sexual continuum. I must try not to emphasize one aspect over another, but my heart and my life story suggest one dominant theme, disability. The recognition I receive in society (including the damage and insults) all stem from disability. Why? Visibility. While I am obviously female, the difference in my walk draws sets of eyes in my direction. My gender and sexuality always get subordinated. But one form of oppression must not take precedence over another. Russell (1998) emphasizes the dominant role disability plays in the lives of people with disabilities, despite their membership in other subordinate groups. She refers to disabled people as an “unexpected minority” and states, “We are the ‘unexpected’ minority having undeniably similar socio/political experiences that make disability our

primary identity” (p. 16). Perhaps, as members of the disabled community, we can use the visual evidence of our disabilities to create space for dialogue regarding difference, physical diversity, and the assumptions and stereotypes surrounding those with disabilities. Rather than fearing dialogue or questions, we can bridge our understanding to that of other marginalized and underrepresented groups. By examining and fighting the oppression of other groups of people, in addition to our own, we assist in the assertion of equality and dignity for all people.

People always talk about similarities because they are afraid of difference. I want to *claim* difference. We have to look at the ways oppressed and marginalized people are *constructed* as different. Sometimes, stereotypes get filled in certain ways. I will be shunned for saying that, but my life is dramatically different than others through the course of my daily activities and the ways I am approached. Rather than existing as the Other in this story, my possession of my own disability puts me in a dominant position for the first time.

CHAPTER 2: AUTOETHNOGRAPHY

My work depends largely on methods of qualitative research and inquiry.

Atkinson and Hammersley (1994) define ethnography as a descriptive process rather than a methodological one in the sense that no theories are tested and no experiments are run. The data of ethnography comes from the subject and the culture rather than from quantitative methods or analytical terms. Autoethnography serves as a framework for exploring my identity development as a person with a disability. I explore convergences and divergences of my experiences in relation to disability studies and identify intersections of my experiences in the realms of feminist and queer theory.

This method allows me to record the palpitations of the human heart, the loneliness and isolation of disability, and the celebration of small victories. It allows me to step both inside and outside of my life as a participant and an observer. It allows me to step back into my childhood and watch as my classmates grapple with the ideas of difference while I analyze my own fears, insecurities, and the judgments of the larger culture. Qualitative research allows me to focus as closely as I would like on my own life. Finally, this methodology allows me to interpret each episode, thought, and emotion for evidence of a greater picture of the meaning of disability and identity in childhood, adolescence, and young adulthood.

Ellis and Bochner (2000) refer to the empowering process of the ethnographer as she dances gingerly between the personal and the larger implications of society. They state:

Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the

cultural. Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations (p. 739).

Because of its emphasis on the larger picture, autoethnography does not necessarily match up in accordance to dominant experience. It offers the opportunity for previously unheard voices to echo across the horizon in pursuit of their own truths. I suspect that my experience will reflect the experiences of other women with disabilities in many ways, and in others, I may stand all alone.

Autoethnography also finds a unique way to fuse the social sciences with the humanities. Ellis and Bochner (2000) state that autoethnography may consist of “short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose” (p. 739). I relish the freedom to include many aspects of self that reflect the ways I live, work, and think. The more abstract world of fragmented and layered writing will dull the pain between reality and fantasy, while protecting the identities of some who touched my world. In regard to the process, Ellis and Bochner (2000) state, “In these texts, concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness are featured, appearing as relational and institutional stories affected by history, social structure, and culture, which themselves are dialectically revealed through action, feeling, thought, and language” (p. 739). Far from being an objective observer, I will reconstruct dialogue and interpret the events that frame disability. I must be willing to place my life and heart under the microscope and

reopen scars freshly healed in order to bring new insight and clarity into the world of disability. At the same time, I must hang on to the analytical tools of the scholar, recognizing that some experiences hold more weight than others in the interpretation of disability.

CHAPTER 3: DANCING WITH IDENTITIES

How then, do we come to identity? Is it nature or nurture? Is it a combination of both factors? Or, is it a complex interplay between context and self-identification? Psychology tends to focus on the individual while sociology focuses on the culture. The best interpretation, at least in terms of disability, comes from modules relating to diversity and social justice. Different scholars define identity in different ways. In "The Politics of Recognition," noted multicultural scholar Charles Taylor (1994) defines identity as:

who we are, "where we're coming from." As such it is the background against which our tastes and desires and opinions and aspirations make sense... Thus my discovering my own identity doesn't mean that I work it out in isolation, but that I negotiate it through dialogue, partly overt, partly internal, with others. That is why the development of an ideal of inwardly generated identity gives a new importance to recognition. My own identity depends on my dialogical relations with others (pp. 33-34).

Tatum (2000) argues that we are who others say we are; she refers to Cooley's concept of the "looking glass self" and how we see ourselves through the mirror in which others see us. However, this mirror often becomes distorted because of factors relating to diversity and the multiple identities we occupy. Tatum (2000) states, "The parts of our identity that *do* capture our attention are those that other people notice, and that reflect back to us. The aspect of identity that is the target of others' attention, and subsequently of our own, often is that which sets us apart as exceptional or 'other' in their eyes" (p. 11). Because of this tendency, people are commonly defined in terms of ethnicity, gender, ability,

socioeconomic status, sexual orientation, and religion, among a variety of other factors. Tatum refers to Audre Lorde's (1995) concept of the *mythical norm* or the idea that each person fits into the dominant groups of traditional society. According to Lorde (1995), the American norm is a young, fit, white, heterosexual, middle-class, Christian man. The effects of this mythical norm extend in two ways: first, individuals receive intellectual reminders that they do not fit within the mold and, second, systematic privilege and power reach those who fit the norms of "American" society. In *Blood, Bread, and Poetry*, Adrienne Rich (1986) refers to the process of being unable to see oneself reflected in the larger culture as "looking in the mirror and seeing nothing." In this respect, a sense of psychic dissonance develops when certain groups face devaluation by society. This occurs when women, sexual minorities, religious minorities, ethnic minorities, old people, and people with disabilities do not receive positive messages from dominant culture.

In "The Cycle of Socialization," Harro (2000) refers to the role multiple social identities play in our access to power and privilege in society. She states:

Instead, we are each born into a specific set of *social identities*, related to categories of difference mentioned above, and these social identities predispose us to unequal *roles* in the dynamic system of oppression. We are then socialized by powerful sources in our worlds to play the roles prescribed by an inequitable social system (p. 15).

These roles vary from person to person, based on the unique categories she possesses. Each person is likely to belong to several oppressed and several dominant groups. In regard to dominant groups, Harro (2000) states, "*Dominant or agent* groups are

considered to be the 'norm' around which assumptions are built, and these groups receive attention and recognition. Agents have relatively more social power, and can 'name' others" (p. 17).

Davis (2002) argues that as "traditional" categories of identity become less distinctive in their ability to shape our identity, the concept of disability becomes even more complex. In terms of identity politics, disability remains the youngest and thus, most developmental, category of identity. In terms of oppositional consciousness, disability is the last to emerge trailing behind the gay rights movement. Oppositional consciousness (see Groch, 2001) refers to the efforts of marginalized groups to protest negative ideas generated about them by dominant culture. Specific acts of consciousness and dissent challenge the claim that marginalized groups possess less value and worth. This trend becomes apparent in the academic departments of many colleges and universities. Disability studies still trails behind and slowly emerges after gender/women's studies and queer/gay and lesbian studies. In my own experience, the absence of disability in many of my academic courses (and its marginalization when covered), makes me even more conscious of my own status as a person with a disability in North American society.

The ways in which recognition does and does not occur in society holds tremendous power over the self-concept and identity of members of marginalized groups. One of the aims of multiculturalism is to restore a positive self-concept to groups who face derogatory messages about their worth and value. Charles Taylor (1994) states, "Our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or a group of people can suffer real damage, real distortion, if

the people or the society around them mirror back to them a confining or demeaning or contemptible picture of themselves” (p. 25). Over time, more diverse and accurate portrayals of people with disabilities appear throughout mainstream culture. The film *Frida* received critical acclaim, “Share a Smile Becky” became the first of Barbie’s friends to sport a wheelchair (and incidentally, could not fit into the elevator of Barbie’s Dream House), and Aimee Mullins, an amputee, was one of *People Magazine*’s 50 Most Beautiful People of 1999.

Frida, with its strong portrayal of a feminist, Chicana woman with a disability, serves as an example of a well-rounded life shaped by disability. The film, directed by Julie Taymor (2002a), possessed some minor faults and even faced criticism for its *lack* of emphasis on disability. Filmmaker Julie Taymor (2002b), commenting on her choices, affirms, “I didn’t want to do another painter-angst movie. Pain is there but pleasure is equally there” (p. 14). Kahlo (1995) herself places emphasis on her zest for life. In her journal she records the joy of living. Taymor’s film illustrates several key principles of disability studies: disability can be acquired at any stage in life (Kahlo had polio as a child followed by a bus accident in her early teens), disability cuts across lines of gender, ethnicity, sexuality, and socioeconomic status; people with disabilities possess sexuality (her affairs with men and women were notorious), and people with disabilities experience a full range of human emotions and rarely indulge in excessive sorrow over their condition. Frida’s life, at least as portrayed on film, contains very little contact with other people with disabilities. Despite this, she develops a positive sense of self and leads a full life with contact with many sectors of society. This remains true not only of Frida,

but of people with disabilities around the world. Like the queer community, we are here and we are not going away.

CHAPTER 4: MODELS OF DISABILITY

Disability scholars use three basic theoretical models to explain the social construction of disability: the moral model, the medical model, and the social model. Eli Clare (2001) provides a concise summary of dominant models of disability. She states:

The dominant paradigms of disability—the medical, charity, supercrip, and moral models—all turn disability into problems faced by individual people, locate those problems in our bodies, and define those bodies as wrong. The medical model insists on disability as a disease or condition that is curable and/or treatable. The charity model declares disability to be a tragedy, a misfortune, that must be tempered or erased by generous giving. The supercrip model frames disability as a challenge to overcome and disabled people as superheroes just for living our daily lives. The moral model transforms disability into a sign of moral weakness (pp. 359-360).

The Moral Model

According to the moral model, disability:

is a defect caused by moral lapse or sins. It brings shame to the person with the disability. In cultures that emphasize family and group over individuals, the shame spreads to the group. The person and/or family carries the blame for causing the disability. Disability is seen as “divine retribution for sinful deeds, as retribution and preparation for the one who strays from the path of the devout, or as a test of a person’s faith” (Olkin, 1999b, p. 25).

The moral model plays quite nicely into society's assumptions of disability: that people with disabilities are evil and bitter (think Shakespeare's *Richard III* or Disney's villainous Captain Hook) or that disability is ordered by God as a form of divine will. Many parents of children with disabilities are told that disabling conditions are "God's will." The moral model, although outdated, still exerts its influence in a society founded on Judeo-Christian tradition and anxious to place the blame on someone or something. Even the view of people with disabilities as "chosen by God" creates unreal expectations and feeds into the idea of the "Supercrip" or someone who ultimately rises above disability and exceeds society's expectations.

The Medical Model

The medical model picks up where the moral model leaves off and places the treatment of disability into the "capable" hands of medical professionals who view disability as a "problem" to be "fixed." Olkin (1999b) states that the medical model views disability solely in terms of medical abnormality. She goes on to say:

Disability is a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological. The goals of intervention are cure, amelioration of the physical condition to the greatest extent possible, and rehabilitation (i.e., the adjustment of the person with the disability to the condition and to the environment) (p. 26).

Potok (2002) agrees with this definition and states that the medical model focuses on "fixing" people with disabilities rather than examining the social and cultural roots of their oppression (p. 160). As Olkin and Potok point out, the problematic portion of the

medical model lies in its attempts to dehumanize the patient, “cure” the patient, and otherwise eradicate the disability in its entirety. Proponents of the next model discussed, the social model, also realize that sometimes medical intervention is necessary for survival or to relieve discomfort. In all cases, the patient with the disability must be given autonomy over the procedures performed and standards related to care.

The Social Model / Minority Model

In place of the medical model, disability rights activists favor the social model (also known as the minority model) in order to properly frame their experiences of marginalization, oppression, and systemic exclusion from society. This model avoids the pitfalls of the previous two models by citing the “problem” of disability as society’s negative interpretation of disability. This model treats people with disabilities as a minority group working to access equal rights in a discriminatory and inequitable society. Olkin (1999b) states:

It posits that disability is a social construction, that the problems lie not within the persons with disabilities but in the environment that fails to accommodate persons with disabilities and in the negative attitudes of people without disabilities. People with disabilities are seen as a minority group—in the same way that persons of color are a minority group—that has been denied its civil rights, equal access and protection (p. 26).

Like Olkin, Clare (2001) uses the social model to focus on the disabling attitudes of society. Disability scholars embrace the social model because it forces people to change their interpretation of disability and analyze the way individual attitudes shape the behavior of the society as a whole. For instance, a belief in accessibility as an individual

problem or a medical problem diminishes the need for universal accessibility to all public places. Clare (2001) elaborates:

Disability, not defined by our bodies, but rather by the material and social conditions of ableism; not by the need to use a wheelchair, but rather by the stairs that have no accompanying ramp or elevator. Disability activists fiercely declare that it's not our bodies that need curing. Rather, it is ableism—disability oppression, as reflected in high unemployment rates, lack of access, gawking, substandard education, being forced to live in nursing homes and back rooms, being seen as childlike and asexual—that needs changing (p. 360).

Clare addresses the core issues of disability politics in her brief summation of the many forms of ableism. Unfortunately, most people with disabilities do not discover the social model until later in life. The social model of disability provides a specific “location” for its subscribers. According to Crow (1996):

It has enabled a vision of ourselves free from the constraints of disability and provided a direction for our commitment to social change. It has played a central role in promoting Disabled people's individual self-worth, collective identity and political organization (pp. 206-207).

Olkin (2002) refers to a variety of benefits derived from the social model: it examines oppression from a societal standpoint, taking away individual blame; it allows individuals to come to terms with their “disabled” identity; and it calls for greater social organization. However, Olkin (2002) also points out the drawbacks involved in recognizing the societal

constraints of disability including “powerlessness” and frustration when making larger structural changes (p. 133).

The social model, although clearly important in its ability to reframe ideas of the self and ability, often does not match the ideas perpetuated by the authority figures in disabled people’s lives. Doctors, teachers, and caregivers still hold on to many of the debilitating ideas surrounding the moral and medical models.

Moral Model Revised: A Personal Interpretation

My own awareness of the social model came over time, and with resistance, because it forced me to realize how hurtful society is towards those with different abilities. I wrote this as a first-year student in an undergraduate creative writing course as I began to process and make sense of disability on my own terms. Largely unchanged from its initial conception, these reflections hint at the lasting presence of the moral model and its impact on my own thinking. Revisiting these thoughts, I recognize my need at the time, and sometimes even now, to find a deeper meaning in the struggles and the pain. I resist the idea that my experiences come ordained from a higher power or from a series of karmic debts I struggle to repay. Instead, these fragments form tiny pieces of a larger mosaic that I continue to create: I am no better or worse than anyone else. I constantly utilize the tools of my existence to become a stronger, wiser, and more compassionate person.

According to the doctors, I was supposed to enter this world on May 20, 1978. I would arrive with much anticipation, but little surprise. My name would be Stacey and I

would have ten tiny fingers, ten tiny toes, and a clean bill of health. I would stay in the hospital for a day or two, and would then be brought home by beaming, proud parents.

According to fate (or the moral model), I would enter the world on February 28, 1978. I would be connected to a respirator and call an incubator home for eleven weeks. I would also be disabled.

Life seems so complex at times, and so many things are impossible to understand. It is so difficult to imagine why pain and suffering exist, why children go hungry, why there is war, or why someone can walk down the street one day and suddenly be in a wheelchair the next. Yet, all of these things are part of the human experience. I believe that these are tools in hiding—they exist in our lives so that we can hold compassion toward others, strive to make a difference, and celebrate our simplicity.

The only experience I have ever known is my disability. I will never know what it is like to walk without effort, or to have a body that automatically responds to commands without a second thought. I will never be able to break into a run and arrive at a destination in the nick of time, or to ice skate on a frozen pond with blade marked ice. I will always know what it is like to struggle to get my body to respond to my impatient commands, and how much effort it has taken to get where I am today. But I will know the simple victory of taking a step and writing my name on a piece of paper, the feel of the numbers being pressed as I dial the telephone, and the wonder of being able to speak clearly to the person on the other line. I will always know what it is like to witness the joy and compassion of other people with disabilities.

I could choose to be bitter and convince myself that I have been dealt a bad hand, that fate interceded and gave me a less than normal shot at life. But I choose not to, I

was given a challenge and it is up to me to take the conquest and find the reward. There are so many things beyond our comprehension; as Hamlet stated, "There are more things in heaven and earth...than are dreamt of in your philosophy." The same is true of life with a disability. Life is not simply the experience of becoming someone and taking a place in the world. I believe it involves exploring the strength of the human spirit, the compassion that people feel for one another, and the appreciation of all the things usually taken for granted. That is the gift cerebral palsy offered me and the one I chose to accept.

I recognize that children with cerebral palsy accept their challenge and gift and offer it to the world without reservation. I recognize the joy in their sparkling eyes, the wonder and magic in their smiles, the pain in their protest, and the simple appreciation of the life given to them. I was introduced to these children in physical therapy and through other paths not crossed without disability. Rachel, Raphael, Jessica, Michael, and Joshua all hold the qualities parents want to witness in their children. These qualities include unconditional love, appreciation, determination, and hope.

I recognize the spirit and love in the eyes of children with disabilities who cannot speak. They are not vegetables, and they are not "better off" when they die. These ideas speak of the problematic nature of the moral model. Olkin (1999b) states, "The moral model frames the problem as one of sin and moral lapse and puts the onus on the individual or the family. In this model, solutions to the "curse" of disability are to be found in the realms of faith, forbearance, exorcism, ostracism, and even death" (p. 27). Contrary to the moral model's insistence on worthlessness, these children serve an important purpose: they teach their parents about the simplicity of life. The meaning of

bending a knee or lifting a leg takes on new proportions when viewed from a perspective of sacredness. These children tell a tale of beauty, unconditional love, acceptance, and joy. The crystal reflection in their eyes speaks of purity and clarity.

Circumstance has a strange way of weaving in and out of our lives, bringing smiles, tears, and lessons that will shape our life experience and determine what we offer to the world. I would not choose to disown my experiences. I am disabled. That simple fact will not change. Despite that, I received a gift that teaches me the mystery of life. I also learned that in my imperfection, I am closer to perfect. According to me, I am Stacey. With my disability, I am complete.

CHAPTER 5: TURNING TO DISABILITY

I entered into disability theory fairly recently; my college career sparked my coming-out process as a person with a disability. Much of the literature addresses the fact that although disability is obvious in many cases, many people choose not to identify with their disability because of the social stigma and prejudice they face by society. Identification carries a cost, society seems to like those who put up the least resistance and who acknowledge similarity instead of difference. In addition to the stigma, a great emotional weight also remains attached to disability. For many, disability acts as a source of pain. It remains difficult to recount the experience of a body that refuses to come through for you and that does not function the way it does in your sleep. I remember all the times I became startled by my reflection in the full-length department store mirror and my own inability to iron out my bent legs.

Turning to disability became a process as I gradually grew more comfortable identifying myself as a person with a disability. I found it easy to identify as a feminist in every aspect of my life while I was reluctant to identify as a sexual minority. I knew the stakes were high at a small liberal arts college. When I began my studies at Rollins College, I possessed a higher awareness of feminism and human rights than many of my classmates. Introduced to the structural inequality and social pressures faced by young women by Mary Pipher's *Reviving Ophelia* (1995), I became determined to fight the hegemonic, dominant systems through my forthcoming studies in education and women's studies. However, I obsessed over disability issues while enrolled in a course on personal writing. In this course, the previous piece came to life after much struggle over whether or not to address the powerful emotions and memories gurgling at the surface, fighting

for air. I looked at the impact on disability in my life: its powerful force in shaping my experiences and my viewpoints, the role it played in my inclusion and exclusion from mainstream society, the messages I internalized as a white, female with a disability, and as a self-identified sexual minority. In my world, few role models and heroes represented my experiences.

In a paper I read aloud to my classmates during a writer's workshop, I boldly asserted "disability is all I have ever known," much to the bafflement and disinterest of my classmates. As I got copies of my work back from my classmates, notes ranged from "disability is *not* all you have ever known" and "Why don't you ever write about anything that does not have to do with disability?" In response to their comments, my mind began to balk at the opposing interpretations of my personal experience and the larger implications of being disabled in an ableist society. First, I challenged their assumptions that disability *was not* the only thing I had ever known. In some effects they were correct; I identify as a feminist, a woman, as queer, and an activist. However, the framework and lenses that denote my experiences are those of disability. I will never know what it is like to take a step without effort or to have a body that follows my commands.

As Olkin (1999b) argues, the experience of disability places individuals in a unique cultural and social position. A forced dual-occupation in the world labels the able-bodied as "normal" and the physically challenged or disabled as "abnormal." She terms the bridge of her experience between the worlds of the disabled and non-disabled as a bicultural experience. Disability, while not possessing its own unique heritage, language (excluding American Sign Language) and other specific markers of ethnicity,

binds its occupants through the collective experience of devaluing those with mobility impairments, who speak differently, and who walk differently. Olkin (1999b) distinguishes between the mobility impaired and others by stating, "In the disabled community we refer to people without disabilities as Abs (able-bodied) or Tabs (temporarily able-bodied). Notice the vantage point—*nondisabled*, *not* like us. We don't call them "normals" because to us they are not the norm. In our world abnormal *is* normal" (p.vii).

If society continues in its present direction, people with disabilities may never exist in a world that values, respects, or positively acknowledges the bodies of those who are different. Benhabib (2002) and Taylor (1994), among others, address the profound impact of recognition, oppression, and marginalization. Benhabib (2002) states:

Collective practices can result in individual injuries: Through the denigration of one's collective identity in the public sphere, individuals in a group may lose self-confidence and internalize hateful images of themselves. Known forms of collective self-hatred, particularly members of outcast and "feared" minorities, like homosexuals, Jews at one time in history, and Gypsies still today come to mind here (p. 51).

Benhabib's statement powerfully illustrates the damage instilled by the misrepresentation of marginalized groups; however, she overlooks the fact that homosexuals still face discrimination and hatred, that anti-Semitism is still alive and perpetuated by neo-Nazi's (among others), and that people with disabilities are often outcasts and feared by people without disabilities.

My own life gets continually shaped by the presence of disability and the ways in which others choose to acknowledge or deny its existence. Disability exists as a category, and essentially a culture, that makes me who I am. My sense of social justice, equity, and compassion is firmly rooted in my experience as a marginalized person in society, as a person who is prematurely judged on the basis of physical characteristics, and who is subjected to stereotypes and beliefs that should have left general society's consciousness long ago.

I retain a feeling of distance and separation from the world at large because of the drastically different experience disability provides. My disability cannot be hidden (in most cases) and is not always treated with kindness and sensitivity. I internalized the belief that I am less deserving of success and acceptance. I also internalized a great deal of anger and self-hatred which diminished over the years.

The incident of misrecognition in the writing workshop made me wonder if someone from another oppressed, marginalized, or underrepresented group would have received the same reaction. Someone who is of a diverse ethnic heritage does not experience the benefits of white privilege, just as a homosexual does not receive the same social validation and benefits as a heterosexual. Many people remain ready to discount my experiences as a marginalized member of society by stating that "everyone has limitations" or "everyone has a disability." While each person experiences a wide array of strengths and weaknesses, everyone does not experience the structural and internalized oppression of disability. Rhoda Olkin (1999a) states that therapists [and I would argue, the general population] "have a responsibility not to define away the 'minority status' by asserting that all people are different, or dismissing the minority experience by stating

that all people have ‘handicaps’ of one kind or another, and we must learn about each client individually” (p. 97). Olkin and other writers who live with disability in both their personal and professional lives remind me of the need for projects addressing the personal and the political of disability. I receive a sense of validation every time I read one sentence that reflects my reality, honors my pain, and reflects my confusion. With each article I read, I feel less alone and more capable to address society’s and my own issues with disability. Olkin’s argument also helps explain the psychic disconnect I feel every time someone belittles my experience as a person with a disability by claiming that “we are all disabled.” Connie Panzarino (1994) says that no one can get inside of your body and know what it’s like. No one can crawl inside of your head and experience the isolation, the frustration, and the loneliness. At the same time, they do not experience the heightened world view, the appreciation of life, and the acknowledgement of fragility.

The pain, as in the nature of any pain we experience in life, ebbs and flows according to various circumstances. As I began to seek out and interpret disability in various forms, I developed a greater sense of awe and anger. Disability occupied so much of my world, yet seems invisible when I look for its presence outside of my immediate field of vision. My frustration with the non-disabled world hit me one day while walking with my walker across the campus. I noticed a young woman ahead of me break into an easy, swift run. When I returned to my dorm that afternoon, I sat down at the computer and began recording my thoughts and feelings about ability; I called it *Guided Imagery*. I later used *Guided Imagery* as a type of guided meditation during a workshop I designed with another student to help facilitate disability awareness among

the non-disabled. This marks one of my many attempts to expand my vision of the world and offer it up to others.

Guided Imagery

You wake up in a body one day and it is unlike anything you have ever known. You know that something is wrong, something is out of balance, yet you cannot quite put your finger on what it is.

Everything in your mind still seems the same; you feel the same emotions, and when you look up, the sky is still velvety black, sprinkled with white stars. But then you notice that you are in a chair and you are unable to move. You send a thought to your limp leg just hanging there. "Move, I command you to move," and you know that you thought it and you know that you said it, but nothing happens.

The struggle begins. It is you, but it is more your body against your mind as you try to make it follow commands that it fails to recognize. This frustrates you because all you want to do is to get up, to change the situation. While the situation cannot be changed, you can.

So, you journey out into the world, attached to your chair, armed with multiple thoughts. Your perception has changed and you hold onto the black velvet sky sprinkled with stars with all of your might. It is your one constant. It reminds you that there is a great mystery beyond your immobile legs, and that there are secrets you have yet to discover and hopes that you have yet to fulfill.

All of this becomes your experience: you try to hang onto it, to conjure it up to the forefront of your mind when people stare as you try to walk; when they ask what is wrong

with you; when they tease you; ignore you; call you crippled; when you feel like no one understands; and when you feel enwrapped in the isolation, but somehow find the courage and the stamina to continue on.

Sometimes you think of it in terms of my world versus their world. They use different terminology and they do not think the same way. They also think of it as their world versus yours. In their world, disabilities are something to be feared, segregated, and ignored. The disabled are another category on another continent, in another classroom because it is too difficult to share the perspective and make the worlds begin to mirror each other.

Somehow you manage to forget all this because in your dreams you fly. Your mind holds no bounds and you find insight within your own experience. Within the separation, there is peacefulness and an appreciation. The mundane becomes beautiful and sometimes what is beautiful becomes mundane to you.

You learn to look for hope where there is none and you marvel at this fabulous opportunity called life. Even though people tell you that you cannot, you should not, and you will not, you will. That is your only option.

Sometimes people tell you that you are brave and strong, but you do not consider this true. You are simply taking the given circumstances. You get angry sometimes, at the world, at the Universe, at whatever, because sometimes it seems like too much to handle. You are so tired, tired of the limitations of your own body, tired of no one understanding, tired of the stares, the feelings of worthlessness, and the people around you who do not recognize everything they have in their own lives.

You are walking one day, with the same legs that refuse to do what you command, and the woman in front of you breaks into a swift run. You are overcome with jealousy for a moment because you know that she did not think about it; she just did it. You wish you could be her, that it was your legs pumping beneath you, with the wind in your hair. But it is not. You keep taking one calculated step after another, but you remain so caught up in the moment you start to think.

You recognize that life is such a gift, despite your own limitations. Everything seems more alive to you, and this is your chance to share what lies within. The outside world may laugh and may not understand, but you have a mission to live up to yourself, to stand up to the world, and to not let anything stop you.

It is so complex, all the images flashing before your eyes. You remember the rage and self-hatred you felt when your physical education teacher imitated the way you ran in front of the entire class. You remember the shame that you felt every time you walked past a full-length mirror and saw how the world views your legs. You were filled with sorrow and terror when you found out that people with disabilities were the first to be murdered in concentration camps.

Finally, you wonder where you are at within this mosaic of images. Most of the reflections of disabilities, of yourself, are smiling poster children or actors in movies who have never spent a minute in your mind. They are heroes or they are bitter, but they are not on the same level as everyone else. Despite this, you know you can change people's perceptions and teach them to recognize the light that shines within you.

You wake up in a body and it is unlike anything you have ever known before. You know that something is right and your limbs will follow your every command with ease.

But, this time, you will think about it with compassion and understanding because you recognize how lucky you are to occupy this location. At the same time, you also recognize that in the stigma, in the way that ableism perpetrates your society, something is lost. But that does not stop you. There are secrets you will discover and hopes you will fulfill.

CHAPTER 6: STRUCTURAL OPPRESSION

Oppression in the Classroom

In the early 1980's, the local public elementary school refused any students who could not completely dress or undress themselves. My only option: a "special" school. In the decade before the ADA, this school would give me less than what would now be considered an appropriate or adequate education. My parents enrolled me in a private, K-8 private school. Although most of my teachers never truly differentiated me from my classmates in policy or treatment (minus the physical education teacher), my classmates were always careful to affirm my status as a "cripple," something they were never afraid to say to my face. My fight to prove myself began. My classmates' ignorance and bigotry motivated me to pursue the best education possible. It also forced me to prove that physical ability and intellectual ability do not always exist in comparable terms. Physically, I possessed limitations. Intellectually, I did not.

Even within a "normal" classroom environment, I faced assumptions regarding my intellectual abilities. Other students attributed my high grades to being a "teacher's pet" and teachers questioned whether or not I "belonged" in the courses they taught. On the first day of a dual enrollment course, "Social Problems," the Seminole Community College professor approached me. Seeing my wheelchair and not the person sitting in it, she asked rather directly if I was in her class. When I replied "yes," she asked if I was in "special" classes. I stated that I was if she considered Advanced Placement, Honors, and Dual Enrollment "special." At the end of the semester, I had the highest grade point average in the course and was the only student in the class with an A.

The previous situation illustrates the pervasive forces that cloud even educated people's judgment and their tendency to equate intellectual aptitude with physical ability. Physical impairment does not automatically mean cognitive impairment. A wide range of intelligence exists within the disabled community. Olkin (2002) states, "Too often, sweeping generalizations are made erroneously in the literature about people with a range of cognitive impairments to all people with disabilities. The fear of being thought of as cognitively compromised is especially acute for graduate students struggling to become professionals" (p. 131). Olkin's comments resonate with me as I recognize the lengths I take to prove my prowess as a student: my perfectionism, my self-doubt, the panic attacks I fought off my first year as an undergraduate at Rollins while maintaining a 4.0. Despite my academic success, a voice in the back of my mind always wonders if I am good enough, smart enough, and if I will make it when I begin my career as a professional.

The disability rights movement suffers precisely because of the structural oppression inflicted from deep-seated ideas of who deserves education, housing, transportation, and other resources vital to independent living. Morris (2001) elaborates on this concept further by stating, "Prejudice, discrimination, services which disempower and segregate us; a failure to use resources to create accessible environments, to use technology to aid communication, to provide personal assistance to aid daily living and so on—these are the disabling barriers that we experience" (p. 16). Structural barriers pose even more problems than disabling conditions themselves because of their pervasiveness in every aspect of life.

Disability is one of the few segments of society facing legalized segregation, although it is not viewed in such severe terms by dominant society. Morris (2001) states:

Disabled children will not have equal access to education unless they have entitlement to changes in the physical environment of schools to ensure physical access, the provision of equipment, materials, interpreters, support to make the curriculum accessible, and the implementation of anti-bullying policies (p. 11).

Clearly, reformulating the problem as a structural issue signifies the power of the social model in generating new attitudes toward equal treatment of people with disabilities.

Olkin (1999b) states, "It posits that disability is a social construction, that the problem lies not within the persons with disabilities but in the environment that fails to accommodate persons with disabilities and the negative attitudes of people without disabilities" (p. 26). This reframing of perspective places attention on the structural inequities involved with physical impairment rather than the supposed lack of ability possessed by the individual.

Why Structure Isn't Enough: Oppositional Consciousness and Identity

Morris and Braine (2001) acknowledge the role social construction plays in creating prejudicial attitudes which eventually result in structural inequities. They state:

One of the most important cultural forces working against a hegemonic culture is the oppositional consciousness of oppressed groups. An oppositional consciousness is an empowering mental state that prepares members of an oppressed group to act to undermine, reform, or overthrow a system of human domination. Minimally, that mental state includes

identifying with a subordinate group, concluding that the mechanisms that have produced at least some of the group inequalities are unjust, opposing the injustice, and seeing a common interest within the subordinate group is eliminating the injustice (p. 25).

The organization of the disability rights movement and its oppositional consciousness suffers because of the diverse range of disabling conditions. Disability occurs across public and private lines, trapping its members in limiting cultural scripts. A universal symbol or representative of disability fails to exist and a consistent set of circumstances does not frame each individual's experience of "disability."

One proposed method of organization and collaboration within the disability rights movement is the reintegration of a new form of consciousness integrating a variety of impairments. Like other disenfranchised groups, the disability rights movement tends to segregate itself among the commonalities of its members: for example, Deaf consciousness centers on different issues and consists of different etiquette than mobility impairment consciousness. Groch (2001) argues that in order to be effective, disability rights advocates, like other marginalized groups, must cultivate oppositional consciousness.

The disability rights movement "borrows" from a wide tradition of activism including feminism, the gay rights movement, and the civil rights movement. The "birth" of the disability rights movement occurred shortly after the passing of the Rehabilitation Act of 1973, mobilizing people with disabilities as a cultural/minority group.

Just as the feminist movement must include men and the queer movement must include heterosexual allies, it remains critical that the disability rights movement consists

of the voices of both people with disabilities and the temporarily able-bodied. In situations where the temporarily able-bodied possess more power, they can act on our behalf. Whenever possible, however, public policy and solutions should result directly from the voices and ideas of people with disabilities.

Disability oppression theory “seeks to combat the stereotypes, misconceptions, and restrictive attitudes that are often internalized by people with disabilities and can lead to unnecessarily abrogating conceptions of disability and self-worth” (Castaneda and Peters, 2000, p. 320). Disability oppression theory, like oppression theories applied to gender, race, and class, acknowledges the debilitating ideas and attitudes surrounding people with disabilities. In order to combat these derogatory feelings, the disability rights movement depends largely on the innovation and inertia of its own members. Groch (2001) describes the process of creation in terms of disability culture by pointing out, “As with other forms of oppositional consciousness, disability consciousness is expressed through cultural artifacts and practices. Yet unlike the members of many other racial and ethnic groups, disability rights groups have had to purposefully create their own culture” (p. 85). Symbols of “disability culture” include a statue of liberty sitting in a wheelchair and Phyllis “the adult-size, wooden and acrylic female bird dressed in brightly colored clothing and high, black boots, who sits defiantly with her legs and arms crossed in a wheelchair (Groch, 2001, p. 85). Both symbols challenge the stereotypes of women with disabilities as passive, child-like, unassertive, and free of autonomy over their own lives.

CHAPTER 7: LANGUAGE, IDENTITY, AND RECOGNITION

Within the disabled community, language is a topic of great dissonance and debate. Arguments occur over the terminology used to describe people with disabilities. Some terms are embraced by nearly all members of the community, while others are seen as derogatory or empowering depending on the individual person. Morris (2001) states, "To pay attention to the words we use is not to be 'politically correct' but to struggle for a language which describes the denial of our human rights, locates our experience of inequality as a civil rights issue, and, at the same time, creates a space to articulate our experience of our bodies" (p. 2). Negative attitudes get imposed on people with disabilities in a variety of ways as demonstrated throughout this paper. One of the most hurtful and pervasive forms of ableism manifests itself in the way language creates and perpetuates ideas surrounding ability. If I had a nickel for every time I heard "That is so lame!" "I am such a rere." or "You are so retarded!" in casual conversation, I could self-publish this manuscript and live off the profits. Unfortunately, we do not live in a society that recognizes the full extent of its hurtful comments or that holds a vested interest in the daily lives of people with disabilities. Sometimes I wonder, momentarily, if I am too sensitive. The years wear me down and make me aware of every reference to disability, in passing or in a more direct form. The pain comes from devaluation. I know that "tiny" words reflect larger attitudes and that the phrases uttered so carelessly hint at the structural barriers impeding my own life and the lives of many others.

Eli Clare (2001) articulates the experience of her body by embracing the word queer. Clare uses the multiple connotations of queer to place emphasis on her outsider

experience in its many forms: she feels outside because of her body, her gender, and her sexuality. She states:

Let me begin with my body, my disabled queer body. I use the word *queer* in both of its meanings: in its general sense, as odd, quirky, not belonging; and in its specific sense, as referring to lesbian, gay, bisexual, and transgender identity. In my life, these two meanings have often merged into one. *Queer* is not a taunt to me, but an apt descriptive word.

My first experience of queerness centered not on sexuality or gender, but on disability. Early on, I understood my body to be irrevocably different from those of my neighbors, playmates, siblings. Shaky; off-balance: speech hard to understand; a body that moved slow, wrists cocked at odd angles, muscles knotted with tremors. But really I am telling a kind of lie, a half-truth. "Irrevocably different" would have meant one thing. Instead, I heard: "wrong, broken, in need of repair, unacceptably queer" every day, as my classmates called out *cripple*, *retard*, *monkey*; as people I met gawked at me; as strangers on the street asked, "What's your defect?"; as my own parents grew impatient with my slow, clumsy ways. Irrevocably different would have been easy, compared to wrong and broken. I knew my body was the problem. I stored the taunting, the gawking, the shame in my bones; they became the marrow. This was my first experience of queerness (p. 361).

Clare easily demonstrates the natural connections between queer theory and disability theory. From both theoretical perspectives, "the body" consists of a series of ideas

subject to change. According to Jagose (1996), sexual identity is fluid rather than fixed. Sexual identity depends on the social constructions of society rather than “stable” categories of sexual orientation such as homosexual, heterosexual, or bisexual. For example, Katz (2004) states, “Contrary to the common sense conjecture, the concept of heterosexuality is only one particular historical way of perceiving, categorizing, and imagining the social relations of the sexes. Not ancient at all, the idea of heterosexuality is a modern invention, dating to the late nineteenth century” (p. 69). Thus, the emphasis does not rely on actual acts of sex, but on the idea of sexual identities. Similarly, in disability studies, the emphasis is not on the physical or medical condition itself, but the manner in which the disability and the “abnormality” of the body continually get constructed. Throughout the literature, on both sides, disability and queerness get linked again and again.

Russell (1998) states:

In our hierarchical society it is the social meanings of words that have power. Why do we choose “disabled?” It has negative connotations; the dictionary definition is “unfit” or “useless.” But being disabled/impaired is not a negative, not something to be ashamed of, rather it is a shared identity among those who have the experience of being disabled in a world dominated by non-disabled people (p. 14).

This embracing of the term “disabled” reflects the pride of a movement that identifies the capability and the inherent rights of its members. People with disabilities face common experiences of oppression, discrimination, and prejudice. We exist in a world that wishes to deny our existence, that refuses to remove physical and psychic barriers standing in

our way, and that historically (in the Nazi era) referred to people with varying abilities as “unworthy of life.”

Wendell (1996), among others, refers to the contradictory elements in identifying with a body that constantly receives criticism, devaluation, and rejection. For some, clear advantages exist by ignoring the idea of the body as destiny (Morris 2001) or by simply not identifying with the body at all. The idea of an “inferior body” often becomes synonymous with the idea of an “inferior mind.” Wendell (1996) states:

In addition, people with disabilities often express a strong desire not to be identified with their bodily weaknesses, inabilities, or illnesses. This is why the phrase “people with disabilities” has come to be preferred over “disabled people.” When the world sees a whole person as disabled, the person’s abilities are overlooked or discounted. It is easy to slip into believing other people’s perceptions of oneself, and this can take a great toll on the self-esteem of a person with a disability (p. 176).

The discussion of language usually cannot occur without some sort of reference to political correctness. However, framing disability in terms acceptable to people with disabilities expands beyond the typical notions of political correctness; it allows autonomy over labels. Certain terms trigger the disabled community.

Groch (2001) refers to the evolution of terms referring to the disabled community in the same manner as the evolution of “acceptable” terms for Black/African Americans. She states:

Like other oppressed groups that have formed a culture of oppositional consciousness, disability rights activists insist on their right of self-

definition. They reject the language of rehabilitation medicine and special education. Activists replace “architectural barriers” with “segregation,” “mainstreaming” with “integration,” and “attitudinal barriers” with “prejudice” (pp. 85-86).

Groch equates racial epithets such as “nigger” with words like “cripple” used to insult people with disabilities. Words shatter the soul.

Because of the power behind these words, terminology is an important element in my life. I spent so much time within marginalized communities and learned that everyday language holds an immense power and impacts my ability to relate to others. I cannot stand the word “crippled” and it serves as my biggest trigger. This outdated term assaults my dignity as a person going through life facing a physical challenge.

“Crippled” speaks of stigma, someone held down, defeated, and destroyed. It tells the story of someone cast aside. The word “crippled” takes away everything I fight for; it strips away the power of the individual. Words used against me contribute to feelings of being ugly, worthless, and abnormal. The misrecognition I experience as a “cripple” determines my feelings of acceptance and belonging in the world at large.

CHAPTER 8: DISABILITY ACROSS THE LIFESPAN--AUTOETHNOGRAPHIC REFLECTIONS

Childhood

Throughout childhood, I remained constantly and painfully aware of my disability. I did not need the reminders of my classmates who questioned the way I walked and teased me because I could not do the things they did. I carried this feeling around and distanced myself from their world. I knew their world was not mine. In place of that world, I gained another and many gifts which will always grace my life.

Childhood, according to disability scholars, poses significant emotional and physical risks because of abuse, substance abuse, higher drop-out rates, and higher rates of unemployment (Olkin, 1997; Shakespeare, Gillespie-Sells, & Davies, 1996).

So many of the human rights of children with disabilities depend on the role parents and care-takers play in their lives in the way they frame the child's interpretation of disability and the decisions they make on behalf of the child. Olkin (1997) outlines thirteen human rights of children with disabilities to ensure quality of life. These include:

Right 1: To be told the truth about their medical condition and to have ownership of the story of their disability.

My parents never formally sat me down and had a "talk" about disability. Disability became something inherent in all three of our lives. Because we addressed it as natural, I remained aware of exactly what cerebral palsy meant and learned to see it as an aspect of myself. In this way, disability did not determine my entire identity, nor did it become something to treat with shame or denial. I always told my own story and claimed ownership of my life.

Right 2: To be in control of their own bodies. This includes (a) being as pain-free as possible, (b) being free from physical and sexual abuse, and (c) being included in making decisions about medical or prosthetic interventions.

Decisions related to surgery and other medical interventions always came from the three of us. I had final say over surgeries, and surprisingly, I never said no. I knew that although surgery involved pain and essentially starting over each time (I always had to re-learn the process of walking because of the drastic changes surgery made to my muscles), I knew these decisions came from a desire to increase my mobility and decrease the daily strain on my body. The scars used to bother me, but now they remind me of my strength and how far I have come in my lifetime. These lines form a map on the body.

Right 3: To not be treated as part-objects or specimens.

Because of the nature of medicine, the medical model, and society at large, it remains virtually impossible to have a disability and not feel like an object or a specimen at one point or another. This occurs over the course of daily life as you go through your daily activities. Someone will always gawk or stare when confronted with difference. I view the interaction between the disabled and the non-disabled as a confrontation of sorts: both sides test each other's boundaries, challenge assumptions about rights and privileges, and make statements about living life in the world. Over the years I grew accustomed to the swivel headed reactions of those who stared and turned around and stared again as I walked by, muscles working together and apart to propel my body into motion. Different gears shifting create a picture of awkwardness for the ableist world

while I recognize the strength and power of my willingness to live my life on my own terms.

Right 4: To see positive role models of adults and children with disabilities.

*This right will reach its fruition only when society breaks down existing barriers and accurately portrays people with disabilities in media, allows people with disabilities full access to education, and publishes works such as this one in order to combat the messages polluting our lives. Negative messages and the invisibility of people with disabilities perpetuate fear, ignorance, stigma, pity, and every other form of able-bodied supremacy we fight against. Society slowly seems to wake up to the idea that people with disabilities touch our lives in multiple ways. A few years ago, I never could have gone to a movie theatre and seen a film like *Frida*, highlighting the controversial and adventurous life of a Latina who refused to surrender to society's ideas about identity and gender/sexuality, ability, and the other categories she challenged. My love of *Frida* developed into a recent obsession because I see so much of myself in her. Although I am not a woman of color, I relate to her aspirations, ideals, and creativity. I also find role models in the texts I pore over as part of my research. Eli Clare's work inspires me and highlights the kind of work I may pursue at the conclusion of my studies.*

*Disney's "Finding Nemo" also provides a positive, if somewhat veiled, role model for disability. I find it strange to give Disney credit for social justice because of insults such as *Peter Pan* and the plethora of "heroines" who find their happiness only when rescued or chosen by a man. *Nemo*, with his smaller fin, demonstrates the kind of tenacity and spirit that does not feed into the stereotypes of the "supercrip," but*

demonstrates that people (or in this case, fish) with differences or disabilities crave acceptance, friendship, opportunity, and everything else that may be taken for granted by privileged populations. I saw extreme significance in the subtext as Nemo's dad struggles to award Nemo's independence and the struggle to find a balance between protection and freedom. I also checked the toys at the Disney store shortly after the film's release to make sure that Nemo's fins did not hold the same proportions. To my surprise and delight, I found one "normal" fin and one smaller film. Although it may seem that I am stretching or looking for arbitrary meaning, I find this toy a refreshing change to dolls whose proportions would indicate severe eating disorders if they existed in real life. Children need positive reflections of difference in order to feel better about themselves and others.

Right 5: To have a positive identity that includes and incorporates the disability.

The right to have a positive identity that "includes and incorporates the disability" seems like a life-long project just from my own experiences. As human beings, I think we all struggle to come to terms with the realities and circumstances of our lives. This project's focus on disability and identity serves as a turning point in my own life. I finally have a forum to discuss my own and other's interpretations of disability. Each day becomes a new adventure and process of exploration to discover myself and the world around me. Each memory, each statistic, and each piece of the puzzle remind me that I am me because of the profound influence of disability. Each step I take retraces the path forged by discrimination and ableism, but also the path forged by inspiration, creativity, and acceptance.

Right 6: To not be made to feel that “people like them” should be prevented.

This right conjures up a plethora of emotions and a great deal of sadness. The Holocaust began with experimentation on people with disabilities and “euthanasia” of lives “not worth living.” My exploration of feminist disability issues reveals a heated debate about the parameters of abortion rights and whether or not pregnancies resulting in “disabled” fetuses should be terminated. As a women’s rights activist, I find myself aching for the rights of fellow disabled people to live and torn by the implications of terminating pregnancies based on the health of the child. I hold no decisive answer in this instance.

Right 7: To be allowed to experience a full range of emotions.

Olkin refers to the dichotomy of emotions placed on people with disabilities, the two choice option of being bitter or heroic. Instead, our lives consist of a range of experiences and analysis reveals the complicated emotional landscape of all human beings. I hope to provide a balanced picture with this autoethnography and try to provide a snapshot that does not dwell too deeply on sadness or happiness. My life cannot be described as anything other than rich and full.

Right 8: To gain a realistic view of (a) others’ reactions to them, and (b) their future.

No amount of preparation exists for the challenges of dealing with an ableist society and the same point applies to any marginalized group. Ignorance, unwarranted questions and assumptions, and just plain audacity occur when a majority group tries to make sense of minority experience. For the most part, many people offer acceptance and understanding. In the case of those who have not yet reached enlightenment, a sense of

humor proves vital for these interactions. Curiosity propels most rude or inappropriate reactions, people just want a basic sense of "what is wrong." Most of the time, I answer their questions with watered-down medical explanations. "Cerebral palsy is caused by a lack of oxygen at birth resulting in brain damage. The parts of the brain that are affected determine what happens in the body. In my case, my legs are affected making it more difficult for me to walk." Any further explanation usually results in disinterest. Since I already know the spiel, I have lost all interest in hearing the sound of my own voice. The vindictive, evil, impatient part of me sometimes creates grandiose, alternative explanations such as a ski accident in Vail. Explanations only do so much; the real key to dismantling ableism lies in the opportunity to demonstrate shared humanity and to help others recognize the stigma and as well as the profundity of disability.

Once again, natural parallels exist between the queer community and the disability community. An email from a friend and colleague in Oregon recently recounted the ignorant and invasive questions curious heterosexuals ask regarding homosexuality. Once unsuspecting friends and colleagues find out Jen is a lesbian they ask, "How do you have sex?" to which she sweetly replies, "Well, how do YOU have sex?" Her witty reply, as she relayed to me, usually stops the line of intrusive questioning.

The second portion of gaining a realistic view of disability, according to Olkin, rests in gaining a realistic view of the future. Questions regarding the future cause a great deal of anxiety for people with disabilities and their loved ones. The future is never really certain for anyone, but for people with disabilities, expectations compound with the diagnoses provided by doctors, the climate of the society, and a variety of other

factors. My fate as proposed by the doctors bears no resemblance to the life I am living today. However, Olkin demonstrates the need to provide a solid support system that enables realistic goals and dreams while cushioning the disappointment of those that cannot or will not be met. From my own experiences, I know what people with disabilities want: we want everything. We want the same rights and opportunities. We want lives filled with passion, creativity, and meaning.

Right 9: To have expectations of sexuality, romantic love, and parenthood. *As a later section in this paper indicates, people with disabilities are sexual beings who want it all: romance, marriage or domestic partnership, and children. Silence surrounds sexuality and people with disabilities due to false assumptions of a non-sexual existence. Dominant ideology rejects the notion of people with disabilities as suitable partners or parents. Similar resistance surrounds people with disabilities and the queer community in terms of beliefs of who it is or is not appropriate to love and who is best suited to raising children. As the gay marriage debate edges on, a slogan exists that applies to the disabled, to gays, and to the world at large: love makes a family.*

Right 10: To affiliate with peers both with and without disabilities. *The segregated nature of disabled and able-bodied society makes it more difficult for children with disabilities to affiliate with a variety of peers. In my experience, I attended mainstreamed, honors, and college level courses all through school so I often served as the token student with a disability. This shaped me in many ways and made my friendships with other females with disabilities even more significant as demonstrated in the vignette following this section entitled "Forever Friends."*

Right 11: To be assessed with appropriate measures against appropriate standards, by professionals skilled in assessing this population.

People with disabilities often get pitted against the able-bodied and unfair comparisons are made. Accommodations do not allocate special privileges, but level the playing field so that people with disabilities can access the same opportunities as everyone else. The use of people without disabilities as the norm presents a great danger in the current era of competition and high-stakes testing.

Right 12: To live in a barrier-free, accommodating, and tolerant physical and social environment.

Right twelve serves as the battle cry of this piece: all people, regardless of ability, gender, sexual orientation, and other factors, deserve a barrier-free, accommodating, and tolerant physical and social environment. We must expand the boundaries beyond mere tolerance so that all people receive love, validation, and dignity. My voice represents one of many pushing for a world filled with social justice.

Right 13: To be a child.

Here, Olkin reminds us that children with disabilities are children and must be allocated the time and opportunity to be a child. In this autoethnography, I chose not to spend much time recounting episodes from childhood. The brief excerpts provide a taste of my experiences as well as a brief overview of key moments essential in the formation of my identity. The most essential piece of my childhood, and indeed much of my overall identity, come from friendship. Friendship with others affirmed my worth and value as a human being and helped me recognize my place in the world. My most significant friendship, as most elements of my life, arose from the circumstance of disability.

Forever Friends

My life changed forever when I was five. That is an extraordinary statement to place on a hazy time of everyone's life. To many, five is a year of finger painting, playgrounds, silly songs, and innocence. Five for me was profound. Not only did I find a best friend, I found a part of myself. Through Rachel Ann Pace I learned who I was and why I was here. Rachel was truly extraordinary.

The day that I met Rachel started off as an ordinary summer day. I was enrolled in a swimming class for children with disabilities. My mom's fear of drowning actualized itself in early childhood swimming lessons. Swimming also provides good exercise and relief for spastic muscles. I find it hard to imagine that such a simple, everyday event could hold such significance over the course of my life.

When we arrived, a blur of protective parents and excited children greeted us. I do not remember what their faces looked like, or how many people were there, or even the essence of the moment. All I remember is the oddity of meeting someone so profound in such an ordinary way.

When you are five, you are not too picky about who you choose as friends. They are the ones who color with you, who dress up Barbie's, and comb your hair into a tangled mess. In the instant that I met Rachel, the universe stopped and the empty part of my heart was complete. The mystery was solved. In the instant I encountered her delicate frame, her sparkling blue eyes, and her laughter, I was whole. I was not trapped in a body that did not follow my impatient commands. I was not on the outside looking in. I was not trying to make sense of a life that did not make any sense. I was lost in a

moment when I knew that the first person who would ever completely understand me was standing right there.

An unspoken connection tied us together, an invisible cord of understanding not shared by anyone else. Although the words we shared were limited, our communication was not. Cerebral palsy affected Rachel's speech so the words she said were even further ingrained with her personality. I was Stayee; she called herself Li Li. I am still struck by her extraordinary speech. Instead of having the mere echo of a sweet little girl's voice, it was filled with the joy, the compassion, the radiance, and the perfection of everything that she was and everything she possessed. I carried on complete conversations with her without saying a word. We were bound by the same thread and the same challenges. Her mere presence was enough to say, "I know you. I know where you're coming from. We are bound in friendship, forever."

I remained constantly aware of how she felt and she did the same. I remember her care, compassion, and concern for me. When I had my heel cord operation and remained trapped in a hospital bed with casts up to my hips, she was frantic. She kept repeating, "Stayee hurt! Off! Off! Stayee hurt!," not knowing how to appease herself. I remember trying to tell her that I was okay.

The simplest memories are extraordinary. I remember going to pre-school with her, daily physical therapy, being bribed by the allure of Barbie clothes in exchange for not biting or hitting the physical therapist, eating hamburgers and French fries, and being playfully pinched when her mischievous side came out to play. I still hear her laughter and see her eyes, but all my other memories scatter. I remember the joy in her smile as she held a wiggling puppy. I remember her floor dancing to "Maniac." I

remember her trying to eat a doughnut flying by on a string at a Halloween party and the white dust that the powdered sugar left across her nose. Rachel was a radiant light.

Rachel died of pneumonia later that year on February 25, 1985, just three days short of my sixth birthday. I was shattered and completely devastated. My dearest friend, the one person who had the deepest insight into my version of life experience, was ripped out of my life forever.

Even though Rachel is not with me on this earth, she is in spirit. She attended my preschool graduation before her death and I know she was there when I graduated from high school and college. She will occupy a special place in my heart when I receive my Master's degree on May 8th. She appears in so much of my writing, and so much of my appreciation of life is based on the moments we spent together. She taught me so much.

There was not one moment that I spent in her presence that was filled with self-hatred or self-doubt. When we were together, I learned that having a disability was completely insignificant in the grand scheme of things. Our disabilities brought us together, but, beyond that, they did not matter. Her spirit and energy were boundless; she enjoyed every moment of her too short life.

Rachel still remains incredibly important in my journey through young adulthood. I want to capture her essence, to learn to live life as she did. Rachel also played a hand in the application process to Rollins. There was no doubt in my mind that she was the person I was supposed to write about, but I do not feel like the English language is capable of doing her justice.

Now a heart shaped pewter picture frame rests on my altar, carefully placed next to my fairy figurines. The picture is simple. Rachel sits on a patio chair outside, dressed

in a fifties' costume complete with a ponytail and a bow and saddle shoes. I am dressed as a clown with complete face make up. I hover over her and hold her hand. In the picture, we are frozen in time. I watch over her and am enthralled with her essence. She looks into my eyes. The moment is simple, perfect. We are friends forever.

I was desperate to hold onto Rachel's spirit and essence the whole time she was here. From the first moment she graced my life, each hug I gave her was bone crushing hard. I wanted her to know how much she meant, that she was everything to me. I wanted her to know that our friendship had no bounds that she was the most amazing person I had ever seen. I also wanted to assure myself that she was still there. She was so delicate; it was as if the wind bowed down before it dared to pass her.

There is still so much I do not understand. I do not understand why the Universe had to take her from my life, or why her visit to this planet was so brief. I feel so incomplete without her. Sometimes I feel so insignificant. But I do understand that she wants me to continue on, to share all the things she shared with me and carry on her legacy. So right now, at this moment, I glance at the picture frame. I think about her influence and her joy. I picture her smiling down on me and skipping off with the fairies, content that she changed my life forever.

A Voice for my People

In this section, I want to provide the reader with a series of episodes from my life that frame my experiences with disability as I gingerly learned to step in-between two worlds: one marked primarily with disability and one that seemed to exist without it. My experiences in elementary school reflect the structural and internalized oppression of

disability. Although disability scholars offer varying accounts of their school experience, many remark on the difficulty of having a disability in a system that emphasizes standardized progress and conformity. The stories of my adolescence contextualize my struggle to find a niche in society and my ability to find it without groups of people who also faced discrimination from society. Finally, the vignettes occurring in college relate the personal growth leading to where I am today.

So much of my frustration, my feelings of “otherness,” comes from isolation. After Rachel’s death, I felt an exaggerated sense of isolation and had limited contact with other children with disabilities who were on my level in terms of experience and intellect. I retained a sense of distance and loneliness. This comes from a sense that so few people around me face similar experiences. It is really hard being the only person in my classes with a disability. When I bring up topics related to disability I always wonder if people are secretly annoyed with me for getting on my soapbox again or if they think I am “complaining” too much.

I feel such a need lately to share my experiences and serve as a voice for “my people.” It is so easy for the general population to forget about people with disabilities. I do not want anyone to forget. I do not feel anger anymore, just a sense of frustration at the amount of ignorance that persists and the difficulty of aligning large groups of people (both temporarily able-bodied and not) around issues of ability.

Small moments of my school history drift through my mind such as my first grade teacher who gave me an “F” in handwriting. Although my handwriting in the first few months of first grade was more illegible than that of my peers, it was a wonder that I could even hold a pencil and begin to make painstaking strokes across the paper. The

doctor who diagnosed me with cerebral palsy left my parents with the tiniest sliver of hope. I would never be able to walk or talk, but one day I may be able to communicate using a typewriter. So, instead of being judged on a sliding scale of progress, of the incredible leap I made just by attempting to write, my accomplishments paled in comparison to those of everyone else. Being afraid of failure, I did not allow my teacher to stop me and I spent countless hours completing self-imposed handwriting exercises.

This experience rocked my sense of social justice in education because it demonstrated a system designed to judge individuals compared to standards that are difficult, if not impossible, to attain. Education is based on such gross inequities: students are forced to compete for resources and for a chance at success that rides on factors such as race, class, gender, and ability, factors that have all been documented as having a large impact on whether or not students are successful. My experiences make me want to challenge and change the system in order to get rid of inequity of all types.

The next incident that stands out in my mind is fourth grade, when my physical education coach imitated the way I ran in front of the entire class. I stood frozen in horror as I watched his legs jutting out in a cruel imitation of my own. Apparently, his demonstration was supposed to show me how to run "properly." Just by watching him, I would suddenly be able to run exactly like him. As tears stung my eyes, I told him that if I could run "properly," I would automatically do it.

Elementary school induced a sense of loneliness and a feeling of difference I never truly escaped. My peers always rejected me. I faced what ranged from open hostility to hushed whispers by classmates claiming to be my friends. It was hard for me to understand their reactions, after all, I didn't see myself as that different from them, so

why should they see me that way? I wandered through elementary school with every ounce of determination and willpower focused on academics (I demonstrated an early propensity toward a type-A personality and this helps explain my INFJ profile on the Myers-Brigg Personality Test). My soul and creativity focused on escaping the body holding me captive. I clung tightly to dreams and wishes that I knew might or might not reach fruition. My strongest weapon against oppression depended on fighting against the status quo by being successful in school. Throughout childhood, I faced the fact that people would see my disability first and me, second. I developed a second skin to preserve myself from the cuts that teasing and misunderstanding made on my soul.

Aside from absorbing feelings of isolation and alienation, I learned about the two entirely different co-existing worlds occupied by the disabled and the non-disabled. The world that I lived in was marked by tears and pain, but also with profound happiness and joy. I learned a sense of survival, but also a sense of sacredness. If I had made it from a traumatic birth and a dire life expectancy, there must be some reason I am meant to be here. I had a sense of sensitivity, but also a sense of immediacy no one else my age ever understood. Now I recognize this immediacy in the people I choose as friends along the path. As our conversations stretch out against the blanket of night as we drive around Orlando, we share similar memories of feeling wise beyond our years and a sense of frustration at the limited expanse of time we have to turn dreams into reality.

I struggle with the fact that I address something through my existence that many do not want to see: I am the “what if.” I am the statistic, the invisible minority, with a condition that many would say graced my life by chance. “She’s so unlucky, what a shame.” “Thank God that never happened to me.” “That will never be my problem.”

Disability is such a complex issue in the eyes of other people because it is something they cannot imagine surviving. It is so far from their version of life experience, yet it is not. It is something they cannot imagine living through, yet they find themselves unable to react with compassion, and even more importantly, unable to deal with the reality that each person is only a step or two away from disability. Unlike personal attributes such as ethnicity, race, and sex (in most cases), which will never change, disability is something that can happen to anyone at any time.

Adolescence

Adolescence was my own personal hell, a place where differences compounded and served as a lion's den for those with sensitive souls. The other kids were remarkably cruel; I was their punching bag, physically and emotionally. When I would fall down in the hallway, people would walk by, kick me, and laugh. I remember feeling so worn down, so defeated by everything, walking down the hall, when I overheard someone say, "She walks like an old lady." In my eighth-grade health class, I became the target of spitballs on an almost daily basis. The teacher did nothing to stop it. The worst part about it was that I internalized the hatred. Instead of hating them, I hated me. I hated the body that would never come through for me, the body that separated me from everyone else, and the body that made me see myself as a monster. I would cry myself to sleep because I felt so desperate and alone. Sometimes I wondered what I had done that was so terrible to deserve so much pain. But I realize that for all the pain, an even greater amount of joy and prosperity exists.

Out of the Classroom, into the Spotlight

The one thing that saved me in middle school was theatre. Acting opened up doors for me that I never even knew existed. Art transcends pain, time, captivity, disease, and every other condition that plagues us in life. Theatre was a world where I made the rules, where I could be someone else, walk a different path, have a different name, and meld all the parts of myself into a collective whole. It was so easy to transform myself into the characters I played; by doing so, I was momentarily free of the chains holding me captive in ordinary life. The dreams of flying, running away, and walking with perfect legs were realized for short periods of time as the magic of the stage, the lights, and the fantasy filled my soul.

Aside from being a creative and spiritual outlet, theatre led me to people who transformed my life forever. David Lee was one of the everyday heroes who touched my life and left a permanent imprint on my soul. He directed me in “A Christmas Carol” and allowed me to live my dream and play “Tiny Tim” when I was in seventh grade. David possessed a unique combination of brilliance and sensitivity that had the power to touch every corner of the world. By watching him, I could almost see the workings of the human mind and the power of imagination.

David is one of the strongest people I know. He was able to teach me about the pain everyone goes through, with or without a disability. Every once and a while I would catch a far off look in his eyes that spoke of the pain, the isolation, and the abandonment he faced. He inspired me with his words and actions. He encouraged me to read the works of Shakespeare to Rostand, something he wished he did as a teenager. He also spoke of cruelty, the absurdity of high school, and what happens when people are teased.

I connected to David on a variety of levels. The same inner vision drove him to be the best he could possibly be. His soul also had many scars. One of my cast-mates in "A Christmas Carol" was a boy close to my own age who claimed that the only reason I got the role of "Tiny Tim" was because I was "crippled." I was enraged by the fact that once again my accomplishments were attributed to the fact that I have a disability. David pulled Lucas aside and told him he would fire him if he ever said anything like that again. David took me aside, put his arms around me, and as tears filled his eyes, he told me I was perfect for the role in ways no one else could ever match. It was so amazing to know that the comment hurt him as much as it had hurt me, and that someone else could be so close to my soul.

Theatre also drew me into a circle of some of the most creative and loving individuals I will ever have the privilege to meet. They each held their own stories that circulated in hushed whispers. They carried their own legacies of pain. Art saved them in the same manner it saved me. Differences could be cast aside as the spirit of something else overtook them. The theatre is sacred: it is a space where lives transform, where lovers quarrel, where ghosts and spirits remain long after their time passes, and where some learn how to be whole for the first time in their lives.

I learned so many life lessons from theatre. Each moment I spent on the stage and in the dusty vaults gave me treasures I never gave to myself. I learned to honor the value of my spirit, which, until that point, felt permanently stripped away. I learned to trust again. I learned that I was a teacher who had the power to touch many lives. Most of all, I learned to love.

Because of theatre, the gay community surrounded me from the age of twelve. This formed my values and emphasized the importance of diversity and honoring all people. The biggest problem with intolerance and bigotry is that people do not learn how to understand the things they fear and/or hate until they are surrounded by them. I learned that being gay means you are stereotyped and persecuted because of who you love. I saw so much pain in the eyes of my gay friends. I found myself wishing they lived in a kinder, gentler world where the stakes were not as high and the pursuit of happiness was easier to follow. All of this made me realize love is not a crime, and if you are lucky enough to find it, you should treasure it and honor it no matter what sex it belongs to. I also developed a fear that some of my friends would lose their lives to AIDS. A constant reminder of its threat arose from the red ribbons everyone wore to various functions and fundraisers.

A similar personal evolution, like the one that developed because of the theatre, happened through the Unitarian Universalist church. My sophomore year of high school, I started attending conferences for youth aged 12-20 at various Unitarian Universalist churches around Florida. Conferences were formative in multiple ways. All my life, I rarely had friends my own age. People my age just never understood me. For the first time, I was around people my age, who also saw their fair share of a world filled with discrimination, injustice, and glimmers of hope.

My friends from conferences were homeless, straight, children of gay parents, drug addicts, homosexual, survivors of rape and abuse, from broken homes, manic-depressive, bisexual, poets, artists, massage therapists, atheists, and any other label you

could possibly apply to my generation. They went through a lifetime of experiences in a short while and held compassion and respect for anyone with similar circumstances. They too sat in the shadows of isolation, felt the sting of rejection, and screamed in silence with voices used in vain. The combined strength of a group of survivors and healers invited me into a world I had never known before, a circle of love that held me as tightly as I held it.

Moonlit Night

My best memory occurred on a Saturday night in Daytona Beach. The whole day had been kind of surreal. I felt outside of myself, watching everyone else interact.

Tonya and I spent some time together talking about mundane things. Those days seem so long ago that I can barely remember the sound of her laughter. Today, she lives in Denmark with her husband and children. Back then, I watched her eat a salad out on the deck with her black Power Ranger's shirt contrasting sharply with the neon pink of her skintight pants and the ruddy coloring of the bench.

I watched the others; everyone swirling together was more like a patchwork quilt of tie-dye than a cohesive group. There were people wrapped in the embrace of one another, people stringing cheap plastic beads together and passing them out as tokens of love, smoke rising in the air as incense burned and clove cigarettes turned to ashes, and toes glittering from the artistic accomplishments of new-found friends.

I sat on the steps; I dragged my feet in the dirt while slowly propelling a rusty playground swing. I talked to people. I sat underneath palm trees and looked at the murky reflection of the moment in a retention pond. Later on, the time arrived to journey to the beach for a special worship the teens had planned.

As the sun inched slowly down and the sky faded from orange, to purple, to black, I felt my inhibitions slowly fade away. I grew tired of feeling outside of myself. I started walking toward the beach with the others. We walked in a group, softly talked. Our voices hushed and echoing gently against the blanket of night, the atmosphere changed. We wanted to get past the mundane, to live a mystery.

The streetlights slowly lit our way. The golden light, the gray shadows in the dark, the glimmer of the businesses closed down for the night, all seemed to pave the way for enchantment. As the signs of civilization faded away, nature overtook me. I sought this experience. I could hear the dull roar of the ocean reflecting the dull ache in my heart.

As I stepped off the sidewalk and on to the sand sinking underneath my feet, nothing else mattered. It did not matter that my jeans were too big and hanging off my frame. I did not care that they were getting tattered from being dragged in the sand. I did not notice that sand was getting lodged in my Converse. All that occurred to me in that moment was the sinking sand beneath my feet and the echo of voices around me.

Then I looked up. Why did I fail to notice the moon earlier? It was beautiful and full. It glowed like a clear crystal reflecting itself on the faces, on the waves, on the sand, casting a magical glow. The light of the moon changed things from surreal to definite. I saw the sparkle of eyes in the dark, the outline of chins, and the shadows of faces. In the dark, I saw the light of others.

Then we began the worship. We closed our eyes and one by one, allowed ourselves to be guided by the others in the circle until we traveled completely around it. In that moment, all I could think of was my unsteady legs sinking in the sand and

collapsing beneath me. I also envisioned being thrust from one person to another, only ending after a moment of swimming vertigo.

I remembered the sky. If I could not trust my dearest friends then I could not trust anyone. I slowly closed my eyes. Instead of feeling fearful, I felt beauty. As my eyelashes brushed softly against my face, the darkness gently overtook me. The darkness felt beautiful and I felt safe.

I stepped forward. Arms gently stretched outward to guide me and I felt completely protected. The sounds of the waves faded and the sounds of the moment intensified. Now I was only aware of the gentle arms embracing me, the strong arms guiding me. Arms propelled me forward yet made me feel completely safe.

I remember the feel of petal-soft lips brushing across my forehead and kissing me on the cheek. These gestures let me know that I was completely loved and completely accepted, if only in this time and space. It was a blur of memories in the night. I did not know whom the lips belonged to, or whom the arms belonged to. For the first time in a year, I did not care. I only knew that I was in the shelter of friends.

At one point, I did not know where to go so I just stopped. I was gently guided forward, but felt tipsy from lack of direction. I reached the end of the circle and felt a necklace being placed around my neck. I was told to open my eyes. The clay necklace consisted of a sky blue circle with vibrant red and yellow spirals and lavender stars. It had a black cord tied off with a red bead. I thought it was one of the most beautiful things I had ever seen. The small cracks and imperfections did not show in that moment. I only saw the love and energy used by a single pair of hands to create an ending to an

amazing night. The necklace was symbolic; it demonstrated the end of my journey around the circle.

I looked up again. The moon seemed even more powerful than before. I felt its reflection seep inside of me; its gentle white light slowly invaded my soul. I began to cry. The knot in my throat tightened and lessened. The salty tears wet my eyes and slowly cascaded down my face. I tasted them slowly, tentatively. Instead of tasting bitter and engulfing me like so many times before, they were sweet. They were released in a moment of total completeness. I was not alone; I was not separate. I was one with the earth. I belonged to the moon, the sand, and the water. They were me and I was them.

The moment dissolved as quickly as it arrived. I wiped the last traces of tears from my face and walked to the edge of the shore. The ripples of tiny waves seeped into my shoes leaving a mixture of water and earth. As I started walking back, the echo of voices changed. Our voices no longer soft against the echo of night, we laughed and talked as the stars shined down upon us. I stepped back inside of myself, no longer watching, and smiled.

Throughout high school I found myself putting disability on hold. My friends from that night on the beach treated my disability with compassion and held my hands as I walked back to the conference site, but I rarely raised my voice in reference to disability issues. In many ways, my resistance stemmed from not wanting to draw attention to myself. I also found myself questioning the tightly drawn parameters of gender and sexuality. These identities concerned my friends and cemented our friendship as we struggled to make sense of our place as women in the world. My burgeoning desire

created a brief respite from the constant presence of disability; now I focused on something else.

I didn't have the opportunity to connect with another female with a disability until college. I finally found an "equal" in terms of intellect and experience in one of my housemates as an undergraduate at Rollins. Lindsay, a psychology major in my graduating class, shared the unique lens of disability and gave me the wonderful gift of her friendship. I am a better person because of the light she shined on me.

Lindsay and I lived in Pinehurst, a co-ed residential organization tucked in a nest of pine trees located centrally on campus. In this little cottage, we spent many hours with other students busily writing papers, fiercely debating, laughing, dancing, crying, and living. The three years I spent in that two-story haven taught me to honor my voice, to get used to boys in the bathroom, and to recognize my independence, worth, and intellect. I remember sitting in the common area laughing until I cried, sides aching as I slid off the armchair and continued to shake uncontrollably on the floor. I howled, "It hurts! It hurts!" while clutching my stomach, only to dissolve into another fit of laughter. I learned what it was like to truly feel alive. I also learned that sometimes my heart felt like it would break because I lived too much, too intensely, and because I recognized and challenged disability in every aspect of my life. In my own attempt to get others to see through my eyes, I sometimes pushed too hard and sometimes provoked alienation in place of acceptance.

It was so nice having Lindsay at Pinehurst because I knew I could always go to her if I was having a specific issue and she would *get it*. I wonder how many people

refused to get to know her (or me, for that matter) because they saw disability as a barrier or they were afraid of what other people would think if they were seen with us.

I know she felt the loneliness and the isolation. You do not have to talk about it; you can see it in the eyes. She hid it well. I never have, my emotions always bubble up to the surface where they cannot be forced down.

Lindsay was always full of sunshine and joy, while being courteous and thoughtful to everyone around her. I admired her so much because she never stopped trying. Even people who were consistently cold, rude, and callous toward her still received a heartfelt, "Hi! How are you doing?" even when they barely bothered to mutter a reply.

I saw so much of myself in her: the way she fell in love with people who would never be hers, the expanse of creativity, and the depth of her sensitivity. I marveled at her ability to keep giving and to keep trusting despite the people who were indifferent or who hurt her. I know we both shared a secret anxiety regarding our likelihood of finding a life partner. Who would love our bodies with scars that marked our battles and journeys? Who would be willing to look deep enough to find the inner beauty that only results from challenges, heartache, and a willingness to overcome barriers? These questions constantly resound in my heart and weigh on my spirit. But, these lessons can only be learned from this body, this life, and these circumstances.

Mad Love

The friendships I gained at Pinehurst challenged me and sustained me on many levels. Also hailing from diverse backgrounds and experiences, they saw past my

disability and accepted me as an equal. Not only did I crave someone who saw me as an equal, but I desired a lover or a partner. My romantic interests that year fell in three different directions: a gay man, a man still sorting out issues related to his sexuality, and a rumored lesbian I admired from afar. My first two choices were safe; I could look as long as I wanted while never being pursued. As painful and self-loathing as it may seem to deliberately love someone you cannot have, I learned through my friendships with these men that I could be touched tenderly, safely. Lying in their arms and confessing my greatest fears and secrets, I learned to trust. My trust, locked in a chamber in my heart, only opened when I handed someone the key. I handed out the key sparingly, gingerly, and sometimes placed it in someone's hand only to take it away an instant later.

My insecurities and my passion led me to the rumored lesbian, a woman who sent my life into upheaval, but who ultimately left me with a greater understanding of myself. I call her my siren. My life will never be the same because of her influence and her inevitable rejection. Our lives melded together like fire and water. Her passion ignited feelings I never dreamed would come to fruition. My mutations and surrender carried me down an ocean of despair. Here is our story.

My Siren

Her words flowed through me like honey. Dark, brown, thick molasses coated itself on the surface of my soul, sliding down slowly, drop by drop, as it threatened to engulf me. She possessed that kind of power. I don't know what it was about her. She was an enchantress with pale blue eyes often clouded by the confusion that she thought no one else could see. She was blond hair arranged carelessly by deft fingers that wove

through it when she was nervous. She was skin turned brown by the sun, legs so perfectly formed that a sculptor must have had his moment with her with blond hairs blended into the perfection. A soul was there, but lost like I was. She was entrapment personified. If you walk too close you get pulled in and she flows through you. And you are never the same again.

Caustic music plays in the background echoing the state of my shattered mind. It is too loud for me to think, so instead I am forced to pull my words out of the air and capture them before they disappear into the oblivion of what writers never capture. I'm chilled by the events of my life. You always promise yourself that you will never make those same dreaded mistakes over and over again, but you do. Each situation seems different. He uses you, you use him, she lies to you, she stabs you in the back, another broken promise, a breakdown, a letdown, a setback; it's all the same. No matter what you call it, it is destiny stepping forward and you stepping back. It's a long way to fall. I connect to the music too easily. Each song speaks directly to my heart. No matter who's singing or what they're singing about, it's just me. I find myself in the middle of their melody making the same fatal mistakes, rejoicing, crying, and trapped because although their saga ends when the song runs out and disappears, mine won't. Mine just continues on. As much as I would like to be a character, an aspect of someone's life so severe that it ends up as a moment, a line, and metronome in history, I am myself. And it's never enough.

The cold seeps through me. When I get into this state of mind I am frozen, mentally, emotionally, and physically. The moon doesn't look the same. While struck by the wanderlust of love you notice the reflection, the glow of silver that is more than just

an expanse in the sky and you are whole. You want to praise it because it speaks to you of everything you are feeling. And when the love is gone, you wait for it to fall out of the sky. The beautiful object that once sung to you now speaks your name in low misery. The crescent sliver reminds you that life continues on and its light attempts to permeate you, but it can't because you are empty. The moon chills me; the cold chills me. The halogen lamp points at me and I wait for the heat of the light to remind me that I'm still alive because I feel so cold. That's what life does to you.

This is the part when the character comes in and tells you their life story, their name, the traumatic childhood that turned them into the figure they are, blessed with the insight to tell you a story more profound than your own, with heaviness, mood, and words so intense that you can't help but flip the pages even though you probably won't find yourself in any part of it. So I'm going to do things differently. We seek out art, literature, words, and experience because we want to see ourselves. We want to see our names, our problems, our idiosyncrasies, and our situations so we know we aren't alone. We want to know that someone else understands just so we aren't on a course so off track that there isn't a point in continuing. Experience isn't that different. Whether man, woman, monster, child, lover, or brother there are enough similarities along the continuum that we are living the same lives under different labels. As much as we would like to believe that our existence is separate and unlike anyone else's, deep down we long for nothing more than the reassurance that someone on this planet, at this moment, is having exactly the same thought.

So I'm going to be nameless, faceless, without ethnicity, and you can fill in the blanks, you can choose. By naming myself I'll pull out symbolism that I didn't mean to

cast, or the name will conjure memories of a person who is bound by memory, and that is all you will see. You want to see yourself, so I will grant you that. Yourself you will see. So, who am I? I am me. I am you. I am no one. I am the child who smiles at you with untainted innocence. I am the man on the corner of the street who you pretend not to see. I am the woman who smiles when she is falling apart on the inside. I am me. I am everything. I am nothing. I am you. So fill in the blank. Pick the name, pick the age, pick the sex, fill in the experience, insert the childhood trauma, and there you have it. That's who I am.

I don't know what first brought me to her, why our worlds collided. But suddenly she appeared and everything changed. She seemed so lost, initially. There was security there, fractured innocence. Her laugh haunted me because it let me know that she had seen more than her share of pain. She ran around frantically, dancing like a creature caught in the wind, not wanting the high to end and the lines to blur. I watched her smoke a cigarette. The smoke curled around and disappeared and her expression changed. She forgot that the world was watching and melted into the woman she didn't want people to see. Once the façade faded and I glimpsed who she was, I found myself wanting more. An insatiable need began to build for my new drug. I wanted to breathe her in, find out what lurked behind the veil of who she was versus what she liked to portray, and eventually, make her mine.

Everyone tells you that you find love when you least expect it, stop looking for it, or don't want it. In the grand tradition of finding one bad relationship after another, despite the fact that they did appear when I least expected it, she showed up in my doorway months later.

She became my religion, my drug, something to build my world around even though I knew it wouldn't last. Things change so fast. You can gain and lose it all in the matter of a second. In the instant that she was mine, I gained everything and lost something. In the instant that she was gone, I lost everything and gained nothing. I must begin to put the pieces back together again, put myself back together again, so my power isn't stripped away again.

It is haunting knowing that I'll never be clean again. Violation is a strange creature. It strips you down and fills you with an emptiness, a filthiness, and a rage that will never be washed away no matter how hot the water is that scalds your skin or how fresh the new bar of soap smells. You are tainted and dirty, reminded of that every time you attempt to return to the center of who you were before. I wonder how many more times I'm going to be beneath him in that dark room. So many nights, I am still on a dirty mattress, with my shirt disbanded while probing fingers explore my unwilling body with jeans pulled down and a scratched stomach.

While the natures of women and men are not that inherently different, the relationships between men and women, and, women and women, are totally different. I will fight that statement to the death if I have to because it is so true. Sure, I've been stabbed in the back, played, and cheated on by both sexes, but the essence and feeling is totally different.

Intensity exists that I'm not capable of explaining. Even when the words disappear, the connection doesn't. The feeling in the room was thick and powerful, comprised of all the hidden lovers before us, the myths, the mysteries, and all that we knew and did not know about each other. She was my safety and my shelter. I found

myself incapable of slipping through her fingers like sand or being sent into the oblivion of nonexistence. I could lose myself in her but I wouldn't lose myself to her. There was no need. We were both victims and neither one of us wanted to disappear again.

The pressure wasn't there; there wasn't an incessant need of having to do something. It wasn't a conquest. Instead there was only losing ourselves in one another, bodies wrapped around physicality and spirituality, a comfort and a longing that could be fulfilled by no other. Lying against her, I lost myself in depths unlike anything I ever knew before. In the silence, two souls connected, chests rising and falling, with desperation not to lose what I worked so hard to gain. Kissing felt different: soft, sensual, carefully measured by both parties, neither wanting to give or take too much. They were bittersweet, haunting, spine-tingling kisses, delivered with tenseness and urgency because I knew it wouldn't last. She also wanted to make sure, with each step, that each element of our shared enchantment was something that I wanted. It chilled me to hear, "Are you okay? Are you sure you want this? Does this feel right to you?" and, to be able to answer back with, "Yes, this feels wonderful. It is so great to finally have you in my arms."

There is no fear left, only sadness. Will I always want something that is so incredibly far out of my reach? Why am I letting her haunt me like this? I want to break out of this, but I can't. Instead, I am reminded of what was and what can never be. Everyone tells me to let her go, to just get over it, but I can't. I knew it would end faster than I would be able to save myself, but at the same time, I thought I would be strong enough. I didn't expect to feel the feelings I felt. I always end up being the coquette and

the whore. I don't understand. I am the meaningless girl caught within a stream of many.

My siren really existed and serves as my first love in both my memory and my reality. Although I possessed as much, if not greater, love for other women and men in my life, she took the first chance and turned things from friendship into romance. However, unlike the men whose lips I kissed, she held no ulterior motives and possessed no intentions of violence. Like the mythological beauties luring sailors to their deaths plunging against the rocks, her call also lured me to a metaphorical death. In this encounter, in its failure, I placed all of my worth, all of my hate, and the internalized oppression into whether our love survived or failed. My heart truly believed that if things did not work out with her, I would never find peace, love, or contentment. At twenty-one, I saw my first, last, and only chance with her. I did not understand that more than one person could look past the physical imperfections. I did not realize that I could not love one person completely for one lifetime.

Our flirtation brought a plethora of issues to the surface: my own feelings regarding my body, the trappings of disability and sexuality, recovery from sexual assault, and the coming out process. Each issue, on its own, can take a lifetime to recover from and some never learn to embrace these issues fully. Brought together, they amounted to an almost incomprehensible amount of turmoil and exhilaration. Finally, I felt alive and passionate at the same time that I felt alienated, scared, and alone. My enthusiasm of finding someone so beautiful faded in stark contrast to the weight of silence and secrecy. My closest friends could be trusted and heard the excitement in my

voice. My family could only be told that I had a new friend. I could not share the news welling up inside my heart and spilling out into every portion of my life. I could not call my mom, breathless and excited, stating that I finally found what I sought after for so long.

CHAPTER 9: DISABILITY AND SEXUALITY

The most painful aspects of my existence merged into two core issues: disability and sexuality. Shakespeare et al. (1996) emphasize the fact that disability and sexuality do not co-exist, at least, they do not co-exist in the minds of able-bodied society. People with disabilities must not possess sexuality in accordance to the same norms curtailing sex among consenting same-sex couples, the elderly, teenagers, and children. If people with disabilities do possess sexuality (and indeed they do), it must not be recognized, expressed, or glorified in the same manner as heterosexual sex. Shakespeare et al. (1996) state, "Just as public displays of same-sex love are strongly discouraged, so two disabled people being intimate in public will experience social disapproval" (p. 10). This also bridges the worlds of disability and queer theory in terms of what is deemed "acceptable" on mainstream television. Although the tide begins to turn, these Puritanical norms forced *Ellen* off the air, kept many gay characters in the televised closet, and continue to keep Will and Jack (of *Will and Grace* fame) from ever engaging in onscreen long-term, meaningful relationships. As soon as Ellen's sitcom character pursued a relationship and began to acknowledge a lesbian identity, viewers and advertisers responded in horror to the "pervasive and blatant" references to homosexuality and the "flaunting" of love between two women. In episodes that were exceedingly chaste and pastoral compared to the raunchy and explicit love scenes between heterosexual couples on daytime television, characters explored the subtleties of beginning a new relationship and venturing outside of the closet as a couple. The same moments of hand holding, kissing, and embracing go unquestioned in heterosexual contexts.

Similar images and ideals cannot be fully separated from disability. The cultural scripts prompting us to fit into the restrictive molds of Main Street USA maintain and perpetuate stereotypes of people with disabilities, especially women, as the recipients of familial love in place of romantic love. I began to believe that I could not find love in someone else, especially if that love happened to be queer. Saxton (1987) echoes the sentiments of many scholars who write on women, disability, and sexuality. She states:

We are women. We share with all women the need for love, compassion, and sexual intimacy. Disabled women may have loving relationships with men or women, in the manner of all women. In the realm of sexuality, disabled women are denied acceptance because of the stereotype that equates disability with asexuality [...] Perhaps it is in the nature of being devalued that we women of difference are not regarded as female. Other myths affecting the perception of disability and sexuality include the idea that disability may be contagious and that sex is somehow a rare and precious commodity that should be reserved for highly-valued people, that is, the attractive and able-bodied (p. 48).

In addition to disability, enormously hurtful stereotypes surround women of color, older women, lesbians, and women who do not fit into the stereotypes of the perfect woman: the airbrushed aesthetic ideal impossible for any woman to achieve without the aid of plastic surgeons, stylists, and others involved in the business of conformity and complacency.

Back in 1997, I think Ellen's coming out scared people because it forced them to realize the normality (on a subconscious level) of same-sex relationships and their

similarity in comparison to opposite-sex relationships. At the end of the day, we all want the same things. We want a partner who inspires us, who believes in us, who offers unconditional love and support, and someone who we cannot imagine living without. In 2004, the issue resides in whether or not same-sex couples are entitled to the same rights and privileges as heterosexual couples. For me, and many others, activist or not, the issue comes down to basic civil rights. Nothing should impede the basic civil liberties of two consenting adults. However, the possibility of gay marriage, according to conservatives, impedes the foundation of family and married life. Because of this ultra-conservative viewpoint and its exclusionary nature, I understand the queer community's resistance to "traditional" marriage and its trappings. The argument usually stems from the idea that marriage, as North American society defines it, defies the ideals embraced by queers: the fluidity of gender and gender norms, the acknowledgement of loving outside boundaries, and the adoption of progressive social structures and policies. From this standpoint, many of us would rather not have anything to do with marriage. On the opposite pole, the option needs to exist. Out of basic respect for our common humanity, love, and ability to make responsible choices, we must possess the option to marry the partner of our choosing even though we may not buy into the staunch ideology of the stereotypical American dream with its 2.5 children, white picket fence, family car, and its pervasive legacy of intolerance, segregation, and bigotry.

Sexual orientation creates multiple challenges for those who identify as both a sexual minority and a person with a disability. Homophobia creates great difficulties for those who "violate" gender norms and who feel attraction for the same or both sexes. In

addition to the constraints of disability, people who fall into sexually diverse categories face additional identity issues. Shakespeare et al. (1996) state:

Disabled people often find themselves on the margins, a common experience for bisexual people, and bisexual disabled people have argued that it is hard to achieve a sense of identity and community when there is no place that one belongs. It is interesting that there are so many role models for bisexual disabled people from history- Alexander the Great, Julius Caesar, Lord Byron, Cole Porter, Montgomery Clift, Frida Kahlo, and Sarah Bernhardt for starters- when there is little room for bisexual disabled people in contemporary society (p. 158).

In addition to a lack of role models, people with disabilities also face a lack of acceptance by the gay community, in a manner frightening similar to the ways heterosexuals treat homosexuals. Shakespeare et al. (1996) state:

It is a profound irony that the attitudes of many in the lesbian and gay community towards disabled people echo those of the heterosexual world towards lesbians and gays themselves. These types of feelings, combined with the generally intimidating atmosphere of many lesbian and gay venues, and the insecurity of many disabled people, contribute to the isolation often experienced by disabled lesbians and gays (p. 164).

Sexual Violence and Disability

Unfortunately, sexual violence against people with disabilities must be addressed. Sexual violence remains a major concern among feminists due to the gendered nature of the majority of sex crimes: most victims of sexual crimes are female while most

perpetrators are male. In *Gendered Lives*, Julia Wood (2003) offers the following statistics:

- The FBI reported that, in 2000, rates declined for most violent crimes, such as murder and robbery; rates for forcible rape increased.
- Twenty-five percent of American women will be victims of rape in their lifetimes.
- Thirty to 50% of women students and as many as 75% of women workers have been sexually harassed.

Contrary to the mythological idea that rape always happens in isolated circumstances, rape is likely to occur within the context of dating, often by acquaintances or even friends. Many survivors of rape and sexual assault know their attackers (Wood, 2003, p. 297). College campuses work to educate all students about sexual violence, but according to several feminists (Buchwald, 1994; Dworkin, 2003), we essentially live in a culture that disrespects women and in many ways, condones multiple forms of sexual violence. The same stigma surrounding the sexuality of people with disabilities surrounds them when they face sexual abuse and sexual violence. Because of the myth of asexuality, many believe that people with disabilities do not get subjected to acts of sexual violence.

Unfortunately, a disproportionate number of women endure these atrocities. I know because I am one of the statistics. The research process for this section creates a flood of emotions in my mind: part of it retreats in horror and disgust at the pervasiveness of the violence against my people. Another part of my mind sighs with relief and recognition; I am not the only one. The analysis provided by Crawford and Ostrove (2003) documents my experience down to the last detail. They state, "The vast majority

of the survivors receive no medical, psychological, or legal services” (p. 182). I refused to speak of my experience to anyone for years. The first to hear my memories tumble from my lips were close friends, many who also endured and survived sexual violence far more traumatic than mine. I did not seek medical, psychological, or legal services. I feared that no one would believe me, that I would be blamed, and that the limited independence I possessed would diminish down to nothing. The emotional impact left me frozen and numb, finding ways to push the experience below the surface to get through high school and put the past behind me. This too, demonstrates a common reaction according to Crawford and Ostrove. A variety of factors help explain this phenomenon according to the authors. They report:

This increased susceptibility has been linked to a lack of social experience. When this decreased cultural knowledge is combined with a deep desire to share closeness, disabled women become easy targets. Obviously, in some cases, physical limitations also prevent these individuals from adequately defending themselves (Stromness, 1993). The threat of violence makes many women believe that they are too vulnerable to leave the safety and security of their parents’ homes for a more independent lifestyle (Hendey & Pascall, 1998). This cycle of violence and abuse solidifies social constructions of women as helpless and dependent. There is a great irony to being depicted as asexual while simultaneously enduring extreme sexual violence and brutality (pp. 182-183).

Crawford and Ostrove (2003) address the tacit nature of sexual violence in the lives of women with disabilities. Women with disabilities do not receive the social support needed to keep them safe or to teach them how to fight back using the physical, emotional, and mental abilities they already possess.

My own experience with sexual assault echoes many of their findings. I became a target because I threw myself at the first man who showed any interest in me. Ending up in an isolated location and completely pinned down, I did not possess the physical strength to fight him off. Even my voice, usually self-assured and dominant, became useless and silent in the face of terror. The actual event, when it occurs, is bad enough—not having any say over what is happening to your body, the claustrophobia, and not knowing when or if you will get out of the situation. Everything changes and it seems impossible to get back to who you were before the incident. It is possible to heal; there are ways to mend a fractured and shattered heart. However, no one told me this new heart will never look the same or beat to a gentle, regular rhythm. The new heart does not trust quite as much and it pounds when you least expect it, sending off warning signals when there is no danger and allowing the memories to resurface again and again. The worst part is not the initial attack, but the aftermath. Surviving presents the greatest challenge. Your mind plays cruel tricks, replaying the nightmare at the most unexpected moments. Flash—it happens in the car. Flash—it happens walking to class. Flash—it happens when you hear someone behind you. With time, the flashes diminish and the recovery process takes over. A long road exists, but it is filled with the courage of many other women and men who know the true meaning of simple words such as survival, and the most important word of all, hope.

In the Blue of the Oblivion: Virginia Woolf, Sexual Assault, and Recovery

My second year of graduate school, I enrolled in a course on Virginia Woolf and the Bloomsbury group. This course, although not specifically related to sexual assault, recovery, or disability, brought me to a new place of healing. In Woolf's words, and the lives of her unconventional, artistic, and sexually liberated friends, I found a passion that I thought lied forever dormant within. Before I even begin reading *The Waves* by Virginia Woolf (1930), I know my experience will not be purely literary. The low thunder of a brooding piano and the voice of a young woman fill my head. She sings softly in my ears, "And there's too much going on / But it's calm under the waves, in the blue of my oblivion/ Under the waves in the blue of my oblivion." These words do not belong to Woolf; they are Fiona Apple's. These words, depicting a life lived in the undertow, guided me for five years. At the same time, I know Woolf's words will guide me for the rest of my life.

I discovered Fiona Apple during my senior year of high school. "Sullen Girl" became a constant presence as I found myself repeating the track over and over again on my stereo. The words and melody resonated within my soul. The string section, overshadowed by a more dominant piano and a mournful voice, spoke of a loss I learned to understand. A loss, and indeed a death of innocence, hope, youth, and everything I had ever known. The child within died on the eve of my sexual assault and I did not think she could ever be reborn.

I did not speak of my experience because I found myself incapable of forming the words. Once a prolific writer, the pages remained blank. The emotions raged: my anger,

my sadness, my innocence, and my loss all rose up and down. I understood what Apple (1996) said: “Is that why they call me a sullen girl—sullen girl / They don’t know I used to sail a deep and tranquil sea / But he washed my shore and he took my pearl / And left an empty shell of me.”

All these things rush at me before I can even open the first page, and will mark my experience of *The Waves*. The back cover of the novel describes it as an experience of grief and this experience describes also describes my own. Although that terrifying night of my life did not steal a loved one, it did ignite a death in my soul. This death required its own grieving period, with the typical state of affairs including shock, numbness, denial, acceptance, and at twenty-four years of age, healing.

The Waves changes the form and scope of the modern novel. Like Apple’s lyrical genius, Woolf’s characters join together to form a mental and emotional landscape. Traveling through Woolf’s novels, I am always captivated by the gems she hides throughout. As in other works, Woolf abandons traditional notions of plot, structure, and character. The narrative consists of voices without excessive descriptions or details. This approach, despite its starkness, reveals the fears and desires of each character.

Woolf never tires of playing with format and I applaud her for her bravery. I dislike convention and the parameters it forces people to fit within. This helps to explain the literary analysis portion of my autoethnography and my unconventional approach recounting a particularly painful incident in my life. As in *Mrs. Dalloway* (1925), there are no chapters. Life rarely divides itself neatly into beginnings and endings, marked by a linear order and a continuous series of numbers. As Rhoda states, “One moment does not lead to another” (Woolf, 1980, p. 130).

As the song lyrics echo in my head and my eyes brush across the lines and down the page, I am struck by one particular passage. As many of Woolf's brilliant moments tend to do to me, this one rushes over and embraces me. At this moment, the disparate experiences of one of my favorite songs and favorite novels become one. Apple's song and Woolf's words reach their zenith together. Rhoda states:

Oh, to awake from dreaming! Look, there is the chest of drawers. Let me pull myself out of these waters. But they heap themselves upon me; they sweep me between their great shoulders; I am turned; I am tumbled; I am stretched, among these long lights, these long waves, these endless paths, with people pursuing, pursuing (Woolf, 1980, p. 28).

Apple's lyrics and Woolf's prose both capture the essence of being pulled into the water and under some greater force. Even as the waves pull Rhoda under, a type of serenity exists. As they pull, they also allow her to stretch and to move within them. Apple describes this same journey and sense of calm; the "blue of my oblivion" describes her ability to submit to the calm that lies in wait.

In my own recovery from sexual violence, I spent many years in denial trying to keep the pain from touching the core of my everyday life. It seemed better not to feel than to face the trauma of what happened. At the same time, I was losing the girl who was just beginning to find her voice before her world was shattered. I wanted to keep myself from falling in so deep that the highs and lows of life were unable to touch me. Rhoda reflects my experience. She states, "Therefore I hate looking-glasses which show my real face. Alone, I often fall into nothingness. I have to bang my head against the hard door to call myself back into the body" (Woolf, 1980, p. 44). Again, I am struck by

the sophistication of Woolf's ideas. I wonder if she also used self-inflicted pain to gain control, to feel something, and to force the connection between mind and body. Decades after her novel graced the world, self-mutilation or self-injury became a common phenomenon among adolescent girls. It crosses barriers of race and class, becoming a coping strategy especially common among survivors of rape and sexual abuse. Susanna Kaysen (1994) brilliantly describes it in *Girl, interrupted* as a way to get through the night and to plow through a barrage of daily tasks that once seemed impossible to conquer.

At the close of the course on Virginia and her beloved Bloomsburies, I found so many connections between music, Woolf's depiction of Rhoda in *The Waves*, and the relationship between women writers and madness. I came to love those women, Lily, Sally, and Clarissa, and the insight they brought into my life. I also recognized Woolf as a friend before her time who brought her world into mine, echoing many of the same thoughts, emotions, and experiences. I am grateful that she had a room of her own in which to record her vision of the world, to break convention, and to show the extraordinary strength that women contribute to society when their voices are allowed to be heard. Like Apple's music and lyrics, Woolf's work could not come to me at a greater time. She allows me to bring my own experiences to the shore and as a result, ride the crest of the wave until I reach an even greater sense of strength, emotion, and relation to the tumultuous experience I am proud to call my life.

CONCLUSION: DISABILITY AND THE MULTICULTURAL DEBATE

The discussion of disability cannot end without attention to the current multicultural debate and the struggle to put disability on equal footing with factors such as gender, race, and class. The treatment of disability in both feminist and multicultural circles remains problematic because of the lack of recognition it consistently receives. Feminists with disabilities face similar issues as Black/African American women who feel slighted and neglected by the aims and tenets of mainstream, white, middle-class feminism. Within the parameters of feminism, the needs of women with disabilities get pushed to the sidelines in favor of issues such as reproductive choice, working conditions, sexual control, and other issues pertinent to the movement. Green (1995) comments, "The movement has come far in acknowledging the diversity of women with respect to ethnicity, sexual preference and economic status. But where the movement still fails miserably is in disability. Women with disabilities are grossly concentrated in the margins. We are women, yet *our* histories and identities are ignored" (p. 143). While issues of ethnicity, sexual orientation, and economic status prove both critical and pertinent to the acquisition of equal rights for all women, those with disabilities face additional concerns or may disagree with the positions taken by some of their activist peers.

For instance, Green (1995) supports a woman's right to choose but argues that women firmly rooted in an ableist society might not make an "informed" choice in relation to disability. Green observes, "However, I am acutely aware that abortion is used as a means to root out those whom society deems imperfect and unworthy of life" (p. 142).

Feminists must clearly examine the ways in which they perpetuate stereotypes of dominant society and further oppress women with disabilities. As a third-world feminist of color, many of Uma Narayan's (1997) ideas prove applicable to disability-centered feminism. Without a direct perspective from someone inside the culture, in the instance of disability, stereotypes continue to manifest. Narayan (1997) states, "[...] mainstream Western culture has not simply been inattentive to Other cultures, but has in fact been historically involved in their *representations*, representations that have often been replete with negative stereotypes and imputations of cultural inferiority" (p. 126). Multicultural education, centered specifically on the social model of disability, helps reconstruct false assumptions about the mobility impaired as an underrepresented group.

Within the textbooks of many diversity courses and their examination of multiculturalism, disability remains pushed to the margins, usually mentioned as an aside to support the idea of how certain populations face marginalization. In order to be fully inclusive of issues central to the multicultural debate, disability must not merely support basic assumptions of dominant hegemony. For example, Appiah (1994) mentions disability as a minor example of the identity politics movement. Benhabib (2002) fares slightly better when she mentions that in poorer school districts, accessibility for students with disabilities usually means the installation of ramps or the discontinuation of music education (p. 112). She fails to address that both these issues resound on underlying themes of what is valued in the culture. Plus, equal access to education should not come down to whether or not certain elements maintain their place within the curriculum.

Current multicultural anthologies (see Adams, 2000; Rothenberg, 2004) address the lack of attention to certain minority groups (including the disabled) by including

modules on racism, anti-Semitism, sexism, heterosexism, ableism, and classism. By including all of these issues and examining their commonalities and differences, scholars learn to examine a much larger structural picture of the inequities that perpetrate our society. Connections within many articles cite similar issues rooted in sexism, racism, heterosexism, and ableism. These issues also speak to specific group studies (including queer studies and disability studies) appearing at some colleges.

Perhaps one of the most important parts of the identity politics movement arises from the attention paid to voices pushed to the margins. In courses specific to identity, students receive encouragement to express their insight and experiences within the constructed academic framework. Without hearing the voices of those who survive their experiences, identity politics fails to transcend the trappings of paperwork and policy. As Morris (2001) reminds us, if we fail to speak for ourselves, those without our experiences feel free to do it for us. Morris (2001) asserts, "We need to write about, research, and analyze the personal experience of our bodies and minds, for if we don't impose our own definitions and perspectives, then the non-disabled world will continue to do it for us in ways which alienate and disempower us" (p. 10).

This power to reclaim our lives and the possession of our stories demonstrates the incredible alchemy of the personal and the academic. Each thought, pattern, and path that we take is distinctly ours, based on the unique series of events we live through. My life dances around disability; my differences make me who I am in this world. By growing up in a world quick to label and judge, I learned about the statute of limitations placed on each person. This does not stop me. As a phoenix with strength, I rise from the ashes of limitation, inequality, and discrimination.

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