

DISABLING CURE IN TWENTIETH-CENTURY AMERICA: DISABILITY,
IDENTITY, LITERATURE AND CULTURE

DISSERTATION

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By

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ABSTRACT

My dissertation argues that Disabled people have a culture and that “disability” is a cultural experience. Scholars in the emerging field of Disability Studies have made the distinction between the “medical model” of disability that focuses on bodily materiality/impairment and a “social constructionist model” where identity is culturally constructed. One place where these two models converge is at the point of cure. This is where I enter, as I argue that cure is a socially constructed concept. Though my recurring theme in this dissertation revolves around the concept of cure, I have chosen frameworks that critique disability and the construction of cure from a position of marginality, i.e. the construction of disability as both a minority group and a minority discourse. I investigate the concept of cure in some prominent sites where theories of science and culture and their impact on disability are examined — in twentieth-century fiction, film, memoir, and performance. I argue that cure is a scientific construction applied to medical impairment, but that disability is a cultural experience and a potential identity, independent of cure.

My argument that medical cure is a specific construction applied to disabled bodies and identities has implications for other fields besides disability — fields that

I draw upon: medicine, sociology, and queer studies — in the ways that both disability and medical cure are configured. Theorizing cure as a cultural concept in literature and film changes our understanding of disabled bodies and thus of how we read and view them. By looking at disability from a constructionist viewpoint, I hope that we understand not only the way(s) that disability is positioned in relation to a dominant discourse of medical cure, but also the constructedness of medical cure itself.

For my family:
who let me follow my own path

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CHAPTER 1

INTRODUCTION

FINDING CURE: DISABILITY IN MEDICAL AND CULTURAL DISCOURSE

*For it is the body's world
they are trying to destroy forever
The best world is the body's world
filled with creatures filled with dread
misshapen so yet the best we have
our raft among the abstract worlds
and how I longed to live on this earth
walking her boundaries never counting the cost*

—Adrienne Rich
“Contradiction: Tracking Poems XVIII”

WHY CURE MATTERS

Adrienne Rich is speaking about the state of our environmental world, and not the physical body as we know it. However, for me, her poem holds particular weight when it comes to speaking of people with disabilities. For many of us, we've been called

misshappen, or worse. Historically, like the plight of those exterminated in Nazi Germany for being physically misshapen, or thought mentally unstable, the “cost” has been our very existence.¹ For others, the “cost” of being thought misshapen has taken form in this concept called medical “cure.” For indeed, if you are thought “misshapen,” then there must be a solution to that, a way to alter that form, that state of being. The solution lies in the idea of medical cure of disabled bodies, an idea that is as culturally pervasive as it is personally damaging. A personal example:

As I was beginning work on this dissertation, my father gave me an article. The article detailed a new experimental treatment for stroke “victims” involving transplanted nerve cells derived from a rare type of brain cancer experienced by stroke victims. It was thought that “the new cells will, in effect, repair damage from stroke by forming bridges to reconnect healthy portions of the brain and adapting themselves to relieve paralysis, speech problems and other disabilities caused by stroke.” If successful, the article claims that scientists believe that the transplant technique could be used to treat Alzheimer’s, Parkinson’s, and spinal cord injury, among other disabilities (*The Wall Street Journal*, February 5, 1999: B8).

“Cerebral Palsy is brain damage, right Johnson?” my father asked.

In its strictest medical sense, cerebral palsy involves the destruction/damage of brain cells and neurological pathways (the palsy) in the brain, so I answered in the affirmative.

“Good, because the article doesn’t mention cerebral palsy specifically, but I already wrote the doctor on your behalf.”

Momentarily, I was shocked into silence. I'm not sure why. Whether because my father assumed I still desired cure or because I suddenly realized that, after all this time, my father still did not accept who or what I was, I don't know. Finally, I managed to stammer out an "ok," and he let the subject drop.

I shouldn't have been shocked. Historically, our culture roots itself in the grit of Emerson's "Self-Reliance," in the ideal of men with healthy bodies who crossed the Delaware and survived Valley Forge intact. America is a nation steeped in the idea of individual freedoms and rugged, healthy bodies pursuing happiness; a nation that holds "healthy/fit" bodies as ideal and views sickness and disease often as contaminants of those bodies in need of cure or management. As Horacio Fábrega Jr. notes in *The Evolution of Sickness and Healing*, "Members of all societies encounter disease and injury and develop social practices to cope with their effects" (1). He writes:

Societies construct sickness/healing so as to be able to assimilate it, normalize it, cope with it, and prevent, undo, or limit its pernicious social effects. The collective thrust or goal of the sickness/healing institution is to accommodate individualistic needs associated with sickness and healing and to not allow them to impair or harm others of the collectivity, or the collectivity itself as an emergent entity. Societies aim to protect themselves, and thus must regulate, control, or police its members' use of the sickness/healing institution, at the same time seeking not to deprive them of some recent prudent autonomy to fulfill their needs. (291-92)

Fábrega here is referring to the epistemology of medicine as consisting of a sickness side which "announces, communicates, and expresses the sufferings of conditions of disease and injury and of the healing side which is but the response aimed at comforting, undoing, relieving, fixing, minimizing and, if necessary, drawing to a close that suffering" (290). Setting aside for the moment, his configuration of a "sick" body as "suffering," his claim that sickness/disease/disability are social constructions and, as

such, are often in need of being “controlled” by the similarly socially-created medical institution is a notable one. As Foucault tells us, “The clinic figures, then, as a structure that is essential to the scientific coherence and also to the social unity and political purity of the new medical organization. It represents the truth of that organization in guaranteed liberty” (*The Birth of the Clinic* 70). As many Disability Studies scholars have pointed out, representations of disability in our literary and media culture are almost always negative, tied up in notions of the disabled body as lacking, diseased, sick, different, inherently “Other.” And as Fábregia and Foucault attempt to show, the position of a sick body in need of healing or cure and the reliance upon societal institutions of medicine and scientific “truth” to provide that healing, relief, or cure, are themselves socially-constructed and perpetuated phenomena.

The hypothesis of this dissertation enters here. That is, if what is thought of and defined as a disability is understood to be not just a point of bodily materiality (an impairment), but the product of a cultural discourse, then medical cure of such disabilities/impairments must also be understood to be a product of medical discourse and cure as likewise a socially constructed entity.

My father’s position that my body was something in need of cure was not a decision made in isolation. Influenced as he was by the media, by the policies of a school system that fought to keep me separate, and by the grave pronouncement of doctors that his son was better off dead, my father’s ideas were the logical by-product of a societal construct about disability as a problem and condition in need of cure.

Still, where do my father’s perceptions of disability in need of cure and of the doctor as the power-bearer come from? Where do such ideas come from for all of us?

My father, after all, is not unlike many parents of disabled people I know who are told that their children are “different/abnormal/disadvantaged.” *The Wall Street Journal* article, for example, refers to those with disabilities and disease as “suffering from” and as “victims” of disease, ailment, disability. Societies abound with such images of disease and disability. In the Fall of 2000, a Nike Air Dri Goat’s Sports Shoe ad campaign had this to say:

Fortunately, the Air-Dri Goat features a patented goat-like outer sole for increased traction, so you can taunt mortal injury without actually experiencing it.

Right about now, you’re probably asking yourself “How can a trail running shoe with an outer sole designed like a goat’s hoof help me avoid compressing my spinal cord into a Slinky® on the side of some unsuspecting conifer, thereby rendering me a drooling, misshapen, non-extreme trail-running husk of my former self, forced to roam the earth in a motorized wheelchair with my name embossed on one of those cute little license plates you get at carnivals or state fairs fastened to the back?”

To that we answer, “Hey have you ever seen a mountain goat, (even an extreme mountain goat) careen out of control into the side of a tree?”

Didn’t think so. (*Backpacker*, December, 2000, inside front cover)

As counterpoint perhaps to such negative “victim” stereotyping of disability experience, American culture abounds with the images of the good doctor who will save folks from such plights, from the wise *Marcus Welby M.D.* to more current incarnations such as the beleaguered yet benevolent Drs. Kerry Weaver and John Carter on NBC’s wildly popular *ER*. As critic Leslie Fiedler notes in his essay, “Images of the Doctor in Literature and the Popular Arts,” “...the medical professionals in almost all such shows, daytime or nighttime, are presented favorably, positively: as caring, supportive, dedicated, and

competent; which is to say as good Fathers, kindly Uncles, or staunch Big Brothers — plus, of course, in response to feminist pressures, equally admirable Mothers, Aunts and Big Sisters” (*The Tyranny of the Normal* 107).

It’s perhaps too easy, in this, our socially-conscious, media-and-internet-infiltrated age to blame all of our society’s ills and negativities on that rather amorphous thing we call “media culture.” Negative responses to disability stem from other areas. Recently, there was a religious revival meeting in my neighborhood. I was, however, unaware of this event as I headed to my apartment and a carload of gangly teens drove by in their car screaming, “CRIPPLE,” at my back. Later that day at a restaurant I frequent, I was attacked again by a bevy of bejeweled, hair-sprayed, blue-dressed women informing me of the revival and how “there were a bunch of empty wheelchairs left up on stage.” Certainly, the negative reaction to disability as both a bodily impairment in need of cure and as a lived experience comprised of “being shunned/suffering” have deeper roots than negative media imagery. A few days later, the manager of the restaurant informed me that several patrons had blessed her for “hugging that poor crippled man.” The idea of disability as inherently negative are bound not only to people’s exposure to literature and media, but also to people’s personal belief systems.²

The fact that statistically more and more people in our country are living longer — thus becoming more and more dependent on medicine and science and the treatments for various disabilities and diseases — has focused our society’s attention on the field of science and medicine, its relation to the body and DNA “code cracking,” and to larger ethical questions of when does a life have “value.”³ What’s so shocking about both my father’s and the “Bible-thumpers” reactions to my disability are not, perhaps, that the

reactions are negative ones. The question that results from these negative reactions is one of “value.” Indeed, in our media and society, a moral and ethical value judgment is being made about disabled bodies and lives in our culture at large. What is the intrinsic value of any body, any life? More specifically what is the value of that life when compounded by a disability, which is often constructed as a burden, financially and otherwise, upon society? If one looks at, for example, Jerry Lewis/MDA telethons that often construct the lives of disabled people as pitiful and tragic, what is the value of the proverbial poster child’s life? Is it a life unworthy of life, a life deserving only of pity? The answer appears obvious. According to Jerry Lewis, “You don’t want to be pitied because you’re crippled and in a wheelchair? Stay in your house” (*CBS News Sunday Morning* program broadcast, May 20, 2001).

The question of the “value” of a disabled body and the lived experience of disability as something other than “tragic” is, for me, a central one if one is to think about disability as a culturally constructed category. To posit disabled bodies as being in need of medical cure is to place a value judgment on the disabled bodies and the lived experience of disabled people, or to use Erving Goffman’s term, to stigmatize those bodies and “spoil” that identity (*Stigma: Notes on the Management of Spoiled Identity*). If we are to think of disability as an identity along a continuum of “human variation, rather than a personal misfortune or bodily flaw” (Garland-Thomson, “The Beauty and the Freak” 181), then we need to reevaluate the need to cure bodies that are not defined as the norm.

In recent years, the work of Peter Singer has created a storm of controversy on the subject of the value of human life in regards to disability. In his essay, “Justifying

Infanticide,” he posits that “infants — disabled or not — have as strong a claim to life as being capable of seeing themselves as distinct entities, existing over time” (*Writings on an Ethical Life* 187). Yet, he goes on to say:

When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second....It may still be objected that to replace either a fetus or a newborn infant is wrong because it suggests to disabled people living today that their lives are less worth living than those who are not disabled. Yet it is surely flying in the face of reality to deny that, on average, this is so. That is the only way to make sense of actions we all take for granted....If there was really no reason that the life of a disabled person was as likely to be any worse than that of a normal person, we would not have regarded this [the birth of disabled babies because of the drug thalidomide] as a tragedy. (189,191-192)

Singer’s position is an indictment of any value being placed upon disabled people’s lives or any potential for a disabled person’s life to have value. It would appear that Singer believes that society never changes and that physical difference is the cause for social inequity in much the same way that Justice Brown believed, over one hundred years ago, “If one race be inferior to the other socially, the constitution of the United States cannot put them upon the same plane” (163 U.S. 537). Singer presumes, as did the Nike ad and the *Wall Street* article, that to possess a disabled body, to have disability as a lived experience, is inherently “tragic.” This type of thinking has had dire consequences for disabled persons who, for example, were systematically singled out, experimented on, and exterminated in Nazi Germany. Cornel West has pointed out that race still matters. So, too, does disability.

My point in all these examples is that the way societies think about disability is largely a process of socialization. James I. Charlton sums it up this way:

People with disabilities are significantly affected by the way in which culture(s) explain the cause of their disabilities (God's will, reincarnation, witchcraft); the images disability evokes (the sick/deformed body); and how they are described (cripple, invalid, retard). These interact to produce the way society at large is socialized to think about disability. Socialization works on simple symbols, simple repetition. Over and over the myth as message is repeated: disability = sickness/deformation; sickness = helplessness and deformation = abomination; helplessness = protection and abomination = asexuality; asexuality = childlike; childlike = helpless/protection; helpless/protection = pity; pity = disability. (*Nothing about Us Without Us: Disability, Oppression, Empowerment* 68)

Returning to the beginning of my Introduction for a moment, it is perhaps a bit easier to see how all these constructions of disability as inherently negative are part of a large socialization process in our culture. Within this configuration, medical cure is taken as a desirable scientific fact (the brain tissue experiment) and the "normalized" disabled body as a desired result. In other words, science presumes medical cure to be inevitable. What is missing in this configuration is the understanding that the reliance upon medical cure is perhaps itself a discourse. Again, my hypothesis: if what is thought of and defined as a disability is understood to be not just a point of bodily materiality (an impairment), but the product of a cultural discourse, then medical cure of such disabilities/impairments must also be understood to be a product of medical discourse and cure as likewise a socially constructed entity.

No one, in recent memory, has focused more attention upon issues of disability and cure than the actor, Christopher Reeve. Since he was paralyzed from the neck down in a horse riding accident in 1995, he has focused all his attention on finding a medical

cure for paralysis. Upon doing a Nuveen commercial in which he was shown “walking,” he had this to say to Diane Sawyer on *Good Morning America*:⁴

SAWYER: (Voice-over) Part of his legacy: how determination can defeat doctor's predictions. He's now breathing on his own ninety minutes a day, something they said he'd never do. But he's not in denial and says he was misquoted saying he would walk by his 50th birthday.

Mr. REEVE: What I actually said back in 1995 was that by my 50th birthday I hoped to be able to stand and thank everybody that helped me. And this is blown so out of proportion. It drives me--who the hell am I to vow that? I can't vow to walk. You know, it's not--you know, I--I vow to quit smoking or something. It was a hope. It was a dream. It was a--this is what I hope can happen.

SAWYER: (Voice-over) He says if we don't dream about the possible, the possible never happens.

So tell me about the first time you see the finished product. I gather there were a number of people in the room.

Mr. REEVE: There was a lot of reaching for Kleenex afterwards. And I have to admit that I had such mixed emotions. I was--I was elated. I was deeply moved.

SAWYER: Were you in tears?

Mr. REEVE: No. I--I toughed it out. I was in tears later, you know? But it really did get to me. I mean, to repair the spinal cord is literally defeating evolution. When you see something, it's much more powerful than--than hearing about it or reading about it. And when people see something and then they're even more motivated to make it happen.

SAWYER: Is it more powerful than dreaming about it?

Mr. REEVE: Much. Because in dreams--in my dreams I've--I've always been walking. In five years I've never been in a wheelchair in my dreams. (February 1, 2000)

I am not indicting Christopher Reeve for his dream. For me, it makes sense that he would desire to walk again, that he would see his disability in negative terms. Being able-bodied is the life that he knows and desires to return to. Rather I want to mention him briefly because no one has focused our culture's collective attention on medical cure and scientific progress as a certainty more than Christopher Reeve. "All I have is a little 28 millimeter gap that is causing all the damage. That makes me a prime candidate for recovery. As its [spinal cord] regeneration is achieved, I'll be in very good shape. It's a game of patience now, but there will be a great reward coming" (*Parade Magazine*, December 12, 1999, 10). And, among the disability community, no figure has generated more resistance to the idea of medical cure as the "solution" to disability than Christopher Reeve. As Pat Williams notes in her article, "Christopher Reeve: What's It Gonna Take?" in the Disability Arts magazine *The Ragged Edge*:

Reeve's Push for Cure is full of nutty lopsided stuff like that; [focusing on cure as the solution to around-the-clock nursing care for some quadriplegics instead of advocating for changes in the care system regarding money] stuff that misses the big points that are right there in front of your nose if you start thinking about them. Things like not everyone is going to be "cured" right away. That people need "care" for arthritis. That they need help because they've got brain injuries. Or we're gimped up from thalidomide. All that stuff. (19)

Disability activists like Williams are focused on the changes that need to be made to such social systems like support care for the disabled and elderly and understand that "cure" does not mean an end to the experience and needs of the disabled in society. Reeve, however, remains focused on cure as the end goal for people with disabilities.

Giving a lecture at Berkeley in 2001, about the constructedness of medical cure, my friend Danny Kodmur said, “We shouldn’t even be talking about cure (because) there is nothing wrong with me that needs to be cured.” This sentiment has been expressed repeatedly to me personally and is the grounding for disabled people thinking about disability not as bodily impairment, but as the product of a socially constructed discourse. In other words, what is “wrong” with me (if indeed anything is wrong with me) is all “in your head/how you see me.” This sentiment is not new. Similar arguments have been made regarding the culturally Deaf, for instance.⁵ Certainly, in our current age of identity politics, where scholars have argued that ethnicity, gender, and sexuality, for example, are all fluid and constructed categories, the argument that bodily materiality should be discounted, if not altogether discarded, in favor of disability as a socially constructed identity is not a new concept.

While I certainly don’t disagree with the social/cultural model of disability identity, I am interested here in the limits of that argument. That is, much of what has been theorized within Disability Studies has relegated medicalization and bodily impairment to the hard sciences while disability as an identity category is taken up in the social sciences and humanities. Simi Linton makes an important contribution in addressing this divide between disability as biology and disability as constructed identity. She claims one, Disability, to be a cultural discipline (Disability Studies) and the other, Impairment/Biology to be “rehabilitation.” She writes, “Therefore just as gynecology can be thought of as an academic response to sex, rehabilitation can be thought of as a

response to impairment, or audiology to deafness” (*Claiming Disability: Knowledge and Identity* 150). Perhaps as Disability Studies grows in popularity, more will understand and adhere to this distinction.

My answer to Danny, at the time, was that we were not really that far apart in our thinking. I reasoned that if we began to think about the way that medicine has constructed not just disability, but also, as Fábregia and Foucault point to, the very constructedness of medicine itself as a discipline influenced as much by society as any other constructed discourse, we might begin to lessen the hold that science has over disability. In other words, if we understand medicine and cure to be a changing discourse rather than just scientific fact, the argument that, “Disability isn’t an identity/has no culture because you will all be cured,” will hold less weight.

I want to be clear here. To examine how cure is socially constructed is not to negate the existence of cure as a medical fact, for science indeed will progress, or to suggest that some people do not prefer/wish for cure (e.g. Christopher Reeve). Rather, examining cure as a social construction is to present an explanation for the position of people who identify as Disabled who resist the insistence upon the cure of people with impairments — a position also claimed by disability political activist groups such as Not Dead Yet, ADAPT, etc. This examination furthers the arguments made by academics in various fields by shifting focus away from an individual’s “problem” or “burdened” body, to the social and cultural creation of a different body as disabled.

I am not the first to theorize medical cure as socially constructed. John Nguyet Eri, in *Unstable Frontiers: Technomedicine and the Cultural Politics of “Curing” AIDS*, writes, “ ‘cure’ inscribes itself in highly specific languages, embodies particular historical

and institutional structures, directs a network of technological practices, and excites deep-rooted popular cultural fantasies about the human body in illness; in short, it is a discourse” (xii). He theorizes that cure is not only a constructed medical discourse, but also a politicized act susceptible, for instance, in how AIDS research is funded to the tides of society. He writes,

We must situate the politics of curing within this historical discourse that places the practices and ideologies of a particular vision of health at its center. If health is no longer considered as a random and natural substrate of life, but as a discourse that passes into power’s sphere of control, then it is hardly surprising that curing arises as the designated ideal in the social and scientific discussion of treatment issues surrounding a disease. (128)

Although Erni’s project is specifically discussing AIDS, his work is important for my purposes in that it situates “cure” and the “disease” AIDS as a constructed part of medical discourse and views this construction as both embedded in and reflective of the social and political construction of bodies and disease in our culture at large. What’s important too, and relevant to a Disability Studies framework, is that he does not negate that AIDS is a “disease” different from the “norm” of “health”; rather he aims to show how the conflation of such configurations influences our societal response to AIDS.

As I told Danny, “Cure matters because it helps shape how disability as both a ‘disease/impairment’ and as an identity category is thought about in our culture at large.”

Cure matters.

DISABILITY V. IMPAIRMENT

As I alluded to previously, in our current climate, some scholars in Disability Studies who employ a social constructionist framework adhere to the distinctions that impairment is biologically defined and determined (bodily materiality) and disability is culturally defined and determined (constructed). Some have relegated impairment to the “medical model” while disability is configured in the “social constructionist model”. But what exactly is the “medical model”? Tony Bilton et al. offers a useful description:

Disease is an organic condition: non-organic factors associated with the human mind are considered unimportant or even ignored altogether in the search for biological causes for pathological systems.

Disease is a temporary organic state which can be eradicated — cured by medical intervention.

Disease is something experienced by the sick individual who is then the object of treatment.

Disease is treated after the symptoms appear; the application of medicine is a reactive healing process.

Disease is treated in a medical environment — a surgery or a hospital away from the site where the symptoms first appeared. (*Introductory Sociology*, 3rd ed. 410)

The definitions here are important for two reasons: medicine presumes 1) that bodily materiality is a non-negotiable truth; and 2) that medical cure is the desired bodily state for those with disability and disease. While Bilton has focused his definition on disease, it is important to note that science, by focusing on impairment and bodily materiality, has

effectively pigeonholed “disability” as pathology in ways similar to how Bilton configures disease above. However, if we understand “medical cure” to be a shifting concept as Erni does, then I suggest that medical impairment must also be understood to be fluid, shifting. Again, I do not mean to claim here that there is no biological basis for impairment; rather I am suggesting that what constitutes an “impairment” and an “impaired body” must also be understood to be culturally constructed. I draw upon the work of Paul Abberly who in his essay, “Work, Utopia, and Impairment,” theorizes that impairment is tied to materialistic production and social factors surrounding that production. For instance, he maintains that factory-era London created a level of impairments not seen before. Abberly is not suggesting that impairment is necessarily devoid of materiality; rather the visibility and literal creation of impairments are intrinsically tied to the environment in which people find themselves. In short, impairment is not ‘natural’ but is socially created — a combination of societal (viewpoint) and environmental factors. Thus, impairment and disability are not opposing dualisms, but rather occur on a continuum of categorical constructions.

Certainly, there is historical basis for this line of thought. As recently as the 1994 edition of the *Diagnostic and Statistical Manual of Mental Disorders*, for instance, intersexuality was listed as a medical disorder, as was homosexuality in earlier editions. (*DSM –IV* 538). Likewise, being Left-handed was once thought of as an impairment, a defect based, as was believed, in deviations of the brain hemispheres. This “impairment” was constructed along a minority-based model, if you will, of the majority of the population being right-handed and, therefore, medically defined as “normal.” However, that definition was shown to be itself socially-constructed in the solution or “cure”

offered. By slapping left-handed people with rulers in school for using their left instead of right hand, for instance, it was thought that being left-handed was a learned behavior, and, as such, could be unlearned. In other words, left-handers could be taught to be normal. Thus, the “impairment” becomes based not in biology, but instead on a socially proscribed norm.⁶ In this way, we might begin to understand, for example, that Cerebral Palsy, an impairment scientifically defined as damaged brain cells, may one day not be classified as an impairment, as a body that needs medical cure by the medical establishment.

Briefly, I’d like to address what I believe is a fallacy articulated by some in the disability community in relation to this thinking between “Disability” and “Impairment.” In my time on listserves and in activist circles, many people have said something akin to, “Disability is the only minority group that anyone can join at any time.” There are several ways of interpreting this assumption. The first, based upon the disability/impairment distinction, is that disability — as an identity category of people — is the only minority category/identity one can gain after birth, later on in life. If one knows history or the law or reads minority literature such as *The Color of Water*, *As Nature Made Him* or *Life on the Color Line*, one knows that this statement is inaccurate. In these memoirs, the authors detail how they were raised as a particular race or gender, and how their identities changed when they learned otherwise. Williams, for instance, was raised white, but found out that he was black. Another concern is that activists and academics are not adhering to the Disability/Impairment distinction that they created. If the adherence to Disability as identity and Impairment as corporeality/materiality is followed, then the logical conclusion of that theory is that a person may become impaired

at any time, but may not/will not necessarily claim to be Disabled from a position of constructed identity. Cancer survivors are a good example. Jean Stewart in her memoir *The Body's Memory* certainly claims her cancer survival as a change to her identity. For example, she paints her crutches green to symbolize trees, as though they were a natural extension of her body instead of some rather unsightly symbol of her impairment. Other people who survive cancer, or who view cancer not as an identity-changing experience, but simply as a sickness that “attacked” their healthy bodies, however, do not share this outlook.

Of late, a scholar raising the question of identity in terms of the context of disability/impairment/cure is Lennard J. Davis. In his essay, “The End of Identity Politics and the Beginnings of Dismodernism,” from his new book *Bending Over Backwards: Disability, Identity, and Other Difficult Positions*, he conforms to the distinction made between disability/impairment. He writes, “Impairment is the physical fact of lacking an arm or a leg. Disability is the social process that turns the impairment into a negative by creating barriers to access” (12). He is explaining the social constructionism of disability, a model that he later contends has “reached the end of its shelf life” (18) in light of our more unstable identity categories. Indeed, he asks later in the essay, “Although we may want to call all these senior citizens people with disabilities, what will that mean? ...And how will this majority of older people redefine disability, since they did not grow up with a disability or acquire one early in life? Who will get to claim the definition of disability or lack of one” (19). Davis seems to be ascribing to the idea of disability as a socially shifting category, while impairment may still be something based in bodily materiality. However, in the very next paragraph, he breaks with this

logic when he writes, “Just as people can slip into disability in the blink of an eye or the swerve of a wheel, so too can people be cured” (19). While this could just be a linguistic oversight on his part, he presumes, in both his stance on cure and on the acquisition of an impairment, a reliance upon bodily materiality. And then he slips back into recognizing the difference between Disability/Impairment when he writes, “Indeed the possibility does exist for cures of impairments that now define a group we call people with disabilities” (19). Again, while this may seem like a minor question of semantics, what it points to is not only a question of linguistic slippage but also a misuse of the term disability to signify bodily materiality when one is really referring to the acquisition and potential medical cure of the *impairment* rather than disability — an identity category. If we are to liken this to thinking in the Deaf community — where Deaf refers to cultural identity, history, and language, and deaf refers to impairment (medical definitions and measurements of hearing loss), then it is possible that a group of seniors may become deaf as they get older, but not necessarily culturally Deaf.⁷ This distinction is an important one because Davis presumes, when he maintains that “cures” can happen in the blink of an eye due to scientific progress, that such cures will shift people out of disability as an identity category as quickly as they can fall into the category of disability “in the swerve of a wheel” when he really means impairment in both cases. Again, while his may have been a linguistic oversight and, as I’ve said before, I do not negate the possibility of actual cure as a medical fact (and neither does Davis), others have not always made a clear distinction between Disability as an identity category and impairment as bodily materiality when making similar claims about Disability as the only minority group that anyone can join at any time.

SOME NOTES ON LABELS

As disability has grown in our social and cultural consciousness, persons with disabilities have become much more aware of the process of labels and naming, throwing off, for example, labels given to us by others such as “cripple” or “handicapped” in favor of naming and identifying ourselves. While some have “reclaimed” cripple, for example, as an insider term and source of pride, others may bristle at its usage. The laundry list of terms referring to physical disability alone is long, from *cripple*, *handicapped*, *differently-abled*, *challenged* to *gimp*, *freak*, *deformed*, to name a few, each with its own set of connotations and political and cultural history.⁸ The decision of what to call oneself is both a personal and a political one, and though there have been some large “group” decisions made, it seems (the decision to call our discipline “Disability Studies,” for example) the issue of naming remains largely organic and dynamic. Here, I offer some thoughts on the particular terminology I use in this dissertation and the reasoning behind it.

Disabled v. Person with a Disability

In much of what some have called “British Disability Studies” the common identifying marker, replacing earlier WHO (World Health Organization) impairment-based “function” definitions, is Disabled Person while in the U.S., People with Disabilities (PWD) is more common.⁹ PWD is based largely on the “People First”

Movement rooted in the idea of putting “People First” (before the impairment) as a model of Self-Advocacy.¹⁰ The difference between the two terms has been a hot debate on various listserves of late. Many British scholars use the term “Disabled People” to refer to themselves for two reasons: 1) to designate that they belong to a particular minority group/social/economic class, and 2) because PWD is often viewed in terms of impairment (something one has v. something one *is*). As theorist Clare Wixon says in an email:

Because disabled people are disadvantaged by society's attitudes, prejudices and procedures and "disabled person" is thus akin to oppressed person, disadvantaged person....we do not say "person with oppression", "person with disadvantage", "person with blackness".

Because "person with a disability" suggests that the locus of responsibility is the individual, when it is society that creates the disadvantage. (July 17, 2002).

Simon Stevens put it this way:

One [DP] is defined and owned by disabled people and the other [PWD] is defined and owned by non-disabled people who use it to abuse us. (July 17, 2002)

Following the distinction I drew between “Impairment” and “Disability,” it would follow that “Disabled Person” denotes identity and not impairment. So I use Disabled people/person from this point on to signify group identity. Incidentally, the same argument could be applied to ethnicity. Chinese American is a term denoting a group/social/political identity. On the other hand, others use Person of Asian Descent to

identify a person with a particular racial makeup, not a cultural heritage. This is also a distinction I have begun to use in my own personal life, and as with all identity categories, it is not totalizing, simply identifying.

Able-bodied v. Non-Disabled

The terms “disabled/able-bodied people” historically allude to the idea of impairment. The terms “disabled/nondisabled people” are gaining parlance in Disability Studies to signify cultural identity. There are, however, specific parts of this dissertation where I am interested in looking at the able-body as corporeal entity —the Performance chapter, for example. Therefore, I will use “able-bodied” strategically at various places throughout the dissertation. By utilizing the term “the able-bodied,” I am attempting to serve a dual purpose of referencing the historical use of the “disabled/abled” paradigm — i.e. impairment — while simultaneously recognizing the reclamation of naming as part of the process of claiming a disability identity.

FROM THE MARGINS

Though my recurring theme in this dissertation revolves around the concept of cure and its social construction, I have attempted to choose a particular way of framing my analysis in each of the chapters. In each chapter, I have chosen frameworks that critique disability and the construction of cure from a position of marginality, i.e. the construction of disability as both a minority group and a minority discourse. My

framework follows from other theorists like Abdul R. JanMohamed and David Lloyd.

They write in *The Nature and Context of Minority Discourse*:

Because relations of domination permeate every facet of our personal and social lives as well as our literature and culture, a critique of culture that ignores such relations can be at best a distorted one. From a minority viewpoint, a visible humanism must be centered on a critique of domination. In the second place it follows that most of those who hold power and those whose subject positions are protected by the prevailing hegemony will be more interested in the efficacious use of power than in examining its misuse. In contrast, those who are dominated will understand the devastating effects of misused power; they are in a better position to document and analyze...how relations of domination can destroy the “human” potential of its victims. The concerns of the victims of domination must be at the center not only of a minority discourse, but also of non-Eurocentric, non-aestheticizing “humanism” — that is, of a Utopian exploration of human potentiality. (13)

For JanMohamed and Lloyd, it is not enough to simply claim a minority status without placing that position within its relation to the larger culture or, as bell hooks phrases it, “dominant ways of knowing” (“The Oppositional Gaze” 110). Thus, in an attempt to both underscore and critique the dominant model of the normal, medicalized, notion of disability/disabled bodies as posited by Davis, Linton and others, I have invoked a particular stance in my analysis — looking at disability as a discourse in relation to larger hegemonic discourses that privilege ableism and Normalcy/Normal bodies which plant disability as marginalized and the need/desire for cure as the panacea to marginalization.

In Chapter Two, I critique bodies constructed as socially or physically inferior in both the genre of science fiction film and in terms of blindness and the dependency of the blind heroine, or the physically disabled Quasimodo. In particular, in the second portion of the chapter, I am concerned with how the gaze of the Disabled is used to reify dominant notions of power. The presence of disability in societal “utopias” and the

repression of the disabled gaze by the nondisabled, in their own ways, help to illustrate the constructed nature of cure as both a particular bodily state and as a power apparatus.

In Chapter Three, I use Bakhtin's idea of the grotesque, which posits disability as a constructed categorical "Other" to look at how Flannery O'Connor and Toni Morrison use that idea to invert who we think of as having a Normal body. In "*Good Country People*" for example, Manley Pointer's sexual fetishization of Joy/Hulga's fake leg is seen as more sexually perverse than her own self-image and naming of herself as a Disabled person.¹¹ Morrison, for instance, posits Eva Peace as not a grotesque figure but a powerful one. The inversion of the idea of the grotesque by these authors is an attempt to get readers to question who (or what) is normal, and thus, who or what is in need of cure.

In the fourth chapter, I look at how coming to one's understanding of oneself as Disabled resists dominant ideas of medical cure such as Temple Grandin's understanding of how her Autism helped shape who she is, and the value of her particular contributions to the world around her. Being able to claim an identity for oneself is a move toward resisting cure.

After a brief personal memoir chapter in which I endeavor to show the impact of social constructionism and labeling on my own life, in the sixth chapter on Disability Performance, I critique how disabled bodies literally act against dominant notions of abled bodies, implicitly and explicitly arguing for a performative and material permanency. For instance, Neil Marcus places his disabled body in continual interaction with able bodies and thereby asserts his right to exist in the world as he is.

By looking at disability from such marginalized positions as the grotesque or the Vanishing Point in performance, I hope that we understand not only the way(s) that disability is positioned in relation to a dominant discourse of medical cure, but also the constructedness of medical cure itself.

NAMING OUR DESTINY

As I was writing the introduction to this dissertation, I received word that one of my mentors, poet/activist/essayist, June Jordan, had died. Everyone had a favorite story to tell about their experiences with June. June, in turn, had a favorite story about just about everyone she knew. Her favorite one about me, one she wrote about and shared with her students again and again, involved her and me and a big white truck. We were walking and talking about a poem I was trying to write about my parents. “It’s *always* all about the parents,” she said, breaking out in a trademark June laughing fit, the giggles gradually growing in volume until laughter overtook her body. Suddenly, in the pathway between Dwinelle Hall and the Life Sciences Building, we realized a moving van was backing up directly toward us. No amount of screaming, waving or other gestures would stop that van. Breathless, we scrambled to safety in the alcove outside Dwinelle, where the driver pointedly ignored us as he dashed past. He never intended to stop, though he did see us.

On the surface, this was June’s “tough guy” story about me that she loved. That Brooklyn girl liked tough. She liked survivors.

We talked a few times after her mastectomy. She was so tired and her voice was sluggish, so unlike the June of her readings and performances. But then she got ignited again. Talking about one “bozo” of a therapist in rehab, she was indignant. “And then Johnson, he took his bare hands and put them directly on the wound. *On the wound!!*” We were horrified at this, not just the questionable cleanliness of the act but the clear invasion of personal boundaries, of someone deeming it ok to touch, without permission, the place where her breast had been. In typical June fashion, she had choice words for the establishment. I made some comment about “stupid doctors” and we soon dissolved into a fit of giggles. This is how we were with each other: fierce, stubborn, passionate, determined one minute, laughing the next.

Over time, the “truck incident” was a story that we laughed over, that we laughed *at*. But underneath it all, was pain, and fear, and anger. The fear of not being able to escape the truck, anger at being ignored, thought expendable, and the pain. The pain of not being valued for who and what you are. She was a Black woman, and I was a non-white man in a wheelchair, and both of us, no matter how important we were to our loved ones and the world around us, in those fleeing moments, were just that: expendable bodies in a largely White, male, able-bodied world.

We were reminded once again that we were never meant to survive.

Reading the essay about the suicide of her mother in *On Call: Political Essays*, I remember June’s statement about parents and I remember at the time that it gave me a lot of courage, that a woman in her fifties was still struggling with certain issues in her

personal life that had been there a long time. Though her parental issues were different from my own, she taught me much about valuing the struggle.

This project is not about my parents, of course, for their reactions to disability and cure are endemic of our larger culture and our larger society. But it is about other things June and others have taught me. It's about love, of yourself as you are and that of others. It's about worthiness and value: of yourself and your body. It's about freedom to live your life as you choose and to do with your body as you wish. Mostly, it's about survival against all those who would name you "wrong," and in the case of Disabled people, in need of cure.

NOTES

¹ Over 200,000 disabled people died in Nazi medical experiments and Hitler's official euthanasia program. The psychiatric institute at Hadamar, Germany, was one of the principal killing centers of the program. At the official conclusion of the program, the carbon monoxide equipment at Hadamar was shipped to Lublin, Poland, to be used in the Holocaust. (From Hugh Gregory Gallagher's *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich*, Revised Edition. Arlington: Vandamere, 1995).

² I do not take on religion as tied to disability very much in this project. For scholarly work in this area, see particularly the work of Nancy Eiland, *The Disabled God: Toward a Libratory Theory of Disability* (Abington, 1994). There, she points to disability as a particular trope within theology as signifier of concepts of sin and salvation.

³ For more on the concept of the genome, see James C. Wilson's "Disability and the Genome: Resisting the Standardized Genomic Text" in *Disability Studies Quarterly* 21.3 (2001): 166-177. Online version at: <<http://www.cds.hawaii.edu>>. Of note are his claims, "Genomic discourse reveals biotechnology's impossible attempt to normalize the chaotic text of genetics," and "Genomic discourse reinforces the social stigma attached to disability by constructing it as abnormal, pathological, and in need of genetic 'correction.'" These claims point to the constructedness of medical discourse and normalcy, and the "stigmatized" status of "disability" as a socially constructed category.

⁴ In the Nuveen commercial broadcast during the Superbowl in 2000, Reeve is shown getting up from his wheelchair and literally walking across a stage.

⁵ See, for instance, Harlan Lane's *The Mask of Benevolence: Disabling the Deaf Community* (19-20) when he discusses the social model of disability and its relevance, in part, to the Deaf community (18-20).

⁶ My thoughts here are influenced by Jack Fincher's *Lefties: The Origins and Consequences of Being Left-handed* (New York: Barnes and Nobel Books, 1977).

⁷ Some people in the Deaf community do not see themselves as "disabled" (impaired) and see Deafness as a completely separate cultural category from Disability. While my lack of exploring Deafness/deafness in the following chapters is not meant to be a pronouncement on that issue, I do wish to remain respectful of that stance in noting that there is already existing a body of work (Deaf Studies) distinct from Disability Studies. In particular, I am indebted to such books as Harlan Lane's *When the Mind Hears: A Brief History of the Deaf* for historical context, and works such as Carol Padden/Tom Humphries' *Deaf in America* for my introduction to Deaf culture, Owen Wrigley's *The Politics of Deafness*, and, of course, Brenda Jo Brueggemann's *Lend Me Your Ear: Rhetorical Constructions of Deafness* for thinking about Deafness as a cultural and political category.

⁸ A good take on some of these terms and reactions to them can be found in Eli Clare's section on "Naming" in *Exile and Pride: Disability, Queerness and Liberation* (68-70) and Simi Linton's section in *Claiming Disability: Knowledge and Identity* (8-17). In both, they go over some of the more common terms and their own interpretations as well as their own reactions to their usage.

⁹ For WHO definitions go to: <<http://www3.who.ch/icf/icftemplate.cfm>>.

¹⁰ For a detailed overview of the People First Movement, see Joe Sharpiro's chapter, "People First" in *No Pity: People With Disabilities Forging a New Civil Rights Movement* (184-210).

¹¹ My capitalization of the term "Disabled" refers to when a person claims disability as an identity. Other times, my non-capitalization refers to the more common usage as either medical impairment or societal label.

CHAPTER 2

WAIT UNTIL CURE: DISABILITY AND FILM

American media is already pushing society toward a Utopian model of bodily perfection and cure. One need look no further than such movements as “Cure Autism Now,” the telethons to find a cure for various birth defects, impairments, and illnesses, or the “I’ll-Walk-Again-Anything-is-Possible” rhetoric of Christopher Reeve, to “see” this medical “truth.” With the recent “cracking” of genetic coding, opening up the possibility of genetic manipulation, a future where medical technology and genetic engineering will have advanced to the point where bodies can be genetically manipulated before birth, or treated and cured so as to make “disability” obsolete, is not beyond the realm of possibility. In this “medical model,” disability becomes “eradicated” through medical cure.

The eradication of disability is not a new theme in media or in American culture. In early-twentieth-century film, eugenics, in its various forms, was a recurring theme. The most famous of these is possibly a 1916 film re-released in 1927 entitled *The Black Stork*. In the wake of the death of baby Bollinger, a “defective” baby who was permitted to die at the urging of doctors, *The Black Stork* reaffirmed the public fear of defectives,

thus spurring the idea that death is better than disability, if medical cure is not possible.

Medical treatment was, in fact, available to baby Bollinger, but “gross physical and mental abnormalities would remain,” and thus death was determined to be better

(Pernick, *The Black Stork: Eugenics and the Death of “Defective” Babies in American Medicine and Motion Pictures since 1915* 3, 4).

Stork traces the lives of two couples. One, despite doctor’s orders that they not marry because of the man’s “hereditary” disease, marry and give birth to a “defective” baby with multiple deformities. His disabilities supposedly make his life miserable, so he eventually shoots the doctor who saved his life. The woman of the other couple, Miriam, believes her mother to have hereditary epilepsy, and refuses to marry. Later, she discovers her stepmother has epilepsy. A healthy Miriam marries, and they have a “very fat and happy” baby (Penick 144).¹ The message is a clear one: death is preferable to disability, unless cure is possible.

I begin my discussion of film with *Stork*, not so much as an indictment of eugenics in American history, but rather because films like *Stork* clearly place a value on the possibility of medical cure over a disabled life. The theme of medical cure permeates many films to this day, particularly in the sub-genre of science fiction.

Employing a social constructionist model of disability, however, could mean that disability would still exist even in “medically advanced,” futuristic science fiction societies. In other words, if we think of disability as not just a medical condition or bodily affliction which can be medically cured or genetically manipulated, but as an identity which is largely defined by society at large, then disability, in cultural terms, should, indeed will still be, present in societies of the future.

The premise that cure is constructed and disability, in the metaphorical sense if not literal/physical sense, is still present in these futuristic societies is what I undertake in the first part of my chapter, *After Cure: (Re) Defining Disability in Futuristic Films*, which looks at sci-fi films *Blade Runner*, *The Matrix*, and *Gattaca*. Using a postmodern framework, I explore how cure is constructed, and how disability is re-defined, and thus still present in these visions of the future.

Visions of the future are not my only focus here. The question of how filmgoers know that medical cure, and, by extension, normalcy is a preferred bodily state to disability — the message underpinning the sci-fi films — is an important one. In part two of this chapter, “Disabled Gazes: Repression and Suppression,” I consider this question through examining the gaze — redefined as a power mechanism by feminist and queer theorists — of disabled characters in film. I argue that the disabled gaze is suppressed by what I term the Normative gaze in film thereby fulfilling stereotypes of disabled people as helpless, infantile, and dependent upon the able-bodied. Seeing disability constructed in such ways, serves, as in the sci-fi films, to remind viewers of the construction of medical cure as a Utopian panacea to the “undesirable life” of having a disability. My analysis in this section will focus on readings of blind heroine films such as, *Wait Until Dark*, and of Disney’s *The Hunchback of Notre Dame*. Before turning to those films, however, I offer a brief synopsis of the major critical work done on disability and film to see how such ideas as representations of dependency are discussed.

THE INNOCENT, THE BAD, AND THE UGLY: SURVEYING DISABILITY AND FILM

Much of the scholarship regarding disability and film has focused on articulating the presence of stereotypes of disabled people in film. There has been some review of these stereotypes in other media particularly in the Pointen and Davies collection *Framed: Interrogating Disability in the Media* (British Film Institute, 1997) and David Heavey's *The Creatures Time Forgot: Photography and Disability Imagery* (Routledge, 1992), which may complement further research on disability and film. Further research, though, will have to address not just the presence of stereotypes of disability in film, but also their meanings and function in cinema more fully, as well as the on-going grassroots debate over nondisabled actors playing disabled characters on-screen.

Perhaps the most well-known work currently is Martin Norden's *The Cinema of Isolation: A History of Physical Disability in the Movies* (Rutgers, 1994). His basic premise is that "most movies tend to isolate disabled characters from their able-bodied peers, as well as from each other" (1). Norden claims that this reduces disabled bodies to "objects of spectacle" which "pander" to the able-bodied, as well as increasing self-loathing among people with disabilities. His assessment that the "sweet young thing/poster-child syndrome" allow these children to be miraculously cured of disability/isolation will be key to my discussion of the gaze and cure later in the chapter. And while this is perhaps a true assessment of disability portrayals on screen, Norden

does not point out that the “poster-child syndrome” merely creates, I believe, another form of objectification and of isolation of disabled characters. His book is important for its scope and filmography, yet his thesis is no different from Paul Longmore’s seminal essay, “Screening Stereotypes: Images of the Disabled in Television and Motion Pictures” which details stereotypes such as evilness and inspiration in relation to disability imagery, as well as equating body deformity on-screen as metaphor for evilness. Of note is his idea of the “realignment/readjustment” narrative which comes into play when the character must either accept or reject his disability. In this way Longmore moves disability in film from character “window dressing” to an issue around which identity is formulated. Paul Darke in his essay, “Understanding Cinematic Representations of Disability” re-works somewhat Longmore’s idea of the realignment drama into what he calls the “Normality” drama which “specifically uses abnormal — impaired — characters to deal with a perceived threat to the dominant social hegemony of normality. The normality drama follows its own genre conventions: a physically or mentally impaired character is represented to reinforce the illusions of normality: a normality exhibited either in a film’s non-impaired characters, or by the impaired character’s rejection of their impaired self” (182). Other collections and essays on representations of disabled people in film abound; however, all seem to detail in some way these ideas of normality, impairment and representation detailed most explicitly in Norden, Longmore, and Darke. To see how some of these issues and stereotypes “play out” in terms of cure, I turn now to science fiction and futuristic film.

PART 1: AFTER CURE: (RE) DEFINING DISABILITY IN FUTURISTIC FILMS

In science fiction films such as *Blade Runner*, *The Matrix*, and *Gattaca*, we are presented with glimpses of our future, of a perfect More-like Utopia.² At first glance, in these postmodern worlds, populated largely by cyborg or genetically-engineered bodies, disability appears to be eradicated. However, a closer examination of these films shows disability as a societal, if not medical, construction to be very much present. Theories of Postmodernism, particularly Jameson's analysis of the construct of Utopia, and Donna J. Haraway's concept of the cyborg, will help ground my analysis. Through articulating the presence of disability as a societal construction in these films, I aim to show how we might rethink not only constructions of disability, but also medical cure as a socially and culturally constructed concept.

POSTMODERN CONCEPTS: READING THE FUTURE

Much controversy has surrounded the origins of Postmodernism and its various characteristics from whether a concept such as postmodernism can actually be true to what constitutes postmodern art.³ Aesthetically, these films are definitely considered postmodern, both in locale and theme. The mixing of architectural styles such as the gritty Gothic-like buildings existing in close proximity to the Techno-lit bar in *Blade Runner*, for instance, created a very postmodern cityscape. Similarly, the unilaterally bland cubicle offices in *The Matrix*, and the antiseptic offices of *Gattaca*, while recalling visions of Fritz Lang's 1927 film *Metropolis*, symbolically denote a postmodern society,

what Irving Howe has called a “mass society,....[in which] passivity becomes a widespread social attitude: the feeling that life is adrift over which one has little control...[where] reflections upon the nature of society are replaced by observations of its mechanics” (“Mass Society in Postmodern Fiction” 25). The films themselves employ postmodern characteristics in their narrative plot structure as well, such as the blending of history and memory, and non-linear shifts in time and place.⁴ While these elements help to place these films within a postmodern framework artistically, it is theories of Postmodernism as they apply to the films’ respective themes and characters which will frame my analysis, and ultimately, help to discern the presence of disability in the future.

While many theories of Postmodernism exist, and it is somewhat differently defined in relation to art and literature, I want to consider particularly the postmodern concept of Jameson’s Utopia and the presence of disabled bodies and identities in these Utopian societies where medical cure has supposedly already taken place to show the constructedness of cure upon disabled bodies. Jameson’s notion, that in postmodernism we have “the disappearance of the individual subject,” will be particularly useful when discussing *The Matrix*. In an era of mass reproduction, the *original*, i.e. the *real*, becomes a much more valuable commodity. The emphasis on the “real” v. the imagined, coupled with technological innovations and mass production in a Postmodern “mass society” leads to a questioning of *knowledge*, indeed of who we are, and what we know.⁵ I want to consider the presence of a “Utopia” in Fredric Jameson’s terms as it relates to visions of our postmodern future. While his primary concern is an examination of the concept of

a Utopia in economic (Marxist) terms, his articulation of the failings of Utopian society will further my own argument of the presence of disability in the Utopian societies presented in futuristic film.

Jameson argues that a “false consciousness” exists in Utopia because of the “bulk of production of a mass or media culture,” where the purpose of material product is “to distract readers and viewers from the nature of their own lives and the relationship of the latter to the socioeconomic system in which they live” (“Marxism and Utopian Thought” 365-6).⁶ Utopia, though, ultimately fails because “commodities” are still valued differently. A “class” system, a system of privilege, still exists. Relationships too, instead of being free from political and individual willpower, are still driven by emotions and values such as “violence, hate, love, sex, or whatever” (“World-reduction in Le Guin: The Emergence of Utopian Narrative” 376).

What, then, does Jameson’s assertion of a “class/value” system in Utopia have to do with disability? If disability is a socially constructed phenomenon, the existence of a class system would demand a system of “have and have-nots.” As theorists such as Erving Goffman, Lennard J. Davis, and Harlan Lane have noted, the “have-nots” occupy a stigmatized place in society.⁷ Although there may be a physical difference upon which the stigma is based, the stigma is socially created. Like class, where a status of “upper-class” or “lower-class” is socially determined by what and how many commodities someone owns, in Utopia, one group assigns value to another based upon a specific valued body structure in much the same way other “commodities” are valued or devalued within society.

Further, as Donna Haraway suggests in *Simians, Cyborgs, and Women: The Reinvention of Nature*, the production of cyborgs — “a cybernetic organism, a hybrid of machine and organism, a creature of social reality, [lived social relations] as well as a creature of fiction” (149) — relates directly to Jameson’s notion of a class hierarchy, where technological knowledge and genetic manipulation, resulting in a hybrid between human and machine, becomes the very foundation upon which a class structure and societal stigma is based. Haraway writes:

Another critical aspect of the social relations of new technologies is the reformulation of expectations, culture, work, and reproduction for the large scientific and technological work-force. A major social and political danger is the formation of a strongly bi-model social structure, with the masses of women and men of all ethnic groups, but especially people of color, confined to a homework economy, illiteracy of several varieties, and general redundancy and impotence, controlled by high-tech repressive apparatuses, ranging from entertainment to surveillance and disappearance. (169)

For Haraway, the reconstruction of humans as cyborgs — products of and bound to technologies in ways heretofore unimaginable — leave particularly women and ethnic minorities occupying particular places in the socio-economic strata of a new genetically and technologically-driven world. If we venture to include people with disabilities — the very population for whom “technologies” such as wheelchairs, ventilators, pacemakers, and the like — are paramount to literal survival and forged identity, Haraway’s use of the “cyborg” as a central figure around which class and stigma are based, has implications for people with disabilities, as we will see shortly in explorations of the films.

If disability, as a social construction, exists on more than a theoretical plane, disability should be present as a social stigma in the future. This is not to suggest that

bodies are immaterial in Utopian societies. Quite the contrary, it is indeed that bodies exist in Utopia which occupy a societal stigma of being unfit, sub-human, inferior, that shows the very existence of disability as a social construction in Utopian societies. In other words, though Utopia is thought to be free of illness, disease, impairment, the fact that these kinds of bodies still exist in Utopia, and that these bodies are stigmatized, illustrates that disability is still a social construction.

To reiterate, a rethinking of disability in social terms either through a redefining of “reality” and knowledge of identity, or through an examination of bodies in terms of societal stigma in futuristic “Utopias” will allow us to understand how disability, thought to be medically cured or eradicated, will still be present in the future.

My analysis of these films is organized chronologically. I begin with *Blade Runner*, in part, because our ideas of science and disability have changed with the times. In the Reagan-era “Star Wars”-driven Eighties, and the aftermath of the Cold War, America was much more concerned with the idea of an Other (Soviets) and the ability of technology to destroy humankind. We see these ideas prominently in *Blade Runner* where cyborgian technology and scientific progression are portrayed as a threat to humankind. In the Nineties, with the advances in technologies such as cloning and genetic manipulation, the central concern is not how technology will destroy humankind, but how technology will alter our identities as human beings. We see this reflected in *The Matrix* and *Gattaca*.

In her book, *Imagination: Popular Images of Genetics*, José Van Dijck traces the evolution of genetics as cultural image, and society’s responses to the changing image of genetics. In the 1950’s the discovery of DNA configured genetic as a structured “code”

based in biology; in the 1980's and beyond, the image of the gene became one of a "potentially dangerous micro-orgasm — a string of manipulated DNA escaping from a lab, unleashing its evolutionary powers onto the environment. The gene, in the environmentalist definition of engineered bug, became the designated enemy of nature, thus amplifying the punitive opposition between 'nature' and 'science'" (179-80). Later, according to Van Dijck, with the rise of genetic manipulation by industry, genes could be viewed as "potential lucrative resources, goldmines for capital investment and profit" (180). The concept of gene as commodity — as part and parcel of a Jamesonian class system — can be seen most clearly in the film *Gattaca*, and certainly there are "real world" implications with this idea, as current debates surrounding such issues as the possibility of the "gay gene" and finding the chromosomal "defective" gene for Downs syndrome, suggest. In these debates, sexuality and disability respectively are, again, reduced simply to medical "defect" or impairment, curable by gene therapy and manipulation. The concept of either sexuality or disability as social/political identity, as "social construction," is ignored in favor of a more pervasive scientific representation. The changing image of the gene and science, and humankind's responses to those changing images, and, in turn, the changing response to genetics and its relationship to disability and medical cure, is clearly evident in the three films under examination in part one of this chapter. To see the relationship of science and genetics to the construction of disability and of medical cure, let's turn to the films.

“BELONGING” IN THE WORLD OF BLADE RUNNER

The quintessential postmodern science fiction film, and one that has received much analysis, is *Blade Runner*. While much critical attention has centered on issues of the film’s production, marketing, and its various versions, including the controversial *Director’s Cut*, little attention has been paid to reading it in terms of disability.⁸ Much attention, however, has been paid to the notion of replicants as cyborgs in such critical collections as *Retrofitting Blade Runner: Issues in Ridley Scott’s Blade Runner*.⁹ For Haraway, a cyborg is “a cybernetic organism, a hybrid of machine and organism, a creature of social reality, [lived social relations] as well as a creature of fiction” (149). Haraway’s blurring of the human and machine in the form of a cyborg is clearly evident in the films *Blade Runner* and *The Matrix* explored in this chapter, but certainly factor in to “real world” configurations of disabled persons — and mainstream society’s response to them as well. If we figure replicants, literal cyborgs, as disabled, as stigmatized and occupying status as a minority group, we can see the reformulation of disability as a social and class stigma in Utopia.

Blade Runner has a comparatively simple premise. In the future, the Tyrell Corporation has created a race of androids, called “replicants.” These are technological, man-made organic doubles of humans. They are superior to humans “in body strength and agility, and equal in intelligence.” They resemble humans in nearly every way, except they are created with a four-year life span. The main motive for their short life span is, that if made to last longer, it is feared that they would become emotionally too much like humans, and would have human desires, such as love. As it is, they were

enslaved by humans, and used to help colonize other worlds. There was an eventual mutiny. They were declared to be “illegal” on Earth, and a special band of police known as “Blade Runners” was created to execute any “trespassing replicants.” These executions are known as “retirements.” As the movie opens in 2019 Los Angeles, former Blade Runner Deckerard (Harrison Ford) is drafted to retire some suspected trespassing replicants.

The replicants can be considered “disabled” from several standpoints. At its base, such a storyline reaffirms some common stereotypes of disability, for one, that disabled people are overcompensated in one sense when another is deficient, e.g. that one hears better if one is blind. The replicants make up in superior strength and agility what they lack in emotional depth and life span. The second stereotype that the film relies upon is the idea that disabled people are bitter about being disabled, causing them either to be depressed or angry, and that they are consumed with the desire to be “normal.” After all, what threat do the replicants pose? The replicants are only a problem when they desire to escape the boundaries of their fate, their enslavement, their bodies, and be more human, more “normal.” As replicant Roy tells his creator, — a human he calls “Father” — “I want more time.” Besides all the scientific reasons “Father” gives for this impossibility, (why, in other words, replicants cannot be “cured,”) he offers this as a balm, “A light that burns twice as bright burns half as long. And you have burned so very brightly Roy.” Overcompensation. In other words, what you lack in one area, you make up for in another. The third stereotype the film uses is the idea that if one can’t be “cured,” it would be better to die. Death is preferable to being disabled. Not that the replicants want

to die; rather this idea is imposed by humans whose response to the replicants' desire to be more human is to employ Blade Runners to kill them.¹⁰

When Roy can't become "human," he murders "Father," but not before he gouges his eyes out, blinding him. Deckerard eventually kills Roy. Similarly, replicant Priss is designed as a "pleasure unit" for humans. When she desires to escape that function, she is killed. In this Utopia, replicants are considered second-class citizenry and stigmatized as such.

DOWN THE RABBIT HOLE AND BEYOND: DISABILITY IN *THE MATRIX*

The Matrix is probably best remembered for its special effects. But there is much more to the story. It is a story about subjugation of humankind to technology, a futuristic Christ fable, and about finding out who we are.¹¹ It is also the film in which we can see the postmodern principles of the real v. the imagined, and the construction of a "false consciousness" most fully at work.

In *The Matrix*, the future of our world is a dream world. That is, Artificial Intelligence has created a computer construct (called The Matrix) of our human world. Artificial Intelligence has hardwired this reality into the minds of humans, and this is the "consciousness," the "reality," that most humans "live in" and "believe." The truth is that humans are kept in incubators and used as power sources for the Artificial Intelligence. In other words, machines dominate humans, and our "experiences" exist only in our minds.

Of course, there is a small band of “freed” humans, The Resistance, led by Morpheus (Lawrence Fishburne) and Trinity (Carrie-Ann Moss) who want to destroy The Matrix, and end the machines’ domination. As Morpheus explains, “The Matrix is a world that has been pulled over your eyes to blind you from the truth...the truth that you are a slave, that you were born into bondage...a prison for your mind.” Like *Blade Runner*, there are traces of a social/class hierarchy at work. In this film, though, it is the humans, not the machines who occupy a subservient status.

The Resistance seeks a savior, known mythically as The Chosen One. Enter Neo (Keanu Reeves) who will lead them. Morpheus gives Neo a choice: “Take the blue pill, and you’ll wake up in your bed, and believe what you want to believe. Or take the red pill, stay in Wonderland, and I’ll show you just how deep the rabbit hole goes.” (There are many references to *Alice in Wonderland* throughout the film.) Neo, of course, chooses the red pill. A great “rebirth” scene follows, with Neo sliding down tubes landing awash into a sea of red, where his body is unhooked from machines that have been using him as an energy source.

The Resistance trains Neo, feeding programs into his brain that allow him to learn such skills as kung fu at a rapid rate. Ultimately, however, the fate of the Resistance and all “humankind” rests in Neo’s ability to believe that he is The Chosen One, something he, at first, resists. There is a great metaphor for how to foster one’s belief. It is the scene with the spoon.

Morpheus takes Neo to see The Oracle, a clairvoyant omnipotent being (think God figure to Reeves as Christ figure), and while he waits for her, he walks into a room

with the other “potentials.” One of these “potentials” has a row of spoons laid out in front of her, and she bends one. Neo is impressed, but she tells him:

Potential: Do not try to bend the spoon. That is impossible. Instead, only try to realize the truth.

Neo: The truth?

Potential: There is no spoon.

Neo: There is no spoon? (Holding the spoon)

Potential: Then you will see it is not the spoon that must bend. It is only yourself. (Neo begins to bend the spoon.)

Here is the principle of the “real” v. the “imagined” at work. In other words, what controls “reality” is what you “believe,” not necessarily what you “know” physically in front of you. If Neo believes it is the spoon that must bend, the spoon will not bend because the laws of physics, as Neo knows them, have not changed. However, if he recognizes that he, not the spoon, needs to change — in this case, what he believes is physically possible within the Matrix — the spoon can and will bend.

In the end, Neo is The Chosen One. In the Matrix, his “body” becomes impervious to the bullets that the Artificial Intelligence are shooting at him, because he believes, in essence, there are no bullets. He ends the film saying, “I will show you (meaning humans) the truth....a world with no borders and boundaries. A world where anything is possible. Where we go from there is up to you.” There’s an ending shot of

“unfreed” humans walking around in *The Matrix*. Neo, it’s presumed, will show them their “false consciousness,” to question *knowledge* of who they are, and what they know, what is real.

Disability works on two levels in this film. On the one level, it can be argued that those “unfreed” humans, are disabled due to their subjugation. They occupy a stigmatized status. Human beings are, after all, hard-wired to a massive computer that acts as a huge incubator. Their sole ability, by virtue of their subjugation, is to act as a power source for the dominant normative group (Artificial Intelligence). From the point of view of the Artificial Intelligence — the dominant un-marked group — “humans are a virus, and we [machines] are the cure.” Human beings have a stigmatized status. In terms of the body, to become “freed” is to become not only self aware but to be “cured” of their automaton status and bodily subjugation.

On another level, we can see the principle of social construction in terms of identity politics operating in this film. Indeed, there are “disabled” persons in the Matrix. However, if we understand that within the Matrix reality is a “constructed,” computer generated reality and bodies look, move and respond the way the individual *believes* their body looks, moves and responds, then disability, if it is merely a physical or mental impairment, should cease to exist. However, disability continues to exist within the Matrix. As Morpheus explains to Neo, within the Matrix, “. . . your appearance now is what we call residual self-image. It is the mental projection of your digital self.” The blind man, for example, is blind because this is how he identifies, sees himself, and this belief may or may not have anything to do with his actual body.

I am not arguing that medical impairment or disability does not exist, now, or in the future. Rather, what I believe *The Matrix* shows us is the way that what we believe about bodies can or should be able to do (as in Neo's ability to stop bullets) is as much about how society has defined what a body can do, as it is about what the body can, in actuality, physically do. In this way, "disability" has not disappeared; its socially constructed status, has instead, become more clear. Though these are science fiction films they highlight how disability can be stigmatized within society.

QUESTIONS OF GENETICS AND ABILITY: DISABLING POSSIBILITIES IN *GATTACA*

Perhaps the most troubling and complex of the sci-fi films is *Gattaca*. Indeed, there is much in the film in terms of genetic technology, eugenics, "passing" and identity, the presence of physically disabled characters, a "classed" society, and many other subjects regarding disability that this film tackles. While there is more to the film than I will be able to examine, the central issue I will look at is the creation of a "class" system within Utopia, and the idea of disability as a social stigma in this version of Utopia.

Unlike *Blade Runner*, in the world of *Gattaca*, it is the genetically-manipulated beings who are considered "normal." The naturally-conceived humans are stigmatized and belong to a socio-economic under-class. It's a world of "Valid" (genetically-manipulated) and "In-valid" or "De-gene-erates" (naturally-conceived), as the movie calls them. The protagonist of the film is an "In-valid" called Vincent, played by Ethan Hawke, who dreams of working for the elite corporation known as Gattaca, of being chosen for one of its space exploration missions.¹² Of course, given the stigma of his

natural conception, noted visibly by his need for glasses and non-visibly by his heart problems, this is an impossibility. In *Gattaca*, the closest that the “In-valids” will get to a mission is working as janitors. “Don’t clean the glass too well,” warns Vincent’s custodial boss, “you might get ideas.”

Vincent does get an idea. In the world of *Gattaca*, Valids who “fall on hard times” participate in a black market system where they can sell their identity — DNA, blood, urine, hair — to In-valids who wish to assume their identity. Here, the fallen Valid is Jerome Morrow, played by Jude Law. Morrow is a first-rate athlete who, because of a broken back, now uses a wheelchair. The general populace is unaware of the accident “because it happened out of the country.” Vincent’s dream of space led him to broker a deal with Morrow, and after some leg lengthening and blue contacts, Vincent assumes Morrow’s identity. As the Black Market broker says, it doesn’t matter that Vincent doesn’t look like Jerome, “When was the last time anyone looked at a photograph?...It doesn’t matter where you were born, just *how*.” “Jerome’s” interview for admission to *Gattaca*, consists of screening a drop of “his” urine (which Vincent now carries in hidden packets), resulting in the computer’s identifying Jerome Morrow as “Valid.”¹³ Thus begins the deception and the passing of Vincent as Jerome.

Reviews of the film tend to focus largely on the ethical questions of technology. If disability is mentioned, it is either “flawed” Vincent or “crippled” wheelchair-using Jerome who are defined as “disabled.” In the film, however, there are other notable “disabled” characters:

1. Irene (Uma Thurman), “Jerome”’s (Ethan Hawke) love interest and colleague at Gattaca is a woman with an imperfection — “an unacceptable likelihood of heart failure.”
2. The bald, fedora-wearing detective, who, although he discovers “Jerome”’s true identity before anyone else, and solves the murder of Gattaca’s director, is not promoted, but still accountable to his superior, Vincent’s genetically-enhanced brother, Anton.
3. The twelve-fingered man who plays the piano.

To see the manifestations of disability as societal stigma, I will examine the presence of the twelve-fingered man, and Jerome Morrow’s interaction in the real world “as a cripple,” and his eventual death.

The twelve-fingered man is an interesting example of disability in *Gattaca*. His disability, unlike either the real or passing “Jerome,” is not only known, but also displayed in society. Viewers are never altogether clear who knows or how much is known about Irene or the detective. Unlike these characters, the twelve-fingered man’s disability (though it is never clear whether it is the result of a natural or technological aberration) is precisely what permits him to exist in mainstream society. He is a pianist whose sole purpose, it seems, is to perform pieces that “can only be played with twelve [fingers].” In the single scene he appears in, he performs that piece under spotlights with an adoring crowd of Valids looking on. Afterward, he tosses one of his white gloves into the crowd, a glove which Irene then puts on her hand, the extra digit flopping awkwardly. Also, to further focus on his difference, viewers see a shot of the posters advertising his

performance. In these, his face is completely covered by his hands, so that what is visible is little more than his twelve fingers. He *is* his disability, and the sole attraction in this glimpse of a futuristic freak show. Like Priss in *Blade Runner*, his only function is to entertain the Valid. Like his predecessors, his difference becomes performance art. He's not considered "human" in any real sense by the Valid. While it could be argued that disability is portrayed in a positive light, from an economic standpoint, his worth is still based on his ability to perform for the Valid, to entertain what Rosemarie Garland-Thomson-Thomson has called "the normate," and their willingness to allow him to entertain.¹⁴ He, literally, embodies not only his stigma, but also he reminds us of a class system, a system of differently valued commodities.

Jerome, Vincent and Irene remind viewers of the negative effects of stigma. For example, while Jerome and Vincent do go out to a local bar together, no one knows the wheelchair-using Jerome as "Jerome Morrow." Everyone believes Vincent is "Jerome," a Valid, a "made-man" and not disabled. The real Jerome, when he is spoken to, is only called "sir" (not Eugene, as he is called by Vincent in public). This suggests that, even in a bar both frequent together often, Jerome is not worth knowing, not quite human. This less-than-human status in society is also shown in Vincent's inability to attain a position above janitor without Jerome's helix "tucked under his arm" and comments made to Irene that her "place is assured." Jerome's, Vincent's and Irene's places in this society are assured due to what society perceives and not due to any particular ability. Although all are stigmatized by society, because Vincent and Irene's disabilities are not physically apparent, they are not as stigmatized as Jerome. In the end, Vincent and Irene are allowed to live. However, Jerome, according to film etiquette expressed by Longmore

and Pernick, among others, must die, supposedly because he cannot be “cured.”

Although Jerome is suicidal prior to becoming a paraplegic, “I wasn’t drunk when I stepped in front of that car,” he tells Vincent upon returning from the bar. The film, though, does not examine his depression and self-hate, attributing it solely to his accident, the moment of impairment, thus implying that his incineration, his suicide, at film’s end, is due to his disability. Clearly, being a cripple, unless one becomes a freak show attraction, is unacceptable in *Gattaca*’s Utopia.

In all of these films, disabled persons, whether human or technologically-designed, occupy stigmatized places in society, either in terms of a lower class, subservient, or minority status. Stigmatization, based on a socially-defined body and what it can “do,” its ability, illustrates the constructed nature of disability in these societies. Disabled bodies in *Gattaca* are not desired. In *Blade Runner* and *The Matrix*, they can only serve specified purposes, and are kept subjugated. While in American society, disability is not subjugated in the same way as the films, disability is also a socially-defined phenomenon. Looking at how disability is still present in these fictional Utopia helps viewers to see how both how disability is stereotyped and how disability and cure are socially constructed.

The stereotype of an unsightly cripple who desires cure has long pervaded filmatic configurations of disability. As Tom Shakespeare in his article “Art and Lies?” *Representations of Disability on Film* notes, “The dominant plot devices [for disability-themed films] often centre [sic]...[on] the attempt at cure of the impairment, often assisted by a non-disabled teacher, doctor or therapist” (164). In the first part of this chapter, I focused on sci-fi films where cure was thought to be already achieved, and

therefore unnecessary. In the second, I'd like to consider the ways in which disability is thought to be, as I said, an undesirable state of being, in other words, how disability is often framed as a state of helplessness and dependency, and therefore a bodily state in need of cure. Understanding the mechanisms by which normalcy is promoted as the desired bodily state shows, in another way, how medical cure is constructed as something that is desirous for disability. Here, I consider the gaze of the disabled as a mechanism through which viewers understand a disabled character's helplessness and dependency, and the implicit call for cures — the dangling “magic carrot.”

PART 2: DISABLED GAZES: REPRESSION AND SUPPRESSION

In her examination of the women's films of the 1940's, Mary Anne Doane in *The Desire to Desire* asserts, “Disease and the woman have something in common — they are both socially devalued or undesirable, marginalized elements which constantly threaten to contaminate or infiltrate that which is more central, health and masculinity” (38). To be disabled or diseased as well as female then, poses a double-threat. While our culture has seen the move toward valuing strong women and repudiating of gender stereotyping in film, many stereotypes about disability — that we are unsightly, ugly, sexually undesirable — remain. In *Dark Victory*, upon learning that her blindness is incurable and has returned, Bette Davis bids goodbye to her doctor and romantic love interest, sends away her friend Anne and the maid, and retreats into her bedroom to die alone. This scene is typical of stereotypes of disability in cinema, what film theorist Martin Norden

has termed “the cinema of isolation.” As I’ve stated previously, while Disability Studies has addressed the presence of various stereotypes of disabled people, it has not articulated how these representations manifest themselves within cinema. I will discuss the presence of a Blind gaze in blind heroine films and of a disabled gaze more generally in Disney’s *The Hunchback of Notre Dame* and theorize how these gazes are suppressed or misused in order to take away the disabled character's agency. I argue that these films reify the dehumanization of Disabled people, particularly Blind women and how they perpetuate stereotypes within the larger society.

While film studies has long been enamored with examining the Male gaze and those within Feminist and Queer studies have articulated the presence of a female gaze and a queer gaze, respectively, little has been done to articulate the presence of a Normative gaze as a means of understanding how a film operates to perpetuate stereotypes of disability. Mulvey writes of the Male gaze:

The man controls the film phantasy and also emerges as the representative of power in a further sense: as the bearer of the look of the spectator, transferring it behind the screen to neutralise the extra-diegetic tendencies represented by woman as spectacle....The character in the story can make things happen and control events better than the subject/spectator. (20)

Just as Mulvey presumes a dominant Male gaze that the female gaze is often reacting to and subjugated by, I presume the Normative gaze as dominant when looking at disability within film. As bell hooks notes, “There is power in looking” (197). I do not intend to examine how disabled characters are looked at in film, per se — a question already examined by other scholars — rather, I consider what is meant by and/or what happens when a disabled character is doing the looking.

I use the term “Normative gaze” to bring disability into larger discussions of the gaze and film. Many scholars who have discussed the gaze — Mulvey and the Male gaze, hooks and the Black Female gaze, queer theorists and the heterosexual gaze upon gays and lesbians — employ a majority/minority group model.¹⁵ All of these presume a dominant spectatorial position and interrogate that dominant position by looking at other subjectivities. In other words, all of these models share a presumption of the dominant gaze as “the norm” and the gaze of the marginalized group as the minority gaze, i.e. a female gaze, a queer gaze, etc. As Lennard Davis states in *Enforcing Normalcy: Disability, Deafness, and the Body*, “This normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject, and so on” (42). Here, I use the able-bodied, Normative gaze as the dominant and Disabled people and the Disabled gaze as the minority population.

It is how stereotypes such as dependency, isolation, and infantilization are constructed by the Normative gaze, and how the repudiation of such ideas should be implied within the Disabled gaze, but are often suppressed for the benefit of the able-bodied characters which concerns me. In *Wait Until Dark*, for example, I reveal how Suzy’s (Audrey Hepburn’s) blind gaze is suppressed by the dominant Normative gaze to keep Suzy helpless and dependent. But first, I review the kinds of blindness portrayed on screen to show how stereotypes of dependency and helplessness are tied to blindness.

SEEING BLINDNESS ON SCREEN

Georgina Kleege in her essay, “Blind Nightmares,” chronicles how blindness is often portrayed in film. She writes, “The movie blind...are timid, morose, cranky,

resentful, socially awkward, and prone to despair. Actors represent blindness with an unblinking zombie-like stare, directing their gazes upward to give the face a supplicating look of helplessness” (45). Kleege’s presumption that blind characters have their own distinct gaze has not been largely recognized or theorized in general film theory, and when it has, as in Linda Williams essay, “When the Woman Looks,” blindness is generally considered as simply an impairment, a sensory lack, an inability to see. Williams theorizes, “to see is to desire” and thus “Blindness...signifies a perfect absence of desire” (561).

However, Williams and other feminist film critics have recognized changes in female representations in film. Molly Haskell suggests that the typical female character of sixties and seventies films was “a mail-order cover girl: regular featured, [with an] inability to convey any emotion beyond shock or embarrassment and an inarticulateness that was meant to prove her ‘sincerity’” (329). Given how women were generally portrayed in films in the 1960s and 1970s, the supposedly desireless and dependent blind female portrayed in films such as *A Patch of Blue*, *Blink*, *Ice Castles*, and *Wait Until Dark* may not seem that far afield from nondisabled female characters in cinema. There was, however, a cultural shift in the portrayal of woman in mainstream cinema in the late seventies to “strong,” liberated women like independent divorcee Meryl Streep in *Kramer vs. Kramer*, union-organizing Sally Field in *Norma Rae*, and Sigourney Weaver in the original *Alien* standing alone after all the human males and the alien have (supposedly) perished. However, in *Ice Castles* released the same year as *Kramer vs. Kramer*, *Norma Rae*, and *Alien* (1979), the “tragically blinded” ice skater, Lexi, is still dependent.

In the final scene, Lexi has supposedly adapted to her blindness enough to pass as a sighted competitive ice-skater. Though viewers see her blurred view of the rink before her routine, she completes the routine flawlessly. At the routine's end, however, instead of skating approximately to where the exit is, she trips on the roses. Prior to this scene, the audience is led to believe she has learned how to pass successfully. Yet, she does something completely uncharacteristic of her — someone who knows how to pass — and of most competitive skaters; she attempts to pick up roses off the ice. Instead, her gaze, constructed as sufficient, if not powerful, at the beginning of her routine, is, in the end, co-opted by the Normative gaze. Lexi is once again helpless and dependent, her blindness constructed as a liability. "Don't leave me," she pleads to love interest Nick as he helps her to her feet on center ice. Of course, Nick doesn't, assuring Lexi and us that he will always be her eyes, that she will always be dependent on his gaze to negotiate the world. Thus, we can see that able-bodied women's portrayals have changed. The portrayal of disabled women, specifically Blind women, though, has not changed.

I would suggest that the film's representation of blindness, because it is predicated on ableist notions of the physical act of seeing, represents a marginalized position in relation to the sighted. Blind people are presumed not to be able to possess the ability to gaze, or to gaze well enough, and remain the object of the dominant gaze. But, as Alenka Zupančič asserts in his essay, "Philosopher, Blind Man's Bluff," the blind do possess their own gaze. He writes, "The blind man does not function as the opposite of those who see. As a (blind) *man* he perceives in his own way everything that others do" (32; italics in original). Zupančič, with his italicized use of the term (*blind*) *man*, claims, in the same way as hooks does for black women, a distinct minority community and

viewpoint. Yet, just as the Black female gaze is co-opted as hooks suggests, the Blind gaze, is often suppressed by the able-bodied and their Normative gaze. As Kleege points out in her examinations of representations of blind women as “gazing upward to give the face a supplicating look of helplessness,” this configuration of blind women as helpless is a continuing trend (45). Therefore, an examination of an older film like *Wait Until Dark* is still pertinent to larger questions within Disability Studies and film.

TRESPASSING AND TRANSGRESSING: SUZY’S WORLD IN *WAIT UNTIL DARK*.

Wait Until Dark, directed by Terance Young, stars Audrey Hepburn as Suzy Hendrix, a woman recently blind who is unwittingly caught up in a drug plot as the possessor of a doll filled with heroin. At play are two major stereotypes: Suzy as determined overcomer intent on being “the world’s champion blind lady,” and Suzy as helpless victim who will fail to achieve that championship status. Though she does “outsmart” the henchmen and is ultimately reunited with her husband, her gaze is continually co-opted, rendering her still dependent. It is the second stereotype, her configuration as isolated, powerless victim that I set my sights on here.

Throughout much of the film’s stalking scenes, we see Suzy as isolated, literally. Young uses the visual metaphor of a prison, filming her, for instance, behind a banister after she learns her phone line has been severed. It is precisely her blindness, her perceived inability to “gaze,” which keeps her isolated and helpless and her helplessness drives the film.

Suzy is often dependent on a seven-year-old girl named Gloria for her connection to the world while her husband Sam is absent. Gloria, a neighboring child who brings Suzy groceries, takes on a significant role. Just before she leaves, Gloria peers out of Suzy's kitchen window and informs Suzy that there is no police car outside, only a truck. Suzy is dependent on Gloria's sighted gaze to know that the henchmen have only been posing as cops. After the henchman, Mike, leaves her apartment, Suzy signals for Gloria to return to the apartment by tapping on the water pipes in her kitchen. Gloria arrives and Suzy gives her a set of instructions about calling the police and meeting Sam, telling Gloria to bring him back to the apartment. Usually this kind of scene would be depicted as the adult instructing the child. Not here, however. As she is instructing Gloria, Gloria stands over Suzy, and holds her hands. Viewers get a close-up shot of Gloria's face, as she peers down at Suzy. Through employing Gloria's Normative gaze, a transference occurs. In essence, Suzy becomes the child and Gloria the adult in this reversal of roles and power. The audience knows this because, just as Kleege notes, Suzy's gaze is directed upward, signifying her helplessness. At the precise moment when Suzy should be empowered, her ability and power, her Disabled gaze, is co-opted by Gloria's Normative gaze.

The climatic scene only further compounds her infantile and powerless status. As she prepares for the confrontation with Rout, the head henchman, we are treated to a series of shots involving Suzy unscrewing and breaking light bulbs. This preparation scene is her transgression. That is, the only way for Suzy to win her battle with Rout is to fight it on her terms, i.e. to disable him by "blinding" him, causing him to enter "her"

world. Indeed, much of the fight scene occurs in the dark with only Suzy's screams as our guide.

At the beginning of the confrontation, the audience knows that Rout has the "upper hand" as he pours gasoline around the apartment. This scene is shot entirely from Rout's point-of-view as we get shots of Suzy imploring, "What are you doing?" and then sniffing and exclaiming, "Gasoline!" Rout's objectifying gaze is meant to render Suzy as powerless. This scene changes to depict the supposed transfer of power from Rout to Suzy when she asks, "Mr. Rout, are you looking at me?" He answers, "Yes," affirming his gaze and position. Then, she throws the acid she has already put in the table vase on his face, "disabling" him. Power supposedly transfers here, but Suzy's gaze is still largely dependent on his affirmation for her to act. Suzy is not a wholly independent character. She does not rely only on her own senses to tell her Rout's position in the room — that he is close, where his head is, etc. Also, acid coming into contact with any part of Rout's body would have disabled his movements, so her insistence on knowing whether he is looking at her is perhaps neither logical nor necessary for her to act. It is not necessary for her to "blind" him to "disabled" his movement. Acid thrown in his general direction, as she does just seconds later, would be enough. Her reliance on his verbal cue is simply meant to remind viewers of the power of sight, and of both her powerlessness and of her stigmatized status as Other.

In the climatic confrontation, she struggles with Rout. Though she is able to gain possession of Rout's knife and douse him with gasoline, she depends on him still. She

tells him to tap her white cane (he does), so she can sense where he is. Again, her dependency is highlighted. Instead of relying on her own senses — listening to his footsteps, his labored breathing from their struggle — she depends on Rout's actions.

As the confrontation continues, we glimpse her dragging herself away from Rout, screaming. Viewers can assume that she stabs and kills Rout while the screen is darkened. When Sam and Gloria come to save her, though, what viewers see is not a strong and capable heroine, but a weak and fearful one. Her back to the audience, Suzy is wedged between the refrigerator door and the wall, afraid. The transgression into Suzy's world of darkness, her supposed "gaze," ultimately fails. In the end, she is still dependent on Rout and his gaze to supply her with the power she needs. Like *Ice Castles*, as Suzy flies into Sam's embrace, viewers are led to believe that the gaze of the sighted partner will protect her. Suzy's Disabled gaze remains suppressed by the Normative gaze; her gaze remains the disempowered one.

While my discussion has so far centered on the suppression of the Blind gaze to other characters in the film: Lexi to Nick, Suzy to Gloria, and even Bette Davis toward her partner, it's interesting that in each of these films there are moments and scenes where the Blind gaze is directed not at another character but through the camera at us the audience. In Suzy's fight scene with Rout for example, she keeps lighting the match as Rout taps toward her. In reality, as a Blind woman, there is no need for her to continue to light the match; it does her no good. She lights the match for the benefit of the audience, and proceeds to stare out at us through the camera with a "zombie-like stare" denoting her helplessness even then. During Lexi's routine, the camera frames her so she's staring not at the audience in the rink, but at us. She stares straight ahead at the moviegoing

audience while her skating audience in the film is behind her or at her sides. Likewise in Bette Davis's deathbed scene she stares straight ahead, dying illuminated in a key light. I am not so much interested in the camera as an apparatus itself filming a blind gaze. Rather what is interesting to me, if we are to believe Zupančič's contention that "a blind man perceives in his own way everything that others do," is the presumption that all blind characters possess a zombie-like stare, an ableist assumption about what and how blind people see. In the real world, most blind people that I know, like the rest of us, are taught sighted conventions of Normalcy, i.e. regardless of what exactly a blind person may actually see, proper etiquette schools us to turn toward the person we are having a conversation with. If a person is sitting next to a blind person engaged in conversation, the blind person does not sit next to someone staring out at nothingness, but rather turns toward the person they are talking to.

In *Ice Castles* when Nick and her coach are schooling Lexi in how to pass, this skill is highlighted. As they are walking backstage Lexi is linked arm-in-arm between the two. As her friend who does not know she is blind approaches, Lexi whispers, "Now?" and they tell her "not yet." As Lexi and her friend are about to pass each other side-by-side, Nick says "Now" and Lexi turns her head toward her friend and says, "Hi." All of this is filmed in a pan shot by the camera, so we see the whole scene. Never does the camera shoot Lexi's face directly here in this scene, for she does not possess that zombie-like stare here; she is passing as sighted, and the camera films her in an appropriate manner. Yet, at the end of the film, when the viewing audience is once again supposed to construct Lexi as helpless, Lexi has a brief moment where she once again stares out at nothing. Likewise, when Audrey Hepburn's Suzy is interacting with Gloria in a typical

manner, such as running around the apartment and staring out the window, the camera films her from the side while in motion. It is only when viewers are supposed to remember that the blind are stereotypically helpless, such as the “prison bar staircase scene” or the ending scenes where her face is illuminated for us by matches, that we get a close-up shot of unfocused zombie-like eyes staring at nothingness. Again, this is not, for me, a question of apparatus theory, i.e. how is the film camera supposed to film a “blind” gaze, for we already know the answer: no differently than it is supposed to film the gaze of the sighted person, unless the stereotype that blind people see *nothing* (which is not true, most blind people have some level of residual sight) and are dependant needs to be reified and showcased on film. Camera shots of the disabled character’s gaze will be showcased in a different way in Disney’s *The Hunchback of Notre Dame*.

OF MONSTERS AND MEN:

GAZES IN DISNEY’S *THE HUNCHBACK OF NOTRE DAME*

Unlike many films dealing with disability, Disney’s *The Hunchback of Notre Dame* has several shots which employ a Disabled gaze, through the character of Quasimodo.¹⁶ This is a marked departure from earlier Disney films such as *Pinocchio* or *Dumbo* where film viewers are given solely an able-bodied perspective, a Normative gaze. Disney executives are clear about their intent in the film. They claim:

Our film tells the story of a person who is made at first to feel deformed, but learns he has great value as a human being. Everyone comes to learn

that it's who you are inside that matters most. It does not suggest, state, or imply that persons with disabilities should be socially ostracized. (Shaw, Barrett, "Why Disney Can't Control Hunchbacklash" 4)

While Quasimodo may not end up being socially ostracized, he is isolated throughout much of the film. Implicit messages are also made about his power, infantilization and sexuality, or lack thereof, through how the Normative gaze objectifies his body, and in how his Disabled gaze is often co-opted.

Seeing the disabled as asexual and infantile is not a new phenomenon. As Tom Shakespeare writes, "As in other areas, disabled people are displaced as subjects, and fetishised as objects." Further, "Stereotypes of disability often focus on asexuality....Just as children are assumed to have no sexuality, so disabled people are denied the capacity for sexual feeling" (*The Sexual Politics of Disability* 10). Disney's Quasimodo often embodies these stereotypes.

For the audience to render Quasimodo as asexual, or at the very least, as infantile, two things must happen. First, Quasimodo must be seen as isolated, making him both physically and socially ostracized. Quasimodo is both physically and socially isolated. He is confined to the bell tower, with only (talking) stone gargoyles and his bells for companions. With only two notable exceptions, all the principal characters must come to him to interact with him. Second, he must somehow be rendered, for lack of a better term, impotent. Both of these perspectives can be seen through analyzing the shots that contain Quasimodo's gaze, and showing how it serves to reify ablist assumptions of sexuality and disability. I am suggesting that Quasimodo's gaze is co-opted and disempowered.

The first time Quasimodo experiences agency in the film is when he ventures out to the Festival of Fools, and he becomes, at first, the King Fool. After a couple men

throw tomatoes at him, the crowd turns from festive to jeering and Quasimodo is tied to the stone platform. This further isolates him from the crowd. This isolation is reinforced through the first shot that is Quasimodo's Disabled gaze. As he is being spun around, the audience gets a panoramic shot of the blurred crowd. This moment when the viewer's perspective shifts from on-looker to Quasimodo's perspective could be interpreted as a moment where the viewer is supposed to identify with Quasimodo. The shifting to Quasimodo's viewpoint, however, focuses the viewer's attention on Quasimodo's state of isolation, as an *object*. Quasimodo is certainly the *subject* in the festival sequences, and while that itself could imply a sense of agency, it does not. Quasimodo is powerless to act in the "real" world outside of the church. "Master, help me," he begs Frolo, and finally he must rely on Esmeralda to free him. He remains powerless to act; rather he is an object that must be acted upon. The Normative gaze objectifies him and renders his Disabled gaze at the festival powerless and co-opted.

Afterward, Esmeralda visits Quasimodo at the church. As she enters, Quasimodo peers down at Esmeralda from above. While his gaze could be read as possibly romantic, no mutual exchange of eye contact signifying the possibility of some kind of relationship occurs. Quasimodo's gaze only serves to remind filmgoers of his isolation. He is not on the main floor of the church, but tucked away in the rafters, so-to-speak. The church, not Esmeralda, is Quasimodo's companion and territory. His gaze holds no power, no agency.

When Esmeralda first visits his home among the church bells, viewers see Quasimodo with his back to the camera, obviously Esmeralda's gaze, where the mise-en-scene and diegetic properties in the shot are the bells, which he is running among and

ringing. He is showing them to Esmeralda whom we don't see in the shot. He has named the bells female names such as Ginamarie. Likewise, when he is showing the figurines he makes to her, the shot is just of him and the little miniature people he creates. In these shots, Esmeralda gazes at everything, including Quasimodo, as though they are simply objects to be looked at.

Several transferences occur here. First, Esmeralda (and the filmgoer) is supposed to see Quasimodo as *object*, as something to be gazed upon, like the bells, the fake, wooden miniatures, the interior of the church itself. In no way is he supposed to be seen as anything more than a friend to Esmeralda. She, then, can and does transfer her romantic intentions to Pheobus. Second, Quasimodo has, and so have we, transferred sexuality, at least for the moment, away from Esmeralda to those female bells, and in some sense to the inner and outer sanctums of the church itself. They are his companions, not Esmeralda.

Quasimodo's gaze at the end of the film further signifies his status as asexual. After he, Pheobus, and Esmeralda have saved Notre Dame and the town, Quasimodo hugs Esmeralda. Since Quasimodo finds her at the Court of Miracles, rescues her, and provides her sanctuary, viewers might expect a sexual or romantic fulfillment between Esmeralda and Quasimodo. As Altman writes of "conventional musical romance," "two characters represent disparate, seemingly incompatible worlds; through romance (and music), their worlds are eventually merged and harmonized in the creation of the heterosexual couple" (qtd. in Erb 52). But the romantic coupling is between Esmeralda

and Phoebus. The camera zooms in on a close-up of Quasimodo's hands joining the hands of Phoebus and Esmeralda. Then Quasimodo steps out of the frame. Again, the church, not Esmeralda, is his companion.

Phoebus and Esmeralda emerge victorious on the steps of Notre Dame. Esmeralda then goes back into the church to get Quasimodo. We get a close-up shot of her face that fills, and exceeds, the frame. The gaze is definitely Quasimodo's, as her head is tilted slightly downward denoting that the gazer is looking up. Then, her hand exceeds the boundaries of the frame. This shot could be read as a shot in which she is reaching not only for Quasimodo, but also for us, the audience, implying that we must align ourselves with Quasimodo as an isolated "Other," thereby recognizing the Other within ourselves.

While this is plausible, such a reading problematizes neither disability stereotypes of asexuality nor of infantilization. In fact, in other shots in the film Quasimodo is as tall as Phoebus, or nearly so. But here, Esmeralda's Normative gaze literally infantilizes him. Even though spectators may experience a momentary identification with Quasimodo, his gaze serves to remind viewers of his asexual and infantile status. Quasimodo remains an isolated "Other."

After he emerges on the steps with Esmeralda, the ending sequences remind viewers that he is still an isolated and sexually impotent figure. Tom Shakespeare writes the following about disabled people's sexuality:

In modern Western societies, sexual agency (that is, potential or actual independent sexual activity) is considered the essential element of full adult personhood, replacing the role formerly taken by paid work: because disabled people are infantilized and denied the status of active subjects, so consequently their sexuality is undermined. This also works the other

way, in that the assumption of asexuality is a contributing factor towards the disregard of disability....Disabled people are often subject to infantilization, especially disabled people who are perceived as being 'dependent'. (10)

Quasimodo's dependency has already been established in the festival sequences. When he is brought out onto the church steps, the adult townspeople gasp and shrink back in horror. It is the blond-haired child who approaches Quasimodo and who touches him, while the adults look on. The little girl does not get her own "gaze" shot — there is no close-up frame of Quasimodo's face as seen by the little girl. Instead, viewers get a fleeting close-up of the little girl's face as Quasimodo gazes at her. Two messages can be read in this exchange: that the child holds no important perspective or position, thereby rendering her powerless and infantile, and that it is Quasimodo who must align himself with the child, not vice-versa.

This idea holds a three-fold purpose: first, it reifies the adult, Normative gaze which is held throughout this scene as *the* dominant gaze; second, it reinforces the idea of infantilization, and therefore asexuality for Quasimodo; and, in so doing, third, it protects the able-bodied townspeople from seeing themselves in Quasimodo. Using Quasimodo's gaze to align him with the child renders him both asexual and child-like. He is still an isolated, asexual Other.

While some might argue that the townspeople's cheering and lifting him up signify a sign of acceptance into the able-bodied adult community, I do not agree. In the same way that his presence at the festival was not a sign of acceptance, but of ridicule and isolation, the cheering here can be seen as an objectification of him as well. Whereas then he was isolated and an object of ridicule, now he remains isolated from the adult townspeople as an object of heroism. As Wolf writes, "Quasimodo is still portrayed as an

ugly, half-formed creature who bounces between being a wimp and a superhero” (32). The ending shot of the film signifies no breaking of either the infantile stereotype or of isolation. The Disabled gaze remains co-opted as Quasimodo remains sexually unfulfilled and isolated.

STARING BACK — RESISTANCE AND NEGATION

The idea that, because of medical technology and genetic manipulation, the future will be “free” of disability and disease is not new, or, given current strides in medical technology, perhaps farfetched. The punch line to many jokes about cryogenic technology, for instance, is “Freeze me till they find a cure.” This line of thinking presumes that disability is nothing more than impairment. If, however, we shift our definition of disability to a social construction through the presence of second-class citizenry, as in *Blade Runner* or *Gattaca* or through a more inclusive definition of identity as in *The Matrix*, or even helpless, dependant child-like heroines and heroes, we might begin to rethink how we understand disability

This shift necessitates not only a rethinking of how we understand disability, but also how we conceptualize cure. In the sci-fi films, the concept of “cure” is seen from a medical perspective, as something that can be garnered through the use of technology. Still, in all these disability-themed films, from Vincent in *Gattaca* to the blind heroine Suzy, the need or desire of medical cure depends on the character’s (and the viewer’s) belief that disability is a “less than” state, that normalcy is the desired bodily state. But if we understand that defining disability as helpless and dependent are a societal

constructions, then we can begin to see how the idea of cure as a Utopian panacea is also a construction. Like the metaphor of the spoon in *Matrix*, if you believe there is no spoon, if you do not believe there is anything that *needs* to be bent, then you are “free.” If you do not believe there is a disability, if you do not believe there is anything that needs to be “cured” or genetically prevented — that disability is indeed a social construction — then you may likewise be freed from the need for cure.

Throughout this chapter, I have presumed certain things about audience and spectatorship. Specifically, I have assumed that the audience and the majority of filmgoers are able-bodied and, consciously or unconsciously, are thus imbued with ableist stereotypes regarding disability. My use of “we” encompasses both able-bodied and disabled spectators. The question of the role of the disabled spectator — of what happens when the disabled filmgoer “stares back” — was not my main concern. It is, however, an important question. bell hooks comments on black female spectatorship when she writes, “Many Black women do not ‘see differently’ [from White filmgoers and their readings of on-screen blackness] precisely because their perceptions are so profoundly colonized, shaped by dominant ways of knowing” (210). Whether we, disabled filmgoers, have bought into ableist stereotypes regarding disability is unknown but important to consider. hooks writes, “Critical black female spectatorship emerges as a site of resistance only when individual black women actively resist the imposition of dominant ways of knowing and looking” (210). Looking at not only the ways Disabled people are configured on screen, but also examining the Disabled gaze in film itself, and how it is often (mis) used by the dominant/Normative gaze furthers conversations about how we, Disabled and Able-bodied filmgoers alike, look at and understand disability and

cure. Looking, however, is not the only way of knowing disability. Accepting one's own body as disabled is another. In the next chapter, I turn to the questions of lameness, the grotesque, and representations of disability and cure in twentieth-century literature.

NOTES

¹ There is only one known surviving copy of the film, housed at the University of Michigan. My comments are based on Pernick's account.

² More, Thomas. *Utopia*. More argues for euthanasia of certain members of Utopian societies if the rest of society agrees that a member has outlived his/her usefulness (60).

³ For further reading, Perry Anderson's *The Origins of Postmodernity* (London: Verso 1998), has been a helpful text.

⁴ See the introduction in Cristina Degli-Espositi's *Postmodernism in the Cinema* New York: Berghahn, 1998 for further explanation. See also Judith B. Kerman's "Technology and Politics in the *Blade Runner* Dystopia" in *Retrofitting Blade Runner* (Bowling Green: Bowling Green State UP, 1997).

⁵ I forego a more detailed discussion of the past, the present, and history, as it relates to Postmodernism here. See the writings of Jean-Francois Leotard, Jürgen Habermas, and Fredric Jameson for reference.

⁶ See the "Utopia" section of *The Jameson Reader* for further reading about Utopia.

⁷ See Erving Goffman's seminal work, *Stigma: Notes on the Management of a Spoiled Identity* (New York: Simon and Schuster, 1963), and later thinking on the concept of stigma as it applies to disability in such works as Lennard J. Davis's *Enforcing Normalcy: Disability, Deafness, and the Body* (London: Verso, 1995), and Harlan Lane's *The Mask of Benevolence: Disabling the Deaf Community* (New York: Vintage, 1993).

⁸ See Paul M. Sammon's *Future Noir: The Making of Blade Runner* (New York: Harper Collins, 1996).

⁹ Kerman, Judith, ed. *Retrofitting Blade Runner: Issues in Ridley Scott's 'Blade Runner'* and Philip K. Dick's *'Do Androids Dream of Electric Sheep?'* (Bowling Green: Bowling Green State UP, 1997).

¹⁰ For more on cinematic stereotypes of disability, see the introduction to Martin F. Norden's *The Cinema of Isolation: A History of Physical Disability in the Movies* (New Jersey: Rutgers UP, 1994).

¹¹ For more on religious interpretations of *The Matrix*, see Paul Fontana's "Generation Exile and Neo Restoration," as well as on-line articles located at: <<http://awesomehouse.com/Matrix/parallels.htm>>.

¹² When referring to the film, I use italics. When referring to the corporation within the film, Gattica is in regular typeface.

¹³ Henceforth, when I refer to Vincent passing as Jerome Morrow, I will denote "Jerome" in quotation marks. When referring to the "real Jerome Morrow" (Jude Law), I will refrain from using quotation marks.

¹⁴ See Rosemarie Garland-Thomson, *Extraordinary Bodies: Refiguring Physical Disability in American Literature and Culture* (New York: Columbia UP, 1997).

¹⁵ See Mulvey, hooks, and Teresa de Lauretis's "Film and the Visible" in *How Do I Look?* Ed. Bad Object-Choices (Seattle: Bay P, 1991): 225-76.

¹⁶ Because *Hunchback* isn't a "horror" film, I don't consider Quasimodo's gaze to be a "Monstrous" gaze. For that discussion, see Rhonda J. Berenstein's chapter, "Looks Could Kill: The Power of the Gaze in Hypothesis Films," in *Attack of the Leading Ladies: Gender, Sexuality, and Spectatorship in Classic Horror Cinema* (New York: Columbia UP, 1996): 88-119.

CHAPTER 3

AND THE LAME SHALL NOT ENTER: LITERATURE OF O' CONNOR AND MORRISON

Toward the close of Toni Morrison's novel *Sula*, Sula and friend Nel have the following dialogue as part of a goodbye scene:

"How do you know?" Sula asked.

"Know what?" Nel still wouldn't look at her.

"About who was good. How you know it was you?"

"What do you mean?"

"I mean maybe it wasn't you. Maybe it was me." (146)

On the surface, this is a relatively simple question about ethics and actions in the novel. Yet, this question undergrids much of what happens in the novel and also speaks to the questions that motivate this chapter. How do readers of *Sula* know how Eva lost her leg? How do we know Eva really hates Hannah's father BoyBoy? How do we know if Shadrak had seen the drowning death of boy Chicken Little at the hands of Nel and Sula? How do readers of Flannery O'Connor know if Johnson committed robbery (before the final confrontation) in her story "The Lame Shall Enter First"? How does Joy/Hulga know if she can trust Manley Pointer when she shows him her fake leg?

How do we know?

Ostensibly, O'Connor's short stories and Morrison's novel are all about the idea and process of knowing: knowing how the world around you sees you; knowing what is real or true about yourself; knowing what it is you desire. Sula's question seems large and looming in its own way.

The field of Disability Studies, indeed all literary study, has asked this question at one time or another: how do we know what it is we know about ourselves, about how we see ourselves both in literature and in the world? While Disability Studies scholarship in literary study has concerned itself largely with the issue of negative representations of disability in literary texts, what lies behind that question is the larger one of "knowing." If representations of disability in literature, like film, are largely negative, where Richard III moral "crookedness" is denoted physically with a crooked spine, or where Oedipus's punishment for sleeping with his mother is blindness, then how do disabled people know any different?¹ How are we to escape the firmament of negative representations around us?

That's, of course, a larger question than a reinterpretation of a few literary texts can handle. However, each of the disabled characters I examine in the stories of Flannery O'Connor and Morrison's novel *Sula*, struggles with some form of that question of knowing and defining what a disability might mean for oneself. The particular lens through which I examine these characters is Bakhtin's theory of the grotesque. Grotesqueness is a label and idea played out in literature and film, from the monstrous *Frankenstein* to the family of Sideshow freaks in Katherine Dunn's *Geek Love*, that fuels literary representations of disability as negative. However, a closer examination of the

disabled characters in the O'Connor and Morrison texts leads to a re-interpretation of what others in society consider grotesque about the disabled in literature. Though O'Connor and Morrison both employ the idea of the grotesque, implicitly or explicitly, in these stories, they "invert" the grotesque asking readers to question what they believe is normal and what they believe is abnormal. While the prevailing assumption, for instance, on the part of Joy/Hulga's mother is that there is something "wrong" with Joy/Hulga that needs to be cured, O'Connor's and Morrison's use of the grotesque helps to point out that the need for cure is a socially-defined assumption. O'Connor and Morrison use the grotesque as a way of getting us to question who we are (disabled readers and readers of all types) and indeed how it is we know what it is we know.

Much of the critical work about disability and literature centers on representations, and Lois Keith specifically connects representations to the concept of cure. I provide a brief overview of literary representations of disability as background and context for my study.

LAME LITERATURE: REPRESENTATIONS OF DISABILITY

While recent work on disability in literary studies, notably in David Mitchell and Sharon L. Snyder's *Narrative Prosthesis: Disability and the Dependencies of Discourse*, has situated disability within larger schools of literary thought (calling, for instance, Katherine Dunn's novel *Geek Love* about a family of sideshow freaks "Postmodern Geek"), much of the early scholarship on disability and literary studies focused on so-

called negative imagery. In the early collection, *The Handicapped in Literature: A Sociological Perspective*, for instance, sociologist Eli Bower critiques H.G. Wells' short story "The Country of the Blind." Bower reads Nunez, a sighted character living in a Blind community as both normal and not normal, saying, "From a behavioral, cultural, and statistical point of view Nunez is deviant. From a biological structural point of view, Nunez is normal and the Citizens of the Country of the Blind are deviant" (89). Bower's observations usually goes no further than this (he is not a literary scholar, after all), but his work is important because of how early it was relative to the publication for instance of Davis' *Enforcing Normalcy* (1980 v. 1995). Davis' work caused scholars to look anew at the concept of normalcy as applied to literature and culture and, I would suggest, helped create interest in older work such as that of Bower. Bower recognized the importance of literature as significant in its own right to the field of disability, claiming, "We need and search for a balance between these kinds of knowing — the artistic/literary and the empirical/scientific" (5).

Similarly, John Quickie's work *Disability in Modern Children's Fiction* recognized what Disability Studies scholars now call "the inspirational stereotype" as a particular kind of disability representation. He writes of reviews of children's literature, "Clichés abound — 'a heartwarming story' or 'one that serves as an inspiration to those similarly afflicted'" (6). While such exposing of stereotypical representations is important and is still useful, and the issue of negative representation has been explored in other essays such as Lennard Kriegel's "The Wolf in the Pit in the Zoo: The Cripple in

Literature,” it is Mitchell and Snyder who take this a step further. They write of their approach, “Instead, each of the chapters analyzes literary works as *commentaries* on the status of disability in other disciplines such as philosophy, medicine and ethics” (1; italics in original). Hence, their analysis of Dunn’s *Geek Love* provides, at its conclusion, the following social commentary:

In comparison to the “real” deformities spotted by the sideshow’s human oddities, the geek was a “behavior” that paid homage to the physical specimens catalogued just beyond the flap of the circus tent. The “performer” whetted the appetites of its audience for increasingly outlandish spectacles promised by the freak show itself. The geek constructed its own status as a “living anomaly” out of the malleable tissue of behavior — biting off the heads of chickens and rats...before they imbibed the real thing. In doing so, the geek demonstrated that “freakishness” was a state of mind: packaged to appeal to its audience yearnings for the unusual. (162)

In this way, those familiar with Dunn’s novel and who bristle (as my students did) at the ingestion of pesticides in order to “create” freaks, can read *Geek Love* as a particular social commentary, not on the Binewski family of circus freaks, but upon societal desires for the unusual more generally. Mitchell and Snyder push readers to question their own role (and the ethical roles of family and medicine) in the perpetuation of normal/abnormal social binaries and labels.

While scholarship on disability and literature has indeed mostly concerned itself with issues of representation and normalcy, Lois Keith’s book *Take Up Thy Bed and Walk: Death, Disability and Cure in Classic Children’s Fiction* explores the idea of cure quite directly, tying it to the way that disabled characters operate and are represented in fiction. She writes, “From the 1850’s, up until very recently (and even now writers kill

or cure their disabled characters with worrying ease), there were only two possible ways for writers to resolve the problem of their character's inability to walk: cure or death" (5). This is similar to Martin Norden's theories about cinematic representations of "sweet young things whose goodness and innocence are sufficient currency for a one-way ticket out of isolation in the form of a miraculous cure" (3). Keith contends, "In stories where such a [unpleasant physical] condition is portrayed as fated or irredeemable, the likely ending is death" (23).

At the end of this chapter, I write about a presentation I gave on disability and performance. In response to a professor's question about the ubiquitous nature of the concept of cure among the disabled population, I make a claim that all the performance artists I explore in Chapter 6, whether explicitly dealing with cure or not, know that such an idea exists in relation to them. I make such a claim based in part on my own experience, but also because of what theorist Keith lays out in listing major stereotypes of disability representations in literature (representations echoed in other artistic work as well). She writes:

This cure is somehow so central to the outcome of the story, so expected, that I and generations of readers and countless commentators have failed to notice it or remember its significance. But even as we failed to take account of it, we were storing up enough perceptions about disability to last a lifetime. We were learning that: (1) there is nothing good about being disabled; (2) disabled people have to learn the same qualities of submissive behaviour that women have also had to learn: patience, cheerfulness and making the best of things; (3) impairment can be a punishment for bad behaviour, for evil thoughts or for not being a good enough person; (4) although disabled people should be pitied rather than punished, they can never be accepted; and (5) the impairment is curable.

If you want it enough, if you love yourself enough (but not more than you love others), if you believe in God enough, you will be cured. (7)

Keith's listing of stereotypes connects the notion of cure to the issue of "negative representation" expressed by Mitchell and Snyder and others.

Lennard J. Davis, in his new book, *Bending Over Backwards, Disability, Dismodernism and Other Difficult Positions*, claims that "the novel as a form relies on cure as a narrative technique" (99). He sees cure mostly as metaphor writing, "When characters change, they undergo a kind of moral or perceptual or moral transformation that cures them. So Emma is cured of her self-centeredness and D'Arcy is cured of his pride" (99). Keith likewise looks at cure as mostly "a powerful metaphor," and her analysis is important for its connection to the issue of cultural perceptions about lameness that I explore in O'Connor's and Morrison's characters. Keith states the following:

But for such a metaphor to work, it must be based on widely accepted images and beliefs: that to be made lame or crippled is some kind of punishment and to walk again is good and right. Such use of metaphor calls on the widely held belief that 'not walking' is a passive and unhappy state which renders the victim powerless, and that a release from that state is desirable above all else. (249)

For Keith, lameness signifies both punishment and unhappiness while the physical act of walking is both an actual and emotional "cure."

O'Connor and Morrison, I would suggest, contest these stereotypes of punishment and unhappiness (and the desire for cure) through the actions of their characters. Though a survey of the literary work of O'Connor and Morrison reveals, of course, many characters with all kinds of impairments from the blind Hazel Motes in *Wise Blood* to the

navel-less Pilate in *Song of Solomon*, I center my analysis in this chapter on O'Connor's short stories "Good Country People" and "The Lame Shall Enter First," and Morrison's *Sula*. My choice of texts is in part because of Keith's idea that lameness is equated with a need for cure (to walk again), in part because the missing or deformed limb is often characterized as particularly unsightly or grotesque culturally.² I wish to explore particularly how the deformed limb is used to invert cultural readings of the grotesque in these works.³ An inversion of the "negative" grotesque, again, to what Rosemarie Garland-Thomson claims are Morrison's "powerful women" calls into question what readers may think of as normal/abnormal, and thus, who (or what) is (morally, if not otherwise) in need of cure. By inverting the grotesque through re-reading the deformed limb, O'Connor and Morrison provide a way of displacing the need for cure from the disabled character onto society. In other words, their work attempts to provide a new social construction of disability in which the disabled person is viewed as sufficient in his/her own right, but society is viewed as deficient for perpetuating grotesque stereotypes about the disabled.

BAKHTIN'S LITERARY GROTESQUE: SOUTHERN LITERATURE AND THE ACT OF BECOMING

In his chapter entitled "Freaks and the Literary Imagination," from *Freaks: Myths and Images of the Secret Self*, Leslie Fiedler writes:

The real world of show Freaks...have turned human prodigies into metaphors for something else: the plight of the artist, the oppression of the poor, the terror of sexuality, or the illusory nature of social life. They provide us, therefore, with no satisfactory clue to what it is like to be a performer of one's own anomalous and inescapable fate. (273)

The freak show or freak oddity (a la Dunn's *Geek Love*) has often been thought of as the physical embodiment of those in society called "grotesque." While the Freak Show itself has since receded into the annals of twentieth-century carnival history, the idea of the freak as someone outside the boundaries of societal normalcy continues to pervade our world. As Robert Bogdan claims in *Freak Show: Presenting Human Oddities for Amusement and Profit*, "Freak is a frame of mind, a set of practices, a way of thinking about and presenting people" (3). The idea of freak as oddity and as a measure of social boundaries can be traced back to a time before the twentieth-century. As Chris Baldick tells us in his work, *In Frankenstein's Shadow: Myth, Monstrosity, and Nineteenth-Century Writing*, the monster is a being or cultural embodiment that has a specific societal purpose "to reveal the results of vice, folly, and unreason as a warning to erring humanity. . . . The monster is one who has so transgressed the bounds of nature as to become a moral advertisement" (10-12). To be monstrous, then, is to teach others proper behavior by illustrating the results of breaking socially accepted codes of conduct, disobeying parents, laws, or norms, or altering nature.⁴

In this way, we see the grotesque body as embodying a set of social codes designed to teach others the limits of proper and improper behavior. The grotesque body is not only visually grotesque, a la "freak" bodies, but is also symbolically grotesque, existing outside social bounds of normalcy. Noted for his work in the grotesque, Mikhail

Bakhtin in *Rabelais and his World* explores notions of the grotesque body, particularly in the context of the ritual *Carnival* or the *carnavalesque*. Bakhtin's work is notable for two reasons. He argues, unlike others who saw the grotesque as negative, for a sort of positive grotesque, writing that the grotesque "liberates the world from all that is dark and terrifying" and it "takes away all fears and is therefore completely gay and bright" (47). Secondly, he argues that the grotesque body is "a body in the act of becoming. It is never finished, never completed; it is continually built and created, and builds and creates another body" (317). Of course, in this section of *Rabelais*, he is essentially referring to the body in transformation, i.e. birth, death, the act of defecation, as ways that a body can be grotesque. For Bakhtin, the body can continually produce grotesque acts such as defecating, and thereby it is in a continual process of transformation. However, we can take grotesqueness in a manner not so bound to literal, actual, physical acts, to mean that the grotesque body is never completed, dependant on others, in a way for its labeling of the grotesque, and also that it is a body always in the process of transformation.

Within Southern literature, the grotesque, according to critic Jeanne Campbell Ressman, "can be tied to an individual's sense of positive power and to the sense of individual freedom. At the same time, the "classical" grotesque illustrates an individual or society's distortion, that is, its distance from some ideal state" ("Women, Language, and the Grotesque" 42). Thus, it seems that the grotesque can function as both positive and negative. Work on the grotesque and O'Connor has largely centered on O'Connor's use of religion and its relation to the grotesque, particularly in Marshall Bruce Gentry's

book *Flannery O'Connor's Religion of the Grotesque* in which he claims that while many critics have focused on O'Connor and the so-called "negative grotesque" readings of her work, she also makes use of the "positive grotesque" as outlined by Bakhtin. He writes:

The typical O'Connor protagonist is oppressed by degradations of society's ideals: by the economy of the South, by ignorance, by physical deformity and disease, by systems of class and race, and by the structures of religion. All of these forms of oppression make O'Connor characters perceive themselves as grotesque in a negative sense, and on the conscious level, the typical O'Connor character sees no prospect for anything but continued degradation. Within this desperate context, the positive use of the grotesque becomes a way to escape some (though not all) oppression. The protagonist may realize that not all the forces of oppression can be banished; the protagonist can, however, take control of one form of degradation, make it more important than the other forms, and then transform that grotesquerie into a force for redemption. (14-15)

In particular, it is this last statement of Gentry's which both intrigues me and which grounds my readings of O'Connor and Morrison's texts. To resist the idea that one's body needs to be cured is to redefine one's own body. In essence, it is to resist societal labeling of a body as deformed, diseased, sick, etc. and in need of cure. It is, to take the degradation forced upon you by others and turn, or "invert" it into a positive attribute, i.e. redefining one's self through the positive grotesque and thereby, rejecting cure.

O'Connor's take on the use of the grotesque in Southern literature is a bit more literal, tied to ideas of plot, character, narrative structure, form. Still, her own reading of the Southern grotesque bolsters Gentry's that the "positive grotesque" can be used to (re) formulate an identity. In her essay "The Grotesque in Southern Literature," she writes:

In these grotesque works, we find that the writer has made alive some experience which we are not accustomed to observe every day, or which the ordinary man may never experience in his ordinary life. We find that connections which we would expect in the customary kind of realism have been ignored, that there are strange shifts and gaps which anyone trying to describe strange manners and customs would certainly not have left. Yet the characters have an inner coherence, if not always a coherence to their social framework. Their fictional qualities lean away from typical social patterns, toward mystery and the unexpected. It is this kind of realism that I want to consider. (*Mystery and Manners* 40)

For O'Connor, the power of the negative grotesque is limited by the character's "inner coherence." The understanding of oneself, as, at times, somehow apart from one's "social framework," which Gentry reminds us consists of forms of degradation, is, I would suggest, a nod to the "positive use of the grotesque." Seeing oneself as apart from a larger social framework is also a "coming to," a self-defined understanding of one's own body. In essence, to borrow from Bakhtin, a body of "inner coherence" is a body that is "becoming." It is these moments that I wish to explore as a way of highlighting a disabled character's resistance to societal need for cure.

Before turning to the primary texts, however, I note that I can find no scholarship on Morrison's use of the grotesque. However, I will suggest that one could (or should) look at the way that disabled characters are accepted into society in Morrison's work as a way of coming to a self-definition, and inner-coherence. In short, community acceptance "inverts" seeing the characters as grotesque by the community. While I don't look at the process of community acceptance and inclusion as a means of "inverting" the grotesque,

specifically, limiting my readings to lameness and naming, I wish to point out that there are multiple ways of reading the grotesque body in Morrison.

THAT HORRIBLE STUMPING SOUND: O'CONNOR AND THE POSITIVE GROTESQUE

In both O'Connor's "Good Country People" and "The Lame Shall Enter First," disabled characters have an impairment dealing with the leg: Joy/Hulga possesses a fake leg which becomes central to the story; Johnson, in *The Lame Shall Enter First*, is a small-time boy-thief with a club foot. Several archetypal disability stereotypes are evident in *The Lame Shall Enter First*. First, the disabled are seen as "less than" the nondisabled. In *The Lame Shall Enter First*, Sheppard, City Recreational Director, who works on the weekends as a counselor at a reformatory for boys tells one of the other boys, "Think of everything that you have that he doesn't!...Suppose you had a large swollen foot and one side of you dropped lower when you walked?...You have a healthy body" (447). Already, then, disability is set up as an unhealthy state and as less than desirable. Second, in the eyes of the nondisabled, as we will see in a different way in "Good Country People," impairment emerges as the paramount issue to the disabled. "Why don't you tell me what's most important to *you*?", Sheppard asks the boy, Rufus Johnson, as "his [Sheppard] eyes dropped involuntarily to the foot" (450). Third, related to the second, and perhaps most important to the story, is the role of the nondisabled as

benefactor. Sheppard arranges for Rufus to get an orthopedic shoe, regardless of Rufus's own desire. Sheppard says, "Your shoe! Today is the day you get your shoe! Thank God for the shoe!" (466). When the shoemaker tells Sheppard, "In that shoe...he won't know he don't have a normal foot," Sheppard "beams with pleasure." (470). The conflict over the shoe which reflects the desires of able-bodied Sheppard and in contrast to those of Rufus Johnson are central to this story and explode in this scene with the shopowner. Rufus declares, "I ain't gonna wear it at all. I don't need no new shoe and when I do I got ways of getting my own." While Rufus's eyes exhibit a "glint of triumph," Sheppard's face is "a dark angry red" as he tells the clerk that Rufus "ain't mature enough for it yet" (470-471). Later that night, Sheppard implores Rufus, "Rufus, you can be anything in the world you want to be...and whatever you set your mind to be you can be the best of its kind" (472). Clearly, the implication is that, in the eyes of Sheppard, Rufus can achieve success in the world only if he appears normal, if his body is presented in a non-disabled state. Sheppard considers Rufus' foot both unsightly, in need of correction, and also as a way that Rufus is "less than" others. His grotesque body must "become" something else. This unsightly, less-than status is in marked contrast to how Rufus, obviously, understands himself.

This contrast in the way Rufus' body is understood leads to the central incident of the story and largely, the central conflict. When it's revealed that Rufus Johnson has indeed continued to commit petty theft even while under Sheppard's care, Sheppard tells Rufus, "That was all you wanted — to shake my resolve to help you, but my resolve isn't

shaken. I'm stronger than you are, and I'm going to save you. Good will triumph" (474).⁵

When Rufus next commits theft and Sheppard is unable to "save him," he laments, "I did more for him than I did for my own child" (481). Rufus explodes:

I lie and I steal because I'm good at it! My foot don't have a thing to do with it! The lame shall enter first! The halt'll be gathered together. When I get ready to be saved, Jesus'll save me, not that lying stinking atheist [Sheppard], not that... (480)

What O'Connor has done here is to allow Rufus to come to a sense and acceptance of himself *with his club foot* as part and parcel of who he is, his identity. He does not see himself as grotesque, just as himself. While I'm not sure that I would argue that this is the "positive grotesque" as others mean it (for I don't think that O'Connor is recommending that we steal), she does paint Rufus as "internally coherent." He understands himself as something other than how society views him and his body. He understands his world and his place in it.

In the end, it is Sheppard who is left morally bankrupt, who readers are left to question. O'Connor writes:

His heart constricted with a repulsion for himself so clear and intense that he gasped for breath. He had stuffed his own emptiness with good works like a glutton. He had ignored his own child to feed his vision of himself. He saw the clear-eyed devil, the sounder of hearts, leering at him from the eyes of Johnson. His image of himself shriveled until everything went black before him. He sat there paralyzed, aghast. (481)

When Sheppard realizes the error of his ways and runs to Norton, his own biological child, to tell him that "he will never fail him again," readers are left with the implication that Norton is dead, by accident or on purpose, because he has fallen off the balcony

while stargazing, where “he hung in the jungle of shadows, just below the beam from which he had launched his flight into space” (482). A grotesque image indeed. Readers are left questioning who is in need of “cure” — Rufus with his club foot, or Sheppard with his egoism and pride?

In contrast to Rufus who views his club foot with little fanfare, Joy/Hulga in “Good Country People” revels in her wooden leg. The fake leg confounds both Western ideals of female beauty and of physical ability. She chooses to drag herself into the kitchen. When her neighbor Mrs. Freeman says, “We aren’t all alike,” referring indirectly to Hulga’s “Otherness,” Hulga responds by stumping “with about twice the noise that was necessary” (282). Here, she highlights her disability, the part of her that others consider unsightly and emphasizes it. This over-emphasis is her way of forcing others to recognize her disability and also a way for her to show that she considers it a part of herself, a part of her identity.

David Mitchell and Sharon Snyder claim that, “The power of transgression always originates at the moment when the derided object embraces its deviance and value” (35). As such, I want to consider Joy/Hulga’s act of renaming herself —from her given name “Joy” to the “ugly-sound[ing] Hulga” — as a moment of such transgression and as a move to make the grotesque positive. Hulga considers this act of renaming “her highest creative act” (275). The narrator writes that her mother “thought of her as a child, though she was thirty-two years old and highly educated” (271). But how does Joy/Hulga think of herself?

When one considers the character of Joy/Hulga in the story in relation to disability, one cannot help but think in terms of power and passivity. Society, as I've said, often thinks of disability as something to be cured or hidden. It follows then, as Sheppard does of Rufus, that one must think of people with disabilities as "helpless" or "limited." Nancy Eiesland in *The Disabled God* writes that, "Historically, rather than naming ourselves, the disabled have been named by medical and scientific professionals or by people who have denied our full personhood" (25). The act of naming then becomes an attempt to re-claim and/or to define oneself.

In the naming of herself as Hulga, Hulga challenges the internalization of disability as stigma, and also attempts, successful or not, to turn that stigma around, to claim herself and her identity. Hulga thinks of herself as ugly by society's "normative" standards. She renames herself Hulga "on the basis of its ugly sound" (275). She compares it to "the ugly, sweating Vulcan who stayed in the furnace" (275). But a few sentences later we see how the internalization of this stigma is turned around. Hulga calls it "her highest creative act. One of her major triumphs was that her mother had not been able to turn her dust (also a negative) into Joy, but the greater one was that she had been able to turn it herself into Hulga" (275). In this way, Hulga embraces her ugliness, her disability, as a part of herself, as a part of her identity. In this act of naming she shifts not only her identity, but also the balance of power from that of the dominant society to that of the minority or "Other." One could read the moment when Hulga "stumps into the kitchen...making that awful [ugly-sounding] noise, as an internalization of negative

disability-stigma. The fact that Hulga *chooses* to make that noise, for “she could walk without making that awful noise” (275), indicates an attempt to shift the focus from how others think of her to a focus on how she thinks of herself. She is playing on the other characters’ ideas of grotesqueness by forcing them to deal with it, by forcing them to face their own discomfort at not only seeing but indeed hearing the grotesque.

I am not saying that Hulga is attempting to change the notion of what society views as disabled, i.e. an attempt to include herself in the norm. I also do not think that her naming herself Hulga is a transgressive moment that lifts her out of a disability identity or “Otherness.” Rather, it is a moment of claiming that “Otherness” for herself. This is similar to some members of the Disabled community claiming the word “Crip” for themselves, thereby attempting to turn a societal negative into a Maslovian self-actualized positive. Hulga is attempting to gain an acceptance on her own terms. She says, “If you want me, here I am -- LIKE I AM” (274; caps in original). Also, she articulates desire here: that is, not the desire to be “normal,” but the desire to be accepted for who and for what she is. What happens is not only an attempted power shift, but also a way of viewing and of claiming her body. The body may still be ugly in others’ eyes, but it is not child-like, and it is *hers*. In short, she articulates a position of empowerment. She attempts, in claiming identity, to make the grotesque positive.

Jeanne Campbell Reesman claims that, “Joy/Hulga’s artificial leg...symbolizes her artificiality of self” (45). The grotesque (ugly) operates in terms of mechanical/human figures. When Mrs. Hopewell calls Hulga “Joy,” Hulga responds “in a purely mechanical

way” (O’Connor 274). Reesman cites the episode where Joy/Hulga “stands against the wall, and rolls her head from side to side” (273) because Hulga is convinced that meaning does not exist, as a moment which shows the artificiality of herself. Taken more concretely, Joy/Hulga remains “artificial,” without meaning, until she meets Manley Pointer, the nineteen-year-old Bible salesman. That is, her life remains without meaning which is symbolized by her fake leg. Because of her fake leg, she does not go out and live life. She does not hold a job, remains isolated from people. The narrator writes the following:

All day Joy sat on her neck in a deep chair, reading. Sometimes she went for walks but she didn’t like dogs or cats or birds or flowers or nice young men. She looked at nice young men as if she could smell their stupidity.
(276)

It is not until she meets Manley Pointer that she begins to experience life, that she begins to experience desire. Indeed, she does “kiss him again and again as if she were trying to draw all the breath out of him” (287). The expression of her “real” sexual identity is symbolized in the removal of her fake leg, and in her allowing Manley to handle it. Read symbolically, this is her sexually transgressive moment, a moment where what was once thought by others and herself as grotesque is embraced, made positive.

While I find Reesman’s idea about “artificiality” plausible and the reading of the above moment accurate, I do want to contest the notion that Hulga leads a “fake” nothing life. If this were true, then there would be no need for her to claim/name her disabled self. In other words, while those around her may think that Hulga leads an artificial life, she does not.

Hulga is acutely aware of those around her and of her actions. Even when she is engaged in the act of kissing Manley Pointer, her mind is “clear and detached and ironic anyway, [her mind] was regarding him from a great distance, with amusement but with pity” (285). She refers to kissing as an “unexceptional experience, and all a matter of the mind’s control” (285-6). Clearly, she is able to determine meaning in her own actions and in the actions of those around her. Most telling is when Hulga defines her nothingness. She says, “We are all damned,...but some of us have taken off our blindfolds and see that there is nothing to see. It’s a kind of salvation” (288). Furthermore, she says, “I don’t have illusions. I’m one of those people who see *through* to nothing” (287; italics in original). In defining her “nothingness” state of being/living, and in articulating that she can see it, Hulga makes that “nothing state” real, not artificial. In so doing, she also moves the state of disability from a point of nothingness, what Fielder and Reesman label as “hidden deformity,” to a level on which the disability is recognized as being something, even if it is by no one other than Hulga herself. Hulga does become more desirable to Pointer when she transgresses her nothingness — when he tries to get her to articulate her desire, to tell him “I love you,” which she refuses to do. Hulga still asserts her desire of recognition of her life — “As I Am” — on many different levels. Her leg may be artificial, but as a metaphor for the meaning of her life and disability, it proves false. As Manley Pointer says about wanting to see her leg, “Because it’s what makes you different. You ain’t like anyone else” (288). If one is to accept Reesman’s idea that “Good Country People” is a story about “not seeing,...about a world in which vision

proves faulty,...[and where] vision itself is grotesque” (46-7), then Hulga’s understanding and acceptance of who she is denotes a clarity of vision, a turning of the grotesque to the positive. Reesman maintains that the loss of Hulga’s eyeglasses denote an “adjustment of her internal vision”; I do not disagree that her internal vision may be readjusted, but I want to point out that Hulga has always had a clarity of vision, an internal coherence, both in terms of her position of nothingness and the position of those around her.

As Pointer makes off with her fake leg, he says, “I’ve got a lot of interesting things this way. One time I got a woman’s glass eye....You ain’t so smart. I been believing in nothing since I was born” (291). One could read Pointer’s actions as “grotesque” — his obsession with and insistence over touching her fake leg. This is most certainly true. Like Rufus, in the end, it is not the physical trait of the disabled character that readers view as grotesque, but the personality traits and actions of the nondisabled counterpart. Again, readers are left to question who, exactly, is in need of cure?

ALL THE IMPORTANT THINGS: EVA PEACE IN *SULA*

In *Sula*, Eva Peace serves as what Rosemarie Garland-Thomson has called the “prototype” for all of Morrison’s disabled women. They “literally constitute themselves with a free-ranging agency whose terms are tragically circumscribed by an adverse social order” (*Extraordinary Bodies* 116). Like Joy/Hulga and Rufus Johnson in O’Connor’s stories, Eva Peace in *Sula* and Morrison’s other disabled women — e.g. navel-less Pilate in *Song of Solomon*, the raped and haunted Sethe in *Beloved* (here I take a wider definition of disability beyond the physical as Garland-Thomson does) — all possess internal coherence amidst external chaos. For example, Sethe and Denver in *Beloved*, despite the town’s perception that “124 [their address and home] was haunted,” manage, at first, to maintain a stable home life until the arrival of Beloved. While there are likely broader issues to consider in Eva’s role in the trajectory of the narrative which traces the relationship between its two main protagonists, Nel Wright, the stay-at-home community figure, and Sula Peace, the big-city woman returned to her roots, I confine my remarks to Eva’s power to name (as with Joy/Hulga, a mark of definition and power) and the mysterious status of her missing leg.

Eva’s missing leg is a thing of mystery never really explained or talked about. “Unless Eva herself introduced the subject, no one ever spoke of her disability; they pretended to ignore it, unless in some mood of fancy, she began some fearful story about it — generally to entertain the children” (30). A story circulated in the town maintains

that she stuck it under a train to collect money or sold it to a hospital for \$10,000 in order to feed her children. Again, there is an aura of disbelief to these stories. Mr Reed for instance exclaims, “Nigger gal legs goin’ for \$10,000 a *piece*? — as though he could understand \$10,000 for a *pair* but for *one*?” (31; italics in original). For my purposes, it is the idea that her amputation *could* be self imposed, an individual choice, as it were, which is of importance. For, as I pointed out, in literature mired in “negative representations,” the acquisition of her disability as a matter of choice (however imposed by external factors) speaks in a way different from yet similar to O’Connor’s characters embracing their disabilities. As Garland-Thomson maintains, “Eva’s act of tough desperation both reshapes her body and guarantees her survival” (116). An act that could be seen as grotesque by others — the amputation of her leg — has positive consequences, the survival of her children. While this, unlike the endings of O’Connor’s stories, does not “invert” the grotesque calling into question those actions of the nondisabled as grotesque, it does spin grotesque action into a “positive.”

Sula has a similar episode with self-mutilation. When a bunch of boys are making fun of her and Nel in childhood, Sula slices her finger. As Nel recalls, “She mutilated herself to protect herself” (101). Disabling acts of mutilation in *Sula* are meant to insure survival of the character, and of others.

This calls cure into question in a way different from that in O’Connor stories. Cure in the two O’Connor stories I’ve examined is, in the end, a construction applied to the nondisabled characters of the story though an inversion of the grotesque. In Morrison,

I would suggest, it is not so much an inversion of the grotesque onto other characters per se, but rather the mutilations that call into question whether readers can indeed define Eva and Sula as grotesque, as desirous of cure. If these grotesque actions insure their literal survival and are self-inflicted, resulting in positive outcomes, can we really define them as grotesque? In other words, while one could argue in “Lame” that Sheppard indeed wants and desires a “cure” for Rufus, in the form of a “normal” appearance for his body (wearing the shoe), in Morrison, can one really desire a cure for oneself if the disability was acquired by choice? While in O’Connor, ultimately, readers are asked to question the grotesqueness of nondisabled characters, in Morrison, readers are left to consider whether Eva and Sula are grotesque, or is it only how others see them that makes them grotesque? However, I would suggest, what is similar in these works is how cure is manifested. In both cases, it is the nondisabled party which frames “cure” as the panacea to disability. In “Good Country People,” Hulga exclaims to her mother, “Woman! do you ever look inside? Do you ever look inside and see what you are *not*? God!” In essence, she asks her mother to question her beliefs about herself and About Hulga. Likewise, Mrs. Hopewell wishes that Hulga “would smile more” for Mrs. Hopewell’s benefit (276). In *Sula*, one could argue that the silence surrounding Eva’s leg is a communal unacceptance of who and what Eva is. That is, as some people in the Disability community claim, disability is socially construed as an individual burden of which one should be ashamed. The circumstances surrounding Eva’s disability are an open secret; normalcy and cure are still prized.

In an interview with Betty Jean Parker in 1979, Morrison claims that, “Eva is a triumphant figure...She says all the important things” (Taylor-Gunthrie 64). Morrison uses the example of telling Sula the difference between “seeing” (non-participatory action) and “watching” (participatory) (64). The implication is that when Sula put her in the old folks home, Eva saw but didn’t watch. This idea of seeing versus watching is played out a few times in the novel, particularly at the funeral of Chicken Little and in the death of Plum. In the first, Nel and Sula are worried that Shdrack saw the accidental drowning of the child Chicken Little. As Sula flees his porch, “he nodded his head as though answering a question, and said, in a pleasant conversational tone, a tone of cooled butter, ‘Always’” (62), implying he saw but did not watch. At the funeral, Sula and Nel “stood some distance from the grave.” Watching the burial they “knew that only the coffin would lie in the earth; the bubbly laughter and the press of fingers would stay above ground forever” (66), implying that their participation in the event would stay with them forever.

Similarly, when Eva burns Plum, her child who stole from them and is a drug addict, there is, again, this play on watching. Eva questions Hannah, “Is? My baby? Burning?,” framed as though she already knows, which indeed she does. Morrison notes, “The two women did not speak, for the eyes of each were enough for the other” (48), implying that Eva, however fleetingly “watched” while Hannah did not even *see*.

The idea of watching versus seeing grotesque acts is important, I believe, to how we understand Eva. Agreeing with Garland-Thomson that Eva possesses “the power to

name, to define” both her children and to rename others, Eva’s watching becomes her own ability to participate in the world, to name and say important things. Again, like my contention that Joy/Hulga’s self-naming inverts the grotesque and her mother’s call for cure, we should take Eva’s ability to name as the right of herself to exist, for her disabled body to exist. As Garland-Thomson notes, “Her enduring body is both her identity and her ultimate resource” (117). The acceptance of her disabled body, however acquired, grotesquely defined by others or not, is her “coherence,” her ultimate triumph, her ultimate refusal of cure.

Earlier in this chapter, I said that I wanted to confine my remarks to stories involving leg lameness and the grotesque. What we’ve seen is that physical deformity of the body can be equated with a certain kind of moral or ethical “unwellness” (Rufus); physical deformity can be equated with (perverse) desire (Manley Pointer); and physical deformity is often thought to be best hidden or downplayed/silenced (Eva). I want to consider Keith’s earlier claim, “that to be made lame or crippled is some kind of punishment and to walk again is good and right. Such use of metaphor calls on the widely held belief that ‘not walking’ is a passive and unhappy state which renders the victim powerless, and that a release from that state is desirable above all else” (249). What is visible in all the stories is that a rejection of normalcy, a claiming of the self, an inversion of the grotesque, are all, in ways, centered on an acceptance of the way the disabled characters not only physically look, but in how they walk as well, the actual way they move. What is contested in these stories are not only ideas of grotesqueness, disability

identity and cure, but also how those issues are often bound up in the way that characters actually move and walk, and what that signifies about how they feel about themselves.

THE GROTESQUE IN “THE REAL WORLD”: SOME THOUGHTS ON THE PLACE OF HUMANITIES AND OTHER RESEARCH

Within Disability Studies, an on-going debate exists between the place of so-called “medical research” which is often thought to objectify Disabled people — studies which document either the impact of an impairment on a body, or studies which sample a group of disabled people without asking their input into the questions, which place the disabled person as the object of social or anthropological research — and its place, if there is one, in literary studies.⁶ A personal example: after the publication of the memoir, “‘The Other’ Side of the Line” (Chapter 5), I was contacted by some organizations (who shall remain anonymous) for interviews. I accepted one or two, but these interviews — under the guise of “helping people” by conducting “research” to effect systematic change to Special Education — ultimately centered on my personal story. Asking questions such as “What did the isolation feel like for you?” or “How did you interact with others after being mainstreamed?” the survey presumed, unwittingly or not, that the “problem” of Special Education lies in the individual, in my ability or inability to “overcome” the situation. Though it purported to look at systemic problems within the educational system, the study located the foci of the “problem” in the individual, not in the social-

cultural-political system at-large. In effect, the study was saying that the failures and problems within Special Education lay within my own actions, or lack thereof, rather than within the system at-large. They did not ask about the societal factors that caused my isolation; rather, they were just interested in “how I worked through it.”

I do not mean to offer a treatise on these kinds of anthropological or sociological studies, other than to say that some disabled people find these types of studies objectifying. Rather, in the context of larger debates about both the place of this kind of research on Disability Studies in the Humanities, and about the relevance of academic research to “real life,” I offer some thoughts on how to bridge literary research with work from other disciplines.

Some disability activists might ask what the relevance of a theory such as my reading of the grotesque in literature has to do with the “real lives” of disabled people? Perhaps little, though I happen to believe that literature reflects society and thus, can influence how we think and act towards others. In other words, the acts of teasing or staring come from thinking of the disabled population as “grotesque.” But how are we to know the negative impact of teasing or staring if the above statement is true? Enter sociological or ethnographic studies. In *Beauty is the Beast: Appearance-Impaired Children in America*, Ann Hill Beuf interviewed several children with disfigurements. Among her conclusions were “that all groups of children noted the pointing of fingers as a form of non-verbal stigmatization incident. Indeed this form of behavior seems to upset them very much, much more than plain staring or asking rude questions” (50). Beuf is

attempting to document the negative social impact of teasing or staring on the disfigured child. This type of documentation, I believe, can serve to bolster the “real life” impact of a reading of the grotesque, in the sense of proving that theories of the grotesque have an impact on the “real lives” of disabled people. Conversely, for someone not schooled in literary theory who “could give rat’s ass about Bakhtin” (I’m thinking here of my disabled peers who don’t understand what it is that I do), a book like Beuf’s can add a practical dimension to the theoretical work of Bakhtin.

Indeed, the impact of teasing or staring is expressed at times quite plainly in disability literature. In facially-disfigured Lucy Grealy’s memoir, *Autobiography of a Face*, she writes:

But I also knew that these children lived apart from me. Through them I learned the language of paranoia: every whisper was a comment about the way I looked, every laugh a joke at my expense....This singularity of meaning — I *was* my face, I *was* ugliness — though sometimes unbearable, also offered a possible point of escape. It became the launching pad from which to lift off, the one immediately recognizable place to point to when asked what was wrong with my life. Everything led to it; everything receded from it — my face as personal vanishing point. The pain these children brought with their stares engulfed every other pain in my life. (6-7; italics in original)

Grealy, like so many disabled children, lived with the social reality of being thought grotesque. Again, this is neither my own condoning of studies such as Beuf’s (like the activists who rally against telethons because they objectify, I believe problems exist with these studies) nor is it my attempt to validate what it is I have chosen to do as a career. Rather, in the writing of this chapter, I became intrigued with the “real-life” social implications of the grotesque beyond literature and literary theory, and turned to Beuf to

find some answers. Though, again, I don't condone the objectifying dimension of these studies or of this kind of research in particular, it appeared to me that there might indeed be a useful place for these kinds of theories within literary studies.

In the chapters that follow, I look more closely at the work of disability memoirist and performance artists, and their own resistances to being thought ugly, wrong, in need of cure. This is not, I believe, an attempt to say that these memoirists and artists have gotten representation "right" while the work I examined previously in film and literature produced by nondisabled people (besides O'Connor who had Lupus) has gotten it "wrong." In fact, I argue that Morrison, particularly, does a good job of problematizing negative representation. Indeed, as the above passage from Grealy illustrates, disabled people, at times, have struggled with and, in fact, internalized those representations themselves. Cultural representations influence quite plainly how disabled people think about themselves; the two are inextricably linked.

After I gave a presentation on Jehan Clare's work (in chapter 6) at Ohio State, a professor asked me if all the performance artists resisted cure so strongly? I don't remember what I said at the time, but I should have pointed out that all the artists whether explicitly dealing with cure or not, know that such an idea exists as related to them, whether they call it cure or not. Many folks know, just as Grealy did, that there were reasons people lived apart from her and possess the desire to change that separation, to become like others through cure so as not to live apart from them. Beuf for example, documents anger and denial of the impairment as "coping strategies" on the part of the

participants of the study. The point, I think, is not whether the following memoirists and artists have gotten the idea of representation “right” or to belittle all the nondisabled writers and filmmakers, to do my own finger-pointing. I don’t think it’s as clear-cut as that. The point is to examine these representations — positive or negative — and their impact on the idea of cure, and to figure out a way to effect some change in how such ideas are constructed and constituted in our society.

NOTES

¹ Many Disability Studies scholars such as Mitchell and Snyder and Kriegal have cited the examples I have as rather common knowledge.

² Though two of the characters I analyze are female, I am indebted to film theorist Peter Lehman’s contention that, “the male’s loss of power is marked not by a disfigurement but by a crippling, that is a limitation of the power to act. For this reason, leg injuries are probably the most common equivalent of the female scarred face” (61). A reading of the impact of lameness seems particularly pertinent for a cultural reading.

³ Morrison herself says that Pilate is not a grotesque character despite her missing navel (qtd. in Garland-Thomson 120). This should certainly not deter anyone from interpreting her as grotesque; however, as I said, I am interested in lameness as a physical characteristic of the grotesque.

⁴ Semantic differences exist between the terms “Freak” and “Monster” (Freak is a term applied to Freak Shows; Monster is generally associated with horror movies). Both are terms that imply the grotesque as I use it in this chapter, so I use both terms “Freak” and “Monster” somewhat interchangeably here.

⁵ This scene as well as much of the story is overlaid with many religious references, as is much of Flannery O’Connor’s work. Similar themes of salvation creep in to “Good Country People” as well. While my own focus is on the grotesque body and the dynamics of the relationship between Sheppard and Rufus, I do not want overlook the possibilities of religious readings of good and evil in O’Connor’s work. In fact, Sheppard and Rufus have an extended conversation about whether Rufus believes in the Bible. When Sheppard claims that the Bible is for cowards, Rufus exclaims that “Satan has you in his power!” (477).

⁶ Here, I cull from debates on various disability listservs. British scholars, Mairian Corker particularly on the Dis-Research listserv, have advocated for “emancipatory research” which tries not to objectify the disabled subjects by involving them in the construction of survey questions by researchers about Disabled or impaired people’s lives.

CHAPTER 4

HOME OF THE SELF: *CURE AUTISM NOW* AND AUTISM

MEMOIR

INHABITING OUR HOUSE

In the opening chapter of her memoir *Remembering the Bone House* entitled, “The Way In,” noted feminist and disability author Nancy Mairs writes:

The body itself is a dwelling place, as the Anglo-Saxons knew in naming it *banhus* (bonehouse) and *lichama* (bodyhome), and the homeliness of its nature is even livelier for a woman than for a man....Still forced to function as man’s Other, and thus alienated from herself, [quoting Cixous] “she has not been able to live in her ‘own’ house, her very body....Women haven’t had eyes for themselves. They haven’t gone exploring in their own house. Their sex still frightens them. Their bodies, which they haven’t dare enjoy, have been colonized. (7)

One’s bonehouse, one’s own body, is a good place to begin an exploration of disability autobiography and cure. Like women, the disabled have not gone exploring in their own house, our bodies long since objectified by medical discourse. Much of what has been written about the experience of disability has occurred in the essentializing realms of educational, psychological, and medical discourses, and has been written usually by the

nondisabled. What has emerged from these discourses, according to writer David A. Sheffield, are particular stereotypes of disabled persons “as angry, deeply embittered, negative persons,” and thus the experience of disability is portrayed as an inherently negative one (qtd. in Johnson 124). Indeed, in Mary Johnson’s article, “A Test of Wills: Jerry Lewis, Jerry’s Orphans, and the Telethon,” Jerry Lewis, in describing his perception of wheelchair basketball and the disabled who play it, “I like to play basketball like normal, healthy, vital, and energetic people. I really don’t want the substitute. I just can’t half-do anything” (122). By defining our bodies solely by disease, illness, or impairment, medical discourse, has effectively colonized a disabled person’s body. As G. Thomas Couser notes, “After a patient presents his or her case to the physician, the role of the patient in conventional medical discourse is to attend to, and to comply with, ‘doctor’s orders.’ The politics of medical discourse thus favors the professional; doctors exercise their medical authority through their privileged place in a specialized discourse” (*Recovering Bodies: Illness, Disability and Life Writing* 19).

The field of autobiography, because it involves self-representation, “offers an alternative to patronizing and marginalizing (mis) representation by others; it thus provides a counterdiscourse that challenges stereotypes and misconceptions” (Couser “The Empire of the Normal — A Forum on Disability and Self-Representation” 305). In this chapter, I wish to explore bonehouses — mine and “recovered autistics” specifically — the ways in which our memoirs challenge dominant medical discourse which has relegated them to “voiceless” entities (to paraphrase Arthur Frank) defined solely by disease, illness, or impairment in need of medical cure, and to explore in these

autobiographies, the journeys of coming to a new understanding to one's body, and one's "self" In this way, autobiography becomes a process. As Couser and others allude to, autobiography becomes a form of reclamation.

OUR BODIES, OUR SELVES

Before proceeding further, I want to set forth terminology I am adhering to here. While autobiography and memoir have become somewhat interchangeable in popular discourse, here I adhere to the terminology set forth by critic Philippe Lejeune in his book *On Autobiography*, simply because his distinctions are useful for my purposes and the distinctions are still invoked by scholars in the field of life writing. He makes the following distinction between the terms "autobiography" and "memoir." Autobiography is, "Retrospective prose narrative written by a real person, concerning his own existence, where the focus is his own life, in particular the story of his personality" (4). Memoir, by contrast, lacks the autographical characteristic "individual life, story of a personality" (4).¹ In other words, autobiography is a retrospective of a person's whole life, while memoir might have as its focus a life at a moment in time or place, not necessarily a full-blown retrospective of a person's life, where the person is always the central focus. In this way, one might understand narratives of illness where illness is the central metaphor, or where illness lasts for a specified duration in a person's life (Robert Murphy's *The Body Silent*, for example) as more of a memoir than a strict autobiography. I use the term autobiography in this chapter, loosely adapted, because it occurs to me that all the

autobiographers here are attempting to construct a life within the larger world; they are finding their place in it by finding themselves. Hence, with Donna Williams and Temple Grandin in particular, their autobiographies can be read as journeying toward *constructing* more socially acceptable personalities. Again, the focus is not, I think, to "normalize" a disabled person (thereby, effectively "curing" him/her); rather it is a coming to an understanding and acceptance of one's own body and self.

The classic definition of twentieth-century autobiography studies has been generally agreed to be Georges Gusdorf's essay "Conditions et limites de l'autobiographie" [Conditions and Limits of Autobiography] published in 1956, and translated into English by James Olney in 1980 [Olney, *Autobiography* 28-48] ² Gusdorf's theory was "emphatically individualistic, featuring a 'separate and unique selfhood' (Friedman, qtd. in Eakin 47). Here, the narrator stood at the center of his own life story, as the one true self.

The limits of this argument are first fully explored by Olney himself in his book *Metaphors of Self: The Meaning of Autobiography*. He writes:

If all selves are unique and, in their uniqueness, only subjectively experienced, ... and if all selves are constantly evolving, transforming, and becoming different from themselves, then how is it at all possible to comprehend or define the self, or to give anyone else any sense of it?...The focus through which an intensity of self-awareness becomes a coherent vision of all reality, the point through which the individual succeeds in making the universe take on his or her own order, is metaphor: the formal conjunction of single subject and various objects. (29-30)

Olney's theory of a "Metaphor of the Self" is useful insofar as the constructed "I," the constructed self in autobiography, here takes on social dimensions beyond Gusdorf's self-referencing narrator by positing that autobiography uses the construction of the self as a

metaphor for understanding his place in the world. The limits of this argument are taken up largely by feminist critics of autobiography, who look toward a less colonizing male “I” as the center. Sidonie Smith and Julia Watson in their introduction to *Women, Autobiography, Theory: A Reader*, state:

Since “autobiography” in the West has a particular history, what we have understood as the autobiographical “I” has been an “I” with a historical attitude — a sign of the Enlightenment subject, unified, rational, coherent, autonomous, free, but also white, male, Western. This subject has been variously called “the individual” or “the universal human subject” or “the transcendent subject” or “man.” Cultural attachment to this sovereign “I” signals an investment in the subject of “history” and “progress,” for this “man” is the subject who traveled across the globe, surveyed what he saw, claimed it, organized it, and thereby asserted his superiority over the less civilized “other” whom he designated, exploited, and “civilized” at once. (27) ³

Feminist critics have critiqued both the patriarchal notions of the (Male) “I” in autobiography, and also the limits of the Gusdorf model in terms of the isolated and often presumed (Male) “I.” This is important for my consideration here because if disability autobiography is to move away from medicalized colonization of our experiences, and away from the “individual burden” polemic that is often tied to impairment, toward a more social and cultural understanding of disability experience, and, in turn, of the disabled self in relation to others, then the idea of “I” at the center, needs critiquing. ⁴

I want to consider briefly the notion put forth, largely by feminist critics, in critiquing the Gusdorf model that “we are relational selves living relational lives” (qtd. in Eakin 55). This idea of community, or learning from others and impacting others as social beings, is important, both for how it destabilizes the “I” in autobiography from a sole configuration of the “self” and for how it redefines the self within a larger social and

communal context. If we apply this destabilizing of the “I” to disability autobiography, we begin to move away from the individual burden polemic tied to impairment, and we can begin to see the ways in which disability as social and political category, as Michael Oliver notes, “arises from social causes” (*The Politics of Disablement: A Sociological Approach* 106). Also, positioning disability experience as relational both to other disabled persons and to the able-bodied world more generally, I would argue, devalues the need for medical cure as the sole end to disability by turning our attention to shared experience, rather than to a medicalized idea of impairment. Cure and pain become not the sole foci of disabled bodies by medical professionals and the cure of the impairment is only one aspect of disability experience. Cure is thus only one construction, one narrative of the disabled self, on the whole spectrum of disability experience. Finding community, seeing oneself as a “relational self” to other disabled persons is yet another construction of a disabled life.

For my purposes, a particular aspect of Eakin’s definition of “Relational Selves” is important. Eakin writes:

The relational stories in my corpus, the story of the self is not ancillary to the story of the other, although its primacy may be partly concealed by the fact that it is constructed through the story told *of* and *by* someone else. Because identity is conceived as relational in these cases, these narratives defy the boundaries we try to establish between genres, for they are autobiographies that offer not only the autobiography of the self, but the biography *and* the autobiography of the other. (58; italics in original)

What this means for disability autobiography is that by positing disability autobiography and experience as relational, and inclusive of the autobiography of the “other,” (disabled and nondisabled persons) then, through this self narration, we can see the discourse of

medicine (itself a story) and how it impacts a disabled life. Again, cure, in this mix, ends up as social construction. With that, I turn, illustratively, to a way of reading disability autobiography in relational contexts more specifically.

MY WAY IN

This is a section of the chapter that I have long resisted. Fed, as I was, on the notions of disability as a social construction, and the search for a social group identity (a disability community), and also, I suppose, an understanding of a medicalized version of my body as part of a larger discourse of medicine and impairment, I adhered to Simi Linton's claim in her book that her impairment itself was of little consequence to the theory at hand. After all, we are talking about disability as a social identity that operates independent of impairment. And while I still believe that, for the most part, I now think it is necessary to offer some sense of how I came to regard the need for disability autobiography to be read in a relational context to larger social issues surrounding disability. If, as Olney claims, "autobiography...is among other things, a point of view on the writer's own past life" (*Metaphors of Self* 42), then I offer a sense of how I have come to read disability autobiography, and also a way for the reader to read both my own memoir (the next chapter), and a way to read disability autobiography in general.

When I started reading disability autobiography in earnest as research for this chapter, I thought of it, I suppose, in classical autobiographical tradition, that is, as an individual story and as a means towards self-representation. I considered disability

autobiography as, at most, “resistant” literature to use Couser’s phrase, to dominant social narratives of disability — the overcoming myth, the restitution narrative, etc. But I saw this resistance only on an individual level, as a singular “resistance,” if you will. For, it seemed to me at the time, that autobiographies were meant to be read and understood singularly. Though *The Autobiography of Ben Franklin* came to be regarded as a narrative for the general American character of the nineteenth century, it was, in my mind, first and foremost an autobiography of Ben Franklin the man. In reading disability autobiography (and in working in the field of Disability Studies), I, like Anne Finger in *Past Due: A Story of Disability, Pregnancy, and Birth*, was looking for community. She writes, “I felt such a commonality there with the other people who had polio....Here I was at last among people who understood, who understood without explanation, elaboration” (16). That, however, was soon to change, at least for me.

In the Fall of 2000, I attended an international conference *Disability Studies: Global Perspectives* sponsored by NIDRR (National Institute on Disability and Rehabilitation Research). The conference brought together disability scholars from around the world from various disciplines: medical, psychological, social, and otherwise. Humanities perspectives on disability, however, were conspicuously absent. While there were many things off-putting to me about the conference, among the most disturbing were the repeated offerings by various medical professionals that the rehab and various agencies that were set up in various counties were a means towards restoring a disabled person’s self worth.⁵ Many persons with disabilities at this conference felt isolated, both in terms of the largely inaccessible room, and what was felt as yet another objectification of the disabled by the largely able-bodied medical professionals and a misunderstanding

of “Disability Pride” as something which can be given by medical professionals to the disabled. As one scholar noted in a private conversation, she felt a real “shutting down” of communication between the rehab and medical professionals and “the rest of us,” and as another scholar noted, the NIDRR conference confirmed his fear that the term “Disability Studies” would be (more so than it has been) largely co-opted by those who were not themselves disabled.

While I have long thought of “identity” itself as somewhat shifting, the conference crystallized for me a long gnawing feeling that for many nondisabled, medical and rehab professionals in particular, the idea of disability identity and pride is tied to normalcy and the idea of “help”, i.e. that the way to make disabled people feel good about themselves is through “restorative” therapies and moves toward Normalcy. As Arthur Frank notes, “the restitution narrative...tells a truth, the will to live, to cure and be cured” (*The Wounded Storyteller* 137). Restitution and restoration lay in the hands of medical professionals, not in our own hands.

Of course, this wasn’t my only encounter with this presumption. About this time, I had taken on a Disability Studies consultant position with Ohio State’s Nisonger Center (a Medical school affiliate). What struck me in working with medical students was both the move toward the personal/individualized narrative, and again how the power of identity formation lay in the hands of medical professionals. As student “Laurie” notes upon the completion of my lecture, “Under Examination: Disabling Medical Constructs,” on disability and the social constructionist model, and subsequent poetry reading for first-year medical students:

I could relate to things he discussed but I never got to a comfortable level of acceptance when people were gawking at me or while enduring countless hours of physical therapy. His self-awareness and confidence was something that I wish I could have had and something that I wish I could instill in others with disabling conditions. (email response to instructor, 23 February 2000)

Laurie's reaction is typical of many to my work. The poem Laurie is referring to, "Birth" [*Disability Studies Quarterly* 19.4 (1999): 345], is based around my own birthing experience relayed through my mother, but it, in my mind, weaves together larger social issues related to disability — the nurse's command of my mother to "suck him [my head] back in, [to her body]," a move which would have surely resulted in my death, and the medical labeling of me, like many others, as "damaged" and "helpless." Yet, these social aspects are largely missed in favor of the "individual burden" model (a model that is of common parlance among Disability circles).⁶ Instead, the emphasis shifts to a model of the personal story, and the idea that Disability identity is something that can be "instilled" in someone. Questions I often get after a reading or talk usually run something to the effect of "How did you get [that confidence] and can I 'give' it to X patient or family member with a disability?" What I find troubling about that is the fact that the very people who want to "help" people with disabilities in this way are often the very folks who have co-opted such moves toward identity and pride, via over-medicalization and cure. As a pediatrician notes in Sandra L. Harris's *Siblings of Children with Autism*, "I guess it isn't an accident that I ended up as a pediatrician. All the time I was growing up, I kept praying there would be a way to cure Rich" (25). Medical cure, and the move toward normalcy, are not ways to instill disability pride and identity, are not ways to understand a shared group context.

The individualized mode of reading disability poetry and autobiography as at once singular and confessional is in marked contrast to the questions I often get regarding my work that deals with ethnicity, which is almost always read in a larger group context. Poems such as “Making Potstickers” [*North American Review* 286.6 (November-December 2001): 17] and “Asians Don’t Make Love on TV” (Muller, et.al. 204), which deal with a Chinese New Year’s tradition and Asian American media representations, respectively, are almost always understood in terms of a larger cultural context. Even though family members may be “in” the pieces themselves, audiences generally understand the larger cultural and historical influences at work. Rarely do I get requests to “counsel” or “be a role model” for a person of my ethnicity, but these kinds of requests happen with some frequency in regard to disability.

What began to frustrate me about these various ways of understanding the construction of and responses to various kinds of life-writing was the chasm that existed between the individual model of disability, which presumed disability to be, as Garland-Thomson notes, my own “personal misfortune and bodily flaw” rather than a larger culturally-based “discursive construction” (“The Beauty and the Freak” 181), and ethnic life-writing which seemed to be understood in a larger cultural context. This, of course, is not only my own finding but has been well-articulated largely by theorist Arthur Frank with his reading of the individual quest narrative, (i.e. “overcoming,”) and by scholar G. Thomas Couser where he writes about the “triumph over [individual] tragedy narratives” which typify dominant readings of disability autobiography.⁷ It is, however, my own experience of this chasm, [no one has yet told me how awful it is to be Asian American,

or prayed to cure me of *that*] which largely drives my readings of disability autobiographies as “relational” to larger community issues.

I am not implying that finding a disability community in and of itself is a negation of the desire for medical cure. Rather, what I offer here is an alternative way of reading disability autobiography against a dominant “individual burden/abnormal body” narrative in need of cure. Reading disability narrative in a “search-for-shared-group” context, in a “relational self” context, will help to foster an understanding of the cultural forces at work which cast readings of disability narrative in terms of an individual body-based burden polemic, and cure therein. The “individual burden” polemic becomes part of a larger understanding of the impact of the construction of an “I” of the “self” in disability autobiography. For as long as we see the “I” in disability autobiography as only a “metaphor of the [individual] self,” the idea of tragic lives/individual burdens as what need to be cured, rather than the larger social forces at work which paint such tragic discourses as the things that need to be challenged, will persist. As G Thomas Couser states in his recent essay “Signifying Bodies,” “I might point out that among the best personal accounts of disability are some that do not merely or primarily narrate the condition in question. Rather, they reflect critically and politically on disability and culture” (*Disability Studies: Enabling the Humanities* 115). To do this, disability autobiography must be understood not just in an individual context, but also in a larger cultural context.

I offer my own autobiographical narrative, “The Other Side of The Line,” (the next chapter) as an example. Not egotistically because I want to claim it as a “best

personal account.” Rather, I point to it because I was quite conscious of precisely the issue that Couser describes. My continual questioning of why this was happening not just to me, but to all of us in Special Education was a conscious effort to broaden the personal experience into the larger culture, and also an attempt to see myself as a “relational self” both to the other children and to the “normal” outside world.

It is quite easy, if one is to follow existing patterns, to read such narratives individually, as simply my own individual experience in the Special education system instead of seeing it as applied to a group. I decided to write about this particular time in my life as a disabled person because I now see the experience in a larger group context. It is, quite simply, the first time in my life that I understood (though I could not properly verbalize it as such) the “negative stigma” to borrow from Goffmann of disability, and understood that that stigma applied not only to myself, but also to the whole group of us, the disabled children and adults on the bus. In retrospect, it was likely my first inkling of a disability community based upon bodily impairment, but also an understanding of such things as the Cartesian Mind/Body split, seen most prominently in the “Spelling Workbook” section of the piece, and of the idea of disability as an external social label applied to a particular group based not entirely upon the body — our impairments are both multiple and different. While it remains on the surface, a personal story centered upon the construction of an “I,” I invoke a group context throughout — my connection to the larger disability community via Miss K, the predominance of therapy for all of us, the impact of therapy and medical definition upon all of us. At the end of the piece, a community and identity that was once shunned is once again embraced via the metaphor

of the inclusive photo. Again, my point here is not simply self analysis or praise; rather it is to show how a reader might identify a group/relational context by asking such questions as “What are the common characteristics of the community this person’s story takes place in?” And “What are the common forces which shape this person’s identity as a group member?”

TESTIFY! TESTIFY! ⁸

I want to pause briefly to consider the matter of testimonial autobiography. It reading disability autobiography, it occurred to me that the classic terms of autobiography left little room for understanding the self in larger social dynamics. Lejeune’s taxonomy offers different types of autobiography (memoir/journal, etc.), but all with “the individual” as the primary center (4, 5). Olney extends the definition to self as a larger social metaphor, and Eakin, at least in earlier work, concerned himself with the subjectivity of the created “I” as constructed through the mechanism of memory and time (see his introductory chapter in *Fictions in Autobiography*). But all autobiography theorists, at least in my reading, took the singular I, the individual self, as the predominant model. Feminist critics move closer to my position by placing women’s autobiography within a wider social context. Still, the term or model for the kind of autobiography that defined a part in relation to a whole seemed marginally noted at best.

Here, I would like to move briefly in that direction by considering the term *Testimonial* as used in minority discourse and applying it to disability autobiography. I

should note here that Frank does devote a chapter in *The Wounded Storyteller* to testimony. While I do agree with his idea regarding Postmodern testimony that particularly represents “fragments of a larger whole” (139), and his claim that “testimony is complete in itself, but it requires commentary in order to be transformed into a social ethic” (145). However, his idea that “suffering” is a pedagogy, and that it requires the voice of the “sufferer” and the action of the listener (in his configuration usually a caregiver) reifies two stereotypes regarding disability:

1. It places a medical person (the listener, usually someone in the medical profession) in a position of dominance over the testifier; the “empathy” of the non-sufferer is required in order to give the sufferer’s actions social meaning. The power position of the caregiver over the ill or disabled is reified here.
2. The configuration that illness, i.e. disability is something a body must “suffer” through, and that such illness is the “gift” of the testifier reifies disability as that something “Special” (the stories of the blind and the deaf have compensatory, and better, senses).⁹

While the definition I wish to borrow from here doesn’t stray too much from Frank’s general claims, its location in political action and minority discourse more generally may deviate enough so as not to reify the above stereotypes.

Traditionally “Testimonio” (“Testimonial” in English) has been considered both a sub-genre of autobiography, and a separate genre altogether. I want to consider here how a definition situated firmly in minority discourse (presuming a narrative of

marginalization and struggle) might help the reader see disability autobiography in a different light than that of suffering and illness articulated by Frank.¹⁰ John Beverley defines testimonio this way:

By *testimonio* I mean a novel or novella-length narrative in book or pamphlet form, told in the first-person by a narrator who is also the real protagonist or witness of the events he or she recounts, and whose unit of narration is usually a “life” or a significant life experience. (92-93)

Testimonio, in this configuration, usually refers to narratives of social or political unrest (Beverley’s example is the text from activist Rigoberta Menchú). Testimonio, is, therefore, “implicitly or explicitly a component of what Barbara Harlow has called ‘resistance literature’” (qtd. in Beverley 93).¹¹ Here, I place disability life writing in a similar political or social context as narratives such as *Past Due: A Story of Disability, Pregnancy and Birth* often mention allegiances to activist groups such as *Not Dead Yet* and *Justice for All* (political groups advocating for disability rights) that understand disability to be precisely the grounds for a political and social movement. These groups are engaged in such self-deterministic struggles as the right to live independently, and to resist groups and individuals such as “Right to Die” and Dr. Kevorkian who believe and advocate that a disability is not a way to live, simply a reason to die. Disability life writing often resists such ideas as having a disability is, by itself, a reason for medical cure, or alternatively, death. The disability activist, like the testimonial narrator, occupies a political position that resists oppression and argues for social and political freedom.

The most prominent feature of testimonio, as opposed to a more traditional definition of autobiography that is seen as a record of the self, is the position of the narrator. Beverley writes:

The narrator in *testimonio*, on the other hand, speaks for or in the name of, a community or group, approximating in this way the symbolic function of the epic hero, without at the same time assuming the epic hero's hierarchical and patriarchal status. (94; italics in original)

Similarly, we might begin to position the narrator of a disability autobiography who comes to understand disability as a social and/or political struggle, and/or who finds him- or herself as a member of a larger community as a “testifier” of struggle, and autobiography as a “*testimonio*,” rather than a strict representation of the self.

I may seem to be splitting hairs here, but there are two key differences in my approach to testimony from Frank:

1. Frank is concerned with the agency of the individual (the sufferer) on an individual level, and then the agency is still commodified by another (the listener). *Testimonio* sees the individual as part of a collective, socially and politically conscious group.
2. *Testimonio* presumes a site of collective social and political struggle, and is grounded within a larger communal context (rather than just the testimony of the ill body/being).

If, then, we are to understand the move to resist (in the autobiographies here) the configuration of the disabled body as simply medical impairment and in need of medical intervention and cure, as a political move with social consequences — the debates surrounding Peter Singer and his contention that it is permissible to kill a developmentally disabled infant up to three months old come to mind ¹² — then viewing disability autobiography in light of a definition of *testimonio* moves disability

autobiography in the direction of group dynamics and social contexts, and away from the characterization of the disabled, ill, or impaired self as an individual burden mired in dominant narratives of suffering, pain, and abnormality.

THE MOVE TOWARD SUBJECTIVITY: REINSCRIBING THE DISABLED SELF

I do not wish to say simply here that the desire for cure is replaced and rejected once one finds community and understands group identity, for it is not as neat as that. Rather, the move toward both bodily acceptance and constructed group identity, toward the understanding of oneself as a “relational” being, as the autobiographies suggest here, helps the narrator to see the social constructedness of medical discourse regarding their body and identity. This, in turn, creates a different understanding of their bodies and selves beyond the realm of medical discourse. By pointing to this chasm between medical objectification and a differently constructed self, the narrator begins to see the limits and constructedness of medical discourse, and thus, the constructedness of medical cure as the pinnacle of that medical paradigm. Using Lejeune’s “Autobiographical Pact” which takes “the position of the reader....they [autobiographical narratives] were written for us, and in reading them, it is us who make them function” (4), I suggest that the disabled narrator’s new understanding of his/her body and identity will help the reader read a disabled life beyond the dominant medical discourse and cure; readers will

hopefully begin to understand, through the shifting viewpoint of the narrator, the idea of medical cure as a social construction. Katherine Young in her book, *Presence in the Flesh: The Body in Medicine*, articulates the chasm this way:

Medicine inscribes the body into a discourse of objectivity. The body is materialized even as the self is banished, creating that disjunction which is the core of medical phenomenology: the mind/body problem. In the realm of the ordinary, the body is the self, the site of my experiences, the fulcrum of my movements, the source of my perspectives. I experience myself as embodied. In the realm of medicine, the body is rendered an object. It is inspected, palpated, poked into, cut open. From being a locus of self, the body is transformed into an object of scrutiny. (1)

By situating the disabled body at the center of the creation of the self in autobiographical discourse, by placing one's experiences back within the realm of subjectivity through autobiography, these autobiographies ask readers to unweave disability experience from medical objectification and cure toward a more subjective reading of disability identity and the disabled self.

I am not advocating that a reader reject medicalized notions of disability autobiography altogether, for I think that depends on the position of the reader in relation to the text. A medical student, perhaps, may have a different interpretation of the theories and autobiographical recountings that encompass Arthur Frank's *At the Will of the Body*, for instance. Rather, akin to Leigh Gilmore's project in *Autobiographics*, which argues for a feminist reading practice of women's autobiography, I have attempted here to outline a "disability-centered" reading practice towards disability autobiography which attempts, in part, to examine the constructedness of medical discourse, and the disabled self, as well as the constructedness of medical cure in relation to both these poles.

Much of the scholarship done in disability autobiography, largely by Arthur Frank and G. Thomas Couser, has concerned itself with deconstructing dominant stereotypes such as the “Triumph Over Tragedy” narrative or inspirational heroism.¹³ This categorizing of disability narratives, coupled with another “sub-genre,” that of narratives of pain and illness, i.e. Arthur Klienman’s *The Illness Narratives* and the like, have narrowed the focus in disability autobiography to what Mairs has called a “Body in Trouble.”¹⁴ These narratives have focused their attention on bodily materiality, and on the impairment itself, or the impact of the impairment or illness upon a body. I do not want to discount the value of this work. Similar to the progression of feminist criticism, which has looked beyond issues related strictly to gender toward larger social meanings of identity, I do, however, hope that disability autobiography production will follow a similar curve. Of course, this is already happening if we read disability autobiography as either narratives of selfhood or resistance to stereotypes. My point is that stories which, for instance, focus solely on the experience of illness, pain, or suffering at the center, reduce a narrative to only being read that way, thereby, directly or indirectly, reifying such dominant cultural paradigms of “courage” or “inspiration” or “overcoming.” The impairment or illness, not the self, is at the center.

My focus on the issue of cure here could potentially be construed along similar lines; however, in the autobiographies of Temple Grandin and Donna Williams, I attempt to read these texts against a backdrop of the “Cure Autism Now” (CAN) movement, especially when both Grandin and Williams address cure specifically to point to the chasm between impairment as fostered by CAN and the idea of claimed identity.

THE MOVE TO VOICE: AUTISM AND THE *CURE AUTISM NOW* MOVEMENT

In recent public memory, with the possible exception of Christopher Reeve and spinal paralysis, or the Deaf community and cochlear implants, nowhere has the spotlight and debate surrounding the cure of disability been more intensely focused than in the Cure Autism Now Movement. I do not wish here to provide a lengthy overview of the medical definitions and biological or environmental determinants thought to cause autism, preferring to look at the organization *Cure Autism Now* in more social terms. For some definitions and an overview of autism, one might read Donna Williams own text, *Autism and Sensing* (1999) or the beginning of Sidonie Smith's article "Taking It to the Limit One More Time" (*Getting a Life* 226-246). I provide a few notes, however. There are a variety of genetic, environmental, and biological factors thought to cause autism. Aspergers Syndrome, once thought to be a sub-category of autism now has separate classification status. A recent *Time* cover story claims that there are nearly 300,000 children affected with some form of Autism in the U.S. alone (May 6, 2002, 48). And lastly, autism is a tricky impairment to research in terms of autobiography because of poor or non-understandable communication skills. Thus, while we occasionally will have an autobiography from someone medically defined as "low functioning" such Birgir Sellin's *Messages from an Autistic Mind: I Don't Want to Be Inside Me Anymore*, Grandin and Williams are both considered "high-functioning," able, for example, in Gradin's case to communicate with other humans with relative ease. The fact that autism

particularly affects communication skills limits the autobiographies published dealing with autism to those “high-functioning” and “recovered autistics” such as Grandin and Williams. The autobiographies of people with other disabilities such as physical impairment are more broad and varied.

Adhering to the medicalized impairment viewpoint regarding disability, Cure Autism Now focuses its energy on science. The goals of their mission are described below:

The Cure Autism Now (CAN) foundation is an organization of parents, clinicians and scientists dedicated to finding effective biological treatments, prevention and a cure for autism and related disorders.
<<http://www.cureautismnow.org>>

In addition to a primary focus of accelerating and funding critical biomedical research, CAN is also committed to broadening awareness and understanding of a disease that has been virtually ignored for over forty years.

CAN's mission takes a three-part approach:

First and foremost, CAN funds essential pilot research. Applications are reviewed and funded twice a year to guarantee prompt attention to the most critical areas of autism research.

CAN also works to unite families, clinicians and researchers across the country in order to encourage collaboration and promote awareness and understanding of this disease. These efforts include the dissemination of the latest in biological and treatment information, conferences which bring together families and members of the scientific and medical communities, and think tanks which bring together the top researchers in the field of autism and other highly relevant fields. This collaborative effort also facilitates research on a pragmatic level allowing researchers to link with families who can then become subjects in their studies.

Finally, CAN pursues a strong activism/awareness program. CAN works with national and local media, Congress and the National Institutes of Health to encourage more aggressive funding of biological research in autism. <<http://www.cureautismnow.org>>

Clearly, the take on autism here is that it is a bodily impairment in need of cure. The focus is all on biological and other research, and treatment. Even the aspects of their mission and methods which have a social component (the mixing of parents and professionals as in caveat 2, is done with the goal of turning the families into medical advocates in the quest for cure. This is illustrated in the following statement:

The largest private funder of autism research, since its founding in 1995, Cure Autism Now has directed over \$5 million to support research projects and a crucial scientific resource — the Autism Genetic Resource Exchange (AGRE). AGRE is the world's first collaborative gene bank that contains information on families with more than one child with autism.

This is bodily objectification at its best or worst. Nowhere in their mission or on other parts of their website is autism seen from a social angle, with the exception possibly in the word “treatment.” Still, further on in the site, there’s a discussion of possible medicines to treat common symptoms of some forms of autism — head banging, screaming, etc. The latest news is the possible link between mercury and autism. Nowhere does it talk frankly about behavior modification as a “cure” for the condition which would place autism in a more social context, by treating the behavior instead of curing the impairment. It’s noteworthy that cure is, for the most part, vaguely defined; that is, when will a “successful” cure be found, and who will get to determine that? Clearly, what is meant by cure here is finite eradication of the impairment (in the brain) through medical means.

RECOVERING/DISCOVERING THE SELF: TEMPLE GRANDIN AND DONNA WILLIAMS

In contrast to the mission statement of CAN, Grandin and Williams argue for selfhood and autonomy for autistic people in their work. The writing styles differ in Grandin and Williams. Grandin is much more free associative in *Thinking in Pictures*, offering, at times, little context for why an episode is where it is in the text, whereas Williams is more “organized.” Grandin did have a ghostwriter for her first autobiography, *Emergence: Labeled Autistic*, and the differences in tone (*Pictures* is more “clipped”) and flow of the narrative itself is noticeably different from *Emergence* to *Pictures*. I mention this to make the point that Grandin claims to “Think in Pictures” (envisioning the cattle chutes she designs as a whole apparatus), and this seems to translate into her writing. Also, while the autobiography has moments of family life in it, there’s a marked shift in Grandin’s work partway through where the latter half of the autobiography feels somewhat like a lecture series on things which matter to her such as “Emotions of Farm Animals” and “Bird Savants” (164). For instance she writes, “Birds migrate by using a combination of an innate sense that enables them to detect the earth’s magnetic field and memories they have acquired. In some birds, the innate magnetic technique is coupled with genetic programming that forms the basis of an instinct to migrate” (165). These offer little in the way of understanding Grandin, but perhaps that is precisely what’s at issue here; her development of self and understanding of self rests largely in her understanding of herself as a “Visual Thinker,” so her ruminations on animals make

sense to her, as an extension of understanding something new about herself and the world around her. She reflects on watching dolphins, "My experience as a visual thinker with autism makes it clear to me that thought does not have to be verbal or sequential to be real. I considered my thoughts to be real long before I understood there was a difference between verbal and visual thinkers. I am not saying that animals and normal humans and autistics think alike. But I do believe that recognizing different capacities and kinds of thought and expression can lead to greater compassion and understanding" (164). We see Grandin accepting herself as a visual thinker and of finding a place for herself in the world. She is developing a sense of self.

What troubles Grandin and Williams, and the topic around which the memoirs are mostly drawn, are social behaviors. Actually, Grandin herself doesn't much worry about social behaviors, not even being aware that her behaviors are off-putting to the people around her. One day her boss walks up to her and slaps a bottle of deodorant down at her saying, "Your pits stink!" (109-110). Similarly, she is unaware that her behavior puts off a person such as her boss until someone alerts her. But what's clear here is that regardless of a medical cure, the social aspects of autism and her sense of who she is in the world are what is important in constructing a sense of self. Not that behavior, again, will simply negate cure for Grandin. Grandin understands that science will continue to try to find treatments and "cures" for autism. But she now understands autism as something more; it's a part of her identity, her sense of self in the world. It is *how she thinks*. She writes, "Autism is a field in which there have been many new treatment fads and wild claims about cures. Each new development has been helpful, but there is not going to be an

instant, magic treatment that will cure autism as though it were a broken leg” (130). This new understanding is reflected in her advice to parents. She writes the following:

Many desperate parents spend thousands of dollars and much heartache on medical tests at different hospitals....tests are a big waste of money. It is better to spend limited financial resources on getting the child into a good educational program by age two or three. (130)

Much of *Thinking in Pictures* reads like that — an advice journal on various topics, a description of making a machine to herd cattle, etc. As such, I suppose it is, in ways, an unconventional autobiography, and, in ways, difficult to critique precisely because it does not relay much about the incidents in her life from a personal standpoint, i.e. the book isn’t full of “scenes” that make my point that it is a self-actualized life and voice not co-opted by ableist notions of that “triumph over tragedy” narrative. In other words, it would be easier to analyze more conventional autobiographies than these autism ones because the issue of both the autobiographer’s voice and his/her coming to a sense of who she or he is in the world is more clearly seen by the reader when we understand the narrative subject’s point of origin, and he or she is more able to describe the changes in his or her sense of self. Grandin never seems that clear on her sense of self in the throes of autism, so it becomes more difficult to document changes. This is not to give myself as critic an “out” for the rather thin level of analysis here. Rather, it points to a problem in the genre of autism: it is difficult to critique changes in a subject’s sense of self when the subject herself cannot express clearly a sense of herself before and the changes in her character.

In the end, though, Grandin does offer readers this: “During the past three years I have become fully aware that my visualization skills exceed those of other people. I would never want to become so normal that I would lose those skills” (180). With this statement, we see some things clearly:

1. She understands the construction of normalcy and how she does and does not fit;
2. She sees herself as a “relational self”; she places herself in a community of others and understands her “difference”;
3. She cherishes that difference (visualization skills) as a part of who she is, her identity in the world, and states quite clearly that she would not want to become normal if the price were the loss of those skills.

In effect, she resists “cure.”

Williams’ autobiography *Somebody Somewhere* is shaped largely by her coming to a new understanding of self. In *Nobody, Nowhere*, Williams employed other personalities (sweet Carol, and brusque Willie) to deal with social situations that, she, because of her autism, could not handle. This, for Williams, was not a sense of self; quite the contrary, she writes, “The Other [way of being autistic] is to be able to do anything based on stored mirrored repertoires without any personal self awareness” (45). Hence, *Somebody, Somewhere* is filled with instances of learning social behavior, and of understanding her body in relation to herself and others. There’s a pertinent episode in which she discovers her hands for the first time as “her hands”. She writes the following:

In twenty-seven years, I had touched my own hands many times. They were just lumps of flesh, blood and bones delineated by type, location, function and image as something we call “hands.” There was no emotional

attachment to them, no personal belonging with them, no significance to the act of touching hands. It was merely a collision of two such objects in space....They were essential for clean toilets and a clean house, but they had nothing to do with closeness. (132)

For Williams, being autistic meant a separation from one's own body, one's own sense of self (which, at several points because of her autism, it's questionable, as in Grandin whether she has an accurate sense of what that self indeed was or might be). Yet, at times in the text, it seems as if she is acutely aware of a sense of self that is different from being "normal." She says, "My hands pulled my hair and hit my face unable to accept that I couldn't just act "normal," that I had feelings that demanded expression, that I could express none of them 'properly'" (132). This sense of self is troubling for the mere fact that it perpetuates the stereotypical notion that people with autism are all "headbangers" with little sense of self. If indeed autistics are acutely aware of themselves, of their identities as different, if the idea of a "recovered" autistic is socially defined as someone who can function as "normal" — along a variation of socially proscribed norms — then "cure," like the left-handed example in my introduction, is a socially constructed phenomenon. Williams writes:

Some people believe that certain autistic people can grow out of autism. Some people believe that some autistic people become cured. When "cures" happen, some people decide the original diagnosis must have been incorrect....I don't believe you can teach autistic people to experience everything they are able to perform. I don't believe you can make them feel emotionally for their images, their "faces," performances and repertoires, as those these are part of true self-expression. Trying to do it the other way around is a matter of analyzing the feelings a person *might* have felt doing the action. You might come up with an idea of a feeling, but that doesn't make it your own, and an idea is never a feeling, just a memory or stored mental repertoire of how one appears. (214)

Williams is making a difference between a “recovered” autistic “performing” normalcy (and cure) and actually being “cured” (if there is such a thing), which would involve understanding feelings, an actual change to one’s identity, and performing normalcy, performing a social cure for the rest of the world. This, is not, I think, “triumph over tragedy,” for she does not see herself as tragic. Rather, “performing” normalcy occurs because she gains a new understanding of herself in the world. She gains a new understanding of her identity. What Williams is saying is that actual cure — an actual change to one’s identity, an experience may be beyond our doing (or we may never know at least), but performing a socially constructed cure for autism may not be. To this way of thinking, the cures that the Cure Autism Now movement may offer (which they aren’t explicit about) are nothing more than constructed, performative cures for autism and its related impairments. What’s more important is developing a sense of self as a means to possibly resist cure.

MAKING A MIRACLE OR THE WAY HOME

In his journal/memoir *On Sight and Insight: A Journey Into the World of Blindness*, John M. Hull writes:

The real miracle takes place when a disabled person is enabled to shatter the normal world through understanding his or her own shattered body. The real miracle takes place when the new reality is grasped, and the illusion of a physical miracle is overcome. This real miracle of acceptance and transformation creates a new coherent world for a body at home in the world. The problem then is how the new world, the state of being blind or paralyzed, relates to the other world, that in which the sighted or mobile people live. Without this negotiation between the worlds of the disabled

and the able-bodied, the disabled person hoping for a physical miracle, continues to live in a broken world, an experience of contradiction and frustration. (176-177)

Hull understands that to accept one's disability involves developing a new sense of self in the world, one not predicated upon waiting for a miracle (a physical cure to the impairment). Such development of a sense of self and understanding in the world is often a constant journey. And here I am not talking "quest" or "triumph over tragedy," those dominant paradigms that pit the disabled or impaired body as "less than" a sense of self, as "unwhole" in comparison to the Normate. Rather, disabled people need to grasp, as Hull suggests, a "new reality." Life stories of disability and illness have often been (and still are?) embroiled in stereotypes of inspiration against hardship, survival of something awful, a life mired in bleakness and tragedy.¹⁵ Disability narrative, if read in this way, often seems to exist in the shadow of medical cure (that "ray of hope"), reifying both the power of medicine and the objectification of the body at the expense of a sense of self. While I do not wish to discount the issue of a medical perspective, that is only one construct of a particular way for a reader (going back to Lejeune's "Autobiographical Pact") to construct a reading and understanding of disability autobiography. I have attempted here to sketch out another, one that finds disability experience and bodies engaged in finding a sense of a disabled self in the world, out (somewhat) from the shadow of a medical cure of our bodies. Instead, we come to understand disability and our bodies as "relational," as part of a shared experience and identity.

I began this chapter with Nancy Mairs' metaphor of a bonehouse, and her search therein. I will end with her call to explore and understand our own houses, our own bodies in a shared context. She writes:

I will write about the yellow house. You will read about your house. If I do my job, the book I write will vanish before your eyes. I invite you into the house of my past, and the threshold you cross leads into your own. (11).

Grandin and Williams have gone into their past and constructed a new sense of self.

They've come into a new understanding of themselves in the world, and, in so doing,

have, perhaps, altered non-austistic readers sense of their past autistic world and of our

own.

NOTES

¹ For his full taxonomy, see *On Autobiography* 4.

² I begin with Twentieth-century autobiography. For a fuller historical view of the field of European autobiography from the Middle Ages on, see James Olney's *Memory and Narrative: The Weave of Life-Writing* (University of Chicago P, 2001).

³ Smith and Watson encompass more than this postcolonial take on autobiography in their introduction. It is a good overview of some of the current debates in the field of Women's autobiography in particular and autobiography in general.

⁴ See Michael Oliver, Simi Linton for more on how disability is often constructed as an individual burden in medicine (Linton *Claiming Disability*) and by economy and society (Oliver *The Politics of Disablement: A Sociological Perspective*).

⁵ I paraphrase here because both NIDRR's conference webcast and their presenter questionnaire are presently unobtainable. I am working from notes.

⁶ Michael Oliver, for instance, claims that disability is almost always viewed individually instead of "arising from social causes" (*The Politics of Disablement: A Sociological Approach* 106).

⁷ See G. Thomas Couser's *Recovering Bodies: Illness, Disability, and Life-Writing*, and Arthur Frank's chapter "The Quest Narrative" in *The Wounded Storyteller: Body, Illness, and Ethics* (115-136).

⁸ I am aware that there is a larger context for "Testimonio" particularly in African American literature and in the field of Rhetoric; however, here I restrict my remarks to Beverley because his is the article that falls more strictly within Autobiography theory.

⁹ For more detail on his theories, see Frank, 145-54.

¹⁰ My comments derive from John Beverley's essay, "The Margin at the Center: On Testimonio (Testimonial Narrative)" in *De/Colonizing the Subject* (91-114).

¹¹ In her book, *Resistance Literature*, she claims literature that resists oppression such as "Protest" literature to be "resistance literature."

¹² Peter Singer. "Justifying Infanticide" from *Writings on an Ethical Life*.

¹³ Couser questions Oliver Sacks claim in his memoir, *A Leg to Stand On*, Sacks ability to truly understand his sick and disabled patients because Sacks had broken his leg, a temporary disability. Couser claims that Sacks exhibits an air of "self-congratulation" here. In effect, Couser is questioning Sacks configuration of his disability experience as "triumph over tragedy" (188).

¹⁴ See her essay of the same title in *Waist-high in the World: A Life Among the Nondisabled*.

¹⁵ Again, see Frank and Couser.

CHAPTER 5

THE “OTHER” SIDE OF THE LINE: A MEMOIR

... I understand, in a very profound way, that in order for me to exist I must transgress boundaries. I think this makes people profoundly uncomfortable. Categories make the world appear understandable and safe. Nonetheless, in this essay I ask you to experience my vision of the world — a world where the categories do not clarify, but only confuse, a world where one must question the very existence of those categories in order to survive.

*Judy Scales-Trent, “Commonalities”
Notes of a White Black Woman: Race, Color, Community*

It’s sometime in the 1970’s. I’m six, or seven. We — my father, mother, sister, and I — have wasted the evening, posing. We are in the living room, my mother seated; me on her right, Rose on her left. Dad’s fussing over the instamatic. Every ten minutes: click, flash, pause, Mom muttering, “Eii-yaa, cua-shee, yo-eee-gaa bu-nung yung.” “Eii-yaa, what a shame, another one can’t use.” Hours later, photos litter the entire coffee table. Looking for the Cheu version of Norman Rockwell, the sifting begins: my parents’ scrutinizing gaze turns solely to me in every photo. Finding one where my eyes are partially open, and my brow isn’t furled in anticipation (of the flash or Mom’s admonishment, I’m not sure), they move to my mouth (mustn’t be drooling), and then, finally to body posture (must be sitting up as straight as my slightly crooked spine will allow). The rest of my family can get away with a half-smile, an eye askew, a few

unkempt hairs. But not me. No, I've got to look perfect, as close to "normal" as my palsied child's body can get. Below the frame, my legs could be braced (they might have been, I don't remember), but not in the frame. In the frame, no traces of my disability anywhere.

My whole life seems to have been about lines. About being inside or outside the frame, and what a particular position — inside or outside the line — means.

It was 1975. My neighborhood had no Special Education program. So, instead of attending the elementary school at the end of the block, each day I crossed a few district lines along with various other "Special" kids from the white/blue-collar suburb of Sterling Heights, Michigan, to the blue-collar suburb of Roseville, Michigan, to Chippendale Elementary, where, yes, our bodies were on display. Sometimes our bodies even gyrated, except nobody stuffed our underwear with bills.

Most days, the two-hour bus ride was fun. Singing *The Wheels on the Bus Go Round and Round* or *Ninety-nine Bottles of Beer on the Wall*, we didn't seem that different from the neighborhood kids we'd left over an hour ago. There was Melissa, the pretty blond, who years later would win some local beauty contest for disabled children, Brian, the boy with the speech impairment, brown-haired Dawn with coke-bottle glasses, blond-haired Kevin who loved playing house with four of us in the back of the bus where we pretended to be grown-ups coming home from work. We were a multitude of

children and adults, a hodgepodge of disabilities — emotional, physical, developmental — herded together under the educational label “Special.” Yet, to us, we were just “being,” unaware of what made us “Special.”

Then it would happen.

“I’ll kill you!!”

I don’t remember what I said, or if I’d said anything to provoke him. All I remember is the smell of urine on Robert’s clothes and his dirty hands around my neck. All reason had left his contorted, grimacing face.

What happened next is unclear: whether anyone screamed; if the driver stopped the bus; or who pulled him off. What I remember is hulking Robert, snapped back to reality, carrying Dawn off the bus, both of them waving goodbye to the bus driver. Why is this memory so blurred? What do I pretend isn’t there?

Something always happened to remind us of our difference, our “Special” status: one of Robert’s or the other EI’s, emotionally-impaired kids, episodes; dwarf-bodied Neru complaining to the bus driver about the incessant pain she felt at every pothole; Rosie needing her bladder bag changed; Brian trying to break my fingers by bending them *way* back; or me, losing my balance, falling sideways out of the seat into the aisle, waiting for the driver to stop and set me right again. There was always something.

Somehow, we would make it to school. The Special Ed wing, where we were housed, was in the school’s backside, away from the main doors and the welcoming Chip

'n Dale mural. The wing consisted of four rooms: the K-3 room, a therapy room, the bathroom, complete with changing table, and the 4-6 room. There was also the fire exit, the hallway, and the line.

The line: a silver metallic strip five inches wide, bolted to the floor on either end that ran the width of the hallway.

“Do not cross this!” Mrs. Clark, Mrs. Hook, or some other aide commanded, pointing to the line. No reason was ever given for this commandment. Yet, it was an order we followed religiously. During recess, we vainly tried to push wooden blocks, to pedal the Hot Wheel and we tried not to notice the Normal kids staring or running away from us. We played inside the line. The “other” children played outside on the swings, seesaws, or other goodies reserved for Normal children.

The line separated us. We were not like them, “Normal” children, nor could we ever hope to be. We couldn’t run, after all. Some of us couldn’t even walk. We were “Special.” Although our 2:00 to 3:30 pm Oreo Cookie, Hi-C fruit punch snack/nap time was a daily event, a part of the curriculum, they didn’t tell us that Special Education amounted to little more than glorified daycare.

I don’t think our parents ever questioned it either — the “education” we were or, more likely, weren’t getting. If they did, they didn’t know *how* to fight, whom to turn to for help. This was the early seventies, after all. Some of the pertinent “Mainstreaming” legislation for children with disabilities was just being written and we were light years away from the A.D.A. Probably most parents, like mine, were told their children, if we didn’t die prematurely, were certainly uneducable. And these were professionals:

doctors, therapists, teachers, and consultants. They were *trained* to deal with “these kinds” of children. To our parents, the mere fact that we were in any kind of school setting was more than they were ever allowed to hope for, a little closer to Normal. Why not trust their advice, their methods? After all, we were in school.

But was it school, or was it therapy? Sometimes it was hard to tell the difference.

Contraption #1: It stood four feet tall. There was a wooden tray table and a door that latched on the outside. It had just enough room for a kid to face forward or turn forty-five degrees to the right or left. My first year at Chippendale, I was dwarfed by it. So they stood me in it for only a half-an-hour at a time. It was part of the daily schedule: Reading; Math; Nap; Therapy.

“Desk or Standing Frame, today, Johnson?” I don’t remember if I was asked my preference or if someone just decided for me. They increased my sessions in increments: forty minutes, an hour, two, three, six. It didn’t matter that my legs grew sore from the pain or that my back sometimes gave out or that sometimes I’d lay my head down on the tray table and nap standing up. It didn’t matter that all six of these standing frames were in the back of the classroom and that their location, coupled with the harsh fluorescent lighting, didn’t help my nearsightedness. I could barely see the words Miss K — short for a Polish name no one could pronounce and I cannot remember — wrote on the board. All that mattered was that I stood, framed, supposedly increasing my endurance, stamina and knowledge too. School and therapy combined. What could be better?

The other contraption wasn’t any better.

Contraption #2: Let's call it, "The Rack." There were three such devices in our classroom. It was the closest I'd ever get to being an astronaut. Thinking about it now, it resembled a launching pad, or some cool S&M device. It was wooden with a square base, and a triangular "tilter." Atop the tilter was a board, "U"-shaped, padded with blue vinyl at both ends for two arms and legs. The aide would place me prone on it and tie my ankles down with the attached restraints. Like I said, S&M device.

Then, I flew. She would raise me so that I was horizontal with my desk, and place a pencil in my hand. For the next forty-five minutes of "English," I would copy sentences Miss K wrote on the board. My right arm was extended in front of me, like Superman in the cartoons I watched on Saturday mornings. I don't remember how long they would keep me in The Rack. I just remember the pain in my shoulders.

Did it matter to anyone that the pain superseded anything I might have learned during that time? Was there a better, less painful, method to increase the range of motion in my arms — the supposed reason for The Rack?

When off The Rack, I would sometimes roll my walker around Miss K's desk. We hovered there because Miss K seldom walked. When she did, it was unaided, taking tiny baby steps. She was the first disabled adult I knew: tough and independent. As a child, she reminded me of a turtle...slow. But I remember doing anything for a smile from her, a "Good, Johnson," a pat on the head.

For years, she was a ghost in our house: a measure of my possible success and my potential failure. My parents sometimes talked about Miss K saying, "It's possible." I still don't know if they meant walking unaided or holding a job. I remember thinking that someday I might walk like her.

A couple years after Chippendale, my father came home mumbling something about Miss K. She burned herself while making tea and would move back to Minnesota to live with her sister. “She can’t live by herself,” I remember my father said, “it’s not safe.” Even now, my parents caution me against cooking, against boiling pasta. I wonder if they are thinking of her.

As a teacher myself now, sometimes I think of her, if she had any dreams denied her? If she ever had a lover? If she had any options other than a job among her own kind? If my twelve-year-old classmates and I were being fed Oreos and drinking Hi-C as part of our “education,” what must “school” have been like for her some twenty years earlier? Who did she have to fight to survive the system of no expectations? And what did she have to sacrifice to survive, even to get to this level? What lines bound her to a low-paying job and spinsterhood?

But as a child, she was my teacher. And when she said it was time to be tied to The Rack or to go see the therapist, I went.

Therapy happened every day. At some point, all of us would disappear into the next room for therapy for an hour or two. There were usually two therapists on-duty throughout the day. One occupational — dealing with my “upper extremities,” what I learned to call my hands and arms, and one physical — dealing with my “lower extremities.” In therapy, my arms and legs are stretched. I tossed balls, tried to balance on large “medicine balls,” tried to climb stairs and to tie my shoes and took short, measured steps. It was no different than the nightly regime I did with Mom and Dad while watching *Happy Days*, except that there was no fancy equipment at my own house.

As a child, I didn't question the need for therapy, its presence in the curriculum. Did it make sense to miss an hour or two a day from class for it? Did it make sense that therapy was also considered part of my schooling, often in lieu of what other children seemed to be learning at my age: fractions, how to write whole, multi-sentence paragraphs, not just letters and numbers. Even when we did learn letters and numbers, there was more emphasis on the steadiness of my hand, on the smoothness of the loop of my "Y" and "B," on staying in the lines, than there was on understanding what I was writing, on reading comprehension. But this was the lesson at hand. All that mattered was the body, was looking "ok;" everything else was secondary. In Special Education, therapy *was* the curriculum.

Oddly enough, I learned more from therapists than I did in class. Big words like "hamstring," "fibia," "tibia," "abductor," "high tone," "low tone," "displacement," "gait," "contraction," and "coordination." I became the sum total of my body parts and their various functions and dysfunctions.

I befriended my therapists. To some, this may seem strange, befriending one's tormentors — the ones who caused me so much pain. But I was a child. I was told that it was all for my own good, that they were there to help me. Other than my parents, these were the adults of my world; the people, as I grew up, that answered questions about my disability. Even my parents bowed to them. My dad's constant refrain at the prospect of every operation I would have was, "Doctor, if he were your son, what would you do?" Even as a teenager, I regarded this as a most inane question. What was the doctor

supposed to say, “No, Mr. Cheu, I wouldn’t recommend the surgery that will make me oodles of money if he were mine, but on your child?...What the heck, I’ll risk it.” Since my parents respected these authority figures, why should I distrust them?

Over time, my disability became a ghost in our house. Something there, but rarely discussed. We *did* nightly therapy; we didn’t *talk* about it. My parents scrutinized for the Norman Rockwell photo, but no one noticed the absurdity of it, of not accepting your child as he is, and no one said anything. Why question it, this move toward normalcy? That’s what everyone was after, the medical professionals, my parents. Better to use canes than a walker. Better to try to walk without any canes than with them. Better to have surgery than not. The body, after all, was the paramount issue; everything else, fractions, stories, was secondary.

Looking back, this seems even more absurd. Why were naps, Oreos, Standing Frames, The Rack, standard curriculum for us? Is that what “Special” means? That what’s expected of us is perpetual childhood? That our minds don’t matter, as long as our bodies look ok? It even makes some sense, in a weird way. What will Johnson be able to *do* in the world, if he can’t even tie his own shoes? Years away from the Independent Living Movement, it didn’t occur to anyone that disabled people would be able to hire caregivers for these tasks, that maybe time is better spent teaching us math and English.

But life among the Normals isn’t allowed. Stay on your side of the line. Where will the line lead, straight from Special Ed to Institution?

But I’m getting ahead of myself. I was seven and in therapy again, missing more wasted classroom hours. Mrs. Foster was my favorite therapist. She was Jewish and

brought me matzah crackers, which I pestered my parents to buy because, “Aay, it’s cool!” I’d say with my thumb in the air, like Fonzie from *Happy Days*. I developed a little boy crush on her, secretly wishing she’d take me out. Once, she came close. Years later, I wrote a poem about our “date:”

Special Education, 1976

The school therapist takes me out
to the boys bathroom.
Today, we will learn to wipe ourselves.
Trousers shucked,
leg braces, buttocks bared,
she spreads peanut butter
on my butt, orders me to begin.
I take right hand to right
buttock, stroking.
Left hand doesn’t turn,
can’t do.
She finishes, suggests I practice,
pretending cure is possible.
I walk back to class dirty.

What will Johnson be able to *do*, after all, if he can’t even wipe his own ass? I don’t think I ever told my parents. Why tell them? My body, always poked and prodded in therapy, always subjected to the Standing Frame and The Rack in class, always subjected to others’ gazes, had already begun, in my child’s mind, to become public property, to become something that wasn’t mine. Like my Superhero dolls from Toys “R” Us, my body was simply something to be toyed with by others, stared at, manipulated at others’ will. This was what therapy was, after all, bodily manipulation in search of Normalcy. Why should my ass be any different?

Nobody thought to call this abuse. In 1976, our society warned simply, “Don’t talk to strangers!” And Mrs. Foster was my therapist, she wasn’t the boogie man; no one to be scared of. There was nothing wrong with this picture, besides, of course, my dirty underwear. But there was something wrong, something to be afraid of.

Scariest than the fact that she was *trained* to do this, to teach me to wipe my ass as *therapy*, scarier than my continued aversion to *JIF* peanut butter, is the fact that this was not and is not an isolated incident. I was not alone in this humiliation; there were other boys and girls in Miss K’s class. But it wasn’t even just Michigan Special Education. There are legions of “Special” children who share similar humiliating experiences. Years later, while giving a Disability Studies lecture and poetry reading at my alma mater, the University of California at Berkeley, I read the Special Ed. poem. The audience, wide-eyed, gasped, nervously shifted in their seats. Ricky, a student and fellow wheelchair-user, exclaimed, “Oh my God! Me too!!”

Of course, Special Ed wasn’t all like that: therapy, infantilization, humiliation, pain. There were, at times, actual academic lessons to be learned, times when we actually *sat* at our desks and received one-on-one instruction.

Brad was my spelling buddy. Weekly, Brad and I sat with Miss K and attacked our workbooks. Maybe this was when I first learned to love words. I mean really love them, their sounds, their shapes. *Pear, Orange, Bear*. I knew I was special because Brad and I were the only ones in this spelling club, the only ones who actually worked from primers, and, at week’s end, turned in something to Miss K for a red check mark. Melissa played with blocks or learned how to hold her spoon. Rosie was in a standing

frame. Brian was having speech therapy. Only Brad and I appeared to be learning in the same way my sister and other Normal children were. There were spelling tests. Once, Miss K asked us to spell a hundred words. I remember my hand cramped from writing all the words. I still remember the one word I stumbled on: *school* spelled with a “k” instead of a “c.” Still, I earned a gold star at the top of the page. Mom and Dad stuck this test on the refrigerator door. For once, I felt special, but in a good way, the normal way.

Was it odd that Brad and I were singled out, that Miss K thought we were smart, educable? Probably. But I was too young to see this, that even in the bordered off area known as Special Education, there were lines some of us could cross and some of us couldn’t. I was too young to understand fully the implications of laws, pushy parents, and IEP’s — Individualized Education Plans. I was too young to understand that an IEP meant the difference between a child who could get “Special services” and one who couldn’t. The IEP defined not only *who* got services but also *what* services a child got. Sometimes, these IEP’s were Godsend, saving children from institutions; sometimes they were more limiting than freeing: the mark of yet another line a disabled child couldn’t cross.

I was too young to know any of this: that the IEP and the changing laws signaled my way out of Special Ed, toward a real education. It wasn’t long before I rolled over the Line into a math class with Normal children a few hallways down. I had to play catch-up, of course, as I would for years, learning all those things other kids did while I was napping and eating Oreos. But at that moment, with a wheelie and a push, I was out.

It was 1980. I was in sixth grade. Three years after I left that Special Education wing for “Mainstreamed” education at my neighborhood school, I returned for a visit. Miss Davis, my third grade teacher, and into whose class I was first mainstreamed, had gotten married. But everything — and everyone — else was the same. Especially my former classmates, all still in that wing three years later, their educational futures static and turning stale.

I made a cursory appearance, exchanged pleasantries with the teacher as an eleven-year-old would, smiling and nodding at adult gibberish. Said hi to a few kids, and bolted down the hall.

“Johnson! Hey Johnson!” someone screamed. Actually, it was more of a mumble, breathy, in the way that only people who have spastic diaphragms speak. The familiar sound of the metal of leg braces rhythmically clanking accompanied that mumble. I stopped and turned around slowly.

“LEAPFROG!” I thought to myself. Clanking down the hall, this was what Gregory reminded me of, a crippled frog, spine dipping with every clank.

“Hi.”

“Hi, Greg.”

“You live next door to my aunt.” Funny, I thought, though I played with the neighbor’s kids regularly, I never saw Greg there.

“Yep,” I said, “Well, see ya.”

“Bye.”

Why I didn't say more to Greg or couldn't think of anything more to say, I don't know. Maybe I hadn't learned the simple rules of etiquette yet. After all, I hadn't been around Normal kids that long. But maybe there was something more to my brusqueness. I had crossed a line, that metallic speed bump that once marked my body, my education, my chance at a future. Greg represented my past. Somebody, some law, said I could cross the line and I did, toward an education and a future. I crossed that line and only now, twenty-some years later, am I gazing back, seeing the line again, trying to understand who it kept in, who it kept out, and why.

I see pictures, of me, of Greg, Brian, Dawn, Robert, Miss K, Mrs. Foster, all of us framed in some way by the line. The faces are blurry, unfocused at first. There was a time when I had to forget. For years, I would play catch-up, toiling for hours over books, math, learning to write with rapidity. But no one besides my family knew this. Publicly, in order to survive, I had to forget where I came from. I had to erase my past. Still, there's no denying it. Their faces were once my own, a reminder of my life on the other side of the line, of what I was and what I might have been. Like my braced legs that were never in the family photo, these people, my past existed just below the frame. Now, I know there are new pictures to be taken.

CHAPTER 6

PERFORMING DISABILITY, PROBLEMATIZING CURE

In her one-woman show *The Woman with Juice*, Cheryl Marie Wade sets forth a new political agenda for people with disabilities.¹ She writes, “No longer the polite tincuppers, waiting for your generous inclusion, we are more and more, proud freedom fighters, taking to the stages, raising our speech-impaired voices in celebration of who we are.” Disability activists, artists, and performers are throwing off age-old stereotypes of the pitiable freak, the charitable, helpless cripple, and the inspirational poster child in favor of a new understanding of the meaning of our disabilities. More people with disabilities are coming to an understanding of something called “Disability Culture,” and we are adopting a new understanding of our bodies and lives

As I stated in previous chapters, recent scholarship in Disability Studies has both reflected and helped spur on this “new” understanding of the disabled body and disability experience, as something more than just a “defective” body. While “disability” is a term largely imbued with medicalized notions of an impaired body, scholars such as Mairian Corker, Carol Thomas, and Jenny Morris have articulated a distinction between the terms “impairment” and “disability.” In this new configuration, “impairment” generally refers to the physical and psychological medical conditions of the body, while “disability”

encompasses a larger cultural understanding of disability experience — teasing, stigma, the history of institutionalization, literary and media representations of disability, and so forth.² In this way, the configuration of “impairment” refers to the body as a corporeal entity, while “disability” refers to a societal and cultural phenomenon, an identity.

While the work of the artists I examine —Neil Marcus’s *Storm Reading*, Jehan Clare’s *Belle’s on Wheels*, Greg Walloch’s *White Disabled Talent* and Julia Trahan’s *Queen of the Girls* — challenge many stereotypes about disability, I focus my analysis on the challenge these artists make to the need for medical cure. These artists see beyond bodily impairment (as something that can, or needs, to be cured) to disability as culture, as identity.

This is a marked difference from, for example, disability portrayals in mainstream Hollywood cinema, such as blind Al Pacino in *Scent of a Woman* lamenting his impairment. “I’m in the dark here! I have no life!” he wails. In *Rainman*, though his brother Charlie accepts Raymond’s autism, Raymond is unable to integrate successfully into mainstream society and boards the bus alone. He fulfills what Martin Norden has termed, “the cinema of isolation.” It is precisely Raymond’s inability to be “cured,” which leaves him no alternative but to be re-institutionalized. True, not all Hollywood representations of disability imply, as these do, that medical cure is desirable; however, medical cure of disability/impairment is indeed not only scientific, but also cultural. As such, it is a cultural concept that many Disability activists and artists actively resist. How others represent us, how others who are able-bodied write about and perform our disability experiences is not always how we write about, define and see ourselves. Bell hooks writes about black female spectatorship in cinema, “Critical black female

spectatorship emerges as a site of resistance only when individual black women actively resist the imposition of dominant ways of knowing and looking” (210). Similarly, in producing their own bodily performances, these disabled performance artists resist cure as a way of complicating bodily impairment and disability experience. Just as the critical black female spectator must resist dominant ways of knowing and seeing, so too must disabled people. These disabled performance artists are questioning the idea of the body as spectacle, beyond the corporeal, impaired body in need of cure. In doing so, the audience is being asked to understand the disabled body as a performative entity within a larger social and cultural context. This shift, however, requires a change in spectatorial understanding on the part of most viewers who must renegotiate a perspective on disability as simply bodily impairment. I apply Herbert Blau’s and Peggy Phelan’s thoughts on the theory of the “vanishing point” in performance to disability, and to the concept of medical cure of an impaired body. In doing so, I move from description of a technique to create a three-dimensional illusion that uses the implicit meaning of Phelan’s theory — that the vanishing point is both illusionary theatricality and a questioning of that illusion. I explore this theory in the Vanishing Point section of this chapter. To understand how bodies have been seen and theorized in performance, I offer a brief overview of relevant Performance theory.

PERFORMANCE AND DISABILITY: AN OVERVIEW

Theories of Performance:

There are some dominant trends in the history of performance theory and certain “schools” or approaches to the field. While my concern is to extend the socio-political readings of performance, I mention the other schools briefly. First, there is the branch of performance theory that deals with the history of theater, and placing performance in historiography.³ Often coupled with this is Stagecraft, concerned with the mechanical staging of the performance itself.⁴ There is also the branch that takes a more folklore-driven approach, studying performance as ritual or anthropology.⁵ And, of course, there is the study of performance art, such as painting and sculpture.

For my purposes, however, I would like to extend the social and critical theories of the body, spearheaded particularly by the feminist movement, to a discussion of the disabled body in performance, particularly in the context of medical cure.

Feminist performance, in the wake of the 1970’s Women’s Movement, began to take a more political stance. As Elenor Antin notes:

[Feminist performance] has been more a social, political, and psychological thing about what it means to be a woman in this society, a particular woman, an artist,...very real political questions are often considered. (qtd. in Carlson 150)

Feminist theories of performance helped, according to critic Marvin Carlson, to spur gay and other [ethnic] minority performance artists. It positioned the performance artist, as noted by Pelias and VanOosting, more squarely than ever before as “social activist.”

(qtd. in James Ferris *The Impaired Body in Performance*. Diss. U. of Indiana 192).

Feminist performance also focused attention on the body as a corporeal entity, as well as representational sign. As Rebecca Schneider in *The Explicit Body in Performance* notes:

As “woman” she is preceded by her own markings, standing in relation to her body in history as if beside herself....explicit body performers call attention to that illusion [of the natural body] by collapsing the difference between the sign and the signified...provoking its implosion across the visceral space of their own bodies. (23)

The collapse of the real body v. the body in representation will be explored more fully in the “Vanishing Point” section of this chapter. For now, my focus will be on the disabled performance artist as invoking both the physical body and the representational body, and thereby emerging as social activist.

DISABLED BODIES AT THE VANISHING POINT

A point of contention in Performance Studies is the transitory nature of the performance itself. As theorist Peggy Phelan notes in *Mourning Sex: Performing Public Memories*, “Performance and theatre are instances of enactments predicated on their own disappearance....it [the “hole” she created after tearing out a pop-up image in a children’s book] was my first sense of the relationship between bodies and holes, and between performance and the phantasmatical” (2). Clearly, there exists a tension between the physicality of a performance, the presence and enactment of the corporeal body on stage, and the ethereal, transitory nature of the performance (and the bodies therein) itself. Performance artist and critic Jon Erickson articulates it thusly:

It is the “problem of other minds” which posits the “as if” of projection, but finds its identification always incomplete. On the other hand, it is a lack of distance, a reflection of human vicissitudes, which makes the sign less than full for the spectator. The body can be seen, then, as both instrument *for* the sign and as something inexplicitly Other. (242)

What Erickson points to is how the performer creates a metaphor by dehumanizing the subject, creating an object. In this way, we might begin to understand how disability in performance might draw one’s focus to the corporeal body as the object of a spectator’s gaze on stage, and as the site of medical impairment.

The disabled performance artist, then, holds a double-edged sword. On the one hand, the artist is exhibiting the body as corporeal object; on the other, the body serves as metaphor, as representational system which denotes a set of experiences, a way of being, as I term it, which revolves not around impairment, but around cultural responses to that impairment.

Medical cure, then, becomes a problematical point between bodily impairment and constructed identity. Peggy Phelan’s reading of performative bodies existing at a “vanishing point” from a theatrical perspective underscores this nexus between corporeality/impairment and disability as cultural representation. Phelan writes:

Put simply, the vanishing point was derived from a theory of optics based on the illusion that parallel lines converge at a point in the distance. The painter placed that convergence at the optical center of his or her composition; that became known as the vanishing point.... Parallel lines do not meet, yet the vanishing point makes it look as if they do. The “as if,” the illusionary indicative that theatre animates, allows for the construction of depth, for the invention of physical interiority and psychic subjectivity. (23-4, 27)

Phelan uses the vanishing point to articulate spectatorial perspective of bodies in painting, “The vanishing point also underlines the hole in the viewer’s body: it points to what painting, and corporeal vision itself, cannot show, cannot see” (33). The vanishing point in painting and performance presumes an illusionary point of convergence between viewer and performer, and thus allows a viewer to add “depth” at the vanishing point. In disability performance, I suggest, medical cure serves as the “vanishing point” because it is the proverbial convergence where medicine and the disabled body appear to intersect. Medical cure lies at the very heart of the tension between disability as medical impairment and disability as cultural identity. If disability is simply understood as a bodily impairment that is medically curable, then disability as culture is non-existent. However, if disability exists as a culture, if the disabled body is to be seen as a representational system upon which experiences of disability in society are projected, then medical cure of the disabled body must be understood as a construction. In other words, medical cure, the possibility of a “normal” body, is a *perspective* that is assigned by the able-bodied viewer to the disabled body. From its hegemonic position, cure stands at the very center of the corporeal impaired body and the disabled body as identity.

In *Take Up the Bodies: Theater at the Vanishing Point*, Herbert Blau writes of the vanishing point that, “The principle issue is perception” (28). The perspective of the able-bodied spectator drives the ideas of normalcy and medical cure in disability performance.⁶ I do not mean, however, to ignore the potential viewpoint of audience members with disabilities. Like Film Studies which, until the rise of Women’s Studies, did not presume a gaze other than the dominant male gaze, the presence of a disabled gaze, as something distinct from what I term here the Normative Gaze, has not been

theorized and deconstructed fully. As Disability Studies expands in ways similar to ethnicity, sexuality, and gender studies, which caused a reevaluation of whiteness and heterosexuality as dominant paradigms, we may begin to see more work on such ideas as a disabled gaze in film and a disability perspective in performance. Like Feminist Studies, Disability Studies should presume a perspective different from the dominant, in this case, able-bodied, perspective. It is, however, the able-bodied perspective on normalcy and cure as desirous, which drives my reading of the vanishing point.

The disabled body is caught, between the impaired body and the life it lives, and the “normal” body and the life it may procure via the possibility of medical cure. Yet, it is the able-bodied viewer who assigns desire for normalcy, achievable through medical cure, to the disabled body. Normalcy serves as the viewer-assigned “depth” and “psychological interiority” of the disabled body. However, neither the disabled body nor the viewer’s able body, can view “cure.” Cure becomes the “hole” in the viewer’s body, pointing to the limits of the viewer’s vision. The body on stage, the one available to the viewer, is the corporeal impaired body. Taken more literally, the moment of medical cure becomes the point at which the disabled body, as corporeal entity and as performative signifier, supposedly vanishes to become reconstructed as “whole, cured, normal,” etc.

In theatrical terms, Phelan uses the vanishing point to articulate an idea of the fictionality of theatrical space and the creation of a viewing point in the audience member. The vanishing point, then, serves as a way for things to appear in dimensionality rather than a way for something to literally “disappear.” It may seem, then, that my use of the vanishing point as both a literal word play and as a theoretical concept applied to

medical cure, is mis-applied. However, I suggest that this is not the case. To the contrary, by asking the viewer to see beyond the impaired corporeal body, by asking the viewer to understand medical cure as a construction that can be resisted, medial cure does not “disappear.” Instead, medial cure, as a dimension of how disability is constructed and represented, becomes more visible and more three dimensional to the audience.

Take the real-life example of the gay adoption case of Bert Lofton. Since he was nine weeks old, Bert, now ten, has lived with his foster parents, Steve Lofton and Roger Croteau, and his other foster siblings, all of whom are HIV-positive. Because Bert no longer tests positive for HIV and is under fourteen years of age, he is now deemed “adoptable” by the state of Florida, unlike his HIV-positive siblings. Since gay adoption is not legal in that state, the state is actively looking for another home for Bert.⁷ What this example shows is the cultural construction of cure as yet another dimension of the issues surrounding Bert’s case, for only after Bert’s HIV status changed, did the state deem him “adoptable.” Also, it speaks to the very issue of a viewing point by others. Bert’s negative status, and his “adoptability” lies not necessarily with how Bert sees himself, but with how others see him and his body. Given the media coverage of his specific case, Bert may never lose his status as someone with AIDS regardless of any medical tests. Even though the medical impairment (the presence of actual HIV antibodies) may be gone, Bert’s social status as HIV-negative and the real-life social implications of that status, have become more evident and he may never lose the stigma connected with what society has deemed an “incurable” disease.

To articulate, to perform a disabled body, thereby positing disability as cultural construction and as “a way of being in the world,” the disability performance artist, then

must refute the need for medical cure and assert the right of the disabled body to exist. The vanishing point becomes the (able-bodied) spectatorial position against which the disabled performance artist produces his/her own bodily performance and thus, an insistence on the permanence of the disabled body. By seeing the impairment, the spectator necessarily sees the cultural responses to that impairment. All the artists discussed here problematize the desire for medical cure through the performance of disability as both corporeal and cultural entity.

There are several actions that a performer might use to challenge the viewer's assumption of the need for medical cure. Jaehn Clare, for instance, incorporates her wheelchair, a marker of her impairment, as a natural extension of her body and space. Neil Marcus places his impaired body into everyday interactions with able bodies. Such actions help viewers to see the permanence of the disabled body, while asking viewers to re-define able-bodied notions of what it means to be disabled. The viewer begins to understand disability as both corporeal entity/impairment and as social construction.

**NEIL MARCUS: *STORM READING* AND JULIA TRAHAN: *QUEEN
OF THE GIRLS***

Touring nationally for several years, Neil Marcus's *Storm Reading* (1997) is the best-known piece produced by the now defunct Access Theater of Santa Barbara, CA.⁸ While the performance touches on many stereotypes such as the body beautiful, media representations, sexuality, etc., I will analyze the monologues and vignettes where medicine and cure are dealt with most explicitly.⁹

Storm Reading consists of a series of vignettes and monologues based on the author's experiences of disability. Marcus has dystonia musculorum deformans, a disability which affects muscle control, movement, and, in Marcus's case, speech. Marcus uses his body, and its various contortions, to convey meaning and humor throughout the performance. The performance is a three-person affair, with an able-bodied actor Matthew Ingersoll assuming, at times, the roles of Marcus's voice, "switching places" with him, and of various characters, and Kathryn Voice who serves as an ASL interpreter while also assuming a variety of roles throughout the performance.

In one sketch Neil is called upon to be the "disabled specimen" at a medical convention, with Ingersoll playing the medical expert. Ingersoll treats Marcus like a trained seal directing Marcus's bodily movements. When Ingersoll is talking about patients with dystonia exhibiting "heavy breathing," and Marcus doesn't, Ingersoll turns to Marcus and implores "heavy breathing." Marcus groans, to which Ingersoll replies, "good specimen." The tension between the medical establishment's objectification of the

disabled as little more than medical aberrations — positioning itself as both the bearer of the possibility of medical cure, and as testifier to the need for cure — is highlighted at the end of the sketch. Ingersoll offers his specimen a treat, holding it out in front of him, as though feeding a dog. Marcus's response is to bite his hand, while simultaneously his leg "jerks" kicking the doctor in the behind. The audience sees the tension between the medicalized idea of an impaired body in need of cure, and Marcus's insistence that his disability is a part of his identity, signified in the resistant act of biting and kicking Ingersoll's doctor character.

The assertion of the disabled body's right to exist as is can also be seen clearly in the restaurant sketch. Here, Ingersoll and Voice play patrons at the restaurant while Marcus is the waiter. Ingersoll has to write down the order himself, get the water, and the food. Marcus still waits on the couple, reporting to the chef and so forth; it's just certain physical tasks that require Ingersoll's assistance. Ingersoll's steamed, of course, and after the food arrives, complains to his wife. His wife responds simply, "But honey, he [Marcus] couldn't do it....Look at this wonderful meal that the three of us have prepared by working together." Voice's comments, and the point of the scene, on some level, protest the need for an able body as the dominant. Disabled bodies can exist and serve a "useful" function as they are. Also, by grouping them all together as "the three of us," Voice subtly includes disabled bodies into the mix of humanity. The disabled body does not vanish; it becomes an accepted body in society. By performing a job, Marcus subtly shows the viewer the usefulness of his "impaired" body while showcasing a different,

more inclusive response to his disability (that of Voice's), calling for the spectator to re-define his/her positioning and presumed response to impairment as something in need of medical cure.

Later in the performance, Marcus addresses the "healing" power of religion, often understood to be a means to cure. Ingersoll holding a candle, as if in church, becomes the voice of Marcus in the following monologue:

Do I believe in God? I have nothing to say to him, if it is a him. I don't want to say there is a power greater than my power. My life represents a continual striving to be powerful....I don't believe in sin. I don't want to give up control or responsibility. I want to believe in reality, my reality,...just reality.

I resent the possibility of religion healing me. I want to work with what is real to me. I believe in people. I believe in nature. I believe in life. God might be life. I might be God.

Marcus asserts his personhood, as a Disabled person, and also his right to exist as he is, challenging both the need and desire to be healed. The fact that Ingersoll voices the monologue for him is interesting. On the surface, using Ingersoll as his voice for longer dialogues and monologues could be simply a matter making things more easily understood to an audience. Here, however, Ingersoll's deep voice sounds stereotypically "God-like" which makes Marcus's ending statement, "I might be God," more powerful and believable than using Marcus's own spastic voice. While religious healing is not a medical "cure" per se, the goal of the eradication of a disabled body is the same. In *Storm Reading*, there's a continual assertion of a disabled body as a point of contention and presence, not of absence through cure. Just as the vanishing point presumes a point of convergence between spectator and performer, in *Storm Reading* Marcus implicitly or

explicitly asks spectators to “converge” at the point of medical cure as well as other points such as romance and daily activities, and, as he has done, to reassess the meaning of his body as the site of medical cure towards a more inclusive identity-based construction.

Likewise, Julia Trahan in her show *Queen of the Girls* asks for an identity-based construction of the disabled body.¹⁰ Julia Trahan, an artist who studied at Antioch College in Ohio, does not confront medical cure directly through her performance as Neil does; rather she validates the disabled body, thereby rejecting the need for medical cure, through sexualizing it (email with author, March 23, 2000). I explore that validation more in terms of performance, than in sexuality terms, but either way, the disabled body, like the aforementioned feminist body in performance, becomes empowered.

Queen of the Girls is in many ways an autobiographical piece charting Trahan’s accident at age eleven [hit by a truck], to her coming to identities post-accident as both disabled woman and as lesbian (in Shaw Interview, *Brother/Sister*, Melbourne, np). Her choice to explore sexuality as central theme in *Queen*, was quite calculated. She says:

I use sexuality in kind of a broad way, all sides of it. Who you love, the act, one’s personality and gender; and lust, which can be good or bad. I also use the idea of living your life with passion and fertility, wanting people and wanting myself to strive for the good in the world or the light in the world. (Shaw)

The audience is confronted with sexuality right off the bat, in the play’s opening line, “My mother says I was born masturbating....My mother talks about my inherent sexual narcissism at dinner parties....Actually, I don’t mind that she publicly talks of what is usually considered a private act. She’s making a political statement.” The performance

continues chronicling her accident, her various hospital stays, and her eventual coming out. All of this is placed in sexual terms, effectively sexualizing the disabled body.

On sex with men and women:

I had learned to walk and talk and swallow well enough to be considered worth fucking by men. Doesn't take much. I fucked and fucked. Wore men out while living in the Art Institutes spray paint room. In the ass or on top. Wanted it all the time. All night long. Fucked their friends when they got sore. Asked for it. Begged for it.

When I touched women it was different . With women I made love and fell in love. Sex was supposed to be like this. Melting into my lover whether she drove a red sports car, dyed my crotch blue with food colouring or smoked too many menthol cigarettes.

We see the embracement not just of her sexuality, but of her disabled body as sexual, desired. Perhaps the most blatant display/acceptance of her body, in both sexual and disability terms, occurs in the closing sequence. In it, she performs a strip dance to Madonna's *Like a Prayer*, dancing in front of her wheelchair. Two acts occur here. One, she takes out a dildo from her pants, and "twirls it overhead as thrust." She literally spins the dildo and "thrusts" it forward towards the audience. Two, she picks up her crutch, and "turns it into rifle" holding it like a soldier at attention. Sexualizing the disabled body as it is, placing it in sexual contexts calls into question the desire for cure similar to how Marcus's inclusion of the disabled body in everyday contexts does. As we will see momentarily, using disability apparatus as part of one's bodily space is a move repeated by Jaehn Clare in her use of the wheelchair. With Trahan, viewers see disability and the disabled body not just as sexually desiring and desirable, but also, as with all the artists examined here as empowerment and political act.

GREG WALLOCH: *WHITE DISABLED TALENT* AND JAEHN

CLARE: *BELLE'S ON WHEELS*

Unlike the previous performances where the performers are actors in the more traditional sense, Greg Walloch's performance is primarily stand-up comedy.¹¹ His show *White Disabled Talent* consists of a series of stand-up routines. Walloch is a comedian based in New York, but tours widely. He is also a member of the comedy performance troupe *Living Room Live*.¹² His experiences as gay and disabled with cerebral palsy serves as the heart of *White Disabled Talent*. Of the show, and its take on sexuality, he says:

I'm telling stories from my point of view, which I believe in some fashion is unique. My show is autobiographical in style. It deals with my being a disabled person as well as a gay person. Underneath, there are some issues, but the bottom line is its a very entertaining, fun show....People often don't expect disabled people to have a sexuality of any kind, much less gay sexuality, so that's always challenging and surprising on some level. (*St. Petersburg Times*, 15 Oct. 1999. Sec. W, 29)

His analysis of sexuality is multi-faceted. He analyzes, for instance, why a friend would assume that he became gay "because he was disabled and couldn't get lucky with women," calling into question the ways that heterosexual desire is equated with a nondisabled body. My focus on cure here though, lies with a routine titled simply, "A Bus Story." In it, Walloch is offered the chance to be healed (cured) of both AIDS and of his disability. It's clear that Walloch understands the cultural ramifications of both his sexuality and his disability. In the vignette, though, the passenger's, and Walloch's use of the term disability, refers more simply to medical impairment. The routine:

I had a strange experience riding home on the bus the other night. I was riding on the M10 down Seventh Avenue. And I was sitting in the front seat of the bus when suddenly this guy slides up next to me. He's wearing a powder blue business suit, and black Wing-tip shoes. Suddenly this guy throws his arms around my shoulders and starts squeezing me really hard! I think, oh, god, what is happening to me? Am I getting mugged? Am I getting felt up? This guy starts screaming: "Right now, I am healing you! Take it into your body! Take it into your body! Believe that I am healing you. In two weeks, you will walk, you will throw down those canes! Throw down those canes! In two weeks you will be healed." Then he takes this small vial of blue water out of his breast jacket pocket and presses it into the palm of my hand. "Take this vial of water and drink it down. This vial of water can heal pain, heal cancer, and AIDS! In two weeks you will be healed!" This guy is grabbing me tighter and tighter. In the meantime, the bus driver is turning around over his shoulder to see just what the hell is going on, and the bus starts careening all over Seventh Avenue, people are screaming. The guy is shoving the vial of water into the palm of my hand saying: "Drink the water. All it takes is believing. When everyone drinks the water, there will be no more plagues, no more cancer or pain, no more AIDS! Imagine that, what would a world be like with no more AIDS?" I look up at him and say "A world with no more AIDS would be really great, but you know what? This is my stop. I have to get of [sic] the bus now...I'll just get off here." I got up leaving the vial of blue water in the seat. and [sic] stepped off the bus onto the sidewalk. I thought to myself *that guy was totally crazy*, and then I started to walk home. As I reached the corner I looked back down Seventh Avenue watching the bus drive away. I thought about the vial of water that I had left behind. And I thought *what if that guy was right? What if that guy can really heal people?* Although grabbing someone and squeezing them... I've never heard of that technique. What if the world is full of people who just don't believe enough? I mean, I didn't believe him, but what if he was right? What if I just blew my really big chance? Then I thought who is he anyway? Coming up to me and deciding that I need to be healed of this. If he only knew. Can he make me less neurotic? Get me a better job? What about what's really inside, what really hurts? But not this, this is no big deal. I wanted to turn to him and say: "This is not a big deal. I'm okay! I'm all right!!" but I didn't. I just got up and left the vial of water behind. Besides, if he did heal me I would have to change a substantial part of my show, not to mention losing any multi-cultural status I've gained as an artist. I mean, think about it. It's like a bad Twilight Zone episode. I meet a guy on a bus dressed in a nice suit who says: "All you have to do is drink this vial of water and it will take away all your pain, your disability." [sic] but with out [sic] it, I find I just [sic]

some boring white guy trapped in my own personal hell for all eternity. I mean you know how it goes. I guess I could always make T-shirts that read: "*Oh my god! I left the cure for AIDS and cancer on the bus...*"

The rejection of cure of impairment in favor of disability identity are at work at a few key points here. First, the nondisabled passenger is obviously thinking of disability strictly as medical impairment, equating Walloch's impairment, symbolized for the passenger by his use of canes, solely with pain, which can be healed.¹⁴ For the blue-suit guy, the idea that disability is anything other than a medical condition is not understood. He does not, however, apply this same way of thinking to sexuality. He does not implore Walloch to drink to heal queerness or sexuality, just AIDS. Walloch's response asserts that disability involves more than just the body. "Who is he anyway? Coming up to me deciding I need to be healed of this....This is no big deal. I'm okay! I'm alright!!" Walloch, it appears is more concerned with other matters than impairment. "Can it make me less neurotic? Get me a better job?" He questions. Walloch is more worried about the cultural ramifications, about changes in identity, that curing impairment would bring. "Without it, [disability] I find I ['m] just some boring White guy trapped in my own personal hell for all eternity." When faced with the offer of cure, of making impairment "vanish," though he briefly questions it, ultimately he leaves the option of cure on the bus.

Like Trahan and Walloch, an attempt to validate the disabled body while repudiating the need or desire for medical cure of the disabled body occurs in Jaehn (pronounced "Jane") Clare's one-woman show *Belle's on Wheels*. Like Walloch, the option of medical cure is offered to her in physical form — a vial for Walloch and a contract for Clare.

The play revolves around the life of a woman, Clarity, a young woman in her early twenties. The play is set approximately three years after the accident that paralyzed her. The play was originally written as “a celebration of survival” for the tenth anniversary of the author’s own paralyzing accident (Clare, “Interview” April 8, 2000).

The play begins with young Clarity’s falling off a tree, making disability the point of origin. The play, then, is not a mourning of the past and a desire to return to that able body, to be cured; rather the play becomes a play of birth and renewal, where disability serves not as the vanishing point, but as the beginning. When asked about this specifically, Clare told me in a phone interview:

Clarity had fallen off trees before. She had had accidents, and fallen before. This was simply the worst one....[The decision to begin the play there] was a conscious one. I wanted the play to be about the process of a reclamation of the self. Everyone already knows the tragedy story. Change is not loss; change is just change. I wanted people to understand that the ‘dis’ in disability is someone else’s ‘dis’ (Clare, telephone interview, September 7, 2000).

Yet, knowledge and experience of that able body, of that way of being in the world, as it has with Christopher Reeve, might make the desire for medical cure more pointed. Clare addresses the issue of cure specifically, presenting it as a “wish fulfillment” sequence with a fairy godmother in the section entitled “Program 9.”¹⁵ Clarity’s fairy godmother, Faith, offers her a contract to “restore the complete and total function of your legs, feet, and toes.” Cure is understood only in terms of bodily impairment, of a body’s ability to “function” physically. The cultural implications of disability are not seen by the able-bodied, signified here by the fairy godmother and the contract. Further, all the experiences surrounding disability are rendered non-existent by the medical cure of the impairment. The contract states:

In exchange for the above-mentioned Blessing, the Beneficiary, as identified in Paragraph Two, shall relinquish to the Agent... those items acquired since the onset of said disability,...including, but not limited to any and all knowledge, experience, wisdom, learning, understanding, advantages, parking privialges, and tidbits, ad infinitum....In receipt of said infinites, the Beneficiary shall enjoy the benefits of said Blessing forevermore, until the end of Time, the Universe, or the existence of said Beneficiary's corporeal body — whichever comes first,... [bold in original]

Clarity, however, understands disability as culture beyond impairment. She responds, “So, basically, I give up everything — anything — I may have learned as the result of ... becoming a gimp, and you do ... whatever it is you do.” The godmother, though, understands disability solely in terms of medical impairment and (restorative) functionality. Seeing Faith’s lack of understanding of disability as a social experience, Clarity elaborates, “I survived... This -- This ... THIS! The accident, the surgery, the rehab, trauma, stress, incontinence, stares, loss, divorce, head-patters, pity, curiosity, celibacy, grief-anger-pain-fear-exhaustion-frustration-oppression ... THIS!”

On the word “THIS,” Clarity pops a wheelie in her wheelchair and spins around in circles, including the wheelchair as part and parcel of her disability experience and claimed disability identity. (She returns the contract.) Indeed, throughout much of the performance, Clarity’s wheelchair is understood to be an extension of her personal space. When she, for instance, kicks out her legs as though swinging on the tree swing, she simultaneously lifts the wheelchair up; the wheelchair acts as her imaginary swing seat, caught on an upswing.

Clarity sharply retorts the godmother’s idea that Clarity’s body can and needs to be fixed and cured by claiming her disabled body and her disability experience in a brief monologue near the end of the scene. She asserts:

No! Clar-i-ty. Like the knowledge and gift of unconditional love from my family and friends. An appreciation for the value and import of simple things; time well-used; eating chocolate. A deeper relationship with the force that keeps me going every day. The dignity of living in a body that challenges society's perception of beauty, and a greater appreciation for my body's sensuality. Understanding that I **choose** my priorities, my life. Awe at having survived. [bold in original]

In this scene, we see not just a repudiation of medical cure, but also an embracing of the experience of disability. Disability becomes an empowering choice, rather than a reason for medical cure. “I *choose* my priorities, my life,” Clarity says.

At the end of the scene, the fairy godmother tells Clarity to keep the magic wand. While this could be read as a desire to hang on to the possibility of cure, the godmother’s handing over of her magic wand could also symbolize the “magic” found in Clarity’s new life, rather than a desire to hang on to the old.

Clarity embraces her new life clearly in the epilogue sequence, where the gift of bells signifies an acceptance of her body and a celebration of her life:

FAITH: “Remember, my beautiful friend: All the people I pick have one thing in common - Life is burning a small candle inside them, and they are looking for oxygen to feed the flame. What brings us together, into the Circle of Life, is finding that little hole through which your breath can feed another's flame. Keep the faith, child.”

[CLARITY opens the gift, pulling out a string of nine bells. A grin of understanding steals across her face.] Oooh! [Tying the string of bells onto the frame of her wheelchair.]

“With rings on her fingers and bells on her ... wheels - - - She shall have music ... whenever she feels.”

[Popping a modest “wheelie,” she jingles the bells slightly, then picks up the candle which still burns softly; lights fade to special as she quietly

sings.] “Out came the sun and dried up all the rain... / - - - “ [Special fades to **blackout**.] “... And the itsy bitsy spider climbed up the spout **again**.”

The inclusion of her disability, of the wheelchair (her wheels) as part of her body and “the music” her life, is seen here as she wheels off-stage, bells ringing to the sound of applause. By reconfiguring the disabled body beyond medical impairment, Clare asks the viewer to reassess notions of a disabled body and the need of that body to undergo medical cure.

RESISTANCE AND CELEBRATION

In *The Woman with Juice*, Cheryl Marie Wade cautions the able-bodied viewer, “we are no longer waiting for your generous inclusion....We are taking to the stages, raising our speech-impaired voices in celebration of who we are.” Marcus and Clare are two such voices and bodies rising in celebration of their disabled bodies and shared disability culture and identity. Marvin Carlson describes minority and feminist performances that challenge dominant hegemonic notions of race and gender as “resistant performance.” Similarly, the disability performance artists examined here resist ableist notions of disability as simply a bodily impairment in need of medical cure. This shift in understanding of disability from impairment to culture and identity necessitates changes in viewer perspective of the disabled body as simply medical impairment, and changes in understanding the experiences of that body as part of larger collective and cultural forces. While neither exhaustive nor totalizing, I have attempted here to sketch out a means of

reading and viewing disability performance and the disabled body in performance. May we all, disabled and able-bodied viewers alike, find in these performers and performances, reasons to celebrate.

NOTES

¹ My gratitude to the Ohio State University English Department's Edward P.J. Corbett Grant for Dissertation Research which allowed me to acquire much of the primary research material for this chapter. My thanks to the artists for their generosity.

² For more on the impairment/disability distinction see such texts as Mairian Corker/Sally French's "Reclaiming Discourse in Disability Studies" in *Disability Discourse*, Jenny Morris's *Pride Against Prejudice: Transforming Attitudes To Disability*, and Carol Thomas's chapter, "Theorizing disability and impairment" in *Female Forms: Experiencing and Understanding Disability* (121-44).

³ See the section of essays entitled "Theater History and Historiography" in Reinhart and Roach *Critical Theory and Performance* (291-351).

⁴ See Richard Schechner's book *Performance Theory*, specifically his chapters entitled "Approaches" and "Actuals" (1-68).

⁵ See the section entitled "Cultural Studies" in Reinhart and Roach, *Critical Theory and Performance* (7-88). Victor Turner's *The Anthropology of Performance*, and Carlson's chapter, "The Performance of Language: Linguistic Approaches" in his *Performance: A Critical Introduction* (56-78).

⁶ The terms "disabled/able-bodied people" historically allude to the idea of impairment. The terms "disabled/nondisabled people" is gaining parlance in Disability Studies to signify cultural identity. By utilizing the term "the able-bodied," I am referencing the historical use of the "disabled/abled" paradigm — i.e. impairment, the focus on bodily corporeality as a particular perspective.

⁷ For more on this case, see <<http://www.lethimstay.com>>.

⁸ Though I saw a live performance in Berkeley, CA, in 1991, my comments here are based on a videotaped version obtained for educational purposes through Access Theatre in 1996. The videotape version contains scenes that were not in the live performance I viewed.

⁹ For more on the history of Access Theatre and the evolution of *Storm Reading*, see Cynthia Wisehart's *Storms and Illuminations: 18 Years of Access Theatre*. *Belle's on Wheels* is also mentioned.

¹⁰ My comments are based on a videotaped performance while the artist was in Australia. The performance, as noted by the author in a Q&A after the performance, differs from the U.S. performances slightly in content as well as in costuming. In this Australian performance, Trahan does not appear as a drag queen. The text is reproduced from the manuscript provided by the author. It is the script of the U.S. performances.

¹¹ My comments are based on a series of videotaped clips from his routines from the author's private collection provided to me by the author. Text is taken from a manuscript provided by the author.

¹² <<http://www.livingroomlive.com>>

¹³ The text here mirrors that found in his script in that there are no paragraph markers or at times, lack of quotation marks.

¹⁴ Walloch uses "Loftstrand" crutches; crutches which cup around the lower arm, as opposed to the more typical use of 'cane' which denotes the wooden or metal walking variety.

¹⁵ As the stage notes point out, the character of Faith can be played by an actual actor, or done simply as a voice-over. Hence, the use of the moniker, "One-woman show."

CHAPTER 7

AFTERWORD

WHERE FROM HERE?

In her essay “An Enabling Pedagogy” in *Disability Studies: Enabling the Humanities*, Brenda Jo Brueggemann asks a provocative question for those without disabilities when faced with disability as both scholarly topic and in “real life.” Assuming an able-bodied position she asks, “Or should we resist? Proclaim our innocence? Our too easy victimization at being labeled evil able-bodied oppressor?” (320). A heady question, and since I am not able-bodied, a question that is perhaps out of my realm to answer. But behind a question such as this looms a larger one: what does this new way of looking at disability mean, really; what do we (both those who are nondisabled and those who aren’t) *do*?

There always seems to be a debate, not just in Disability Studies but more generally about the relevance of academic pursuit to the “real world”? What does a feminist critique of Madonna (who is in my CD changer as I write) mean or what does it

do? Does it help the plight of Third World women who couldn't afford a Madonna CD anyway? Better scholars than me have struggled with that question, and in my time as a scholar and writer, I don't think we've found an answer to the "relevance of the academy" question. But it's a question that I'm faced with constantly. In fact, at a recent speaking engagement at Davidson College, someone asked that question again. I'll admit, at sixteen when I wrote my first essay asking what would happen if all disabled people had the power to give tickets to all those who park in Handicapped Parking spaces (what I call my "wanting to be Andy Rooney" period), I wrote with a much different understanding than I do now. I wanted to set the world ablaze, make all these proscriptive actual changes for people with disabilities, call out the "able-bodied oppressors," and I thought that the act of writing itself would do that.

Now, I don't believe that.

I still believe in the act of writing, the power of it. Students and teachers buzz me about the work that I've published with a fair amount of frequency, so I know I'm making some change, which is good and desired on my part. But I'm not naive enough to believe that a poem or a piece of scholarship would have stopped the gassing death of disabled child Tracy Latimer or the work of Dr. Kevorkian. And teachers, the ones who, like me, understand the act of teaching to be a kind of public service, understand too that our efforts are often thankless and that we don't see the fruit of our labor often beyond the end of the actual quarter. I have no idea if my ramblings about *The Hunchback of Notre Dame* will have any long-term effect on the way students view films. Will someone be sitting with his or her sweetheart at *X-men 2* and suddenly exclaim "Ah-Ha! Disability there! That's what Johnson meant!!"? I told the student at Davidson about the

“thankless” aspect of teaching and writing, but I also said something akin to, “At the end of the day, I write mostly because I enjoy it, the *work*, the *process* of it — being paid to think about things that are important to me. I teach for the same reasons: enjoying putting lesson plans together, interacting with students.” I write (mostly) for me.

That doesn’t mean I don’t want to effect social change, or that I’m saying “my way is the right way” to those who write and teach motivated by external change, tangible outcomes, rather than internal enjoyment. Not my place, really. And those who believe in “reader response criticism” or the “death of the author” know too that readers bring themselves to the work, that authorial intent is not the same as ultimately what others take away from your work.

All of this is to say that the work that I’ve done here to push readers toward a reconceptualizing of cure might ultimately prove fruitless, or at least not have the desired effect. But I’m not certain that taking responsibility for the thoughts of readers (beyond the clarity of my prose) is something for which I can or should be responsible. Early on in this project, one of my advisors wrote:

Yes, it *is* a social construction, but you often suggest that if we only realized this, we could get rid of it. Because disability (like other identity categories) is always represented in terms of language and images, you’re not going to be able to release it from its status as a social construction. Rather, your point should be that we need to revise *how* it is socially constructed. (Debra Ann Modellmog, email, July 5, 2002).

Of course, my shirking responsibility is not an attempt at a cop-out plea: “But it’s not me!

I can’t be responsible for *that!!*” Well, maybe just a little. Yet, I think she’s right too.

I’ve attempted to challenge how our culture constructs cure, specifically its construction

in relation to disability, but also at times, its impact on queer identity. Though my chapters do address how cure is constructed in literature and media — through the employment of the gaze, through the inversion of the grotesque, etc., — I think one of the major reasons I’ve spent energy trying to prove that cure is constructed, is that within the field of Disability Studies little attention has been paid to the concept of cure, relegating it to the “medical model” in favor of social construction. So my point of origin, my opening position that “cure matters” was in a way, two steps back from perhaps where it should have been. For if Disability Studies and Cultural Studies want to address *how* cure is constructed, then there has to be an understanding that it is indeed a construction in the first place.

So, if we agree, or maybe even if we don’t, that cure is a construction, we’re still plagued with the questions that Modellmog and Brueggemann raise. Is it possible to “resist” the representations of disability, the idea that “narratives involving disability always yearn for the cure, the neutralizing of the disability” (Davis, *Bending Over Backwards* 99), and, if so, *how* do we inscribe a new representation, a new construction?

Where do we go from here?

Again, I’m not really sure if I can adequately answer that question. For one, I’m not sure what a new representation or representations — ones that are neither overtly positive or negative — might indeed look like. What exactly is it that I, as someone disabled, would want? For another, what someone might do with a new construction, just like the old, might not be my authorial intention in positing the construction of cure as a particular entrée in the representations of disability and medicine.

I can, however, offer a brief, albeit imperfect way of thinking about how an understanding of my hypothesis might impact a rethinking of medicine and culture more generally. My own way of going from here to there, wherever that there might be.

For the past two years, I've been serving as a curriculum consultant to Ohio State's LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Program. LEND is a leadership development program for first-year medical students who are tracked over a ten-year period to see if they take a leadership role in their respective fields. My position as consultant has been to infuse a Disability Studies in the Humanities perspective into the medical school curriculum and with these trainees in particular. Getting students who are just coming into their own professional identities to question those very identities which they are trying desperately to grasp has had its own set of challenges, too numerous to name here. But it's interesting to me that "cure" often serves as the unwritten motivating factor for their choice of profession (and that cure and "help" are often synonymous). Getting students to see the "humanity" within medicine when all they are taught in many of their other classes is to view the body a "roadmap" to be measured, operated on, etc., and to view the impairment as the person's defining characteristic, getting them to question the cultural impact of medicine, and the roles and powers they play in other people's lives, has often felt like a proverbial pulling of teeth. But we soldier on.

One activity that has proven useful in getting them to question the objectifying practice of medical examination of their patients is to get them to examine the way medical observations are conducted. LEND students participate at times in "arena diagnosis" and team observations. In these examinations, a team of doctors and

observers gathered in a large room examines families, or families see smaller teams throughout the day-long examination. On the whole, they might encounter fifteen to thirty or more medical professionals and students in a visit.

Because the Disabled Community has written about the objectifying practices of medicine, we bring up these practices in the classroom. We read Lisa Blumberg's "Public Stripping" about being paraded in her underwear before doctors galore and show performance artist Greg Walloch's vignette of him walking around on stage in his underwear willing himself not to get an erection as he waits to be examined. We ask the students to examine their own practices and to reflect on perhaps a different way of doing things that might make the patient feel less objectified. In reality, the possibility for immediate and actual change is, of course, somewhat slim. Yet, we hope as they move toward their own practices and careers, they might consider another way of practicing examinations.

I can see now folks within the Disabled Community who want to keep a definitive line between "Disability Studies" and "Rehabilitation Studies" and/or those who want to ascribe fully to the mantra "kill the medical model" in favor of constructionism, to be up-in-arms. My path is not for everyone. And as much as I believe in the distinction between Disability Studies and Rehabilitation Studies in theory, it doesn't fit our current social reality. As long as people with disabilities are dependant upon medical authority for everything from obtaining medications, getting educational accommodations, receiving disability benefits and money for caregivers and appropriate aids, the medical establishment and the power of its social labeling of disabilities will remain a necessary evil. (As I alluded to at the end of the literature chapter, there is a place for the medical

model within Disability Studies.) However, the Disability Community's examination of labels has caused a ripple effect within society and the medical fields, however small.

Pejorative terms such as "Handicapper" are fast disappearing on medical forms.

However, the power of such labeling is still held within the medical establishment.

Given this, the larger question becomes not only *what* does it mean to the medical establishment to embrace an understanding of medical cure as a cultural construction applied to disability, but also *what* might happen as a result of this understanding? The above example is only one small change that my colleagues and I have tried to enact in our own desires to reconstruct cultural notions of disabled bodies as more than just impairments. It does, too, get them to question, both implicitly and explicitly, *how* disabled bodies are constructed within the medical establishment.

As I said, my path is not for everyone, nor should it be. I stated at the beginning of this project that cure is a problematic point between medical and social models. I suspect I was then hoping to find a distinct line between the two models, that one might someday exist without the other. I suppose too that, for me, if we believe that medicine, cure, disability and impairment are all socially constructed terms, I could argue that that might, in effect, be true, at least on a theoretical plane. But living in this world, in this body, having to deal with the real-life implications of what labels mean, what services I can get to live the life I want to live, that I want to be entitled to live for myself, has taught me, if nothing else, the very power of the social construction of disability and the power of the medical establishment upon our lives. I suppose indeed that my desire to construct or reconstruct medical cure as an idea intrinsic to both the medical and social models is my own answer, ultimately to both Brueggemann's question of resistance to

ableist notions of disability and Modellmog's question of how something is constructed. I'm not sure, still beyond my work with LEND, what that means, and certainly what it might, in real terms, mean for others reading this dissertation down the road. I do know that my work with LEND and within medical humanities is movement from "here to there." But, in the grand scheme of things, where others may want to go is a question they'll have to answer for themselves.

Since beginning this project, America has lived through 9/11 and is currently engaged in a war, which as Paul Abberly alluded to, is a means by which the disabled population of this planet will likely increase. When asked for my response to 9/11, I wrote the following:

My other thought through all this, perversely maybe, is how it ultimately might "help" the cause. All those sentiments and rhetoric about disability being so awful/I don't know what I'd do, that permeate mainstream thinking, well suddenly that changes to where it's "I don't care, I just want him/her alive." Well, what comes out of that is that disability can be a way of life, not a reason for death.
(email, September 14, 2001)

I'm at the very end of this very long process of the dissertation. At times, it has hit close, a bit too close, to home, getting me to question whether I'd want cure or not, my relationship with my parents (what does it mean, in the context of his brain tissue transplant story, to feel as though I'm still not good enough, still not the son he desired), and undoubtedly many other issues I still don't have all the answers for. But this much I

do know as I sit here in reflection: thinking about medical cure as a construction is my way of saying that disability can be a way of life, not a reason for death. If nothing else, this project has helped me see that.

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