Faces of Disability

A Sabbatical Report

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For Aunt Madge and Aunt Khaki
My pioneers in the field

Note: For works that were not useful for the classroom, I did not include discussion questions.

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When I began my sabbatical project, I had no idea how consuming it would become. It seems the new discipline of Disability Studies has become more mainstream and popular in the years since its inception. New films like The Diving Bell and the Butterfly and Blindsight as well as books like Unheard seemed to pop up overnight. And perhaps my radar grew attuned over the months and weeks I began investigating this field. It began to seem everywhere I turned there was some reference to disabled people or characters. I began to notice that Family Guy had a character in a wheelchair and started to ask questions like 'What does it mean that the doll in Lars and the Real Girl is in a wheelchair?' and "Is Stevie in Malcolm in the Middle portrayed fairly?" I ended up doing things I never expected, like attending a musical version of Mask (which was actually pretty good). To say I got into my topic is an understatement.

The new availability and awareness of works about the disabled is an exciting thing and, as I found in my study, much more enlightened than earlier works on the subject. While Children of a Lesser God was considered groundbreaking in its day (1986) and sympathetic to the deaf, today some of the attitudes seem almost barbaric. Even Sound and Fury (1993) about the cochlear implant seems antiquated. Today, it is refreshing to see the disabled portrayed as people first and disabled second.

I began studying the theory behind Disability and the way the disabled have been treated historically. Among the worst treatment is in the Indian and Asian culture, where disabled people were treated as untouchables – and their disabilities were considered punishment for behaving badly in another life. Considered an embarrassment to a family, a disabled person was often kept at home and not permitted to be seen publically. Another trend in the United States was to view the disabled as "freaks" and put them on display for the amusement and profit of others. Often disabled people were housed in mental institutions which further challenged them.

Another line of inquiry looked at the terms for disabled people. (Simi Linton and Nancy Mairs). This a fundamental place to begin, with Mair's insightful essay "On Being a Cripple" and Linton' s exhaustive look at many of the associations of terms we use for disabled people. (i.e. *differently abled, handicapable*). Also valuable is sociologist's Erving Goffman's landmark essay on how the disabled are perceived and interact within society.

The literary portion of my project netted some clear winners. Lucy Grealy's Autobiography of a Face was beautifully written narrative of her life-long battle with her disfigurement. Nancy Mairs' phenomenal essays On Being A Cripple were both insightful and amazingly candid. Road Song by Natalie Kusz had some nice parallels to Grealy's book, but seemed only a touch less candid. Other books by Simi Linton seemed less valuable, but still illuminating. David Sedaris added some nice comic relief. And Robert Hughes is so brilliant, it is amazing.

In the film category, the recent film Murderball was among the most moving and enlightening. Even though the film was ostensibly about the world of wheelchair rugby, the portrayal of two of the players is unforgettable. Older films like Children of a Lesser God and My Left Foot, showed their age – and in the case of the latter, were shown to be misleading and false (A new biography of Christie Brown shows he was beaten and abused by his wife who is portrayed as loving in the film). Because two films became available late in my sabbatical-- I did make a premature substitution --Sharon Greytak's Weirded Out and Blown Away – which was a surprising and honest documentary about five disabled subjects. The film King Gimp also showed why such artistic expression is important; historically, the disabled have others speaking for them; writing and painting allow the disabled to communicate directly. Even though my list was set, it seemed everyone had a work to recommend and I began to feel bad, since there is not enough time in the world to accommodate it all. One older film which was visually dated , but pitch perfect in its understanding of newly injured paraplegics was The WaterDance—a true and ,at turns, painful, funny and emotional account of Neil Jimenez' recovery after a spinal chord injury.

While many people commented that a year spent studying disability sounded "depressing", I found the opposite to be true. What struck me most about many of the authors and subjects of the films was how inspiring they were. The human spirit transcended the corporeal in many of their lives, and some achieved feats that were nothing short of amazing. In fact, after seeing the odds that many of the authors had to overcome, I felt a little like a slacker.

Nancy Mairs also opened my eyes to the difficulties a person in a wheelchair faces everyday. Her simple, but effective exercise of imagining if a person in a chair were to come to your house and the trouble they'd encounter just to visit your home, is one that anyone in a Disabled Studies course should do. (Try it.) You'll never question the need for wheelchair access ramps, curb cuts and special handicapped toilets again.

The writing segment of the sabbatical project began with Steven King's On Writing. His book, part autobiography and part writing manual, offered more than one surprise. King, who was often sick as a child, became an avid reader at a young age. This is echoed by many of the authors, and this love of reading and words (plus the temporary disability) provided a kind of groundwork for their later interest in writing. Books were companions and a lifeline to the world – and so we can see how writing could be a response to disability. The second surprise in King's work was a personal one—a mention of LaVerdiere's Drug Store in Bangor, Maine. Seeing this store mentioned in King's book led me to call my great aunt Charlene LaVerdiere (whose in-laws owned the store). Though I only chatted with her briefly, I was glad I did, as she passed away a few months later.

As often happens, the academic becomes the personal and my study of disability was not immune from this phenomenon. I was immensely inspired by Flannery O'Connor's grace and humor about her own disability, and glad I saved her work for last. The correspondences between O'Connor's own experience and her heroine Hulga in "Good Country People" is uncanny. But even more amazing is her gallantry in the face of her disease. As I was forced to wear a cam walker for an ankle problem at the end of my sabbatical, I had to laugh at O'Connor's humorous response to using crutches and be awed by her graciousness in the face of her difficulties. Her work was a comfort and a delight to me—almost a friend in difficult times.

The theme of disability came close to home for me this year; I spent several days with my mother in the hospital as she was recovering from knee surgery. I wish I could say these moments in the hospital were informed by all I learned this year, a putting into action of all the wisdom of those pioneers ahead of me. But if I have learned one thing – it is that disability is personal. Certainly, there are common themes—the Super Crip, the "Good Patient", the disabled person as "sexless" and invisible, the Rebel—but disability is test of one's will and spirit and so many of the people I studied shone brightly in those moments. They were human – tenacious and striving and humble -- in the best sense of the word.

Disability Studies – Disability Studies Reader

The title essay of the Disability Studies Reader, "Constructing Normalcy: The Bell Curve, the Novel and the Invention of the Disabled Body in the Nineteenth Century" by Lennard J. Davis, begins his essay in what initially seems like a counterintuitive way. Instead of defining "disabled", Davis offers the history and etymology of the word "normal". It is a bold move, but one that actually makes sense. Much of the nineteenth century approach to disability was to eradicate it and to make the disabled less prevalent and/or freakish to the extent that eugenics was considered and in some cases employed. Normalizing the masses became the goal, according to Davis.

Interestingly, the original meaning of "normal" was "perpendicular" relating to the norm or tool of a carpenter (Davis, 3). It was between 1840-60 when the term became used in the current sense. Next, the term began to take on the meaning of "the ideal" (4), the desirable model for the average person to emulate. Davis cites the Venus d Milo as such a model of beauty. He also discusses the painting "Zeuxis Choosing as Models the Most Beautiful Girls of the Town of Crotona", which shows an artist choosing various limbs and body parts to create the ideal woman . This should speak to today's students very well.

Next, Davis discusses the rise of the statistician and the resulting term "L'home moyen" (the average man) (4). This is pertinent to disability studies as disability always deviates from this model and the makes disability more pronounced and less desirable. This leads Davis to his next point, that of the various eugenics movements that sprang up, in part, to eradicate disabled people. According to Davis," Darwin's ideas serve to place disabled people along the ways ideas evolutionary defectives to be surpassed by natural selection. So eugenics became obsessed with the elimination of defectives, a category which included the 'feebleminded', the deaf, the blind, the physically defective and so on." (7) Figures such as Sir Francis Galton were instrumental in this movement, but it was Alexander Graham Bell in 1883 who actually suggested that the deaf be prevented from marrying and reproducing with deaf partners.(7). Other eugenicists focused on 'feeble mindedness', a term which included "low intelligence, mental illness, and even 'pauperism', since low incomes was associated with 'relative inefficiency'" (9). Another eugenicist Charles Davenport felt, "the influx of European immigrants would make the American population' darker in pigmentation, smaller in stature…more given to crimes of larceny, assault, murder, rape, and sex-immorality'" (9). Davis argues that this established the link between disability and "sexual license" and "criminal activity" (ibid).

In terms of literature, the first appearance of a disabled character is especially noteworthy. Appearing in Gustave Flaubert's Madame Bovary, the character of Hippolyte is a club footed stable boy. Charles Bovary, a doctor, is convinced by his wife Emma and Homais, the pharmacist, to correct Hippolyte's defect, to improve his work performance and life. Davis finds this significant, as the first appearance of disabled character is one in which the character is being fixed or normalized. Bovary's operation, though successful, leads to a gangrenous infection and ironically, Hippolyte's leg is amputated. Almost all modern novels, now have a disabled character. Some (like Tiny Tim and Esther Summerson) arouse pity with their defects but rarely are they the central characters of the novel. Often, according to Davis, they again serve to contrast, with what is normal.

Questions for Discussion

1. How is the etymology of "normal" important to understanding disability?
2. The "normal" and "ideal" images are prevalent in society. How do they influence our view of disability?
3. How do the eugenic attempts of Galton and Graham Bell seem by today's standards? Are there any lasting repercussions? What are they?
4. How do the disabled fit in Darwin's evolutionary scheme?
5. How has literature treated disabled characters?

6. Think of three disabled characters. How were they portrayed and treated. Do your examples agree with Davis' assessment?

In Disability Studies Today, three essays discuss the sociological aspects of disability: "American Pragmatism: Sociology and the Development of Disability Studies", "Disability Theory: Key Ideas, Issues and Thinkers" and "Disability and the Body". All three essays discuss the "social" model of disability as opposed to the "medicalized" model. The social model concerns itself more with the social aspects of disability than the medical concerns. When dealing with the disabled, earlier discussions seemed to focus on the latter. Now, however, attitudes toward the disabled have shifted radically.

The first essay, "American Pragmatism", written by British author Gary L. Albrecht, discusses how American attitudes toward the study of and accommodation of disability have been shaped. Albrecht writes, "Indeed, a society can be judged on how well it treats its children, women, elderly citizens and disabled people" (18). On page 20 of his essay, Albrecht defines pragmatism and lists its many founders, including Charles Sanders Pierce (1839-1914) and William James (1842- 1910). According to Susan Haack, pragmatism is a method in which the "meaning of a concept is determined by the experiential or practical consequences of its applications" (Albrecht, 20). Albrecht notes several major breakthroughs in the field, notably the observation by Fujiura and Rutowski-

Kmitta (2001) that the disabled need to be identified and counted correctly so that health services may be provided for them. Irving Kenneth Zola, another leading theorist in disabled studies, "explored experiential perceptions of pain and differences in behavior when seeking medical help" by three different ethnic groups (28). He is notable as both a medical doctor and a visibly disabled person. Much like the perception of minority groups, Albrecht notes, "Not all disabled people have disability as their defining role." (30) He explains that, for example, inner-city African-Americans who are disabled, don't consider disability as their main identifier, whereas white, privileged, disabled people seem to control the discourse, simply because they identify more closely with the disabled, rather than another group. (30). In the American culture, "disability is often perceived as an individual problem with which a disabled person must deal", according to Mudrick (1997). Many social programs exist to re-integrate the person back into the working world, but that is the extent of these programs. Albrecht also has harsh words for Simi Linton, who he accuses of "re-inventing the wheel because (she) does not have a deep historical anchoring in (her) disciplines." (33). This is significant as she is a major component of this sabbatical project.

In Carol Thomas' "Disability Theory", she too veers away from the medical model, but considers the social implications of disability. In Thomas' view, the disabled are often stigmatized. The term handicapped often is synonymous with begging (i.e. "cap in hand" from the Industrial revolution). She also looks at other terms such as "disablism"(38), which refers to prejudice against a disabled person and "disablement", which indicates "limits to activities" (42) Finally, there is "impairment", which suggests "loss or abnormality of psychological, physiological or anatomical structure or function." (42) She also feels disabled women are more oppressed than disabled men "because more than one system of oppression is in operation." (48) In terms of culture, the disabled have been previously seen as "abominations" and a cultural depiction of them is vital to changing this and other perceptions. (49)

Finally, Bill Hughes in "Disability and the Body" gives an historical perspective of how disability was perceived in Victorian England. Just as people who had physiological differences were "confined" or kept away from polite society, the disabled, too, were part of what Foucault called the "great confinement", because of their "flawed bod(ies)" (60). Such segregation amounted to a "social death" (ibid). A further darkening of this sentiment occurred with the eugenics movement. According to Margaret Sanger in 1919, one of the first birth control proponents, "More children from the fit, less from the unfit—that is the chief issue of birth control." (62) Some eugenicists supported limiting reproduction of the disabled or, worse yet, genocide. This was all part of the movement toward "social hygiene" regarding the disabled. (ibid).

Even those who are sympathetic provide other hurdles to the disabled. "The non-disabled gaze is structured by pity and fear…" and often result in "charitable paternalism and exclusion." (62). Hughes also argues that judgments are made about the disabled based on their physical appearance. He writes, "Such judgments are self-fulfilling prophecies because they take place in a cultural context in which values regarding physical appearance are not only inseparable from moral order, but also inform a system of aesthetic stratification. (Synnot 1993 ibid). Hughes points out that most of the victims of disability England were the working class of society: "Women made unfit for childbearing, children deformed, men enfeebled, limbs crushed, whole generations wrecked, afflicted with disease and infirmity, purely to fill the purses of the bourgeoisie. " (Engels, 1987,184) (ibid).

The antithesis of this argument shows the disabled person to be the "victim of a cruel whim or circumstance or nature and became the kind of person, that her body allowed her to be."(63) Because of his/her "impairment", some theorists (Imrie, 2000, 1652) feel, "their mobility is their own fault and the consequence of a deviant corporeality which requires medical care, or failing that, the application of charitable works." (63)

In today's world there is a new sentiment of "body fascism" in which "the body is very amenable to reconstruction and re-formation by way of regimes of maintenance and enhancement that imply that the body we have is the body we deserve'"(70). To further this thought, Hughes notes,

> The spaces and places people carve out for themselves are not only products of bodies (what the existentialists call 'projects', combinations of the schemes of the imagination and the physical and mental labour that makes them possible.(ibid)

Finally, Hughes talks about the way the disabled are objectified. In the everyday world, disabled people experience such discrimination that they "*dys*-appear". In everyday encounters, their bodies determine how they are treated and they become "objects" rather than people. According to Hughes "Dys-appearance, therefore refers to the dehumanization of disabled people, as well as the immanent experience of alienation that is associated with it." (71)

Hughes also claims, "Disabled people do not recognize themselves in the way in which space and time are organized, precisely because they have little or no part in the constitution of the carnal order of modernity." (71) He suggests the "ride to inclusion and emancipation" is a "bumpy" one. (73)

While the ideas on these essays are quite valuable to the study of the disabled, they seem far too academic for Mount SAC students. Hughes' essay seems the most accessible and informative. Still, a certain amount of decoding academic language has to occur, for the students to understand many of the author's points. Giving a group of students several pages of the essay for them to decode might be a way to do this. Or selecting specific quotations (as the ones displayed here) for them to decode and discuss might be helpful.

Questions for thought:

1. List three ways the disabled have been treated in history (all essays).
2. Explain the term the new "body fascism". How does it apply to modern society? (Hughes)
3. Do the terms used (disablement, impairment) made a difference in the way disabled people are perceived? (Thomas)
4. Do disabled people *dys*-appear? Why do you think this is? (Hughes)
5. Why do some disabled people not have disability as their defining role? (Albrecht)

Lesson 3: Disability Laws

Three key pieces of legislation, Section 504 of the Rehabilitation Act, the Education Act for all Handicapped Children, and the Americans with Disabilities Act, are among the most important laws affecting the disabled.

Enacted in 1973, Section 504 states: "No otherwise qualified Handicapped individual in the United States…shall solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program conducted by any Executive Agency or by the Unites States Postal Service." According to a later law (1977), state and federal programs need to make "reasonable accommodations" to those with disabilities. The Education Act for all Handicapped Children passed in 1975, mandates "free, appropriate public education" for all children. The act was later renamed IDEA (for Individuals with Disabilities Act).

In 1990, the ADA or Americans with Disabilities Act outlawed discrimination on the basis of disability. It defines disability as "a physical or mental impairment that substantially limits one or more of the major life activities of an individual" (www.disabilitystudiesforteachers.org). Employers and other organizations must make "reasonable accommodations" to individuals with disabilities "unless these would impose an undue hardship" (ibid).

Questions

1. Discuss the types of programs that might be affected by this legislation.
2. What is "reasonable accommodation"? Is there any kind of accommodation that would be unreasonable?

Lesson 4. Freak Shows

One of the saddest aspects of Disabled History is that of the Freak show. Originated by Phineas. T. (P.T.) Barnum, the American Museum was established in 1841. On view at the museum were human oddities or freaks, as they were called at the time. Barnum, who has been called "the father of modern advertising" (www.disabilitystudiesforteachers.org), exhibited bearded women, albinos, giants and, most famously, small people (in the person of Tom Thumb). Born Charles Sherwood Stratton and standing two feet eleven inches tall, he was discovered by P.T. Barnum and became a sensation at the American Museum in New York City. Sherwood was put on display at the age of four and renamed "General" by Barnum, since it added a continental air to his name, which was popular at that time. Barnum also inflated Sherwood's age from four to eleven. The name "Tom Thumb" was derived from a dwarf knight in King Arthur's court. Sherwood was photographed by Matthew Brady, famed Civil War photographer and married another dwarf who Barnum had on display, Lavinia Warren. Their wedding was headline news. The museum burned down in 1865 and so ended a chapter of disability history.

Questions

1. Consider the ethics of displaying human beings with disabilities for profit.
2. Tom Thumb did become a very rich man. Does this excuse Barnum's treatment of him?

Lesson 5. Euguenics

While eugenics (the study of the methods to improve inherited qualities of a species), has an, at best, controversial history, there are two cases which are noteworthy for their pertinence to Disabled Studies. The first is a 1927 court case in the United States involving a seventeen year old woman, Carrie Buck (Buck vs. Bell) . Because Buck and her mother were considered "feeble minded" (a euphemism for "mentally retarded") and promiscuous (Buck had a daughter out of wedlock), she was the first person to be sterilized under Virginia law.

According to Dr. Albert Priddy, Superintendent of the Virginia Colony for Epileptics and Feeble Minded, where Buck was institutionalized, the Buck family "belong to the shiftless, ignorant and worthless class of anti-social Whites of the South." (www.disaiblitystudiesforteachers.org) Supreme Court Justice Oliver Wendell Holmes writing for the majority claimed,

> that Carrie Buck is the probable potential parent of socially inadequate offspring, likewise afflicted, that she may be sexually sterilized without detriment to her general health and that her welfare and that off society will be promoted by her sterilization... It is better for all the world, if instead of waiting to execute degenerate offspring for crime to let them starve for the imbecility, society can prevent those who are manifestly unfit from continuing their kind. ..Three generations of imbeciles are enough. (ibid)

It is important to note that Buck's seven month old baby was also judged "retarded". Ironically, by today's standards Buck would not have been considered mentally retarded. The pregnancy was a product of rape by her foster parents' nephew. Buck's daughter also excelled scholastically until her untimely death from intestinal ailment.

The other famous case of eugenics is that of Nazi Germany. In order to help promote "racial purity", Hitler felt it was important to sterilize those with chronic illnesses, and physical disabilities. (ibid). Between 1933 and 1936, 225,000 people were sterilized because it was feared their conditions were hereditary. Such conditions included "blindness, deafness, congenital defects and 'crippled' states". (ibid.) Ninety percent of those who appealed were refused by German courts.

Some Nazis took this idea of racial cleansing even further. Some with mental illness, blindness, deafness and other disabilities were marked for death. These people were judged as "lebensunwertes leben" or "life unworthy of life" (ibid). 200,000 people were murdered simply for being disabled. (ibid).

Questions for Thought:

1. Does the state have a right to terminate the reproductive rights of a mentally disabled person? Why or why not?
2. What was the state's justification in Buck vs. Bell?
3. List the reasons why you object to the Nazi cleansing of disabled people.
4. Consider the claim that sterilization is one step away from murder. How are the two linked?

Disability Studies—Erving Goffman from Stigma

Erving Goffman(1922-1982) , famed sociologist, is known mainly for his Presentation of Self in Everyday Society (1959). In this seminal work he discussed how we are different "offstage" (in our homes and private lives) than "onstage" (in our public selves). He also wrote about the institutionalization of the mentally ill and, notably, for this project, a book on Stigma . Goffman's work focuses on how those who are different or disabled are treated by the "normal" society and how the stigmatized individual is insecure when interacting in "normal" society.

In the opening of his essay, Goffman gives the etymology of the word "stigma" Going back to the Greek, a stigma was a sign or marking "designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor—a blemished person, ritually polluted, to be avoided, especially in public places. " (203) "Today," according to Goffman," the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it." (ibid)

Goffman notes that we often categorize people based on "first appearances" (203). We often judge a person's social status and identity in early encounters this way and anticipate certain behaviors based on these judgments.

Often, we treat those with a "stigma" such as a shortcoming or handicap, in a way that "discredits" them. We tend to "stereotype" the stigmatized person (204). Those with a stigma are separated from the "normals", a term seen routinely in the Disabled Studies literature. In fact, life for the stigmatized individual is worse than a mere disregard. As Goffman writes: "By definition, of course, we believe a person with a stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances." (205) He continues:

> We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents sometime rationalizing an animosity based on other differences, such as those of social class. We use specific stigmata terms such as cripple, bastard, moron, in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning. We tend to impute a wide range of imperfections on the basis of the original one… (205)

Goffman also noted that we tend to add imperfections to the disabled, for instance talking extra loud so that a blind person might hear us.

The disabled person often responds with shame and fear. According to Goffman, "Shame becomes a central possibility, arising from the individual's perception of his own attributes as being a defiling thing to possess, and one he can readily see himself not possessing" (206). When a stigmatized individual does not receive acceptance, he may try to master other skills to compensate.

(208) Also, he/she may find a "blessing in disguise" in his/her situation, or use his situation as an "excuse for ill success". (208). Goffman captures these possibilities with anecdotes.

One of the most difficult scenarios, though, is that of "mixed contacts" between the stigmatized and the "normals". "The very anticipation of such contacts can lead normals and the stigmatized to arrange life so as to avoid them," Goffman writes. He quotes Sullivan: "The fear that others can disrespect a person because of something he shows means that he his always insecure in his contact with other people." (210). According to a student of physical disability:

> Uncertainty of status for the disabled person obtains over a wide range of social interactions in addition to that of employment. The blind, the ill, the deaf, the crippled can never be sure what the attitude of a new acquaintance will be, whether it will be rejective or accepting, until the contact has been made."(210)

Goffman asserts,

> The uncertainty arises not merely from the stigmatized individual's not knowing which of several categories he will be placed in, but also where the placement is favorable, from his knowing that in their hearts others my be defining him in terms of his stigma (ibid).

In the face of this uncertainty and insecurity, the disabled person strives for acceptance. Goffman says acceptance becomes "the central feature of the stigmatized person's life" and this vague question of whether he/she will be accepted. There are those who mean well, and humanize the stigmatized person by including his disability in conversation. Such conversations are awkward at best and include such stock phrases as: 'My dear girl, how did you get your quiggle. 'My great uncle had a quiggle, so I feel I know all about your problem'. (212, sic) The tone of "morbid curiosity" or of "offering help the (disabled person) doesn't want or need" can only increase his burden or make him or her feel even more 'exposed". (212) Ranging from "hostile bravado" to cowering anxiety, the stigmatized person can have a variety of reactions. Rarely, according to Goffman to "mixed contacts" go smoothly:

> This, as my informants described it, is usually accompanied by one or more of the familiar signs of discomfort and stickiness; the guarded references, the common everyday words suddenly made taboo, the fixed stare elsewhere, the artificial levity, the compulsive loquaciousness, the awkward solemnity. (213)

Even though "mixed contact", does prove difficult it does improve with repeated practice. And it is the stigmatized individual who has one advantage:

> In social situations with an individual known or perceived to have a stigma, we are likely, then to employ categorizations that don't fit and we and he are likely to experience uneasiness. Of course, there is often significant movement from this starting point. And since the stigmatized person is likely to be more often faced with these situations than are we, he is likely to become the more adept at managing them. (214)

Although Goffman's concepts were first published in 1963, they still resonate today. A scene from Murderball in which Mark Zupan claims how he has been categorized would make an excellent scene for analysis of Goffman's concepts.

Questions for Discussion

1. Define "stigma". Explain the history behind the term.
2. List four to five characteristics of how "normals" treat the stigmatized individual.
3. How do stigmatized individuals respond to the treatment of "normals"? Give at least four characteristics of such treatment.
4. Give two possible scenarios for a "mixed contact" interaction.
5. Analyze a scene from Murderball, for instance where Mark Zupan and his teammates discuss their treatment by "normals". How does the scene support/discount Goffman's theory? (You might also use scenes from Waterdance or a passage from Autobiography of a Face.)
6. How can disabled people overcome stigma?

Disability Studies—Simi Linton, Body Politic

In Simi Linton's My Body Politic, she chronicles not only the tragic accident that killed her husband and best friend and paralyzed her, but her adjustment to life as a paraplegic. Also covered is her awakening as a social activist for the disabled. Primary on Linton's mind after waking from the accident that left her a widow and disabled her at the age of twenty one, are the concerns of a young person. Will she ever been seen as a person again, as a woman and as a desirable woman? The second chapter chronicles the difficulties of rehabilitation after such a devastating blow. A flurry of activities and parties reaffirms her personhood and a lover reaffirms her desirability. As she enters the academic world (in the early 1970's before many wheelchair accommodations were made), she notes the difficulties of navigating the campus in a wheelchair and the humiliations she endures as one who has to be lifted up steps and is at the mercy of freight elevators. Even bathrooms are traumatic, as she must leave the door open to use a stall. She recounts being invisible or worse yet, shunned by the hippies she wishes interact with because of her new and lowered status as someone who uses a wheelchair. A trip to Berkeley opens her eyes to a disabled friendly environment, with curb cuts, greater access and an actual disabled students' office. Her sexual desirability continues to be a question as she takes on some questionable partners. She shuns one wheelchair bound suitor, because she is unsure how such an arrangement would work.

As Linton studies for a degree in psychology, she is distressed to find little literature on disability and decides her original goal for working with the disabled is no longer of interest to her. She fears she will be backpedaling to a safe world and that succeeding in the ambulatory world is a better use of her time and talents. She relishes being a professor of psychology and the statement she makes as a disabled person teaching in a college environment. It is only when she attends a Disability Studies conference that she finds her true calling. As a visitor in elementary schools, she discovers that many disabled children have no role models and need them desperately. She also decries the way the disabled are segregated from the non disabled in schools and argues for full inclusion. Intermixed in all this are her memories of her mother, a strong independent woman who raised Linton single-handedly, stories of the father who died when Linton was eight, stories of meeting and marrying her husband David and of friends who transcend the "disabled" label.

In the early chapters, Linton captures the recovery phase with incredible honesty and awareness. At times, her writing is adjective-heavy, for instance when she writes, "her sad eyes shed a tear" and describes the weddings of disabled friends, which are otherwise quite moving. At times, the writing seems to have a political agenda infused with the personal narrative, which makes the narrative less immediate. It is her honesty about things like sexuality and her envy of a disabled man in Berkeley that make for compelling reading. The difficulties of navigating in wheelchair are also clearly drawn and educational for the non disabled, but when she starts her chapter on her motorized wheelchair, which she names Rufus, as if she were describing a pet or person, this seems like a juvenile writing trick.

Still, she is a compelling protagonist, but Josh Swiller's "Unheard" seems more student-friendly. He recounts his life as a deaf person with uncustomary candor and humor; his insights about pretending not to be disabled are priceless: "just because you imagine you're wearing golden underwear, doesn't mean you are," he writes. Deaf students will find him especially compelling, but his story is exceptional and also paints the bleak educational prospects of deaf students in Africa where he was in the Peace Corps.

Questions for Thought

Chapter 1: Conscripts to the Cavalry

1. How does Linton become disabled?
2. What are the attitudes of those treating her? How do they address her fears that she will never lead a normal life? (4, 14)

3. How do they break the news to her that she is paralyzed? Is this done in a humane manner? Why or why not?(4)

4. What is her response?

5. What are the songs that touch her? What do they seem to be saying? (11)

Chapter 2 Brave New World

1. How do others respond to Linton now that she is paralyzed? (28)

2. What happens when she needs things from others? Does she feel guilty or as if she has a right to accommodation? Why or why not? (21, 32)

3. How does she cope with disability out of the hospital? (35)

4. How does she feel about God now that she is disabled? (32)

Chapter 3: Coming Out in the West

1. How is Berkeley different than New York in terms of handicapped access? (41)

2. Why does she shun a disabled suitor and accept a selfish non-disabled one? (46, 47, 48)

3. How does the man on Shattuck Avenue change Linton's perception of the disabled?(42)

4. Is there a kind of prejudice against Linton when she travels to New York?

Chapter 4: A Special Education

1. Does Columbia University provide adequate handicapped access for Linton? Give examples of her difficulties in reaching classes. (58-9)

2. Part of the problem is the timing. Explain the Public Law 94-142 which was passed in 1975 (61). Was the college in compliance with this code? Why or why not?

3. How does Linton feel about "cures" for paralysis? (65-69)

4. Were there any opportunities for Disabled Studies? Why or why not? (64)

Chapter 12:

1. What are the lesson she learns from children? (168-171)

2. Are there enough role models for disabled children? (167)

3. Are disabled children afforded an equal education according to Linton? Why or why not?

Chapter 15: The Cripple Girl and Blind Boy go to the Museum

1. What does Linton think about the 'blind bars" which are popular in Europe? (215)

2. Should blind patrons be able to touch strippers? (219)

3. "Ideas make the world we live in and impressions furnish ideas"—Helen Keller. What do you think Keller was saying?(217)

4. What does Linton think of touch tours of museums for the blind?

Chapter 16: Our Body Politic

1. What do the t-shirts and bumper stickers sported by the disabled protesters suggest about their attitudes about being disabled? (226)

2. How do the tourists respond to the protestors?

3. What are they protesting and why?

Chapter 17

1. What percentage of the disabled are employed?

2. What are the remaining changes that need to be made?

Disability Studies—Simi Linton, Claiming Disability

Simi Linton, in the introduction of her book Claiming Disability, offers a different perspective on disability than many of her predecessors. For too long the disabled have been "hidden" (3) in institutions and attics, according to Linton and need to "let (their) freak flag fly" to quote Crosby Stills and Nash. As a wheelchair-bound activist, Linton, like many in the field, wishes to "challenge the notion that disability is primarily a medical category" (2), but one of social and political importance. In her rallying cry for the disabled she writes:

> And we are not the only the high toned wheelchair athletes seen in recent television commercials but the gangly, pudgy, lumpy and bumpy of us, declaring that shame will no longer structure our wardrobe or our discourse. (3-4)

She also cites some major literary characters and images of disability in her introduction:

> In the absence of the specifics of my condition, and my life you may find yourself conjuring up some of the readily available images of disabled women, both fictional and real: "the beholden Blind Girl in Chaplain's *City Lights*, the shame-riven Laura Wingfield in *The Glass Menagerie*; the doleful poster child gazing up at you from the collection box on the supermarket checkout counter; the defiant disability rights activist arrested for civil disobedience; your neighbor down the hall—or you may see yourself. (5)

She is tired of disability being "inextricably linked to pathology" (6) and "covered over" (7) and hopes to provide a new way of looking at the disabled.

This refreshing tone and approach makes her book, I think, worthy of study in a community college course.

The second chapter of her book is the widely anthologized "Reassigning Meaning". The first half of the chapter is covered in a discussion from the Disability Studies for Teachers website. The second half of the essay covers additional terms which are especially pertinent to Disability Studies. Two key terms in the popular thought about disability are: "overcoming" and "passing". "Overcoming" according to Linton is not generated from within the disabled community, but "is a wish fulfillment generated from outside. It is a demand that you be plucky and resolute and not let obstacles get in your way." (18) The problem with "overcoming" is the impact on the disabled person: "When disabled people internalize the demand to "overcome", rather than demand social change, they shoulder the same kind of exhausting and self-defeating "Super Mom" burden that feminists have analyzed." (18). Additionally, Linton writes, "If we, as a society place the onus on individuals with disabilities to work harder to "compensate' for their disabilities or to "overcome" their condition" this negates the need for legislation and affirmative action (19) . "Passing" is the disabled of equivalent of racial and sexual orientation passing that has occurred in this country for much of the last century. The problems with passing are manifold: First, they are an indicator of "internalized self loathing" (20) and take a great "emotional toll" on the disabled person. It is common for families of a disabled person to "create mini-fictions" (ibid) and for disabled people who can hide a prosthesis to do so. Passing and Overcoming create, "loss of community....anxiety, and...self-doubt" (21). So the term "coming out" co-opted from the gay culture is an important one in Disabled Studies. In discussing passivity and control, Linton also mentions that "Some of the stereotypes that are particularly entrenched with people with disabilities are that (they) are more dependent, childlike, passive, sensitive and miserable and are less competent than people who do not have disabilities."(25) Linton rejects this image of pained victim and even the term "victim". Words like "suffering" and "afflicted" also project a negative image. When discussing HIV "victims" Linton objects to the idea that disabilities are "punishment for sin in this or a former life" (26). Instead of AIDS victim, she recommends the term "*living with AIDS*" (26). Other terms she examines are: "wheelchair bound", "invalid", "disability" (and the etymology 'dis" or apart") and "normal" and "abnormal" (25-30, 22-23).

Questions for Discussion.

1. How does Linton's image of a disabled person (in the introduction of her book) differ from the conventional image we have come to expect?

2. Discuss the concepts of "Passing" and "Overcoming". What are the psychic costs of these activities?

3. What are the benefits of "coming out"?

4. Explain the etymology or meaning of "disabled", "invalid" or "normal/abnormal".

5. How are the terms employed for the disabled important?

6. Think of a disabled character in film, television or literature. Describe him or her. Discuss whether he/she is portrayed fairly.

In Chapter 3 of Claiming Disability Linton explores the way in which the disabled have been treated in society. The chapter opens with an alarming quotation from a Dear Abby column from a diner who is distressed by having to eat while watching a disabled person in the same restaurant. Surprisingly, this column is dated 1987. This introduction illustrates the ways in which the disabled are objectified and cast in society. Linton lists six categories which various cultures around the world tend to place the disabled in: Pariah, Economic Liability, Tolerant Utilization, Limited Participation, Laissez Faire and Active Participation and Accommodation. It is important to note that although, the Western countries may congratulate themselves on their humane treatment of the disabled, this is deceptive.

The Pariah . According to Hanks and Hanks pariahs are "denied all claims to succor by the protective group and (are) deemed a threat to the group itself." (38) They are also "despised by society." (39) In developing countries, such as India, there have been some instances of disabled infants being killed shortly after birth. Some minor disabilities, such as an extra finger, might be grounds for death in other cultures. Linton documents infanticide of the disabled in some African countries (41) and describes the "disposal" of adults and adolescents who become disabled. (ibid) In the Chinese culture there are "dying rooms" for defective babies and disability is thought to be "evidence of a heinous crime in a previous life" (42). One of the saddest cases Linton describes involves a disabled Japanese man, who was hidden at home and not allowed to leave his house until he was twenty six years old.

Economic Liability. According to Linton, the disabled were considered an economic drain on society. Often relegated to the role of town fool and shoemaker to despised outcast, the disabled were supported financial and cared for by society. At times, this care seems grudging at best.

Tolerant Utilization. Though still a marginal figure, the disabled person is allowed to contribute to society in this model. During WWII, the disabled were permitted to work in factories. In other examples, the disabled were displayed in museums and circuses. Linton mentions the Elephant Man and the Hotentot Venus as examples. The final example is that of a candidate for college admission in 1967 to whom the interviewer admits he is "reduced to (interviewing) the lame, the halt, the blind and the women." (52).

Limited Participation. According to Linton the term is ambiguous, but it allows the disabled to participate depending on their competence. Linton feels this is a dangerous model because: 'It promotes a false sense of acceptance because the norms and standards of the able-bodied majority are imposed and held up as the ideal to which all should aspire" (53).

Laissez Faire.

In a laissez faire system: "the norms of the able-bodied majority are centered on and held up as the ultimate goal of all people and the society makes no effort to reconstruct its goals or acceptable means of achieving them to reflect a broader range of citizen" (54). Linton notes the problem with this approach: "In such situations the dominant group decides what disabled people need and attempts to meet those needs but does little to engage with disabled people as a constituency to work together to set the terms of the accommodation" (ibid).

Participation and Accommodation

Linton focuses mainly on education for disabled children in this section, which seems to her to be the best hope for leveling the playing field. She lobbies for "inclusive classrooms where disabled and non disabled children learn together in cooperative groups designed to maximize the participation of all children in the learning process" (55). She argues, "The presence …of (disabled children) in a classroom not only helps the children who have never had such exposure see the disabled children as complex human beings, recognize their strengths and weaknesses, and learn from their abilities…" (62). One the most notable examples of this approach is a school in Burbank, California in which one-third to two thirds of the students in a given classroom are deaf." (61) Classes are team taught in a combination of sign language and spoken English. This sort of inclusive approach to integrating the disabled is exactly what Linton argues for. (An internet search yielded the name of the school Linton cites: George Washington School on Lincoln Avenue in Burbank).

Chapter 7

Linton offers excellent exercises in the final chapter of her book Claiming Disability "Applications". She asks readers to imagine they are teachers, architects and travel agents, among other things, and presents them with a series of complicated professional and personal dilemmas. These are excellent for classroom instruction. Small groups of students would each read a different scenario and give their responses, as well as the reasons for the solutions to the dilemma they chose. If a choice has already been made, the group could evaluate the professional's response from a Disability Studies standpoint.

Chapter 6

As a point of interest, Linton has some less than favorable things to say about Oliver Sacks, one of the foremost popular writers on disability today. "Unfortunately, there is a clinical overlay to his material and an assumption of doctor/patient configuration that compromise (sic) his project," she writes. In a searing indictment, she quotes Tom Shakespeare, another leading academic in the Disabled Studies field, "Oliver Sacks the man who mistook his patients for a literary career, violates every existing principle of disability equality…" (141). Also hindrance to equality is the objectification of disabled people (142). Another area of inquiry which is new in the discussion of impairment is that of pain. According to Morris in his book "The Culture of Pain", pain "engages the deepest and most personal levels of the complex cultural and biological process we call living" (139) A list of major problems in Disability Studies is listed on page 134.

Questions

1. Given the terms for disabled people (pariah, laissez faire) how do you think the disabled are treated in elementary schools?

2. Is it true that including disabled children in classrooms will make non disabled students more open-minded towards the disabled? Why or why not? (Linton has been criticized for this belief).

3. Imagine what difficulties a disabled architect or teacher might confront. List them.

Disability Studies --- Samantha Dunn, Not By Accident

Born in Santa Fe, New Mexico, Samantha Dunn was an avid horsewoman, until the fateful day her horse Harley crushed her leg with his hoof. She had been thrown from horses before and endured minor injuries (like a broken tailbone) but this was much different. The massive blood loss was life-threatening and without the aid of an actor who happened to live nearby, Dunn would've died. Her leg was virtually torn in two and was missing a great deal of bone. Not by Accident chronicles her year-long recovery and the emotional ways she copes with disability.

Many of the markers of disability literature are here. The desire to feel normal (page 81) is described by the hospital-bound Dunn as she contemplates the difficulties of even simple tasks like walking to the bathroom. Eating a McDonalds Filet o' Fish sandwich gives her some sense of the real world, but getting her hair washed for the first time since the accident causes her to comment: "This must be how people feel when they open their front door and the van from the Publisher's Clearing House Sweepstakes is parked outside;" (83) There is the hospital humor about drugs: " I once heard a story about a former junkie who was so committed to his sobriety that as he was dying of cancer her refused morphine and all other painkillers. About two hours after I just took one Percodan I began to appreciate what that junkie had accomplished. I now ask for three instead of two as a matter of personal policy. She just gives me two." (78) Dunn also contemplates religion as a priest is at her bedside, but instead relates a story of a religiously zealous NAPA parts truck driver who informs her of the oncoming apocalypse (38).

Unique to Dunn's story are two features. One is a long, well-researched section on accident proneness. (She is, after all, a magazine writer) The other is a meditation on the grades of friends who see her through her accident. The section on accident proneness offers several possible theories from a psychoanalytic approach to a theory that those who are left handed are more likely to die younger as an answer for Dunn's obsessive search for a reason for her accident. Also intermixed is an ADD theory and a personality-type (daredevils and risk takers) who are more prone to accidents. This section is less compelling than the rest of her narrative and the challenges she faces a disabled/recovering person. The grades of friends that Dunn describes are recognizable to those bed-ridden by disability. There are three grades of friends, according to Dunn: grades 1, 2 and 3. (116-118) Grade 1 friends call often according to Dunn and will listen to the details of the accident and recovery in great detail. Grade 2 friends tolerate less "self absorption and graphic detail

"(116) according to Dunn. Grade 3 friends call only once a week. These definitions reoccur in the book.

Another distinctive feature of the book is Dunn's discussion of her love of horses and the intimate role they play in her past. From a young age, Dunn felt connected to horses and they were a part of her life. (63-74) Though Dunn and her mother were often poor, they did what they had to to afford a horse (89-93).

The fear of relying too heavily on others comes out as Dunn tries to walk unattended instead of calling a nurse. She explains that her mother never accepted help while raising a child by herself. Dunn agrees," no welfare Velveeta in this house." (77) Vanity and fragility also play a role in this section (76).

As the ability to ride horses and be a productive member of society is temporarily taken away, Dunn confronts her identity as a disabled person as she asks the question, "Who am I? What am I?" (110) Even her earning power becomes an issue when her husband, Matt (who comes off as an ogre during one part of the narrative) asks the bed-ridden Samantha "Can you pay anything on the rent this time?"(120) Absent during much of her recovery , he manages to stare coldly at her when asking for money. As a result of her accident, their marriage derails.

The real threat of amputation brings Dunn the classic images and rationalizations of amputees (63). She pictures the wheelchair athletes and imagines sexuality after amputation.

Towards the end of her recovery, Dunn also turns to yoga and Eastern mysticism as part of her treatment. Dunn meets Gurmuhk, a yogi-to-the-stars, as part of a magazine assignment and she (Gurmuhk) invites Dunn to take yoga. This leads Dunn through a world of Eastern medicine (acupuncture, cold showers, a vegetarian diet). She also encounters a former Navy SEAL (another trainer-to-the-stars), who offers her insights and walking instruction. Dunn's pursuit of these "alternative" approaches is successful and leads her back to her horse and a more conscious life. She is also a fan of her doctor, Dr. David Mesna and has many humorous exchanges with him.

Finally, though, it is horseback riding which Dunn credits with her full or almost full recovery. An Eastern mystic tells her to let her horse be her guide – and after a return to the riding ring, the bones in her leg begin to provide the "union" the doctor has been hoping for.

Questions

Initial Accident

1. How severe is Dunn's accident? Is there anything she could've done to prevent it? How does she feel about this?

2. Are there any forewarnings about the accident? What are they? Why does she see/not see them?

Initial Response

3. According to Erving Goffman, disabled people often wish to appear normal. How does Dunn wish to be "normal" in the context of the hospital?

4. Many disabled people, again according to Goffman, fear the potential response from "normal" society and possible rejection. How does Dunn deal with this?

The Wake –Up Call

5. Describe her spiritual journey. How does the theme of the wake-up call resonate in the book? What are the things Dunn needs to wake-up and see and the changes she needs to make?

6. Who are the people who facilitate the wake-up call process and what do they bring to Dunn?

Identity and Values Shift

7. How does the accident affect Dunn, as someone who works for a fitness magazine and is an avid horsewoman?

8. How does the accident affect her marriage and the roles in it?

9. Does the accident have an effect on her friendships? How?

10. How does she relate to losing her self-reliance?

Spiritual Awakening

11. What sort of spiritual lessons does Dunn learn?

12. How does she finally answer the question of accident proneness?

Disability Studies—Lucy Grealy, Autobiography of a Face

Lucy Grealy's heartbreaking and beautiful Autobiography of a Face is perhaps the best and most literary of all the works about and by a disabled author. Though she loathed the word "disfigured", Grealy was just that, left with a piece of her jaw missing from a childhood bout with cancer. Her chronicle of the discovery of cancer, her many hospitalizations, the horrors of chemotherapy, and her personal response to being ugly in a beauty-obsessed culture are moving and honest and brilliantly observed.

Grealy, born in Ireland in 1963, moved to the United States when she was two. Her father, a well known journalist, had gotten a job with CBS. When Grealy was nine, she was hit in the face with a softball at school. Her jaw swelled so terribly that tests were done. They revealed that she had jaw cancer. After several operations and two years of chemotherapy, Grealy was cured of cancer, but the cost was a deformed jawline with a missing piece. Her book, Autobiography of a Face, which chronicles her hospitalizations and difficult life, debuted in 1994. It won critical acclaim and was re-released in 2003. Though Grealy enjoyed critical and commercial success with the first release, the second one followed her tragic death in 2002, by suicide. Many feel the pain of her disfigurement finally got the better of her.

In an interesting note, Ann Patchet, a writer and close friend of Grealy's, wrote her own book, Truth and Beauty following Grealy's death. In it she chronicles her friendship with Grealy and gives a strikingly different account of Grealy than Autobiography does (she portrays her as vain and self-involved). Subsequent letters by Grealy's sister also complicate the two portraits.

It is amazing what can happen when a brilliant and honest writer covers the painful territory of disability. Grealy does so unflinchingly. For the first few pages of Autobiography, we do not know that Grealy is deformed; all we know is that Grealy was a horse handler for children's birthday parties. In fact, Grealy describes the affluence of the families and the details of the party first; then on page 3, she makes us aware of her disability:

> My pleasure at the sight of the children didn't last long, however. I knew what was coming. As soon as they got over the thrill of being near the ponies, they'd notice me. Half my jaw was missing, which gave my face a strange triangular shape, accentuated by the fact I wasn't able to keep my mouth fully closed. (3)

Although Grealy acknowledges it was odd for her employer to require her to work at pony parties, she was so thrilled to work with horses that she accepted the stares of those at the parties and learned to hide her face. Still, the pain, when it was inevitably revealed was overwhelming:

> The cruelty of children is immense, almost startling in its precision. The kids at the parties were fairly young, and,

> surrounded by adults, they rarely made cruel comments outright. But their open, uncensored stares were more painful than the deliberate taunts of my peers at school, where insecurities drove everyone and everything like some looming evil presence in a haunted machine. But in those back yards where the grass was mown so short and sharp it would have hurt to walk on it, there was only the fact of me and my ugliness. (7)

In addition to an awareness of her physical difference, Grealy was also aware of her socio-economic difference (9). "Panthesim ruled," she writes of the natural laws she had to follow in her cobbled together and in-need-of-repair home.

She also describes her parent's fights and her mother's bi-polar nature (9-10) with equal descriptiveness.

In the second chapter "Luck" Grealy describes the discovery of her jaw cancer. The chapter opens with the words "Ker- Pow" and the image of another girl's head colliding with Grealy's face in gym class (14). Grealy describes the concussion in both accurate and poetic terms: "I felt as if I could speculate and theorize about a thousand different beautiful truths all in the time it would take my lips to form a single word." (16)

Although the pain of the collision was great, Grealy explains why she didn't feel it as keenly as she might,

> Anxiety and anticipation, I was to learn, are the essential ingredients in suffering from pain, as opposed to feeling pain pure and simple. This alien ache was probably my first and last

> experience of unadulterated pain, which perplexed me more than it hurt me (ibid).

After being treated for a toothache, Grealy wakes up with lockjaw. Like many children, Grealy is actually excited about her medical treatment:

> My two absolute hands-down favorite television programs were Emergency and Medical Center, and the possibility of personally living out one of these thirty minute dramas elated me.(20)

Before the diagnosis of cancer and early in her treatment, Grealy learns to be a good patient, "… I was courageous and didn't cry and thus was good."(21).After testing, she has what is thought to be a dental cyst removed, but then her jaw worsens six months later. It is then the cancer is discovered. Grealy meditates on fate at the end of the chapter: "Our fates were already perfectly mapped out within us, just as we once waited perfectly inside of our mothers, who themselves were once held within the depths of their mothers, our great-grandmothers." (27)

The "what ifs" that most people struggle with are also part of Grealy's psyche,

> It's impossible for me not to revisit this twenty-one year old playground scene and wonder why I didn't go right when I should have gone left, or, alternatively, see my movements as inexorable. If the cancer was already there, it would have been discovered eventually, though probably too late. Or perhaps that knock set in motion a chain of physical events that created an opportunity for the cancer to grow which it might not otherwise have found. Sometimes it is as difficult to know what the past holds as it is to

> know the future, and just as an answer to a riddle seems so obvious once it is revealed, it seems curious to me now that I passed through all those early moments with no idea of their weight. (27-8)

One of the themes of the early part of Grealy's treatment for cancer is that of the search for approval. For both her mother and her doctor, Grealy tried to be the "good" patient.

> One had to be good. One must never complain or struggle. One must never, under any circumstances, show fear and prime directive above all, one must never, ever cry. I was nothing if not harsh. Had I not found myself in this role of the sick child, I would have made an equally good fascist or martyr. The subtleties of my first visit to the emergency room, where I'd been praised as good for being brave, were already arranging themselves into a personal treatise in much the same way that a seemingly inconsequential architectural miscalculation on the ground floor can result in a sweeping chasm in the penthouse. At the time when everything in my family was unpredictable and dysfunctional, with my mother recently discharged from the hospital herself, here I had been supplied with a formula of behavior for gaining acceptance and, I believed, love. All I had to do was perform heroically and I could personally save my entire family. (29-30)

Grealy's behavior as a patient was critical in her mind to her family's happiness and the love and approval every child desires.

In the second chapter Petting Zoo, Grealy also writes of coming to America (31-35) and her early experiences of American culture. It seemed much of America – television, candy bars and culture- -was vastly inferior to that of Ireland in the eyes of Grealy's older brothers. The tension at home was also great, as Grealy describes being in the hospital:

> The sense of comfort continued in the following days and weeks. There were definite problems to face here, but to me they seemed entirely manageable: lie still when you're told, be brave. It didn't seem like so much to ask, really considering what I got in return: attention, absence from school, occasional presents, and though I wouldn't have admitted it to anyone even if I could have articulated it, freedom from tensions at home. (38)

The title of the chapter "Petting Zoo" refers to a field trip of sorts that the children organize in the hospital to see animals that they have heard live there. In fact, the animals are lab animals and the sight of them is extremely disturbing (50-2). This foreshadows the seriousness of Grealy's illness and the pain for her treatment. As she puts it, "Sooner or later we all have to learn the words with which to name our private losses, but then we just stood there in front of the nurse's desk, speechless" (52).

Attesting to Grealy's ability to write great titles, "The Tao of Laugh-in" is no exception. In this chapter Grealy explores her denial about the severity of her disease. When well-meaning adults tried to warn her about potential pain and discomfort of her treatment, Grealy shrugged them off. She had already established a sort of "super patient" persona. In example of this is: "On the day I finally went home, I felt only proud of my new dramatic scar and eager to show it off" (62). The war wound and all that she had endured to get it were a kind of bragging right and testament to her strength, as they are for many patients. Her denial is striking in this chapter as well, when she describes, how her friend Evan's father approached her to hint at what might be next in her treatment:

> He mentioned something vague about chemical changes in my body and about how my hair might be affected. Having no idea what he was talking about and sensing something serious I'd rather not pursue, I made a joke to Evan about how my hair would turn green, my eyes purple. This was the second time an adult had tried to approach me directly and seriously about my situation, and it was the second time I had turned it around, refused to tackle it. (63)

The title of the chapter refers to the television show Laugh- In which Grealy says offered a kind of "salvation" (65) to the questions of death and illness that plagued her. After watching a skit about a supplicant going to Tibet to ask a holy person for the meaning of life, Grealy, then six, asked her father how much a plane ticket to Tibet was. Though his answer was "a million dollars", Grealy "decided to start saving" (66).

In the ensuing chapters, Greally describes violent sickness that swept over her after chemotherapy treatments (at times she was so ill she had dry heaves), hair loss, and attempts by well-meaning friends of her mother's to buy her a custom wig. She describes the cycle of life following chemo (two days of sickness, better by the third day and finally well on the fifth) (79-80), and the impending doom of having to repeat the cycle. Since Grealy knew she could not have chemo if she was sick, she began trying to make herself sick by sitting in freezing rain and scraping her skin with a rusty nail. None of this worked, however. (94-97). She is eloquent about the pain and convalescence:

> I was becoming aware that I was experiencing my body and the world, differently from other people. For hours I'd lie in bed either at home or in the hospital and run my finger back a forth along the wall or bedrails beside me, conversing silently to myself in the third person, rationalizing the situation, setting down the basic premises of my secret philosophy, occasionally even telling myself I was lucky, lucky to have this opportunity to know such things. At times I was desperate and could find no solace anywhere. Nothing seemed to work, and the weight of being trapped in my own body made it difficult to lift even a hand off the sheets. Each breath was an important exchange with the world around me, each sensation on my skin a tender brush from a reality so beautiful and so mysterious that I would sometimes find myself squealing with the delight of being alive. (91)

This cycle of despair and hope is one that recurs in her life. It is further complicated by her mother's admonition not to cry or express fear, which Grealy certainly felt. (78). And Grealy is one of the few writers who describes chemo with incredible accuracy: "My body wanting to turn itself inside out , made wave after wave of attempts to rid itself of this unseeable intruder, this overwhelming and noxious poison. I shook with heaves so strong they felt more like convulsions" (76)

Baldness is another side effect Grealy discusses with unusual candor:

> My hat was my barrier between me, and what I was vaguely becoming aware of as ugly about me, and the world. It hid me, hid my secret, though badly and when people made fun of me or stared at me, I assumed it was only because they could guess what

> was beneath my hat. It didn't occur to me that the whole picture, even with the hat, was ugly; as long as I had it on, I felt safe. Once on television, I saw someone lose his hat in the wind and I immediately panicked for him, for his sudden exposure. It was a visceral reaction. (106).

The hat seems like a kind of security blanket or shield, and her connection to it is clear, when she feels horror at the thought of a television character losing his. Grealy's descriptions of an ill-fated wig buying expedition further reinforce how odd she looked and how complete her baldness was. Her family, to their credit, made fun of the donated wigs people gave them.

Her only relief from the self consciousness from her appearance comes on Halloween, in the form of wearing a mask.

> I walked down the street suddenly bold and free: no one could see my face. I peered through the oval eye slits and did not see one person staring back at me, ready to make fun of my face. I breathed in the condensing, plastic tainted air behind the mask and thought I was breathing in normalcy, that this freedom and ease were what the world consisted of, that other people felt it all the time. How could they not? How could they not feel the joy of walking down the street without the threat of being made fun of? (127)

This projection, like that of the hat, feels, entirely natural to the disabled experience. Her inner life, though, was becoming "macabre" (126). And she briefly became addicted to pain pills (142) She, too, loses patience with normal people who complain about their appearance since her own is so different. (131, 151, 168)

Because of her appearance, Grealy is taunted at school and spends much of her school life, either dodging taunts, eating lunch in the counselor's office or staying home from school due to illness. She tries to rise above the taunts, quoting Martin Luther King (to herself) and "aiming for sainthood" (152) by not responding. At times the pain seems unbearable (145). Her relief comes in working with horses (149) . In an unguarded adolescent moment among friends, when they are discussing a boy they like, Grealy realizes that she is not in the romantic running (150.)

After the chemotherapy is done, Grealy is given some hope for cosmetic surgery to improve her appearance. The cycle of hope (157) and despair continues. After a skin graft, Grealy is swollen and her skin looks patched together. To compensate she becomes more academic:

> I picked out thick books by Russian authors and carted them around with me. Sometimes I even read them. *Anna Karenina. The Brothers Karamozov, Dead Souls,* I read *Jude the Obscure* simply because I like the title, and anything else that sounded difficult and deep. Often I missed the subtle nuances of these books, but they presented a version of the world in which honor and virtue and dedication to the truth counted (177).

Literature and art are a salve to her (189). Both pain and beauty are represented in them.

Grealy's theme of repeated surgeries and the hope and loss involved in them is clear through much of the later part of the book:

> My face was my battle scar, my badge of honor. The people in plastic surgery ward hated their gorgeously hooked noses, their wise lines, their exquisitely thin lips. Beauty, as defined by society at large to be only about who was best at looking like everyone else. If *I* had my original face, an undamaged face, *I* would know how to appreciate it, know how to see the beauty of it. Yet each time I was wheeled down to the surgical wing, high on drugs, I'd think to myself, Now, I can start my life, just as soon as I wake up from this operation. (187)

Much of her teenage and young adult life, Grealy is waiting for her new face and her life to commence.

Grealy does find acceptance at college, and a lover (actually several) in graduate school. To compensate for her face, she begins to work out obsessively:

> This is when I began dressing in earnest slinkiness. I began spending two hours a day at the gym, imposing a killer regime on myself. My body was one thing I had control over. If I had put a tenth of the energy I spent obsessing over my face and body into my work, I could have written *War and Peace* ten times over. (208).

In pursuit of the final surgery that will return her face to normal, Grealy moves to Ireland and undergoes additional punishing surgeries. Though they ultimately fail, because the grafts get re-absorbed, Grealy is offered a few weeks of looking "normal". The mantra *"when my face gets fixed, then I'll start living"* has become just that. (221)

At the end of the road, Grealy seems to makes some peace with this dashed hope when she writes,

> Without another operation to hang all my hopes on, I was completely on my own. And now, something inside me started to miss me. A part of me, one that had always been there, organically knew I was whole. It was as if this part had known it was necessary to wait so long, to wait until the impatient din around it had quieted down, until the other internal voices had grown exhausted and hoarse before it could begin to speak, before I would begin to listen (221).

Historically, we know this wished-for peace was not to happen.

Themes to Consider:

Denial

Cruelty of Others

Compensating ’

The Brave Patient, Super Patient Syndrome

Projection

Romantic Rejection/Longing

Beauty Vs Truth

Completion of Self

Disability Studies – Ann Patchett Truth and Beauty

Truth and Beauty by Ann Patchett chronicles the close and personal friendship between Lucy Grealy and Patchett in lovely and amazing detail. Throughout the book, Patchet uses the analogy of the ant and grasshopper to compare the two women, Patchet being the worker ant, who sets aside grain for the winter and works at a plodding pace, and Grealy being the mercurial grasshopper, who is glamorous and impractical and waits till the last minute, but still manages to be brilliant. While Patchet's love for Grealy is deep and abiding, Patchet manages to make Grealy look selfish, insecure and self-involved, due to the suffering she experienced as a result of her disability. There is some controversy about this. An August 7, 2004 letter to the Guardian, a London newspaper, by Suellen Grealy, Lucy's sister, chastises Patchett for her portrait of Grealy and her (Grealy's) "frailties"; Suellen goes on to call Patchett a "grief thief" and of "hitching her wagon to (Grealy's) star" (http.//books.guardian.co.uk/departments/biography/story/0,6000,1277240,00.html). She also claims that "Lucy was a uniquely gifted writer. Ann, not so gifted…" (ibid), which is a sentiment generally shared in the literary community.

Though Truth and Beauty is an amazing portrait of a friendship, it is not as helpful in terms of Disability Studies. It does offer an outsider's perspective on suffering, and insights into Grealy's personality, but it only discusses a few of the concepts of Disability Studies. Grealy's super patient tendencies are captured by Patchett. (57)

Grealy's letters (which are included in Patchett's memoir) also capture the great loneliness of her post-operative life (64-5). Patchett also shows Grealy as someone obsessed with love and the idea she might never find a lover.

Since the work is a portrait of a friendship, it begins when Patchet and Grealy first met each other briefly, during their years at Sarah Lawrence College in New York, but their friendship began in earnest at the Iowa Writer's Program. Though Patchett had a passing acquaintance with Grealy at Sarah Lawrence (and their first meeting wasn't terribly flattering to Lucy), their friendship began with a letter from Lucy asking her to look for an apartment for her. Patchett found one for them to share and they became roommates. Their intimacy is best captured by notes that Grealy left for Patchett. Her salutation begins:

> Dearest anvil, dear deposed president of some now defunct but lovingly remembered country, dearest to me, I can find no suitable words of affection for you, words that will contain the whole of your wonderfulness to me. You will have to make due with being my favorite bagel, my favorite blue awning above some great little café where the coffee is strong but milky and had real texture to it. (7)

The closeness and love conveyed here speak for themselves.

Patchett felt protective of Lucy, staring down those who gawked at her (9) and becoming indignant when they did. While Patchett had been in a car accident when she was younger, and sustained some serious injuries, she felt the trauma she experienced did not begin to compare with Grealy's. She uses a literary metaphor for the comparison: "I read one slim volume of the available information. Lucy read the library" (10). Despite the stares and gawks, Lucy preferred to be asked directly about what happened to her and would improvise when answering,

> If they have the nerve to ask me, I'll tell them the truth," she said. Unless of course, they asked her on the bus, in which case she would lean close and whisper, "Bus accident." Or "plane crash" or "car wreck", depending on the mode of transportation at the moment. (12)

Patchett shows how sick Grealy must've been of this question.

The grasshopper/ant dichotomy is explored on page 20 and becomes a reoccurring theme throughout the book. She also explains that due to Grealy's missing jaw, could only eat simple, soft and bland food, which Patchett calls "Lucy food". (24) Since Patchett prepared much of the food, she (Ann) characterizes herself as the ant, and Grealy's profligate ways with spending (28) also put her in the grasshopper camp.

The unflattering portrait involves much of Grealy's emotional pain, and, at turns, Patchett shows that Grealy was so involved with her own suffering, she couldn't acknowledge that in others. According to Patchett, who was visiting Grealy in Ireland after the break-up of her (Ann's) marriage, Grealy simply said, "Oh, you'll be fine" (72). This is the nature of Grealy's personality, as Patchett explains it (and Suellen Grealy seems to agree). Patchett also makes another insight into Grealy's grief:

> Lucy tried constantly to find and fully participate in any joy that was available to her, but still she was pulled into scorching bouts of depression. Her grief about feeling ugly and her desire to be loved in a way that would be huge enough to meet her needs would regularly roll her into a little ball and paralyze her. She would cry for hours and then for days. Lucy's sadness terrified me, in part because it made such perfect sense (42).

She gives a sense of the pain that later Grealy tried to escape with heroin.

The ant/grasshopper analogy continues with Patchett's description of Grealy's work habits. Writes Patchett, "I have never known another writer who enjoyed the actual act of writing less than Lucy, which is saying something because just about every writer I know sits down to work with some degree of dread" (113). Though poetry and ideas were central in Grealy's life, she often delayed writing to the last possible minute. Of "Autobiography of a Face," Patchet says,

> Lucy finally buckled down and blasted through the last one hundred pages of her memoir. For the rest of her life she figured that this was the way she worked best, writing very little through most of the time that was allotted to her, them making a heroic eleventh-hour save." That's the way I wrote my book," she would say, proof that the system worked. (117)

Patchett later says that this stalling tactic ruined Grealy's attempts at a novel.

Even though Grealy was a great talent and sometimes insecure person, her love of art also suffuses the book. She describes the works of Basquiat and the children of Terezin (concentration camp artwork made by children) in a letter to Patchett with great emotion. Also, in her early days, poetry was central to her being. As Patchett writes, "Poetry defined her" (46). Grealy, in one of her letters makes a connection between poetry and her suffering," I am sure, that this new importance of poetry and art in general is having for me has to do a great deal with my precarious emotional state." (47) It is a touchstone for her, of experience and emotion.

Patchett's book offers a warts-and-all portrait of Lucy Grealy, with a seeming emphasis later in the book on the warts. But we get to see the Grealy who because she'd been hospitalized lacked the normal inhibitions of others (26) and the girl who minimized her pain in front of doctors because she loved them so. The great friendship between the two writers shines brightest, though, as one that should go down in the ages.

Disability Studies—Natalie Kusz, Roadsong

Natalie Kusz' Roadsong details her family's move to Alaska, an attack by sled dogs which left Kusz missing part of her face and one eye, as well as the extraordinary lengths her family goes to merely to survive. Like Lucy Greely, Kusz (pronounced "cush") was young (she was seven, Greely, nine) when she was disfigured. Though Kusz, formerly a writing professor at Harvard, describes the aftermath of her accident and subsequent surgeries, her book seems less about the lingering physical and emotional effects of disfigurement and more about her family's experience in Alaska. While beautifully written and movingly described, Kusz' book seems more like disability "lite" when measured against Greely's. Another reason for the differences (though Kusz did go through the traumatic pedestal transplant procedure that so terrified Greely) is that Kusz seems to distance herself from the emotional pain and fallout of disfigurement and merely sticks to the objective facts when reciting the attack and her life thereafter. While some might argue that Kusz is more resilient than Greely, those hoping to understand the emotional component of facial disfigurement glean more of the physic toll from Grealy than Kusz.

Kusz' book starts with the hope her family experiences on its way to Alaska from Los Angeles, California. Many of Kusz' descriptions and details resonate with the sense of adventure and hope the family experienced as pioneers on a journey to a new land. Kusz' family had no way of knowing just how dark and difficult life in Alaska would be, however. The descriptions of the family's trip include adjectives like "infinite", "vast" and "indefinite" (13) painting a picture of endless possibility. Music also colors the hopeful mood of the opening chapter—as a way of connecting with other people on the same adventure they were. The festive music gives way to a sense of calm and wonder: "The adults indulged us and let us play, luxuriating as they were in one another's company" (19).

Upon the family's arrival in Alaska, they endure incredible poverty. Kusz describes "threadbare" clothes and powdered milk (32) and her father discovering dumpster diving for the family's survival (35-6). The family also coins a new term for affluent people who have running water and a conventional home with electricity, "Rodneys", based on a Listerine commercial featuring a polo player named Rodney with a Harvard accent who claimed to have everything he needed in life (31). The term is used often in the book and becomes a humorous catch-phrase for the well-off. Sadly, having a winter parka and mukluks for the thirty degree below zero winters qualifies one as a "Rodney". Kusz and her family spend their first winters surviving on noodles and wild mushrooms (which they harvest themselves) and living in a trailer with poor insulation and no running water.

Because the winters are so severe, Kusz has a pact with her mother that if she (Natalie) is home alone, she is to go to a neighbors' house and wait. The neighbors keep dogs, which we are warned experience a kind cabin ever of their own (38). This "fever" sometimes causes the dogs to attack people. It is such an attack, after Natalie bends down to pet a dog, that nearly ends her life. Her description of the attack seems surprisingly matter-of-fact:

> He surged forward on a chain much longer than I thought, leaping at my face, catching my hair in his mouth, shaking it in his teeth until the skin gave way with a jagged sound. My feet were too slow in my boots, and as I blundered backward they tangled in the chain, burning my legs on the metal. I called out at Paul's window expecting rescue, angry that it didn't come, and I beat my arms in front of me, and the dog was back again pulling me down.
>
> A hole was worn into the snow, and I fit into it, arms and legs drawn up into me. The dog snatched and pulled at my mouth, eyes, hair: his breath clouded the air around us, but I did not feel its heat, or smell the blood sinking down between the hairs of his muzzle. I watched my mitten come off in his teeth and sail upward, and it seemed unfair then and very sad that one hand should freeze all alone: I lifted the second mitten off and threw it away, then turned my face back again, overtaken by sudden loneliness, A loud river ran in my ears, dragging me under." (47)

Perhaps it is because of her age (she was seven when she was attacked) or the shock she endured, but the description seems muted and almost Stanislavskian in its spareness. (Stanislavski was a well-known acting theorist who encouraged actors to cut thirty percent of emotion from every scene). Kusz describes her doctor's take on her injuries in precise medical terms:

> I had sustained over one hundred lacerations from the shoulders up, and had lost my left cheekbone along with my eye...They had spent four hours just cleaning out the wounds, pulling out dirt and old berries and dog feces, Even with heavy antibiotics, I would likely have massive infection and they would probably spread to my brain. (57)

The injuries are severe enough that her mother wishes that she would "die before morning" (48) Described from her mother's point of view the results of the attack seems even more horrifying:

> She saw one side of my face gone, one red cavity with nerves hanging out, scraps of dead leaves stuck to the mess. The other eye might be gone, too; it was hard to tell. Scalp had been torn away from my skull on one side, and the gashes reached to my forehead, my lips, had left my nose ripped wide to the nostrils. (49)

Instead of focusing on her pain and suffering, Kusz instead turns to her mother's guilt when she states, "my mother seems to have lost more in the accident than I did" (63). It is the psychic toll of the accident that Kusz prefers to focus on and, in fact, end up, according to her being more significant: "But those who are truly insightful will know this fact: that the greatest injuries are never those of the body. "(64) Her mother becomes protective and the veil of safety is forever lifted. Kusz details her mother's unwillingness post-accident to let her out of her sight. (71- 72) Of her mother Kusz writes:

> "She said that mothers had a thousand thoughts to get through with in a day, and that most of these were about avoiding disaster. A mother learned early to turn pan handles in towards the stove, to keep roller skates off the steps, to lock the medicine chest. And it would seem , she said, that if you got through enough days where your children were not eaten by bears, did not fall down the outhouse pit, did not lose more than half a finger to frostbite, you would begin to relax a little and to worry less in your sleep."(72)

Additionally, Kusz suggests that her mother feared the specter of mental illness which her grandmother suffered from. Kusz is also concerned with the suffering of the caregivers of those who suffer illness or disability. She writes of her friend whose husband was dying of cancer and says most people were interested in the mechanics of her husband's treatment rather than about her husband's "pain, or anything that would involve them in unpleasantness." (64) Her grief was expressed in private because most people shunned a public expression. Kusz seems clearly to side with caregivers over the patient when she writes: The truth is, I think, that the casualties among us include not just those who are dying, or bleeding, or recovering from injury, but also the caretakers around the edges, whose selves fall sacrificed to their charges." (65)

In the hospital, Kusz is not only given dolls with amputated limbs (which seems extremely enlightened to me) but several role models. The first is Mrs. Goodman, a kindergarten teacher of Natalie's who wore an eye patch. Natalie was asked to consider the "hard parts" of life for a "teacher like that" and to see how Mrs. Goodman had a role beyond that of cripple. (96). Another role model is the three year old Samuel who is dying of cancer. Kusz notes his dignity and bravery in her description of him. It is in reference to him that she asks one of the most poignant questions in the book: " I have heard debate over whether terminally ill children know they are going to die, and I can't, even after knowing Samuel, answer this question." (102) His sudden death is all the more felt for this admission.

Unlike Grealy, Kusz does not look forward to surgery. In her chapter "Surgery", Kusz describes the feeling of going under anesthesia as something she had to learn not to fight. About the surgeries themselves she writes," I hated surgery from the start, dreading its slug -footed approach to and my helplessness in the face of it." (105). The uncertainty of each procedure also has its effect; there are no guarantees the surgeries will succeed and, in fact, although Kusz does have successful skin transplanted to her face, she never does get the coveted glass eye to fill in for her missing one. It is no wonder, she "(wakes) up feeble in the recovery room, sounds of struggle still pooling around (her) head." (110) Ultimately, "surgery was a terror for (her) , a day of mad battle with no certainty of success" (ibid). It is the hospital, though, where she comes to feel safe and comfortable, like so many other disabled authors:

> Yet, in all this, it was only the surgery I feared, and never the hospital itself, for in that place more than anywhere else I fit smoothly in, was only one of many other sick people, and amputees, and folks whose bandages were hardly unusual. I

> remember that a teacher from my school came once to visit, and before she left, she stood in the hall with my mother saying, 'She seems almost to like it here.' And in this way it was true, in a way perhaps that my teacher did not realize, for a stay in the hospital was not for me confinement but a refuge. In this place, children did not ridicule shaven heads, did not tear at bandages, did not care to know how many names I would swallow before I started to cry." (110)

While Grealy was excited to be in a place glamorized by television, Kusz simply enjoyed the refuge from prying eyes, questions and taunts about her condition. In fact, she says she was the "darling of the ward" at one point (ibid). She came to feel the outside world was "unsafe" and to defend the hospital when others felt it an undesirable place "as if they had insulted (her) country" (113,112).

Upon reentering school, Kusz developed the coping strategy of pretending her disability did not exist: "Before and after that day, I strove hard to be usual, to blend in, to pretend that my eye patch was not there (118)." Kusz also went to great lengths to make sure the placement and color of her eye patch was the same each day, so as not to call attention to it. She also tried to hide behind her hair. This, however, did not stop the cruelty of her schoolmates, and her classmates from "inventing, new and monstrous names for (her)" (119). Nicknames like 'Hindenberg" and "Cycle 3" (a dog food given to overweight dogs) led her to fight repeatedly throughout her school career (121). It seems her answer to this pain was to laugh before others could ridicule her and try her best to fit in "at an age where popularity depended entirely on one's precise and self-conscious likeness to everyone else" (123). In addition to fighting, Kusz also turned to drugs, alcohol and sex. The sex was mainly a validating activity for as Kusz says, "I believed more than anything that if a boy would sleep with me it meant I was less ugly than everyone said."(137). She also dumbed down her performance in school as not to appear too intelligent.

Eventually, Kusz' school behavior caught up with her and she became pregnant by a boy she loved at the age of sixteen. Before this she had lead a sort of double life, being the model citizen at home and a self-styled delinquent with her peers (home and school were "entirely separate planets, " she writes 121). Her façade to her parents came crashing down with the revelation of the pregnancy and their support was instrumental in her reconciliation with them. She calls the time of her pregnancy "sweet and hideous months", which seems like a metaphor for her entire experience (151).The sweetness of the hospital is contrasted with the hideousness of returning to school. The sweetness of summer in Alaska is stark against the winter. She uses the term "bushy" to describe her isolation; it describes the state one experiences after being alone or in the bush too long and coming back into civilization and being unable to make small talk. (148) She decides to keep the baby and names her Charity. Then Kusz goes to college with her daughter in tow.

The pain of rejection Kusz feels is evident in a joke she later makes with her mother, who has come to stay with her at college and is returning home. Each time her mother leaves, Kusz says, "Really no problem, I've taken rejection before, I can take it again." (173). This on-the-surface-humorous protestation, actually seems to express a deeper sense of rejection (from her classmates, the father of her child who deserted her) that seems to plague her throughout her life.

Kusz is also proud of being a survivor. She admits to her mother, "I don't know when it started...but I've gotten to feeling superior, like we've seen so much tragedy and here we are, afraid of nothing , leaping tall buildings at a single bound." (177). She also tells the story of her grandfather Peter, who survived the slaughter of Russians and brought his two sons to America by various miracles. This sense of survival is undermined by her mother's unexpected death. But for strength Kusz turns to the adage: "sometimes we must turn away from hard things and pray before we turn back to do them."(245)

Unlike Greely who hoped against hope to have a "normal" face, Kusz actually gives up the quest for a glass eye with grace. Her final meeting with her doctor is a difficult, but powerful moment:

> Was it really so bad, Wennen said, to look this way? My wounds were old news; I was used to them. Maybe I should stay the way I was—blending a few of the more of the worst scars in, perhaps, but keeping this, the familiar face I had learned. He said I

> looked remarkable for what I had been through: the night I was hurt, the skin hanging off in shreds had all been shaven, then pieced back on to cover my bones, no one had know then what piece went where, or if, when the hair grew back, I would have scalp on my chin or cheeks on my head. "It's turned out beautifully," he said, holding up my hair and looking. "Maybe it's time to like things this way. To be grateful, I mean, to stop struggling."
>
> I felt that I might choke; for here was one of the few others in the world, others like myself, who had believed in medicine like strong magic, who had struggled all these years against failure, who had I thought, been prepared to go on until we prevailed against this body. Now my champion was bowing out and leaving me—admitting it seemed to me, defeat. I had not answered Wennen then, just listened and thanked him and gone home with my mother and slept, for sleep was always my escaping place and I very much wanted escape now.
>
> Wennen had spoken as I say what had seemed at the time difficult words, but in the months since, I had grown more conscious of myself, the habit of running my tongue inside the dog-tooth marks left in my mouth, of putting my first finger inside the tooth hole in the back of my neck. I noticed my impatience, at times, with strangers who saw only my eye patch and not the faded scars, who assumed I had an easy illness and not a long struggle behind me. I began to feel, in a sense, that I had stopped just in time, before all traces of history had been smoothed from my face. (210)

In this way Kusz seems radically different from Grealy, whose desire to correct her defects with surgery was so central to her life. One wonders just how comfortable Kusz was with her own face when no pictures of her exist on the Internet and she deliberately omitted a photo from a writing conference brochure stating "Natalie was absent on picture day."

Kusz does offers some profound insights on the nature of illness:

> For most of us, it becomes clear, that horror can only last a little while, and then it becomes commonplace. When one cannot be sure that there are many days left, each single day becomes as important as a year, and one does not waste an hour in wishing that that hour were longer, but simply fills it, like a smaller cup, as high as it will go without spilling over. Each moment for the very ill, seems somehow slowed down, and more dense with importance, in the same way a poem is more compressed than a page of prose, each word carrying more weight than a sentence. And though it is true we learned gentleness, and the shortness of time, this was not the case of everyone there, and in fact there were some who never embraced their mortality. (99)

At the end of the book Kusz has decided against becoming a doctor and wishing to heal others. This is another way she differs form Greely, who always knew she wanted to be a writer. But it is telling of Kusz' personality that at one time, she wanted to do for others what had been done of her. In the end of Roadsong, Kusz is singing with her father another of the eponymous road songs that run through the book, the night before he is to undergo surgery. But before that she says she and her father were preparing for the surgery emotionally: "there was still the turning of our faces aside, the gathering together of faith" (246). This, in a great part, is what her book is about.

Questions

1. Compare Kusz' experience with Lucy Grealy's.

Disability Studies—Robert Hughes, Things I Didn't Know and Goya

Robert Hughes, art critic for Time magazine and author of numerous books on fine art, is a surprising entry into the field of Disabled Studies. Known for his vast knowledge of art history and unmistakable wit, Robert Hughes didn't become disabled until the age of sixty five, when he was in a life-threatening car accident in Ireland in June 1991. He details the events and aftermath in Things I Didn't Know and his book-length biography of the Spanish artist, Goya, which was inspired, in part, by his brush with death.

Unlike Lucy Grealy and Natalie Kusz, who spent much of their childhood in hospitals and had sickness define their early childhood and later life, Hughes was an octogenarian when he became injured. Also diverging, from the vivid narratives Grealy and Kusz provide of the hospital experience, Hughes spends more time on the accident and its aftermath than on his hospitalization. What time he does spend on his hospital narrative, deals with the vivid hallucinations and daydreams he had while *in situ*. In fact, in one daydream, the artist Goya comes to him and tightens a contraption around his calf to hold the bones in his shattered leg together. (16-19). He describes the five and half weeks after his accident and the hallucinations he experienced:

> at least some of the time I was living with literally fantastic intensity, my mind pervaded by narrative phantasms of extreme clarity and unshakeable, Daliesque vividness but I couldn't communicate them to the outside world, or to anyone in it, including the doctors nurses and my worried and puzzled friends. I was sealed off, boiling with hallucination (Things, 14).

It is sometimes the case that elderly patients experience such vivid hallucinations (under the effect of painkillers, I suspect), as my own mother-in-law (and another elderly relative) recounts such fantastic visitations while hospitalized. While his vision is well described and quite detailed, reading it (for me, at least) recalled the well-known writing adage "Write a dream, lose a reader."

When Hughes, who is an Australian native, finally is lucid, there is what he calls a "light moment" in his delusion:

> At a certain moment, Cathy reported, I was signaling wildly, miming the act of writing. Pencil and paper were brought, and with a shaking left hand I managed to write in Spanish—a language that neither Cathy nor any of the doctors understood. Eventually a Filipino wardsman was found. "I am dissatisfied with my accommodations," my note read, rather formally." Please call a taxi and take me to a good hotel." (17)

Clearly, Hughes' brain has an agenda of its own.

We do learn, though, about a significant fear of Hughes, as he describes his terror after the accident. It seems the fear of fire outstrips that of being a uadriplegic for Hughes. He writes that being unable to end his own life if he were so disabled leaves him "appalled" (Things, 7). Even worse though, is the prospect of being killed in a fire:

> What I am afraid of is, and mortally, is burning to death. Some are afraid of heights, others of rats, or mad dogs, or of death by drowning. My especial terror is fire, and now I realized that my nostrils were full of the banal stench of gasoline. Somewhere in the Nissan, a line had ruptured. I could not move. I could only wait. There seemed little point in praying; in any case, there is no entity I believe in enough to pray to. Samuel Johnson once said that the prospect of being hanged concentrates a man's mind wonderfully. The prospect extended over hours, of dying in a gasoline fireball does much the same. It dissolves your more commonplace troubles—money divorce, the difficulty of writing—and shows you what you really want to use your life for. (7)

This wake-up call or revelatory moment is common in life-threatening accidents. Fortunately, the fire which Hughes dreads so much never happens. But he does come face to face with Death:

> At one point I saw Death. He was sitting at a desk, like a banker. He made no gesture, but he opened his mouth and I looked right down his throat, which distended to become more like a tunnel: the *bocca d'inferno* of old Christian art. He expected me to yield, to go in. This filled me with abhorrence, a hatred of nonbeing. Not fear, exactly: more like passionate revolt. In that moment I realized that there is nothing whatsoever outside of the life we have, that the "meaning of life" is nothing other than life itself, obstinately asserting itself against emptiness and nullity. Life was so powerful, so demanding, and in my concussion and delirium, even as my systems were shutting down, I wanted it so much. Whatever this was, it was nothing like the nice, uplifting kind of near-death experience that religious writers, particularly those of an American fundamentalist bent, like to effuse about. (7)

Hughes says his face-off with Death is not the one so often popularized, but one that made him cling to life even harder. Unlike the familiar "white light and tunnel" image which is so popular, Death looks much more grotesque in Hughes' imagination. He goes on to analyze these perceptions of Death:

> Perhaps, the simple truth is that, near death, you have visions of what most preoccupies you in life. I am a skeptic to whom the idea that a benign God created us and watches over us is something between a fairy story and a bad joke (ibid).

He goes on to call the "tunnel with white light with Jesus at the end" "kitsch" which belongs to "American Kmart mystics" (ibid). While confronting death requires one to consider the idea of an after-life and religion, Hughes balks at it. He writes," Jesus must have been busy when my time came: he didn't show, There was, as far as I could tell, absolutely nothing on the other side" (7-8).

Often, art and literary metaphors pepper his descriptions of the accident. He says the car "was folded around me like crude origami" and that he was "bloodier than Banquo" (6). So great is his fear of dying in a fire, he importunes his friend to shoot him.

His injuries are so great that he does fade from consciousness quite a few times, but his is told that the Aborignes have called a "feather foot" god to save him. (11) This god decides that he is fit to continue living.

Hughes endures almost five years of recovery and even after numerous operations (the first of which lasted thirteen hours and almost killed him), Hughes still suffer a great amount of pain:

> (In terms of pain, that accident was the gift that keeps on giving. I cannot run or wade a trout river, and, even now, more than six years later, there are days when I can hardly stand up. Not, maddeningly, can I do a long walk through a museum. But when it is a choice between deep pain and opiate addiction, there is really no choice. You deal with the pain.) (25)

Hughes chooses the pain over a lifetime of medication and this seems a noble choice. He is further insulted by a lawsuit against him which he must attend in great pain. Since his car was on the wrong side of the road, it was assumed he was in the wrong. He also notes that the other driver had a checkered history with the law and was driving over a hundred miles an hour. Still, Hughes must appear in court rather than plead guilty. He is philosophical about this point: "It is, as Mark Twain observed about confessions, good for the soul, but bad for the reputation" (24)

Ironically, Hughes must spend $12,000 on a first class plane ticket to Australia (because his doctor requires him to travel with additional leg room), to defend himself against a maximum fine of $2,500. But Hughes lists the human price above the legal one: "Of course there had been an accident, but were my injuries not punishment enough?" (25) Although the case is dismissed, the resulting retrial is a disaster and Hughes is forced to pay the fine after a protracted media blitz against him.

Still, he is driven to remember his love for Australia and to complete the book on Goya he has wanted to write. His repeated visions of Goya in the hospital are humiliating and instructive. Hughes writes:

> One does not need to be Dr. Freud to recognize the meaning of this bizarre and obsessive vision. I had hoped to "capture" Goya in writing, and he instead imprisoned me. My ignorant enthusiasm had dragged me into a trap from which there was no evident escape. Not only could I not do the job, my subject knew it and found my inability hysterically funny. There was only one way out of this humiliating bind, and that was to crash through it. Or so it seemed. Through all the pain and psychic confusion, Goya had assumed such importance in my subjective life that whether I could do him justice in writing or not, I couldn't give up on him. It was like over coming writer's block by blowing up the building in whose corridor it had occurred. (Goya, 10)

Ian addition to the haunting visitations Hughes receives from Goya, there is also another facet of the accident which drives him to write about the artist. Says Hughes, "It was through the accident I came to know extreme pain, fear and despair, and it may be that the writer who does not know fear, despair and pain cannot fully know Goya." (Goya, x) Although he regrets having the accident, Hughes says the value is one of experience: "Perhaps if life is fully experienced, there is not waste" (ibid). The value of the accident is a deeper understanding of Goya.

Finally, there is another moment in Things I Didn't Know that pertains to Disability Studies. While on assignment for a magazine in the 1960's , Hughes goes to Lourdes, France, which is famed for its healing waters. Many disabled pilgrims flock to Lourdes annually for a touch of that which is said to be holy and healing. Among one of the people who come to Lourdes is a quadruple amputee. Hughes says,

> This, he told me was his ninth visit to Lourdes, he came every year and had every intention of keeping up his visits. Eventually, with some hesitation, I got around to what seemed to me the crux of the situation. Did he really think the intercession of the Virgin was going to make more of his limbs sprout again? 'What do you take me for?' he said sharply. 'I come here because I like to be with my own class of people.' It was the one completely logical explanation of Lourdes that I had heard, then or since. (Things, 274)

Hughes is describing what Erving Goffman had already noted, that disabled people wish to be with others like themselves. The fear of rejection is much less and some comfort is found in the company of others.

Disability Studies – David Sedaris, Me Talk Pretty One Day

Humorist David Sedaris (1956) was raised in Raleigh, North Carolina and emerged on the literary scene in 1992 with "The Santa Land Diaries", in which he recounts his time as a Macy's elf. Known for his humorous take on everything from living in France to cleaning houses and going to a nudist colony, Sedaris is often featured on NPR and "This American Life". His work is so original and funny that one listener likened hearing a piece of his on the radio to finding a twenty dollar bill in the pocket of his pants. His latest work When You are Engulfed in Flames will be published this June. The Wikipedia entry about him claims he sometimes exaggerates and invents in his stories for comic effect. Sedaris refutes such charges. Currently, he lives in France with his partner Hugh.

In David Sedaris' Me Talk Pretty One Day, he relates the story of his speech therapy when he was in grade school in "Go Carolina". While a speech impediment isn't a major physical disability in Sedaris' case, his is magnified by his homosexuality. His lisp seems to be a marker of his homosexuality for all to hear and a cause of some embarrassment in general.

Sedaris uses the metaphor of the government agent in describing how Chrissy Samson, the speech therapist came across. He compares his being taken out of class for speech therapy, to the apprehension of a criminal. "My capture had been scheduled to go down at exactly 2:30 on a Thursday afternoon," he writes (4). "Prison" and "suspect" are other words, Sedaris uses to show the way he felt about these appointments. The teacher's announcement of twelve year-old David's appointments to the class also didn't help much:

> I didn't see my sessions as the sort of thing that one would want to advertise, but as my teacher liked to say, 'It takes all kinds.' Whereas my goal was to keep it a secret, hers was to inform the entire class. If I got up from my seat at 2:25, she'd say, 'Sit back down David. You've still got five more minutes before your speech therapy session.' If I remained seated till 2:27, she'd say, 'David, don't forget you have a speech therapy session at 2:30.' On the days I was absent, I imagined she addressed the room, saying, 'David's not here today but if he were, he'd have a speech therapy lesson at 2:30. (8)

The lack of sensitivity shown by the teacher is clear. Most people don't want to be publicly reminded of that which makes them different.

Sedaris continues to view his therapy as either a set of questions designed to trip him up (and make him use the letter "s" with which he has difficulty) and a certain kind of torture. He explains:

> If I wanted to spend the rest of my life as David Thedarith, then so be it. She, however, was going to be called Miss Chrissy Samson. Had her name included no "s's" she probably would have bypassed a career in therapy and devoted herself to yanking out healthy molars or performing unwanted clitoridectomies on the schoolgirls of Africa. Such was her personality. (9)

Like many disabled people, Sedaris begins compensating for his twin "disabilities." For his sibilant "s", he changes the way he speaks:

> At school where every teacher was a potential spy, I tired to avoid an "s" sound whenever possible. 'Yes' became 'correct' or a military 'affirmative'. 'Please' became 'with your kind permission' and questions were pleaded rather than asked. After a few weeks of 'endless pestering' and what I called 'repeated badgering', my mother bought me a pocket thesaurus, which provided me with s-free alternatives to just about everything. I consulted the book at home in my room and at the daily learning academy other people called our school. Agent Samson was not amused when I began referring to her as an articulation coach, but the majority of my teachers were delighted. 'What a nice vocabulary," they said. 'My goodness, such big words.' (11)

He compensates for his homosexuality (his perceived disability) by feigning interest in sports and pretending he wants to be a firefighter when he would rather sleep with one (10).

Sedaris manages to humanize his speech therapist by the end of the essay, explaining she had a fiance in the Viet Nam war and goals of moving to Florida. She seems a sympathetic figure by the end of the essay, who had respectable goals but failed. Sedaris writes, "Despite that woman's best efforts, no one seemed to make any significant improvement. The only difference is that we were all a little quieter" (12).

Samson does do one thing at the end of the final session which seems a particularly unprofessional and ill-advised. When David attempts to comfort her and says "I'm thorry", she says "Ha-ha…I got you" (15). This seems unthinkable.

In "Giant Dreams, Midget Abilities" Sedaris describes his guitar teacher, who just happens to be a midget. Sedaris has an adversarial relationship with Mr. Mancini during most of their time together (Mr. Mancini seems more interested in his heterosexuality and having David name his guitar after a girl, which young David is not eager to do.) But after some boys mock Mr. Mancini telling him, "Go Back to Oz, munchkin" David becomes protective. (26) Sedaris writes, "Beneath my moral outrage was a strong sense of possessiveness, a fury that other people were sinking their hooks into my own personal midget." (27) Then, he begins to feel a connection with Mancini:

> …I broadened my view and came to see him as a wee outsider, a misfit whose take-it-or-leave-it attitude had left him all alone. This was a persona I'd been tinkering with myself, the outcast, the rebel. It occurred to me that, with the exception of the guitar, he and I actually had quite a bit in common. We were each a man trapped inside a boy's body. Each of us was talented in his own way, and we both hated twelve year old males, a demographic group second to none in terms of cruelty. All things considered, there was no reason I shouldn't address not as a teacher but as an artistic brother. (27)

Sedaris mistakenly thinks of Mancini as a brother and shares his talent for signing like Billie Holiday with him. However, Sedaris' revelation doesn't go as planned. Mancini calls him a 'screwball' and says, "I don't swing that way.' (29) It is awkward and a little less than devastating for Sedaris who lies to his father to get out of future guitar lessons.

Sedaris presents the lighter side of disability and difference, the non-textbook reality of what can and does go wrong. For this and his delightful sense of humor, I am grateful.

Disability Studies-- Nancy Mairs Waist-High in The World

Biography

Nancy Mairs was born in Vermont in 1943 and lived a normal and quiet childhood until she was diagnosed with multiple sclerosis at the age of twenty five. A young mother, she and her family had just moved to Tucson, Arizona and she had gone to see a doctor about a weak ankle. After noticing consistent weakness on her left side, the doctor sent Mairs to a neurologist, who after months of tests and misdiagnoses, discovered Mairs had multiple sclerosis. Mairs chronicles the degenerative process of MS with skill and grace and is especially candid about the difficulties and insights life in a wheelchair yields. This book is an excellent book for students to help them understand what it is like to live in a disabled body.

The Book

Waist High in the World is notable not only for its candor and insights, but for the eloquent way Mairs covers the disabled territory. Adding her voice to the debate over terminology for the disabled, Mairs gives her take on the various names ("handi-capable", "physically challenged") with perception and humor. The term she prefers is "crippled", which expresses her state most fittingly. (11-13) She discusses both her abilities and disabilities in light of her other talents:

"I'm so uncoordinated that I'd never have gotten any good at tennis, even if I hadn't developed MS; but then Monica Seles probably can't write her way out of a paper bag." (14) Her book is a "feel real" book instead of a "feel good" one (18). The phrase "waist high" "also resonates with 'knee deep". According to Mairs: "This is no piteously deprived state I'm in down here but a rich complicated and utterly absorbing process of immersion in whatever the world has to offer." (18)

"Ups and Downs", the second chapter of Mairs' book chronicles her discovery of MS. She describes the early symptoms (tiredness) and the eventual discovery of her disease. Though she has come to terms with her disease and does not wish to be considered apart from it (9-10), she does admit to some pain and anger at times.

> I feel—and feel fully—the ordinary complement of negative emotions in response to specific triggers: anger and frustration at my clumsiness; embarrassment about my leaky bladder; wistfulness for the dancing and hiking and cycling I'll never do again; guilt that my helplessness burdens family and friends; anxiety about further deterioration. I simply don't feel especially sorry for myself,

writes Mairs (31).

In terms of how emotionally difficult having a degenerative disease is; Mairs notes a surprising observation,

> People disabled traumatically –say by a spinal cord injury sustained in an auto accident—have told me that they have an

> advantage because they know the worst from the outset, and any change can only be for the better. Others, congenitally disabled, claim that theirs is the easier lot because never having known another way of being, they find their lives completely natural. (29)

Another difficulty Mairs has had to combat is the feminist desire to "have it all" (34) Although she "vastly overextended " herself as a young woman serving others as wife, mother, teacher, cook and housekeeper, the loss or diminishment of any one of these roles has "wounded and shamed" her (ibid). Although she experienced guilt over not being the perfect mother, Mairs says her children were surprisingly unaffected.

She also discusses the "You're so brave!" response normal people have to a disabled person. "Admiration," she writes, masking a queasy pity and fear, serves as a distancing mechanism, in other words," (32).

"Body In Trouble". In this chapter, Mairs discusses her relationship to her body. Body-image handed to us from the media and plagued Mairs even before becoming handicapped:

> Mostly I was, as I was trained to be, disappointed in myself. Even in the fifties before the dazzle of shopping malls and the soft pornography of advertising from every product from fragrance to bed linen, a girl learned to compare herself to an ideal flashed at her from glossy magazine covers and cinema screens and then to take measures to rectify all her too glaring deficiencies. (44)

Now, as a disabled person, Mairs is not immune to the desire for clothes and self-decoration: "Although—or perhaps because—I am appalled by my own appearance, I devote an absurd amount of time and expense to its decoration"(46).She continues:

> I buy garment after garment in the hope of finding one that will fit well enough to clothe me in come tatter of grace. Designers conceive tall bony pubescent bodies swinging down the runways to some hectic beat on skinny, but serviceable legs, and even the apparel that makes it to the outlet store where I shop is cut for a lithe erect form in motion. This is who I want to be, of course, and so I cruise the aisles searching for a magic cloak that will transform me into her. (47)

Such sentiments are refreshingly universal. She is equally candid about her sex life. And she notes that as a disabled person, she is not considered sexually desirable," On the contrary, the general assumption, even among those who might be expected to know better, is that people with disabilities are out of the sexual running….'They' can't possibly do it, the thinking goes; therefore, 'they' mustn't even want it; and that is *that*" (51) . Mairs also discusses how the disabled have been perceived in earlier times, and how they perceptions may linger. "In biblical times, physical and mental disorders were thought to signify possession by demons, (56) she writes. She also discusses how women were perceived as witches with "insatiable" desires. (58) But as a disabled person, she often feels invisible, even among the most enlightened people (59); a crowd of Dalai Lama worshippers ignored her completely. Other times she is marginalized by her disability—or stigmatized as sociologist Erving Goffman says, "removes (her) from normal life into a 'discredited' position in relationship to society."(61) Also, since she is as tall as a six-year-old in her wheelchair, people often treat her as such. (62)

In "Taking Care" Mairs, describes a day in which she is left to care for herself, because of a miscommunication between family members. While taking a shower may not be a difficult task for most people for Mairs it is a task fraught with potential peril.

She says that taking a shower is:

> Not an adventure on a grand scale, I'll admit, but for me it will require the concentration of walking a tightrope without a net. The myriad small actions that most people would perform all but unconsciously tax my ingenuity. (66)

Though Mairs is pleased by her self sufficiency, she knows it is dangerous to think it could be safe on a regular basis. She writes of her husband and herself:

> We both recognize that such efforts aren't a wise use of my limited resources and that the more often I tried to repeat them, no matter how cautiously, the more likely some serious mishap would become I owe much of today's triumph to pure luck. We both know – that unmade bed, the crumpled damp towel, the dirty dishes all attest – that left entirely to my own devices, I would soon founder in the messes of my own making. We both understand that, over time, my competence at even the simplest tasks will decrease rather than increase. (68)

She discusses her frustration at not being independent as occasionally being like "a two year-old's temper tantrums" (69) and her "craving for personal independence" (70) being a force she still possesses.

Another difficulty she faces as a disabled person, is that of answering the unwitting stupid question from the non-disabled. For this she quotes John Hockenberry from his book Moving Violations:

> 'I guess you are the first handicapped person I have ever seen up close. "Have you even thought of killing yourself?' I wondered if this question appeared in this flight attendant's official training manual under the heading of : "Handicapped Patrons: Suggested Conversation Starters." (72)

Mairs also objects to the government's resistance to providing financial assistance to the disabled. She writes of such government leaders, "(A professed Christian, I am ashamed to own the distinctly ungenerous wish that each one of them, sleek and smug, would be stricken with multiple sclerosis). " (76)

The toll of patience and dependence on others is not just financial, but emotional: "If rage and sadness are left unacknowledged, they transmute readily into depression, to which I have always been susceptible." (81) She soberly recognizes the risks, though, of trying to do too much for herself:

> I must be careful physically, for example, searching out the line between doing what I safely can and taking silly risks. An

> injury as simple as a broken wrist, which would merely inconvenience most people, could incapacitate me completely, by preventing me from driving my wheelchair. Thus regardless of the rush of satisfaction my morning of stolen independence has brought me, it held too many chancy moments to furnish a practical pattern for my day to day existence. True, I can take precautions, like carrying the portable telephone around with me, but the last thing I want it to play I've-Fallen-and-I-Can't –Get-Up with a bunch of paramedics while I'm soaked and stark naked and slippery on the shower floor. (82)

According to Mairs, there is one ability and gift she has that disability can't ever take away. In addition to becoming a more patient listener, Mairs also celebrates her ability to write. "Above all," she says, "I can still write, which for me has always been an act of oblation and nurturance, my means of taking the reader into my arms, holding a cup to her lips, stroking her forehead, whispering into her ears…" (84). Here is Mairs' power.

"Opening Doors, Unlocking Hearts" starts with an eye-opening experiment; it asks the reader to imagine Mairs is coming to their homes and to imagine the difficulty she might have navigating in their dwellings. It is a sobering thought, given that even a single step on the front porch would make it difficult for her to enter. She broadens her discussion to the ADA requirements for accommodating the disabled in the workplace and she interviews a friend of hers, a small businessman, who describes the difficulties he'd face in making his business handicapped accessible (note: small business that would experience "undue hardship" accommodating the law are exempt) (92). Mairs points out that though many handicapped people want to work, the unemployment rates are high. According to an article she read, "a staggering 67 percent of the 43 million Americans who are disabled are unemployed, and 82 percent of those want to work." (91) Because the handicapped are so anxious to work , Mairs says they sometimes fall prey to the "Supercrip" mentality:

> Work of average quality won't gain them the edge necessary over fellow workers they are required (in all kinds of subtle, perhaps even subconscious ways, by themselves as well as others) to show in order to earn a place among the "normals'. (92)

The Supercrip mentality produces workers with "diligence, low absenteeism and long-term commitment" but may "half-kill" the disabled person in the process. (ibid).

Mairs also describes being told by a cabbie that she shouldn't be seen in public, further describing society's resistance to the disabled. Upon further research, she finds he has been diagnosed with a degenerative disease and is projecting on to her. Mairs, explains,"...people who seem most hostile to my presence are those most fearful of my fate." (102)

In the next chapter , "Freeing Choices", Mairs discusses the "right to die" movement, using selective abortion as an example (i.e. aborting a fetus due to its gender). For the disabled Mairs, this leads to the question of whether she might've been aborted if her mother knew she carried the Multiple Sclerosis gene

(112). Should such selective abortion and by extension, euthanasia be practiced? Mairs is understandably concerned that the idea of physician-assisted suicide is dangerous for the disabled. She cites several of the eugenics movements (i.e. the Nazi Germany cleansing of the disabled and infirm) as possible dangers of assisted suicide. In a startling revelation, Mairs also reveals her own bout with depression and suicide attempts she has made.(114-6) At the end of her essay, she lists several disabled artists (Lautrec, Beethoven) to make the case that their lives should not have been terminated, nor should they have artificially ended them. (124)

The last three chapters of the book have limited efficacy for the disabled studies class. The first "Writing West" discusses the nature of Western writing (i.e. the Western United States) and whether there is a Western character and definitive literature. The next, "Into the Wider World", deals with a trip to England Mairs took. The English are surprisingly accommodating to the disabled, and when the physical accommodations are unavailable, they are willing to help. Mairs recounts receiving free tickets to theatre productions as part of the way England serves the disabled. Another chapter, "Young and Disabled" recounts letters Mairs received from young disabled women as part of an article she was writing for Mademoiselle magazine. The attitudes of the young women were surprisingly upbeat and the descriptions of their lives is inspiring. The discussion of romance is candid and varies a great deal from the positive to negative. "Getting Byrned" discusses her undercover role in a sting operation against some con artists who preyed on MS victims,

In all, Mairs' book is an excellent book for a Disabled Studies class. Her candid assessment of her own disability and her observations of how her daily functioning interrupted is clear and compelling. For the disabled and non-disabled alike this is an eye-opening, provoking book. The last sentence provides a clear picture of Mairs' philosophy, "I choose joy." (209)

Questions

1. Give three details from the letters in "Young and Disabled" that Mairs received which surprised you. What was surprising about the letters?

2. In "Freeing Choices" where does Mairs stand on the "right to die"? Why does she hold this position? How does she compare to other activists in the field (i.e. Simi Linton)? Is Mairs' position complicated by the fact she attempted suicide? Why or why not?

3. What are the difficulties of "self care" for Mairs? What are her feelings about being dependent on others for her care?

4. What do you think of Mairs' choice of "cripple" to describe herself? How does she feel about the other terms used for the handicapped?

5. In "Body in Trouble" Mairs is very candid about the failures of her body. How does she handle the subsequent loss of function?

6. On page 44, Mairs discusses the body image messages of her day. Are the pressures the same or worse today? How would a handicapped person perceive these pressures?

7. What do you learn about being handicapped from "Ups and Downs"? List five revelations Mairs make about life in a wheelchair.

8. How does writing figure in to Mairs' life?

9. Describe the "Supercrip Syndrome". Why do the disabled feel more pressure to perform at work?

10. How wheelchair friendly is your home? List ways in which it is not.

Disability Studies—Nancy Mairs, Plaintext

Nancy Mairs' Plaintext (1986) includes several essays on living with disability as well as others on topics as disparate as hating sex, falling in love and mental illness. While the essays range from the heartfelt and illuminating ("On Being a Cripple") to playful ("On Having Adventures") to gimmicky ("On Hating Sex", which is almost irritating in its reliance on wordplay), her writing on the more serious topics is intimate and honest in ways that is surprising. Of her suicide attempts ("On Touching By Accident"), Mairs is painfully honest, and her candor is not the showy kind, but that of a quiet conversation with a friend. There are times when she seems to be wrestling with a feminist agenda (such as in "On Falling in Love") to examine the dynamics of rape, rather than addressing a terrible situation with all of her feelings, but her landmark essay "On Being a Cripple" is remarkable and moving for its honesty and first person account of what it is like to be disabled. It is a must for any course examining disability literature, a profound look at the ups and downs that a disabled person experiences, the shattering lows as well as the amazing strength and wisdom of such a vantage. Also notable is "On Having Adventures" which does address the limitations of the disabled to have adventures in the conventional sense of the word.

While setting out on my own adventure (a car ride on a rainy Sunday to the Laguna Art Museum), I began to read "On Having Adventures". Mairs starts the essay by describing a conversation with a non-disabled friend about the adventures he wishes he were having. She next describes her cat, Burton Rustle, and the adventures he managed to have all the while living a typical domestic cat's life. Such adventures include: "Burton Rustle and the Water Swirling in the Toilet Bowl. Burton Rustle and the Orange Dust Mop. Burton Rustle and the Folding Table Under the Bed." (4) Her anecdote seems to suggest that adventure is relative and even everyday life can provide adventure. Still, as a disabled person, who wasn't always disabled, Mairs does is painfully aware that her adventures are limited:

> Nearly ten years ago, I was told that I had a brain tumor, and this experience, I think, changed my relationship to adventure forever. I thought I was going to die, that all my adventures were over. I did not, it turned out, have a brain tumor, but rather multiple sclerosis, which meant that although they were not over, the nature of my adventures would have to change. Each morning that I wake up, that I get out of bed, is a fresh event, something that I might not have had. Each gesture that I make carries a weight of uncertainty, demands significant attention: buttoning my shirt, changing a lightbulb, walking downstairs. I might not be able to do it this time. Inevitably, the minutiae of my life have had to assume dramatic proportions. If I could not love them, delight in them, they would likely drown me in rage and self-pity, that tempting obliterating sea. (6)

Mairs describes the difficulty of her life so eloquently and precisely, it is breathtaking. She goes on to describe the books she reads as adventures she has vicariously:

> With Peter Mathiessen I have trekked across Himalayas to the Crystal Mountain and seen no snow leopard. One blistering July I moved with John McPhee to Eagle, Alaska above the Artic Circle. I have trudged with Annie Dillard, up, down, into Tinker Creek in all seasons...With wonder I contemplate the actions of the rugged and courageous figures, who can strike out on trips of miles—two, two hundred and fifty, three thousand—ready to endure cold, fatigue, human and natural hostility, ready not just to endure but to celebrate. (6)

It seems her thirst for adventure is still intact, but lived through others. Still Mairs finds wonder and adventure through her daily life:

> But as for me, I can no longer walk very far from the armchair in which I read. I'll never make it to Tibet. Maybe not even to Albuquerque. Some days I don't even make it to the backyard. And yet I'm unwilling to forgo the adventurous life: the difficulty of it, even the pain, the suspense and fear and the sudden brief lift of spirit that graces—unexpectedly, inexplicably-- the pilgrimage. If I am to have it too, then I must change the terms by which it is lived. And so I do. I refine adventure, make it smaller and smaller, until if fits into this little toad that struggles through the jungle of clover under my bare feet. (7)

It seems, even though Mairs is limited, her sense of wonder and gift for amazement, are still active, even though she has had to redefine adventure.

Even more significant than "On Having Adventures" is "On Being a Cripple". This is perhaps the definitive first-person essay on multiple sclerosis and the emotional fall-out of physical disability. Her first major point in the essay is made in the title: "On Being a Cripple" (emphasis added). By choosing the word "cripple, she has rejected the less appropriate to her "disabled" and "handicapped." (9). According to Mairs:

> I made a choice years ago without thinking, unaware of my motives for doing so. Even now, I'm not sure what those motives are, but I recognize they are complex and not entirely flattering. People-- crippled or not—wince at the word "cripple" as they do not at "handicapped" or "disabled". Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but can face the brutal truth of her existence squarely. As a cripple, I swagger. (9)

There is a sort of braggadocio to the term in Mairs' eyes, a sense of survival. She also examines the etymology of "cripple" and the meanings it invokes for her:

> "Cripple" seems to me a clean word, straightforward and precise. It has an honorable history, having made its first appearance in the Lindsfarne Gospel in the tenth century. As a lover of words, I like accuracy with which it describes my condition: I have lost the full use of my limbs. "Disabled" by contrast, suggests any incapacity, physical or mental. And I certainly don't like "Handicapped" which implies I have been put at a disadvantage, but whom I can't imagine (my God is not a Handicapper General), in order to equalize chances in the great race of life. These words seem to be moving away from my condition...(10)

Mairs's discernment between the terms is an informed one and her reference to Kurt Vonegut's story "Harrison Bergeron" (Handicapper General) is an amusing one. She reserves her greatest disdain for "differently abled", though:

> "Most remote is the recently coined 'differently abled', which partakes some semantic hopefulness that transformed countries from "undeveloped" to "underdeveloped" then to "less developed" and finally to "developing" nations. People have continued to starve in those countries during the shift. Some realities do not obey the dictates of language.
>
> Mine is one of them. Whatever you call me, I remain crippled. (10)

Maris deplores what Orwell called 'the slovenliness of our language' and the 'foolish thoughts' that go with them (ibid). She also notes that being crippled in our society is something people wish to sidestep. She writes," Society is no readier to accept crippledness than to accept death, war, sex, sweat or wrinkles." (ibid) Language is a way to do it.

One reason Mairs might be able to embrace the term 'crippled" more easily than others is that she has not always been so. For this, she is "soundly grateful" (ibid). But at the age of twenty eight, she began to experience the early symptoms of multiple sclerosis. At this time, doctors misdiagnosed her ailment as a brain tumor. For a year and a half, she worried that her death was imminent until the truth was discovered. As a result, she explains, "Each day for the last ten years, then, has been kind of a gift. I accept all gifts."

(11)

She describes the degenerative symptoms of M.S. and all of its "horrifying" possibilities: losing the ability to walk, control of bladder and bowel function, loss of vision and hearing. But she says losing one's sense of humor is a critical loss: "That's the easiest to lose and the hardest to live without."(ibid)

Although she is upbeat about her illness, she does not want to sound falsely optimistic or cheerful, "like Pollyanna", as she puts it, that artificial and saccharine bringer of sunshine. In fact, she quite honestly hates having M.S.;"...let me say I don't like having M.S. I hate it," she writes (12). She continues:

> My life holds realities—harsh ones, some of them—that no right-minded human ought to accept without grumbling. One of them is fatigue. I know of no-one with MS who does not complain of bone-weariness...I wake up in the morning feeling the way most people do at the end of a bad day, and I take if from there. As a result, I spend a lot of time *in extremis* and impatient with limitation, I tend to ignore my fatigue until my body breaks down in some way and forces rest. Then I miss picnics, dinner parties, poetry readings, the brief visits of old friends from out of town....I cannot view these lapses without shame. My life often seems a series of small failures to do as I ought. (12)

While life with MS is difficult and frustrating, Mairs is grateful for her "solitary, sedentary and bookish" nature (12). She is able to write and teach, which she celebrates, but equally aware of what she cannot do. As with many disabled people, she begins to project her disability onto others," Of late, I have begun to catch myself wondering how people can propel themselves without canes." (13)

So conditioned is she to disability, she begins to feel everyone endures what she does.

She tells a horrifying story of falling in front of a colleague, due to her disease and soldiering on as if nothing has happened and then of the "crippling bouts of depression" which may of may not be caused by MS, but are certainly "concomitant". (13)

She is also aware of the responses of others to her disease. While one student was encouraged by Mairs' bravery in the face of adversity ("One was immensely cheered by the information that I paint my own fingernails; she decided, she told me, that if I could go to such trouble over fine details, she could keep on writing essays."), other caregivers come to feel quite natural resentment (14). Few marriages, she says, "survive the MS test" (ibid). She feels lucky that her marriage has survived the difficulties: "Not many are equipped for catastrophe: the dismay, the depression, the extra work, the boredom that a degenerative disease can insinuate into a relationship (ibid)." Resentment is natural and even her children experience it to some degree:

> Anne and Matthew vacuum floors and dust furniture and haul trash and rake up dog droppings and button my cuffs and bake lasagna and Toll house cookies with enough grumbling so I know they don't have brain fever. (ibid)"

Such insight is comforting to caregivers, who, on occasion, need an outlet for their "grumbling".

There are some "rules" for the disabled, among them the expected role they might play in society. Mairs explains, "Like fat people, who are expected to feel jolly, cripples must bear their lot meekly and cheerfully. A grumpy cripple isn't playing by the rules "(15). The possible roles for the disabled vary from "Tiny Tim" to "Caliban", Shakespeare's "most scurvy monster" (15). Although, Mairs sometimes gives in to the latter's behavior, she assures us, it is short lived.

Particularly difficult for the disabled is the self loathing that comes with dependency. Although Mairs says she feel lucky that "our society no longer connects deformity and disease with evil," she still meets with disapproval from a large segment of society:

> Physical imperfection, even freed from moral disapprobation, still defies and violates the ideal, especially for women, whose confinements in their bodies as objects of desire is far from over." (16)

Because her body no longer is even capable of capturing the idealized feminine image of magazines and advertising, which eluded her even before MS hit, she has an even more "uneasy relationship with (her) body" than ever (ibid). Mairs writes, "When I think about how my body must look to others, especially to men, to whom I have been trained to display myself, I feel ludicrous, even loathsome (17)." It takes reminding herself that her self-loathing is related to disease and not herself.

As someone with an incurable chronic illness, Mairs refuses to let MS define her.

Still, she has moved through the stages of grief outlined by Dr, Elizabeth Kubler-Ross in On Death and Dying. Because the nature of MS is degenerative, Mairs knows there is a fate worse than dying – living with the knowledge that her disability will only get worse.

Such thoughts have nearly driven her to suicide, she writes, but in the end she felt that this was not the best action:

> Gradually I came to understand that the Nancy who might one day lie inert under a bed sheet, arms and legs paralyzed, unable, to feed or bathe herself, unable to reach out for a gun, was not the Nancy I was at present, and I could not presume to make decisions for that future Nancy, who might well not in the least want to die. (18)

This knowledge and insight is what saves her.

In addition to deciding to forgo suicide, Mairs decides to continue living actively, even when disease threatens to derail her plans. When she suffers an exacerbation while on vacation, she must decide whether to go ahead or go home. "I think we'd better get the hell to California, "she said and the trip ended up being unforgettable. (19). She credits a role model, which seems to be quite important in the disabled community, with helping her choose the active path (18).

One of the great gifts of disability is gentleness, according to Mairs. Her physical state has required it.

> "It has opened and enriched my life enormously, this sense that my frailty and need must be mirrored in others, that in searching for and shaping a stable core in a life wrenched by change and loss, change and loss, I must recognize the same process, under individual conditions, in the lives around me. (20)

Such sensitivity is indeed a gift. There is another moment at the end of the essay, when Mairs does ask the inevitable question that all people given a disability in life ask, "Why me?" Mairs answer is surprising in its nonchalance: "Why not?" (20). While she would not turn down a cure for MS, or trade lives with someone who did not have it, she feels as if she has had enough practice at being cripple to continue. "I might as well do the job myself. Now that I'm getting the hang of it, "she writes to close her essay (20). This is the "tough customer" spirit she starts the essay with, spunky and hardscrabble. Not only does she survive being a cripple, she embraces it and thrives.

Disability Studies – Murderball

The 2005 documentary Murderball by Henry-Alex Rubin and Dana Adam Shapiro is an excellent choice for a Disability Studies course. In addition to exploring the world of quadriplegic rugby (also known as "murderball"), it also looks at the difficulties and attitudes faced by quadriplegics. The intimate interviews with the wheel-chair bound athletes are among the most honest and revealing discussions on discrimination, injury, rehabilitation and sexuality. There is also humor and copious amounts of profanity, since these rugby players are not the angelic choirboys the disabled are sometimes assumed to be.

In fact, Dana Adam Shapiro, the documentary's director/author said, when he first encountered the story about the murderball team that sparked the documentary, "The article was pretty mind-blowing. I thought all quadriplegics were like Christopher Reeve—very mild mannered and weak and fragile." Certainly, Murderball explodes that myth. While quadriplegic rugby sounded like "an offensive joke" when Henry-Alex Rubin first heard of it, he came to understand the fierce competitors who rule the game, which was invented in Canada in 1982. The documentary took its inspiration from Shapiro's 2000 article for Maxim magazine.

Among the athletes featured in Murderball are Mark Zupan, the spokesperson for the 2005 USA Paralympics team, and Joe Soares, coach for the

Canadian team. Because both men have incredibly strong personalities, it is possible to see beyond the wheelchair and view them as people. The film also centers on the rivalry between the US and Canadian Paralympic teams, culminating in the 2004 Paralympic Games in Sweden. Additionally, there is a portrait of Keith, who is a newly injured paraplegic.

Some of the most striking interviews occur early in the film. The athletes in various interviews are intercut talking about how they are treated by the outside world and the stupid comments well meaning people make. Scott Hogsett says." I've been out in clubs and I've been out all over, and people will come up to me and shake my hand and say 'It's good to see you out' and I like, look at them and I say 'Good to see me out? What am I supposed to do, be in a closet hanging out?"

"I go up to people and start talking shit," Mark Zuppan says, "and they're like all "oooh" and I'm like "What? you're not gonna hit a kid in a chair? Fuckin' hit me. I'll hit you back." Andy Cohn, another player, says people offer him help at the grocery store and it frustrates him.

Because Quad Rugby limits the mobility of its players to a score of eight on the court at any time, there is an informative discussion of the levels of disability within the quaadriplegic community. The players also discuss the events that injured them early in the film. When hearing of the accidents which preceded most of their injuries, it becomes clear, just how vulnerable we all are.

"Everyone who gets hurt thinks they're gonna walk again," Cohn tells us, later in the film. Hogsett says,

> What's really hard are the first two years (after injury) Quadriplegics when they come out of the hospital after they've broken their neck and they've got very little function when they get out. They can't do anything for themselves ...and they work for the next two to four years. It's a mind fuck in the beginning and then you either you make it or you don't.

Post spinal-chord injury sex is also discussed in the film. From the clinical perspective, there is a video shown in the film (with some nudity, but no explicit detail) and then there are the anecdotes told by the men themselves which involve sexual acts and positions, as well as their ability to achieve and sustain erection. Hogsett claims that masturbating was the "first thing I learned how to do," after his injury, explaining it was more important to him than learning to hold a toothbrush. While some might find these discussions offensive, they are candid and refreshing, meant to show the disabled person as a whole person. Andy Cohn called his first time having intercourse after injury, "a very great moment in my life", because it reassured him he could experience something he'd thought would be denied him.

In addition to discussing sexuality, the men also share their approaches to women. According to Hogsett, "Everyone's like 'What's your approach, Scott?'

and I'm like, Fuck it, man, the more pitiful I am, the more the women like me.'" Mark Zupan's girlfriend, Jess, says, "I really think it's curiosity that attracts a lot of girls to quadriplegics. And also, I think, to some extent, the mothering instinct."

While informative, the film is certainly not static. The revelations about what it's like to be disabled are intercut with action sequences and edge-of-your seat rugby matches between two fierce competitors, the United States and Canada. Both Zupan and Joe Soares emerge as central figures in this conflict, with Soares playing the villain. Soares, a former United States player, who became a Canadian coach when he was let go from the US team. He is seen as a traitor, a self-involved husband and father and a bit of an ego-maniac. As Zupan says, "If he was on fire on the side of the road, I wouldn't piss on him." In one scene, Soares is seen telling his son Robert to behave in an authoritarian voice and in another, bullying him into tasting the steak he has cooked. In perhaps the most damning scene, when Soares and his wife are toasting their twenty second anniversary, she toasts him and he toasts Team Canada.

Zupan's story thickens as we find out about the silence between him and Christopher Igoe, the driver on the night Zupan was paralyzed. Although Zupan seems nicer than Soares, he is still no angel. A friend at his 10- year reunion says, "My hypothesis on Mark was that he was very much an asshole before he was in the wheelchair and before the accident, so any attempt to try to point to the wheelchair as a cause of his grumpiness would be an utter hoax." Even Zupan's father says, "He's always been what I call a tough kid. I knew very few people that would ever fuck with Mark." But Zupan's eloquence about his misdeeds and his willingness to lead the way for others redeems him. According to Zupan, he abused Igoe's friendship after the accident as a way of getting back at him,

> I was pretty hard on him. After rehab, I'd have him come get me. I would just continually call. He had a pager and I just blew up his pager. I would project my anger onto the people I cared about. I mean when you come out of rehab. There are traces of your old self everywhere.... You figure out home isn't necessarily comforting, but it gets to you inside.

Yet, he is kind to the new quads he speaks to and tries to show them that there is more to life. And he and Igoe reunite at the end of the film.

Another illuminating moment is one in which Andy Cohn describes a dream he has. He dreams of flying and that he has the use of his arms and legs. This is a common fantasy among disabled people.

In anticipation of the Paralympics, Hogsett shares the common confusion people have between the Paralympics (with its truly gifted athletes) and the Special Olympics (for those who are mentally challenged). When his girlfriend's mother asks if he going to the Special Olympics, Hogsett says, "I went from being the man at the wedding, to a fucking retard." He says of the Games, "We aren't going for a hug. We're going for a fucking gold medal." In the end, the gold proves elusive (USA takes the bronze and Canada, the silver), but the hugs that follow are so caring and heartfelt, that we count the team lucky.

As an addendum to the film, Soares tries to set the record straight about who he is and how badly he is portrayed in the film. Unfortunately, he only succeeds in digging the hole deeper.

Questions

1. How do the athletes in Murderball upend our myths about people in wheelchairs?
2. Name three things that surprised you about paraplegics from the film.
3. Are the athletes portrayed in an empathetic way? Why or why not?
4. Who is your favorite athlete and why?
5. Who is your least favorite athlete and why?
6. Do you learn anything about how disabled people wish to be treated from the film? How would treat them differently after viewing Murderball?
7. Pick a person from Murderball and analyze three main personality traits. Use several supporting examples for each trait.

Disabled Studies—Mark O'Brien Breathing Lessons

Mark O'Brien, the subject of Jessica Yu's 1997 Academy award winning documentary Breathing Lessons spent his life in an iron lung. Born on July 31, 1949, O'Brien contracted polio when he was six years old. After being hospitalized, he spent the rest of his life unable to use his hands, legs and body. Despite a life expectancy of eighteen months (after diagnosis), O'Brien went on to earn a degree in English from UC Berkeley and become a poet and journalist. He published several books of poetry, his most proud accomplishment, though, was his book "Breathing" which came out in 1990. A disabled advocate, O'Brien died in 1999. His candor and openness are clear in Breathing Lessons which takes a clear eyed look at disability.

The interview with O'Brien is intercut with his poetry and photographs (and video) from his life. This gives the film a lyrical and moving quality—and lets us see beyond O'Brien's immediate circumstances and into the life of his soul.

One of the most moving poems is "Mrs. Garcia". It details the treatment by a nurse at a nursing home which O'Brien calls the worst two years of his life.

Constantly afraid of injury, he says the nurses were incompetent or mean and sometimes both. He depicts Mrs. Garcia this way:

> Garcia was a crazy bitch
> Swinging me on the Hoyer lift with enough abandon but careful enough
> To say "Now what was all the yelling about?
> I didn't hurt your feet. You were in the chair
> You polios are screamers. Always were."
> Exhausted by the twirlings and the dips, I didn't say a word.
> She's push me to occupational therapy
> Where I'd type my skinny novel, think of revenge.

The revenge fantasy is one of the most satisfying parts of the poem, as the speaker who has little power can at least celebrate retribution that he imagines. After his release from the Fairmont Hospital, he then went to UC Berkeley where he became part of the world.

O'Brien's poetry also describes his sister Karen, who was born in 1953 and died of pneumonia in 1961. "Death took you instead of me, "O'Brien writes, of the terrible surprise. He also describes his father's "howling" at the news of his sister's death. It seems that even at a young age, O'Brien was aware of his mortality.

He also describes the myths that often surround disabled people. "Disabled people are often invisible to able bodied people" and he notes that there is a stereotype that disabled people can "overcome (their disability) by working hard." "It ain't that easy," he says. The two biggest myths are that "One: we can't do anything and two: can do anything." Instead of the Super Crip mentality, O'Brien says, "We are just humans." He also mentions Danny Glover, who as a black actor "does not play black men, but men". This example indicates that O'Brien wants to be seen as a man instead of a disabled man.

Another issue the disabled face is despair. As O'Brien puts it, "I have tried killing myself." As a young child he scooted himself to the edge of the bed and tried to make himself fall off but couldn't. One of the reasons that the despair is so great is that many disabled people are poor: "We don't have money. We can't work. We aren't taken seriously by adults." According to O'Brien one of his friends says, "She doesn't want to talk about death with dignity until we have life with dignity." He also says, "The boredom and loneliness are the worst things."

One of the biggest surprises is O'Brien's willingness to discuss his sexual self. He admits to falling in love with several of his caregivers, both male and female. And he writes a poem about his fantasies involving Linda, one such care giver:

> Linda would've been a pretty girl
> To touch, to hold, to take to bed,
> Her pale perfect skin, her Tudor court face

He explains his attraction to her and wishes he weren't "her savagely crippled employer". Also, he admits to feeling like the "the dried out bubblegum stuck on the underneath of existence" in her presence, but if she did come back to him, he "would kill this poem and tell her how much (he) love(s) her."

At one point, his desire to experience sex, leads him to hire a sexual surrogate. He describes the experience as "the most fun I ever had" and seems especially touched that the surrogate kissed his chest, which he was extremely self-conscious about. After the surrogate's appointments were over, though, he admits inevitably, to feeling as undesirable as ever.

O'Brien does admit to being angry at able-bodied people and at God for his fate. But he does see a divide between the body and the spirit. Since his body is broken, he celebrates the spirit. "Gratitude," he says, "is the opposite of despair." And it is this gratitude he celebrates as well.

Questions

1. List three things you admire about Mark O'Brien.
2. What are the roles for the handicapped according to able-bodied mythology?
3. How does he feel about nursing homes? Why?
4. Pick one of O'Brien's poems and analyze the images and the theme.
5. How do you feel about O'Brien's use of a sexual surrogate? Why?

Disability Studies— Neil Jimenez, The Waterdance

The Waterdance (1991) by Neil Jimenez is a semi-autobiographical film about Jimenez' own experience after a hiking accident left him a paraplegic. Educated in the famed UCLA Screenwriting Program, Jimenez' first produced screenplay, River's Edge marked him as an early and edgy talent to watch. The same year his first film debuted, 1986, Jimenez was in a terrible hiking accident and suffered a broken neck, leaving him in a wheelchair. The Waterdance offers a look at post spinal chord injury rehab and it is notable for its look at the kind of adjustments, both personal and social, one has to make when confronted with a life-changing trauma. There is humor, a bit of nudity, and a remarkable camaraderie between the characters in the film and it shows the hospital in all its imperfections.

The film opens with Joel Garcia (Eric Stoltz), who is modeled after Jimenez, waking up in the rehab ward with a halo securing his head in place. He is unable to move his head at all and lying in his hospital bed, he is confronted with a flickering florescent light. The opening sequences, seen in part from the perspective of a patient in a halo, are very effective. His significant other, (Helen Hunt) is saying "Hi honey. Hi. I'm sorry." The nursing staff is caring, but harried, and Les, the male nurse offers Joel some quick, near-platitudes about his condition. "It's all right, man. They got computers now. You can type with your tongue,"(6:00) is what Les (William Allen Young) says, upon learning Joel is a writer.

On the ward, Joel meets, Ray (Wesley Snipes) and Bloss (William Forsythe), and Victor (Tony Genaro). In the background Vernon is moaning "I am" as if to reassure Joel that he is alive and exists. A race war exists over the television set and Bloss tries to enlist Joel to form a Caucasian alliance, only to learn Joel's last name is Garcia.

It is Ray who tries to humanize the situation, first, by wheeling up to Joel and holding his head to match Joel's. It's a hard knock, isn't it buddy," he says, "but one thing you got to remember is God's got a plan."(8:37) He calls the halo "a crown of thorns" and that encapsulates Joel's suffering beautifully. The alliance between the two men is perhaps one of the only redeeming things about Joel's injury.

As we learn about the patients on the ward, Bloss, a biker who is waiting for a big settlement, and Raymond, a former ladies' man and teller of tall tales, Joel copes with his new status. In an interview with a staff psychologist (who is off camera), Joel is asked whether he is ready for the inevitable depression that follows such an accident. "I should be more depressed than I am, but I'm not. Why is that?" (15:00), he says. When the therapist makes a note on her pad, Joel responds by saying, Oh no, I'm anticipating a psychological crash. I have one penciled in. I think it happens next week sometime." He is painfully aware of his denial.

In addition to denial, there is also grief and anger that Joel goes through in trying to come to terms with his disability. Joel, who is having an affair with Anna, expresses jealousy towards her husband, because she is still sleeping with him. The theme of sexual loss is also covered in a talk delivered by one of the hospital doctors, who is also wheelchair bound. "Even though the spinal chord patient can still get a reflex erection, orgasm as you've known it is very rare. You have to learn to experiment with your partner, to communicate," he says (29:05). The ensuing discussion of oral sex is fairly comic.

Like anyone who has been hospitalized for any length of time, Joel also sings the praises of a shower. The sensuous image of water poring on his body (31:00) is especially powerful.

As Joel's recovery progresses, his anger at Anna comes further out. In a confession at Verne's (Casey Stengl) bedside, Joel pores out his heart:

> She touches me and I don't feel a thing. Nothing. Like piss or shit. The smell of this place… I can't be nice to her. Sometimes I feel this anger coming up inside me and I lash out at her. I don't mean to. She is so good to me. I hate her for walking. For feeling. If we live together when I get out, oh God, I can just see the pity in people's eyes, falling over themselves to help me or pretending not to see, or pretending nothing happened to me when it did. It did. I fell, Verne. I can't walk." (114:00)

When Joel finishes his speech Verne is sound asleep. It is almost as if Joel confides in him because he knows, he isn't listening. Anna, too, expresses her sense of loss, when Joel lashes out at her. "I lost something, too. You may not understand but it's true."

In a subplot involving a stripper named Annabelle Lee, the men go to a strip club to do some background research. The film's main literary allusion comes in this scene, when Joel says, "If we were in a Zola novel, we'd be a symbol of society's decay. That's so fucking obvious, but if we were in Flannery O'Connor short story, there's not telling which one of us might be redeemed in a place like this." (1:24) In fact, one of the film's characters, Raymond, is redeemed by the events that unfold. Later, Bloss is redeemed when he overcomes his prejudice to help Ray.

In a comic twist, some square dancers come to perform for the paraplegic men on the ward and we marvel at the misguided soul who thought this would be appropriate entertainment for people who recently lost the ability to walk. In fact, the reminder of the loss of his ambulatory skills sends Bloss into a fury. The term "waterdance" comes from a dream one of the patients has. As Ray describes it, he is momentarily able to stand as long as he keeps dancing. If his dancing ceases, then he will fall and drown since, in the dream, he is unable to swim. "I get tired," he says, "I get so tired." This seems like a metaphor for the mental gymnastics people go through as a response to a spinal chord injury.

The climax of the film, revolves around revenge on the telephone operators at the rehab facility. Both ineffective and unapologetic, they deserve the attack they receive at the hands of Joel and Bloss (1:30). Another plot, the love affair between Joel and Anna, comes to an unclear conclusion. Although Joel tells Anna to go back to her husband, and informs Rosa (Elizabeth Pena), the nurse, that he and Anna are friends and there are other fish in the sea ("other fishes", he says), she (Anna) arrives to take him home at the end of the film.

In all, "The Waterdance" is a moving portrait of life post-injury, despite some dated 90's fashions. Jimenez tells the story of adaptation with humor and honesty, and it is welcome addition to the canon of Disability Studies.

Questions

1. Pick a character (Joel, Ray or Bloss) and analyze the difficulties creates by his spinal chord injury. Explain how these difficulties are resolved by the film, if at all.

2. Anger, grief and denial are several key emotions in the mourning process. Show hoe Joel goes through each of these emotions in specific scenes of the film.

3. How is humor used to deflect the serious issues of disability?

4. The issues of race, family, infidelity are all raised in The Waterdance. Choose one and show how this them is explored and resolved. Does the addition of disability complicate this issue? How?

5. Examine how Anna, Les or Rosa treat the disabled characters in the film. Do you think they behave appropriately?

Disability Studies—King Gimp

"The human spirit is the most powerful thing on Earth. Our bodies are prisons of that spirit. " – Dan Keplinger a.k.a. King Gimp

The moving documentary King Gimp begins with Dan Keplinger a.k.a. King Gimp trying to get into a doorway with his wheelchair. His movements are spastic and he has to try several times, but after kicking the door he succeeds. He gets into the building and sails along. At first glance, it might be hard to believe that Keplinger is an accomplished artist, but he is. Through his perseverance and determination, Keplinger has achieved a great deal. William Whiteford and Susan Hadary's Academy award winning 1999 documentary chronicles Keplinger's life from the age of twelve to twenty five and his remarkable journey.

Keplinger was born January 19, 1973. His mother was eighteen and unprepared for the horrifying events that happened at his birth. Keplinger wasn't breathing when he was born and the doctor assumed he was dead. He went without breath for a full minute when he began breathing on his own. As a result, Keplinger developed cerebral palsy. When Keplinger's mother refused to institutionalize him, her husband divorced her and she raised Keplinger on her own. Keplinger attended a special school for the handicapped, Ridge School, where he had friends and felt comfortable, but at one point, when Dan was putting together a puzzle with his knees, they discovered he was gifted. Until that moment, Keplinger says, "no one could understand I was an intelligent person in this body." Keplinger's career at Ridge School was undercut by the death of his best friend Pete, which hit him hard. With some trepidation, Keplinger's mother Mary, lobbied to have him mainstreamed to a public high school. While the transition was difficult and Keplinger struggled to keep up academically, sometimes doing four hours of homework a night with the help of a tutor, he discovered art. "The best thing that happened to me was art. I allowed me to express myself without anyone interpreting for me," Keplinger says. This desire for independence and self-expression seems a common theme among the disabled. Keplinger elaborates:

> When I paint there is a sweet siren who is telling me what to paint. I obeyed the brush and the brush became my force. Painting can be something deep, dark. A part of you only you know.

To paint, Keplinger must use a paint brush attached to his head. He is able to attach the head gear himself, but with some difficulty. (Also, watching him dress makes the able-bodied appreciate the gift of independence.) But with art, his inner-self could be expressed. "I confess I like to shock people, " he says. He loves to imagine the visitor at one of his art show saying, "How the hell can this guy paint like that? He can't even write his name." At the age of 19, he was part of his first group show, the Statewide Challenged Art Show in Maryland.

In addition to the physical obstacles he faced, there were emotional ones as well. When he entered college, several of his professors discouraged him from becoming an artist:

> My first term was hell. I wanted to major in art, but my teacher told me that I would never be an artist. Two professors wouldn't speak to me. I felt so bad. I didn't want to paint anymore.

But Keplinger found a champion in Stuart Stein, one of the art professors at the Towson University, where Keplinger studied. In fact, Stein came to admire Keplinger and his fighting spirit. According to Stein, "Painting isn't convenient. Danny understands there aren't easy solutions to things." Stein wishes some of his other students shared Keplinger's determination.

In fact, Keplinger's definition of the word "gimp" shows this. "Most people think 'gimp' is someone with a lame walk, but it also means someone with a fighting spirit." This is why he is proud to be 'gimp'. "Everybody has a handicap," he says, 'but few are true 'gimp'". Keplinger earned his nickname at the age of fifteen, when a neighbor felt his wheelchair looked like a mobile throne.

In addition to struggling to be an artist, Keplinger has struggled to be independent. He moved into his own apartment when he was a senior in high school. In one scene, he is shown taking popcorn out of the microwave and bending over to eat it on the floor. His one regret is about his love life, a common complaint among the disabled. Keplinger says.

> "What is love? I have loved a few women always dreaming about them, but it never leads anywhere. I love Laura (his caregiver) and care about her. I think she feels the same about me but not quite....I'm sure with other people it would lead to sex. My female friends say I will meet someone someday, but I see myself becoming a very old man whacking off to porn. "

Keplinger's candor seems noble here.

The film climaxes with Keplinger's graduation from college. It is a tearful moment for him, his mother and Laura, a hard won victory in a difficult life. His success as an artist has continued and Keplinger is represented by a gallery in New York.

Now, Keplinger works not only as an artist, but a motivational speaker and he has earned some fame as the subject of an Academy award winning documentary. Despite his professional success, he still longs for love, which even years later, has proven elusive.

Questions

1. How do you feel about the filmmaker's decision to show Keplinger doing potentially embarrassing things like kicking a door and eating popcorn on the floor? Is this respectful to their subject? Why or why not?

2. Define "gimp" according to Keplinger. Give examples of "gimp" behavior.

3. How do the stories of the art professors who discouraged Keplinger seem to you? What do you think of their sentiments? How do you feel about those who encouraged him?

4. Is it true that everyone is "handicapped" but few are "gimp"? Why or why not?

5. Describe your favorite moment in the film. What makes it your favorite?

6.
7. Conversely, what is your least favorite moment and why?

Disability Studies—A Brief History of Time

Stephen Hawking, the famed astrophysicist, is profiled in Erroll Morris' documentary A Brief History of Time. Hawking is confined to a wheelchair as a result of ALS and the disease has a part in Hawking's scientific career.

The film which chronicles Hawking's life and discoveries is told chronologically with the years displayed on a stark, black background. Since much of the film is about the nature of time and space, this somehow seems fitting and almost ironic. Through interviews with family members, colleagues and Hawking himself, we hear not only a narrative of Hawking's ground-breaking discoveries about the nature of the universe, but of the progress and effect of Hawking's illness.) In the beginning of the film, we hear a robotic sounding voice-over asking, "Which came first? The chicken or the egg? Does the universe have a beginning and if so, what happened before then? Where did the universe come from and where is it going?" The voice is that of Hawking's voice synthesizer which compensates for his inability to talk. These theoretical questions are the basis of Hawking's research and a sharp contrast to his earth and chair-bound demeanor.

Early in the film we meet Hawking's mother, Isobel Hawking, who describes the bombs falling in England when she was expecting Stephen. She also comments on Stephen's battle with ALS, which was actually a galvanizing influence on him:

> Luck, luck....We have been very lucky. I mean my family and Stephen and everybody who has had disasters. But the point is we have survived. Everybody has disasters and yet some people disappear and you don't ever hear from them again. (3:00)

Another notable thing about Hawking's birth was that he was born three hundred years after Galileo's death. Although Hawking is aware 200,000 other babies were born on this day, he still notes the significance. Hawking's family was a bookish and "eccentric" one and guests at the Hawking household says that the family read books at the dinner table and the only member of the family who would socialize with guests was Stephen. According to Basil King, Stephen was the most normal member of the family. (7:48)

Of the early gifts Isobel Hawking gave her son, one was a giant atlas which she said "proved to be prophetic" and was he actually a poor student in his early scholastic career at St. Albans where he was "third from the bottom". She asked Stephen, "Do you really have to be as far down as that?" (12:23) Despite his poor showing, he was still considered intelligent, and he won a divinity prize for his knowledge of Bible stories. Young Stephen was also interested in Scottish dancing and "took it quite seriously" a cousin said, forcing the family to dress up in coats and ties when they danced. (15:08) A fun loving young man, his fellow students at Oxford said they first met the seventeen year-old Stephen in his room where he was drinking beer from a crate he'd purchased because he was too young to legally go to a pub. (15:37). He was also known for organizing beer parties on crew boats where he served as a coxen. (16:27).

In his Oxford days, Stephen's abilities to do physics problems far outstripped those of his classmates. In terms of work, Derek Powney says, "I think it was then we realized we weren't just in the same street. We weren't on the same planet "(17:00). Hawking himself admits to doing "one thousand hours of work" in his time at Oxford, or about an hour a day. "I am not proud of this lack of work. I am just describing it to show my attitude at the time, an attitude that nothing was worth making an effort for," he explains (17:15)

While brilliant, Hawking had a modest work ethic. His decision to do graduate work at Cambridge came simply because he was awarded first- class degree in stead of a "second". Hawking says: "Before my condition had been diagnosed. I had been very bored with life. There had not seemed anything worth doing." (19:08) But the diagnosis of ALS in 1963 (after Stephen suffered several falls and a diminished use of his hands) at the age of twenty one, changed all that. Given two and a half years to live, Hawking "flatly accepted it and started to do work" according to Derek Powney, who said Stephen was aware the disease would leave him mind, heart and lungs intact, but ultimately leave him with " the body of a cabbage" and make him "unable to communicate with the world."(28:10) At first he didn't think he could to finish his Ph.d, but the progress of the disease slowed. He had also proposed to Jane Wilde, who helped ease his depression, and Hawking had to find a way to support them both. A series of nightmares that Stephen was been executed, awakened his desire to do something positive with his life. He says, "While I was in the hospital, I dreamed I was executed. I suddenly realized there were a lot of worthwhile things I could do if I were reprieved." (27:15)

There is an odd connection between the questions Hawking asks about the universe in his research and the disease that disabled him. Whether the expanding universe will reverse and fall in on itself, reversing the movement of time, is a question Morris illustrates with a falling teacup (1:08). For someone with a debilitating illness, the question of whether we might age backwards would be one of interest. Another insight into the randomness of the universe also seems telling in light of Hawking's fate. According to Hawking: "Einstein was doubly wrong. The quantum effects of black holes suggest that not only does God play dice, He sometimes throws them where they cannot be seen." (52:00) A beautiful montage of Hawking as a baby, being held by both parents is bookended with the voice-over question: "Where do the past and future come from? Why do we remember the past and not the future?" (5:21)

Another inquiry into whether there is a Creator in the universe or if the universe simply existed without a Big Bang and moment of Creation, leads to the greater question of why we are put on this planet (118:00):

> Why does the universe bother to exist? Is Unified Theory so compelling it brings about its own existence? Or does it need a Creator, and if so, who created him? If we answer this question, it would be the ultimate triumph of human reason. Then we would know the mind of God (120).

Ultimately, Hawking does predict an end to the universe, ten billion years from now. Hawking predicts the universe will end in an event called the Big Crunch after the currently expanding universe collapses on itself. Hew says, "I do, however, have advantages over other prophets of doom. Whatever happens ten billion years from now, I don't expect to be around to be proved wrong." (1:14: 00)

In the end, Isobel Hawking notes that Hawking "believes intensely in the infinite possibility of the human mind" (114:00. He is someone who thinks about the "unthinkable" and is a "searcher, someone looking for things". At one point in the film she says, even Stephen admits to the role his illness played in his discoveries: He says himself, if he hadn't been ill he would've never done all he is known for. As Johnson said, 'Knowledge you are to be hanged in the morning concentrates the mind wonderfully.'" (52:00) Isobel believes that Hawking's ALS while not "lucky", was "less bad luck than for someone else since he could live in his mind so much". "People must extend the boundaries of knowledge," she says. (118:00).

It is Hawking, though, who has the last word. He believes that not only scientists and philosophers, but also ordinary people need to consider the idea of why the universe exists and try to know "mind of God" (1:20).

Questions for Discussion

1) What does it mean that Hawking is shown with a Marilyn Monroe poster behind him?

2) Do Hawking's theories have any relation to his illness? If so, how are they related?

3) Does Hawking's early interest in religion have any play in his later life and/or research? If so, how?

4) How do you view Hawking's decision to continue his research in the face of his disease?

5) What does it mean that Hawking finds it easier to communicate with his speech synthesizer than before? (1:05)

6) List several key traits of Hawking's personality as presented in the documentary. How do these traits influence his ability to survive and thrive?

7) Discuss the theme of luck and chance in the film.

8) How does Morris' editing style (stark cuts to black between interviews) and lack of CG's (character generated subtitles for the interviewee's names) enhance the theme of the film?

9) Characterize Phillip Glass' score with several adjectives. How is it appropriate to the subject matter?

Disability Studies-- Sound and the Fury

The 2000 documentary Sound and Fury by Peter Aronson focuses on two families in New York, who must decide whether to provide their deaf children with a cochlear implant. At the time, the procedure was considered controversial and as a major threat to deaf culture. The film focuses on two families, Peter and Nita Artinian and their three deaf children and Chris and Mari Artinian and their deaf son who is brother to a hearing twin. Though Chris and Peter are brothers and the sons of non-deaf parents, they are divided on this issue. One of the reasons is that Chris and Mari are hearing (but both have close family members who are deaf) and Peter and his wife are both deaf and champions of deaf culture. The fear is that the cochlear implant, which simulates nerve endings and restores hearing, will rob Artinian's children of their deaf culture. Adding to the debate are the children's grandparents Marianne and Peter Artinain (who are hearing) and Nancy and Michael Mancini (who are deaf).

In some ways the debate over the cochlear implant feels anachronistic. Over the last eight years it seems the attitude towards the cochlear implant has changed dramatically. And much of the objection to the implant feels inflated and a little artificial. While Peter Artinian's concerns about the implant replacing his children's deaf culture with a hearing one have some validity, it seems he is too vehemently in the role of deaf culture defender to consider the benefits. The filmmaker's choice of providing voice-over actors to speak for the signing principals seems false and objectionable, adding further drama to the issue. This move seems decidedly insensitive to the deaf culture which prides itself on the beauty of sign language. Closed captioning would've leveled the deaf/hearing playing field a little, though hearing audiences would've found it distracting.

The film opens with the voice of Marianne Artinian asking her granddaughter Heather, who is partially deaf and five years old, "Do you know everything makes a sound?" Marianne is an excellent person to begin with since she is perhaps the most sensitive about the difficulties deaf children face, having raised a deaf son as a hearing person. She is sensitive to young Heather who wants to be able to talk on the phone and hear alarms, and smoke detectors (although we do get the feeling Marianne has implanted some of this information in her 5:00). We also meet Peter, Marainne's deaf son and Heather's father, who says: "If somebody gave me a pill that would make me hear…would I take it? No way…I really am happy being deaf. It's very peaceful." (1:28) Even though Heather's mother Nita says: "I want her to be happy the way she is", she seems more willing to consider the cochlear implant.

Next we meet Mari Artinian, whose 18 month old son Peter (III) was born deaf, unlike his twin brother Tim, who is hearing. She says she was "devastated" when Peter was born deaf and plans to have the implant. On learning just how profound his hearing loss is she says, "It killed me…a part of me died." (10:00) She knows that the sooner Peter is implanted the better his chances will be for near natural speaking skills. We find out in a subsequent scene that Mari is no stranger to deaf people; her own mother and father were deaf and she had to have years of speech therapy (because she spoke like a deaf person) and serve as an interpreter for her family. "I didn't have a childhood," she says. We don't blame her for wanting a better quality of life for her son. (20:00). She makes the analogy of blindness, asking that if a blind child had a chance to see, wouldn't the parents want that for their child? She sees the cochlear implant in a similar light.

What follows are several visits to schools for children who have had the implant and seem to be thriving as well as a deaf community in Frederick, Maryland. The debates between the family members are particularly vehement. At one family party, Nita backpedals on her decision to let Heather have the implant and Marianne becomes irate. She calls not implanting Heather, who she clearly loves, "abusive" and "fearful". (58:00). Her son Chris says the decision is "criminal" (118:57) "I stand by my decision 1000 per cent," he says. Marianne reminds Nita that she herself was considering the implant and looking forward to hearing music and a baby's cry and she is robbing Heather of this opportunity. (35:00)

On the other side of the argument many deaf people feel that the implant will turn the children into "robots" or 'Frankenstein" (48:00) they call the hearing world "selfish" for wanting to change deaf people. (45:00) Many of the deaf feel that hearing people consider them inferior and the implant only reinforces that perception. They are afraid the children will be "guinea pigs" and the implant will kill deaf culture. Peter Artinian says he fears he, will be betraying everything (he) knows." (51:00)

But Mari has the most compelling argument. "Deaf schools stink," she says in a candid moment with Nita (59:00). People come out reading at a fourth grade reading level. She says that Heather will have more opportunities with the implant, socially and scholastically, than without. This is reinforced later when Marianne points out that Nita can't even read a recipe (1:08).

But it is Peter Artinian who seems entrenched in the deaf side of the debate. (20:00) He complains that the cochlear is invasive and that for a deaf person the natural communication is signing. "Sign language has emotion", he says, "English is just moving lips". Home footage of him as a child shows him struggling to understand those around him with little success, but sign language was like a rebirth. "I could communicate for the first time," he recalls. He is afraid Heather will not fit in either the deaf or hearing world if she has the implant and will become an outcast. "I don't want her to get hurt," he says." Instead, he chooses to move his family to a primarily deaf community in Maryland, so they might feel more at home. His mother accuses him of running away from his problems.

While many of these concerns are genuine, it seems like much of the passion Peter has is misguided. As I watched the film, I felt the either/or debate seemed forced. Why can't a person be a part of both cultures? Though cochlear implant patients are encouraged not to rely on sign language while acquiring language, it does seem unfair to tell a child who has asked for surgery, she can't have it. Though Nita tells Heather she'll do what Heather wants, the events don't seem to unfold that way. And the benefits of cochlear implants are so great—less isolation and frustration for those in the deaf world, as well as better scholastic aptitude—the debate seems false and forced. Even if the implant is installed, the family must be committed to speech therapy and hard work to make it successful. Why anyone would deny a child this "miracle" or "key to the world" is mystifying to Chris Artinian, whose joy at seeing his son's first response to sound speaks volumes (118:00).

While Peter Artinian said he wanted his children to be safe and putting them in the hearing world would be akin to locking them up in jail (105), he finally relented three years after the documentary and had Heather, and his son Timothy, outfitted with the implant. According to Nita, "Looking back, we were so overwhelmed with all of the information about the implant at the time the documentary was made. It was too new for us, and we had so much information from both sides that we weren't ready for any of it." (www.handsandvoices.org/articles/misc/V8-4_soundandfury.htm) One motivating factor was that her son Timothy was having difficulty signing and wished for an implant like his cousin Peter's (ibid). Nita also had an implant herself, although it took her a year and a half to finally adapt to it. She says the constant filming of the documentary was "overwhelming" and shadowed her decision, as well as took a toll on her family.

Because the attitudes toward the cochlear implant have changed so much (in part due to the film) there is a follow-up movie: Sound and the Fury : Six Years Later. However, it is not readily available. National Public Radio also did a follow-up segment(March 28, 2006.)

Discussion Questions

1. List the benefits and drawbacks of the Cochlear Implant. (At least five on each side)

2. Which person in the documentary do you agree with or relate to most? Give three reasons for your choice.

3. Do you agree with Peter's decision to move the family to Maryland? Why or why not?

4. Do you agree with Mari and Chris' decision to have their son implanted? Why or why not?

5. Ultimately, where do you stand on the issue of cochlear implants? Do you think attitudes have changed since that time?

6. If you had a deaf child, would you get that child cochlear implants based on this film? Why or why not? (Use arguments from the film to back up your position).

7. What do you think about the voice-over narration? Is it respectful to the deaf people in the film? Why or why not?

Scenes of Interest

Opening sequence (00-5:00 minutes)

Who are the principals and how do they feel about deafness?

Peter's Story (20:00-25:00)

Why does he feel so strongly about deaf culture? What in his past may have influenced this?

Mari's Story (25:00)

How are her attitudes towards deafness and the implant influenced by her experience?

Mari and Nita (59:00)

Marianne and family (43:00-47:00)

Show the two sides of the debate.

Deaf Culture's Response (49:00)

What is the deaf culture side of the debate?

Disability Studies – Children of a Lesser God

The film Children of a Lesser God (1986) directed by Randa Haines, is one of the first films in my memory that features a disabled character. In fact, the film was so well received that Marlee Matlin, who plays a deaf woman, won an Academy Award for Best Supporting Actress that year. The fact that she herself was deaf was a noteworthy thing, and she, no doubt, broke ground for other disabled actors with her success. Twenty two years later, on viewing the film again, it looks less ground-breaking but more like a traditional melodrama, complete with the requisite break-up of the lovers we know are meant to be together and their reunion. This film is helpful in demonstrating just how far the disability genre has come, though modern students may find the fashions laughable and the filmic conventions terribly obvious.

The film opens with a wooden shutter hitting a window frame and young woman lying in bed. We learn later that this is Sarah (Matlin) a troubled deaf woman, who graduated at the top of her class, but is currently working as a cleaning woman/ janitor at the school for the deaf she attended. She seems a bit like a temperamental Cinderella, throwing pots across the kitchen and cursing out the cook in sign language. Next, we see James Leeds (William Hurt), the well-meaning new teacher crossing the channel on a ferry to get to the school for the deaf at which he will be teaching. Although noble, his goal seems barbaric by today's standards: to get the deaf students to speak and read lips, implying that sign language is not enough. Today, I would not even consider forcing a deaf student to speak, but instead encourage him/her to sign. Forcing a deaf student to speak seems inappropriate and disrespectful in the current deaf culture. (Raising a contrary voice is deaf author Josh Swiller, who was grateful for his speaking lessons).

Another hopelessly outdated character is that of the headmaster, Dr. Curtis Franklin, who tells Leeds in his opening interview that he does not want him (Leeds) to push the students to excel, but to simply let them coast. "I'm sure you have a lot of energy and a lot of new ideas…Nobody's trying to change the world here. Just trying to help a few deaf kids get along a little bit better. Everything else is razzle dazzle. Am I making myself clear? " he says, content with the status quo. When Leeds asks him about Sara, Franklin tells him that "She is a pain in the ass. She's always been a pain in the ass." He also claims she is "content" being a janitor and that she is productive and pays taxes. "Look Hotshot," he says, "Not everyone wants to be a star." In fact, Curtis seems more concerned about the cost of reseeding the lawn than Sarah's future.

The troubled first meeting between Leeds and Sarah is straight out of the Hollywood playbook. When Leeds asks Sarah to sit down, she stands, and when he stands up, she sits. Finally, when she is ready to begin the lesson, he turns to get something and she is gone. Their chance meeting on a beach leads to their first date and then film becomes slightly more enlightening and original. Sarah can't read the menu which is in Italian and Leeds must help her. He must explain what "veal" is and can't. Then, Sarah leads him to the dance floor, where she dances in a sensual and hypnotic way. Their date ends and Leeds is smitten.

Sarah remains elusive, until her back story is revealed; she has been used sexually by hearing boys and feels she is worthless as a result. When Sarah reveals this dark secret, Leeds assures her he doesn't care and a few scenes later he confesses his love for her in an indoor swimming pool. The swimming pool scenes are among the most vivid and poetic; Sarah and James' are accompanied by a mystical sort of soundtrack, but in some sense, they convey what it is like to be deaf, immersed in silence, below the surface of the hearing world.

When Sarah and James' romance comes to light, he is threatened with the loss of his job; however, he convinces the headmaster that the romance is honorable. Sarah and James live together and Sarah flourishes until the paint-by-numbers argument that threatens to break them up for good. Here would be a good place to quote Sarah's objections that Leeds is always speaking for her and that she is tired of it, and needs to be out on her own, but the lines are so trite, it seems insulting.

Leeds then tracks her down and the two are reunited once again. Much of the film is signed and translated by Leeds so we see sign language used and this seems radical for its time. Also, the deaf students that Leeds teaches, do not seem like victims. He inspires them with a 50's pop tune "Boomerang" and even wins over the headmaster. Today, though, the winning scene of deaf students dancing to "Boomerang", might seem like a pyrrhic victory. Also, there is a scene, where Leeds has insisted that Sarah speak and she shrieks at him. It is a horrifying moment and one that is unthinkable today.

The film does show a mother who uses sign language, however nominally, and this is an issue that plagues perhaps half of all deaf students. Parents who refuse to learn sign language are more prevalent than is imaginable and the toll on the deaf student is devastating.

The students in the film, seem less like real people than like two-dimensional caricatures (the punk with a Mohawk, the nerd, the outgoing girl), but they are played by deaf people which seems like a small coup for the disabled community.

In terms of classroom use, Children of a Lesser God seems like it should be relegated to the cloak closet, for a film that broke ground in its time, but is of limited use today. Modern choices like The Diving Bell and the Butterfly or Murderball, speak more to the current disabled zeitgeist.

Disability Studies --The English Patient

The English Patient (1996), directed by Anthony Minghella is one of the most romantic and beautiful films ever made. However, for the purposes of Disability Studies, its use is limited. An Academy Award-winning film (Best Picture among the nine awarded), it provides a painterly and loving adaptation of Michael Ondaatje's novel of the same name. Based on several events in the life of Count Lazlo Almasy, an Hungarian artistocrat, in the period preceding and during World War II, the film is mainly a love story, which is recalled in flashback by a burn victim (Almasy, played by Ralph Fiennes). A secondary plot involves Almasy's nurse Hana (Juliette Binoche) and third involves David Carravaggio (Wilhem Dafoe), out to get revenge against Almasy.

The film itself takes on new meaning with the recent death of director Minghella on March 18, 2008, and the spate of articles praising him for his literary interests and poetic style (among them an interview with Charles Frazier, author of Cold Mountain, which Minghella adapted—Los Angeles Times March 28, 2008). This poetic style is one that is fully evident in The English Patient, as well.

The film opens with a close-up of an artist's hand, drawing the limbs of a swimmer on a golden piece of parchment. It is a sensuous image, and one that has a play in the story later (Katherine gives the image to Almasy later). The film centers around a globe trotting count and his colleagues on a desert expedition.

Almasy falls in love with Katherine Clifton (Kristin Scott Thomas) the wife of Geoffrey Clifton (Colin Firth) and the resulting affair leads to Katherine and Goeffrey's death. After Alamsy's plane is shot down while carrying Katherine's dead body, Almasy is badly hurt, leaving him with severe burns over his entire body and a single lung on the verge of collapsing. After Carravaggio tries to divine his identity, Almasy explains, "I'm a bit of toast, my friend."

Unable to move, Alamsy is nursed by Hana (Juliette Binoche), who herself is facing the death of a lover or fiancé as well as the death of a fellow WAC, Jan. "I must be cursed," Hana says, "Anybody who loves me. Anybody who gets close to me. Oh, I must be cursed"(Chapter 8). Her opportunity to nurse the dying Almasy in a war torn Italian villa in all of its ruined glory, seems an escape from war's stress and this curse. As the character of a nurse, she seems especially sweet, kissing a wounded GI simply because he asks (of course, this behavior wouldn't fly in the hospitals of today)(Chapter 3) . When Carravaggio accuses of her of being in love with her patient, she claims, "I am not so in love with him I am in love with ghosts. So is he. He is in love with ghosts," which is perhaps a metaphor for several characters in the film (Hana, Almasy, Kip, Chapter 8).

As Almasy aka the "English Patient" convalesces, the events which led him to his current situation unfold and we learn of his doomed, but torrid affair with Katherine. The comparison of Almasy's stark conditions as a burn victim and the lush, and sensuous scenes of his earlier life and affair show that even the most disabled patient, might've had an incredibly vibrant life. How helpful this might be to students of disability is not clear.

During one particularly moving scene, Hana feeds the dying Almasy a plum, fresh from the orchard, indicating that even a small treat that most of us take for granted can mean worlds to a convalescing person. She also obliges his wishes to be read to, another small gesture, which sustains Almasy at his worst. Almsay also says, "I long for the rain on my face…..", indicative of yet another simple pleasure he desires and is later granted. Finally, Hana is asked to euthanize Almasy (he requests it) and though it pains her, she acquiesces, out of respect for the patient and her new, burgeoning future.

Hanna has a love affair of her own while at the villa, and as her patient, Almasy notices the changes in her leading up to her liaison. Almasy, while not granted any particular powers, does seem to intuitively know her heart. "You like him, don't you? Your voice changes, " he notes. "Hana was telling me you're indifferent…. To her cooking," he says, trying to spur the romance (Chapter 9).

Even the toxic Carrvagio, bent on revenge on Almasy, for crimes he mistakenly attributes to him, is somehow cleansed by the time in the villa. "I can't kill you now," he says, realizing, in part, that Almasy's status as a burn victim and the death of Katherine, is perhaps, even worse punishment. That Almasy takes responsibility for his hand in Geoffrey and Katherine's death, though inadvertent, is enough for Carravaggio.

Many of the final scenes seem hopelessly romanticized by today's standards, but a final speech by Katherine seems one of the most significant in the film and pertinent to disability studies:

> We die. We die rich with lovers and tribes, tastes we have swallowed, bodies we have entered and swim up like rivers. Fears we have hidden in like this wretched cave. I want all this marked on my body. We are the real countries. Not the boundaries drawn on maps or the names of powerful men. (Chapter 30)

The elemental nature of human life (taste, lovemaking and emotion) is celebrated here, in Katherine's elegy and her wish for "and Earth without maps." In the symbolism of the explorer, the real exploration is that of the individual, the human.

Questions

1) Analyze Hana's nursing techniques. Do you agree with her decisions to kiss a patient, remove Almasy from the transport vehicle?

2) Describe how Almasy responds to the plum, the rain and being read to. What does this indicate about his situation?

3. Analyze the final speech. What does Minghella seem to be saying?

4. How does the respite in the villa seem to heal some of the characters (Hana, Carravaggio)?

5. Do you agree with Hana's decision to euthanize Alamasy? Why or why not?

The story of Christy Brown is a remarkable one. Born in Dublin, Ireland with cerebral palsy, Brown was thought by his family to be mentally retarded until he was five years old. When he began writing the alphabet with his left foot (the only part of his body he could move), his family realized his disability was only a physical and not mental one. He became a painter and then writer, painting and typing with his foot. Some credit Brown's loving family (including thirteen brothers and sisters) and his mother's care with making him the success he was. Writing six novels and several books of poetry, Brown was successful beyond anyone's initial expectations.

The film My Left Foot (1989) was acclaimed and produced two Academy Awards, one for Daniel Day-Lewis (Best Actor) and the other for Brenda Fricker (Best Supporting Actress). The film is especially notable for Disabled Studies because it demonstrates just how severely disabled people can surpass the expectations others have of them. It is also a portrait of a poor Irish family and of Brown's devotion to his mother and the women he loved.

The film begins with a framing device. Brown, in a tuxedo, and his family, all dressed to the nines, are being taken to castle for a benefit, in which Brown will be honored. While his family enjoys the musical portion of the afternoon, Brown is left in the care of a nurse and taken to a library where he waits for his appearance. In the time he is waiting, he flirts with the nurse, convinces her to read his book and drinks whisky through a straw. As she reads the book, the scenes of Brown's life unfold.

The sequences begin with Brown's birth. His father is informed that there were complications and the following scene in a pub encapsulates the attitudes towards disability at that time. Brown's father is asked if he will put Christy in a home, as is the expected course at that time for a disabled child. Brown's father says, "No one's gonna put him in a home. I'm going to my coffin before any son of mine goes to a home." Another pub-goer asks Brown senior if this means "the end of the road in the breeding stakes" and pere Brown becomes outraged, punching his interrogator in the face. "A closed mouth catches no flies," he says in his defense. But again, this sentiment that a disabled child should mark the end of reproduction for a man, seems like another piece of prevailing wisdom.

Young Christy seems almost mute and his speech is virtually incomprehensible. He does, however, save his mother's life after she falls down some stairs and he scoots himself down the stairs with his one good foot and makes a racket by kicking a door. Even after this heroic rescue, the neighbors still don't realize that Christy is a sentient being. "He's got the mind of a three year-old," one says of the ten year-old Christy, "what would he know?"

One central moment in the film is when Christy's father recognizes his mental abilities. Christy writes the word "MOTHER" on a slate with his foot. Brown senior is overcome with pride when he says, "Jesus suffering Christ. He's a Brown. He's a Brown alright. This man deserves a jar." With that, pere Brown slings Christy over his shoulder and takes him to the pub for a jar of whisky or beer. One wonders if this was the beginning of Christy's own problems with alcohol.

Christy's devious sense of mischief is seen clearly when he and his brothers plot to steal coal, by using Christy as a decoy. His brothers park him in front of a coal truck and then they remove a peg from the back gate of the truck bed. When the truck drives away, it dumps the entire load. Another surprising scene is when Christy serves as goalie for the street soccer game his brothers play. He uses his head to save the ball and then is laid on his side to kick a goal. His condition is so well accepted and embraced by his siblings that Brown only truly begins to recognize his limitations when it comes to falling in love. He has an unrequited romance with a young girl and, after sending her a painting he has made, she tells him, "Did you paint this? I can't take it."

Christy's life takes another turn when he meets Dr. Eileen Cole, who he initially tells to "Fuck off." Her response characterizes their relationship. "With speech therapy I could teach you to say 'Fuck off' more clearly," she says. Her sense of humor and hard-nosed work ethic help lead Christy to clearer speech and a sense of purpose. "I wish you'd stop feeling sorry for yourself," she tells him at one point. She also introduces him to Hamlet's soliloquy at one point. When he discovers his love for her is unrequited, Christy throws a public fit in a restaurant where they've gone to celebrate his art opening. This is in part due to the large amount of alcohol Brown has consumed, which is one of the troubling elements of Brown's life.

When his love for Cole is unreturned, Christy turns suicidal and attempts to slash his wrists with no success. Before his attempt he writes a line "All is nothing, therefore, nothing must end." In some ways this is the beginning of his literary career. Witty and humorous, Christy tells the nurse, who will later become his wife, "Looks can be deceiving." He asks Mary for a light and then for a cigarette, and gets her to pour him whisky. He even bellows for her, "Mary, stay with me", in front of the gala crowd, to win her over. In the end, he is successful. They married on October 5, 1979. Sadly, two years later; he died.

A subsequent biography released in November 2007, maintains that Mary Carr, who is painted as a wholesome nurse in the film, was a actually a prostitute and drug addict, whose poor care may have sent Brown to an early grave. This is a troubling note at the end of a positive and heart-warming film, but a necessary one. The film takes some liberties with Brown's story for dramatic effect. In terms of its usefulness in a Disabled Studies course, the film seems a mixed blessing. Brown's is indeed an inspiring figure, but his violent outbursts and alcoholism are troubling. His love for his mother is perhaps the most redeeming aspect of the story. At one point he gives the entire advance for his book (800 pounds) to her as a sort of tribute. It seems it is she who helped make his life the success it was.

Disability Studies—Weirded Out and Blown Away

Weirded Out and Blown Away (1988) directed by Sharon Greytak takes a look at the personal difficulties of disability in an unusually candid documentary. Greytak interviewed six disabled subjects (including herself) about what it is like to be disabled and how the disabled are sometimes tempted to use their disability for favors or attention. The documentary features: artist Mark Gash, writer Anne Finger, psychotherapist Harilyn Russo, filmmaker Greytak and actor Clark Middleton. The subjects in the film tell of job interviews, their encounters with other disabled people and about their own questions regarding their suitability in terms of dating.

Finger opens the film talking about how unfair it is that disabled athletes are so celebrated. These "Supercrips" give an unfair picture of how disabled people navigate the world. On the other side of the spectrum are those with such limitations that getting out of bed it difficult. So the images of the disabled range from completely debilitated to the Supercrip. As someone who has difficulty walking (due to polio) three blocks to catch a subway train, these depictions frustrate her and create an unrealistic depiction. She also tells a story about a blind man who serenades her at a bus stop. She feels awkward leaving because she is somehow breaking the unwritten law of cripples—that they must stick together.

Mark Gash admits to letting others do things for him and using his disabled status. An artist, he does draw the line at advertising his disability along with his art. This doesn't seem right to him. He is aggressive with women and says his disability forces him to be this way. He cannot be shy about approaching women as a man in a wheelchair. He is afflicted with brittle bone disease and tells the story of a woman who stated to him, "I'm a virgin. Can you do it?" The strange juxtaposition is a humorous moment in the film.

Greytak is most surprising, telling the story of a job interview gone awry. Her interviewer invites her to a luncheon interview and noting that she'd probably be exciting to sleep with. She explains that despite his vast sexual experience, he'd never had sex with a disabled person and considered it "exotic". Greytak is suitably insulted and explains that her disability has stood in the way of jobs numerous times. A rheumatoid arthritis sufferer, Greytak wears stockings and pumps despite the fact she is in a wheelchair, as sort of fashion statement that shows she is a sexual being despite her disability.

Most poignant is Harilyn Russo, as psychotherapist with cerebral palsy. She did not even consider dating until she was twenty eight because she felt her disability precluded it. Extremely articulate, Russo is both fascinating and horrifying to watch, because her disease distorts her facial mannerisms so much. She explains the hierarchy of cripples, explaining that some disabilities are more acceptable than others. Disabilities that affect motor coordination are shunned more than those involving a loss of a limb, for instance.

Finally, Clark Middleton, is a dour personality who talks mainly about his life as an actor and his need to be competitive. Of all of the subjects, he is the least appealing. It seems fitting, somehow that such an honest documentary has one unlikeable subject.

At the end of the forty three minutes of Greytak's film, one is left with a sense of disappointment that her film isn't longer. That is a tribute to the film's success.

Questions

1. List three surprises from Greytak's subjects.

2. Who is your favorite subject and why?

3. Who is your least favorite and why?

4. List four issues that come up during the documentary and explain what is said about them.

Disability Studies—Stephen King, On Writing

Stephen King, horror author extraordinaire is a surprising voice to add to the discourse on Disability Studies. However, the writer of such works as Carrie and Pet Sematary, was struck by a van while on an afternoon walk in June of 1999 and has worked hard to overcome his disabling accident. In his book, On Writing (2000) King is vivid in describing the accident, and the ways retuning to his craft helped him recover.

King, who was born in Maine, resides in the same town that my grandparents did. In his book, King mentions a drugstore, La Verdiere's, which is in downtown Bangor (87) and his attempt to buy a "wild and extravagant gift" for his wife Tabitha there. Until I researched it a little, I did not know I was related to the owners of this establishment.

King, is a prolific author of thirty five novels and the son of a single parent. He was encouraged by his mother to write at a young age, and actually paid a quarter by her for his first story. As he wrote these initial stories, he found he loved the sense of possibility. Wildly successful, King has been a repeated bestseller and has an incredible following. I actually crossed paths with King briefly in Bangor, Maine in the early 1990's. I went to visit his house while on vacation—and it was easy to find. He has wrought-iron bats adorning the gate around his home. While there, he drove up and went inside his house. This is the extent of our "meeting", but it made even more interested in On Writing and King's accident in particular.

King's genesis as a writer began when he was bedridden as a child. When he was six years old, King was often sick with severe ear infections (that required lancing) and missed much of the school year. He describes his life this way:

> Most of the year I spent in bed or housebound. I read my way through approximately six tons of comic books, progressed to Tom Swift and Dave Dawson (a heroic World War II pilot whose various planes were always 'prop-clawing' for altitude) than on to Jack London's bloodcurdling animal tales. At some point I began to write my own stories. (27)

Many disabled writers began their interest in writing and books during long convalescences. King is no exception. Much of the first section of the book is spent on autobiography and a bildungs roman of how King became the writer he is today. King describes piercing ear pain, a hilarious bout with poison ivy, his early days as a high school journalist and his struggles to become a writer. He also chronicles his teaching days, early publishing life and a bout with drug abuse.

In the second half of the book, King offers advice on craft. He discusses his views on adjectives, grammar, and whether writing supports life or vice versa. Since King is so intimately connected to his writing, it is surprising to see him admit "Life isn't a support system for art. It's the other way around." (101)

It is the third section where King's book is most useful to Disability Studies. In it he describes the accident, the aftermath and his recovery— and the surprising way writing brought him back to the world. The driver of the van, Bryan Smith, was weaving down the road that King happened to be taking a walk on. Smith seems like a "character right out of one of my own novels" according to King, as he (Smith) claims he was on an errand to buy "one of those Marzes bars they have up to the store" (256) when the accident occurred. King, who is badly injured, (his pelvis is broken, right leg shattered, lung collapsed) fears paralysis. From the accounts of the EMT's on the scene, King is lucky to be alive today; one thought he might not survive long enough to get to the hospital. Once there, King experiences the typical "delusions and hallucinations fed by the morphine and Dilaudid being dipped into (him)" (261). King states, "there are echoing voices and hands that reach down to paint my dry lips with swabs that taste of peppermint. Mostly though, there is darkness." (261).

King catalogues his injuries thoroughly only after describing his arrival at the hospital. Among them, his right leg is broken in nine places, his right knee cap is split in half and his right hip fractured. Additionally, he writes: My spine was chipped in eight places. Four ribs were broken. My right collarbone held, but the flesh above it was stripped raw. The laceration on my scalp took twenty to thirty stitches." (262)

The word "lucky" takes on an ironic twist when King describes his first attempt to walk since the accident, six days later,

I got up for the first time, staggering three steps to the commode, where I sat with the hospital Johnny in my lap and my head down, trying not to weep and failing. You try to tell yourself that you've been lucky, most incredibly lucky, and usually that works because it's true. Sometimes it doesn't work, that's all. Then you cry." (263)

The shift to second person (you) at the end is a distancing mechanism, no doubt, meant to convey the emotional and physical pain of the moment. King also experiences the remorse, so common in such narratives, 'I should have stayed home; I think; going for a walk today was a really bad idea" (257).

After King endures "five marathon surgical procedures that left (him) thin, weak and nearly at the end of (his) endurance" (263), he returns home in July. In August, after returning to the hospital for one more procedure, he comes home to try to write.

> I didn't want to go back to work, I was in a lot of pain, unable to bend my right knee, and restricted to a walker. I couldn't imagine sitting behind a desk for long, even in my wheelchair. Because of my cataclysmically smashed hip, sitting was torture after forty minutes or so, impossible after an hour and a quarter…Yet at the same time I'd reached one of those crossroads moments when you're all out of choices. And I had been in terrible situations before which the writing had helped me get over—had helped me forget myself for at least a little while. (266)

King uses "you" again, this time in the universal sense. Writing proves to be a temporary salve, an escape from fully attending his pain.

He describes his first writing session fully:

> The first writing session lasted an hour and forty minutes, by far the longest period I'd spent sitting upright since being struck by Smith's van. When it was over, I was dripping with sweat, and almost too exhausted to sit up straight in my wheelchair. The pain in my hip was just short of apocalyptic. And the first five hundred words were uniquely terrifying—it was as if I'd never

> written anything before them in my life. All my old tricks seem to have deserted me. I stepped from one word to the next like a very old man finding his way across the stream on a zigzag line of wet stones. There was no inspiration that first afternoon, only a kind of stubborn determination and the hope that things would get better if I kept at it. (268)

The act of writing becomes easier for him in subsequent sessions:

> My hip still hurt, my back still hurt, my leg, too, but those hurts began to seem farther away. I started to get on top of them There was no sense of exhilaration, no buzz not on that day- but there was a sense of accomplishment that was almost as good. I'd gotten going, there was that much. The scariest moment is always just before you start. After that, things can only get better (269).

King's return to the world is accomplished through writing. He claims his wife not only knows when he is working too hard, but also "that sometimes it's the work that bails me out." (268). As King continues to mend, his writing days continue to improve:

> On some days, writing is a pretty grim slog. On others—more and more of them as my leg begins to heal and my mind reaccustoms itself to its old

> routine—I feel that buzz of happiness, that sense of having found the right words and put them in a line. It's like lifting off in an airplane: you're on the ground...and then you're up, riding on a magical cushion of air and prince of all you survey. That makes me happy because it's what I was made to do. I still don't have much strength—I can do a little less than half of what I'd been able to do in a day—but I've had enough to get me to the end of this book and for that, I'm grateful. Writing did not save my life—Dr. David Brown's skill and my wife's loving care did that—but it has continued to do what it has always done: it makes my life a brighter and more pleasant place. (269-70)

While King asserts that writing is not a panacea, it does give him a sense of joy that complements his healing, and gives him purpose ("what I was made to do"), an integral part of recovery. He extols the virtues of writing in one of the final sentences of his book: "Writing is magic, as much the water of life as any other creative art" (270). He urges the reader to "Drink and be filled up" (ibid), even while admitting not everyone is meant to write. But his sense of re-finding his purpose and the soaring sense of accomplishment that comes with it – gives life and recovery meaning and no small sense of joy.

"It's about getting up, getting well and getting over. Getting happy, okay? Getting happy," King writes on the final page (ibid.) And writing is King's recipe for that.

Disability Studies – John Gardner The Art of Fiction

John Gardner is a novelist and an exacting instructor of writing and his The Art of Fiction: Notes on Craft for Young Writers is a rigorous, almost curmudgeonly look at what makes a good short story. Gardner's hatred of academia is painfully clear in the book as is the attitude that seems to be culled from reading many terrible student assignments. The book is an exhaustive look at technique, subject, example and theory, some of which is highly instructive. Other parts seem to be grinding an ax, against university professors in particular and badly written stories in general.

Though Gardner doesn't believe in "magic " when it comes to creating a work of art, he does think feeling has its place in artistic inspiration: "Art depends heavily on feeling, intuition, taste," he writes.(7) While he counsels budding writers to read widely and know how to analyze fiction, he states "The primary subject of fiction has always been human emotion values and beliefs" (14). Though, he doesn't explicitly discuss disability in the genesis of a story, he does note that feeling and being drawn to a topic make the best literature. He reaffirms this when he claims, "Write the kind of story you know and like best." (18). So, at the heart of writing is the subject that touches the writer deeply.

According to Gardner,

> The novelist Nicholas Delbanco has remarked that by the age of four one has experienced nearly everything one needs as a writer of fiction: love, pain, loss, boredom, rage, guilt, fear of death. The writers business is to make up convincing human beings and create for them basic situations and actions by means of which they come to know themselves and reveal themselves to the reader. (15)

Gardner takes great umbrage at the conventional wisdom of "Write what you know" and says it is "limiting to the imagination" (18) and "turn(s) on the psychological censoring devices and distortion systems", and he also feels like the grammatical issues are best left to composition courses. "Learning fiction is too serious a business to be mixed in with leftovers from freshman composition," he writes (17). Good writing, he says, "create(s) a kind of dream in the reader's mind, and avoid(s) like the plague all that might detract from that dream." (33)

One connection between disability and creativity, may be the type of person who is driven to write. According to Gardner, "True artists, whatever smiling faces they may show you, are obsessive, driven people". The sort of obsessiveness that is needed for creativity may be something possessed by certain disabled people. Gardner also states that art forces people to go to dangerous places emotionally, that not every personality type can endure: "Art at those moments when it feels most like art—when we feel most alive, most alert, most triumphant—is less like a cocktail party than a tank of sharks.

Everything's for keeps, nothing's just for exercise." (35) Also common to artists is an interest in "truth" or more specifically, emotional truth:

> Fiction seeks out truth. Granted it seeks out a poetic kind of truth, universals not as easily translatable into moral codes. But part of our interest as we read is in learning how the world works , how the conflicts we share with the writer and all other human beings can be resolved, if at all; what values we can affirm and, in general, what the moral risks are. The writer who can't distinguish truth from a peanut-butter sandwich can never write good fiction. (79)

The marketability of such truth is unquestionable:

> But if a writer writes only of what honestly interests him, and if he thinks of his work not simply as a thoughtful exploration, as it should be, but also, as an entertainment he cannot fail to have, at least for some group of serious and devoted readers, both immediate and lasting interest. (78)

He also supports working slowly, ensuring good craft and subtlety.

These are lofty aims and not all of Gardner's book is so noble. His attacks on academia seems vicious in comparison (40-41) (166). The snobbery and limited range of the teachers is something Gardner finds reprehensible. Also, he sings the praises of the novella and calls it the perfect form. "Nothing can be more perfect or complete than a good novella," he writes (183).

In all, "The Art of Writing Fiction" seems more of a record of Gardner's biases and his irritation with writers who strive for anything less than art ("Howard the Duck" seems a favorite target of his). He also uses many examples from his own writing (he discusses Helen of Troy for at least ten pages, who was the subject of one of his novels.) Jim Krusoe, well known writing instructor, suggests "On Becoming a Novelist" is a more helpful work for the beginning writer.

Disability Studies- Flannery O'Connor, Good Country People" and The Habit of Being

One of the great Southern Gothic writers, Flannery O'Connor was born March 25, 1925, in Savannah, Georgia. When she was twelve, her parents moved to Midgeville, Georgia. Three years later, O'Connor's father died. After attending college in Georgia, O'Connor did graduate work at the famed University of Iowa Writing Workshop. She was a fellow at Yaddo Writer's Colony until 1949, when several of the writers staged a revolt. Contracting lupus in 1951, O'Connor was forced to live at home for the remainder of her life. There she wrote several remarkable short stories "A Good Man is Hard to Find" and "Good Country People", which even today are among a handful of influential short stories for writers and scholars. She also wrote two novels despite a weakened condition, giving her few productive hours a day to writing. Given all that she faced, she possessed an unusually wry sense of humor and a seemed incapable of self-pity, as evidenced by her letters. She died in 1964, after complications from lupus (according to *Wikipedia*, though accounts vary).

Many of O'Connor's short stories deal with disabled characters (namely "Good Country People" and "The Lame Shall Enter First") and often in her work bizarre, disabling accidents occur (a woman is gored by a bull in "Greenleaf")

(129) . O'Connor's letters show some delightful and amazing correspondences between her disability and her writing. Most notable, though, is the grace and humor with which she discussed her disease in her letters which are compiled in The Habit of Being (1979, Farrar, Straus and Giroux).

Among the most amazing of discoveries is the correspondence between O'Connor herself and the character Hulga from "Good Country People." In the story Hulga, a philosopher with a Ph.d. is forced to live at home with her mother because of a heart condition. This mirrors O'Connor's own fate, when she was confined to her mother's farm, Andalusia, in Midgeville due to her lupus. Throughout the story, Hulga wears a worn and shrunken sweatshirt with a stained and ragged skirt. The outfit gives her a perverse pleasure. In her letters, O'Connor describes a similar sweatshirt, she herself owned:

> The only embossed one I ever had had a fierce looking bulldog on it with the GEORGIA over him. I wore it all the time, it being my policy at that point in life to create an unfavorable impression. My urge for such has to be repressed, as my mother does not approve of making a spectacle of oneself when over thirty. (94)

She also describes a coat her mother dislikes as well: "Parent has taken passionate dislike of coat and waits for colder weather when I won't have to wear it" (46).

This similarity is surprising. Hulga takes great pride in her ensemble and annoying her mother with it.

Also, in the story, the narrator discusses the meddlesome hired help, Mrs. Freeman, and her daughters, Glynese and Carramae. In one letter, O'Connor mentions the difficulty with hired help and her niece named "Starene" (50). But Mrs. Freeman goes on about her daughter's love lives and it seems to be taken from O'Connor's life. She writes of a hired woman who works on their farm: "Big doings around here, Mrs. P's youngest, age 17, is going to get married on the 4th of July. We get all the gruesome details, twenty-four hours a day "(71).

Another correspondence is that the antagonist in "Good Country People", Manly Pointer, is a bible salesman, and O'Connor mentions that a "text book salesman" from Harcourt Brace, (58) came by her home. Finally, though these details seem superficial in light of O'Connor's pronouncements that she and Hulga are quite similar: "My disposition is a combination of Nelson's and Hulga's. Or perhaps I flatter myself." (101) O'Connor declares later, "My heroine already is, and is Hulga....Hulga in this case would be a projection of myself onto this tragic-comic action (106)." Like Hulga, who has according to novelist Rick Moody "certainly among the best names ever for a philosopher in modern fiction" (PEN USA website), O'Connor was greatly interested in religion and philosophy and wrote eloquently on the subject. Hulga, like

O'Connor had difficulty with the intellectual capabilities of those around her and their refusal to consider important issues. O'Connor in one letter describes a conversation with her mother about the books she has sent to her. (O'Connor is "me" and Regina, her mother, is "she".)

> She*: 'Mobby Dick*. I've always heard about that."
> Me: *'Mow-by Dick.'*
> She: *'Mow-by Dick. The Idiot*. You would get something called *Idiot*. What's it about?"
> Me: 'An idiot.' (56)

This exchange echoes Hulga's frustration with her mother, who claims that her philosophy textbooks are written in gibberish. "Do you never look inward, woman?" Hulga screams in exasperation.

O'Connor diagnoses Hulga's problem by comparing her with the optimistic and foolish Mrs. Freeman : "...Poetry is always dependent on realism, ...you have to be a realist or you can't be a poet. Mrs. Hopewell is a realist but not a poet, whereas, Hulga has tried to be a poet without being a realist (121)" Hulga's interest solely in academics and the world of the mind, lead her to foolish behavior at the end of the story. O'Connor calls herself a "hillbilly nihilist" (81) and was criticized for not writing about happier things (85) and Hulga could be charged with many of the same faults (save the "hillbilly" part).

Unlike, Hulga, though, who stomps around her mother's house and glares at others, in part because of her disability and her enforced captivity, O'Connor handled her own situation with humor and grace. In a letter to Robert Lowell, she writes,

> I am making out fine in spite of any conflicting stories…I have enough energy to write with and as that is all I have any business doing anyhow, I can with one eye squinted take it all as a blessing. What you have to measure out, you come to observe more closely, or so I tell myself. (57)

She calls her ailment "energy depriving" (91) and writes almost cheerfully to her friend Sally Fitzgerald, when she opens her letter with, "Greetings from my bed of affliction to yourn." (39). She maintains her sense of humor even when describing her hospital stay:

> I stayed there a month, giving generous samples of my blood to this, that and the other technician, all hours of the day and night, but now I am home again and not receiving anymore awful cards that say to a dear sick friend, in verse what's worse (24).

As her condition deteriorates, O'Connor was forced to use first a cane and then, crutches. At first, she claims the cane adds, "a great air of distinction" (74), but it seems crutches are more complicated and frustrating (as anyone who's ever had the pleasure of using them knows). O'Connor calls them her "aluminum legs" (106) and says they make her feel like a "large stiff anthropoid ape" (104, sic). She explains the shift from normal walking to crutches beautifully:

> …my crutches are my complete obsession right now. I have never used such before and I am to be on for a year or two.

> They change the whole tempo of everything. I no longer am going to cross the room without making a major decision to do it. (105).

She does, however, see that the impact on her is less than on someone else:

> Anyway, it is not as great an inconvenience for me as it would be for somebody else, as I am not the sporty type. I don't run around or play games. My greatest exertion and pleasure these last years has been throwing the garbage to the chickens and I can still do this, though I am in danger of going with it. (107)

One of the funniest comments O'Connor makes is about the crutches she is forced to use:

> I have decided I must be a pretty pathetic sight with these crutches. I was in Atlanta the other day in Davison's. An old lady got on the elevator behind me as soon as I turned around she fixed me with a moist gleaming eye and said in a loud voice, "Bless you, darling!" I felt exactly as the Misfit and I gave her a weakly lethal look, whereupon greatly encouraged, she grabbed my arm and whispered (very loud) in my ear. "Remember what they said to John at the gate, darling!" It was not my floor but I got off and I suppose the old lady was astounded at how quick I could get away on crutches. I have a one legged friend and I asked her what they said to John at the gate. She said she reckoned they said, "The lame shall enter first." This may be because the lame will be able to knock everybody else aside with their crutches" (117)

This feisty attitude conflicts with the image of the long-suffering cripple and seems to show that O'Connor is one of the "bad girl" cripples with a sense of her power and a little resentment. The story obviously stuck with O'Connor when she titled one of her stories, "The Lame Shall Enter First."

She is also tired of the patronizing attitude of those who talk with her:

> After my talk, one lady shook my hand and said, 'That was such a nice dispensation you gave us, honey.' Another said, 'What's wrong with your leg, sugar?' I'll be real glad when I get too old for them to *sugar* me.' (120)

O'Connor seems aggrieved at the familiarity of the women and the condescending "sugar" which the crutches only seem to encourage.

It is also interesting to note that much of O'Connor's letters are devoted to other matters: her writing, the lives of her friends, religion and philosophy. Disability only takes up a brief segment of the letters and often goes unmentioned. O'Connor is an artist and person, first, and her identity as disabled is far down the list of things that occupy her time. She uses grant money (from the "Rockerfeller Foundation" (49, sic – O'Connor was given to spelling things like a hick Southerner might for humorous effect) to pay for her medications and adapts her life to the disease. It is so integrated into her life, O'Connor even begins talking about her writing in terms of ACTH, the medication she takes to keep her symptoms at bay: "Please send this (story) back to me and in my spare time I may give it a shot of ACTH and send it back in some better shape" (88). It seems that O'Connor is demonstrating a sort of transference, conveying power to alter her writing onto the medication she takes. It has become such a part of her routine, it has become part of her. Some argue O'Connor's only fear was that her mother would die before her, which proved to be unfounded. She didn't know if she could get along without her. But Sally Fitzgerald, who edited O'Connor's letters put it best when she said,

> The mindless camera records on Flannery's face the ravages of ill health; her letters wipe them all away, not in a cosmetic sense, but by means of something that lay within and imparted the fine clarity and youthfulness Katherine Anne Porter perceived. And her offhand way of speaking of her physical ordeal, when she did, tells more about her gallantry than any encomium could make real." (xii)