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A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature

By

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This book is dedicated to those with disabilities, and to the authors who seek to redefine disability culture(s) in the U.S. by molding language and images used to convey disability in literature

Miles Beauchamp: "This book exists not only because of the work of the authors but also because of the care, compassion and beliefs in the project by family and friends who supported, worked with, and understood the importance. I dedicate my small part of this enormous work to Michelle – my wife and "guidance counselor" who makes every minute of every day so much better; to my son Ryan whose energy and desire to explore keeps it interesting, my daughter Paige who can make me laugh like no one on earth, my parents, Jo and Hank, and my grandparents, Pauline and Jim who were my very first muses. They are amazing people who have enriched my life beyond measure and make every day a wonder. To Svetlana, whose brilliance, tenacity, and ability to perform amazing feats of literary CPR kept the project moving. To the San Diego Writers Haven Writers who make Tuesday nights so much fun, and finally, to Mary See whose sweetness helped during the rough times."

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Svetlana Zakinova: "To Stan - my co-pilot, my pal, my husband, without whose relentless support none of this would have been possible. To my mother, the kindest person I know. And to Miles, who'd asked me to be a part of this amazing project."

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PREFACE

In an age where sensitivity to persons with disabilities is reflected in law, access to institutions, and rights awareness, there remains one area where progress has been lackluster. The manner in which those with a disability are portrayed in modern and contemporary American literature has, for the most part, shown them as feared, reviled, misunderstood, or pitied. We wanted to look at the why and the how. The overriding purpose behind this study is to answer these questions, as well as to finally bring together a broad showcase of the literary works featuring characters with a disability. This book will discuss how these characters have been used primarily to elicit pathos, fear, or hatred.

At the time this work was initiated, approximately twenty years ago in a small university classroom, there was little existing data surveying American literature that targeted the portrayal of individuals with disabilities – including physical, cognitive and emotional disabilities. A survey of university libraries, literary data banks, and other horizontal and vertical searches were conducted. No data were obtained that cross-referenced disabilities and individuals with disabilities in general American literature. Rarely was there even a cross-reference to a specific disability in fiction. Therefore, a system was devised to contact authors, university professors, instructors in American literature, publishing houses, critics and others with a goal toward identifying works that included individuals with disabilities either as central characters or characters central to the storyline.

After titles were obtained, the works were examined with a specific focus on disability. How were people with disabilities portrayed, and what did they say, do, or become? What was reality-based and what was a plot-driven necessity? Once this information was gleaned, appointments were made to interview medical personnel familiar with the disabilities represented so as to become more able to separate accurate portrayals from fantasy. Deeper research was then conducted into primary and secondary sources to obtain information on the ramifications of those portrayals.

It is important to note that this survey of iconic English-language works is by no means a complete one. We do think, however, that these works have stood the test of time, have contributed to the literary landscape and contain characters that both add to and reflect awareness of people with disabilities. It should also be noted that while our focus was American literature, some works, because of topic or author, blur that focus. For example, *The Elephant*

Man was originally an English phenomenon, the play was written by Bernard Pomerance, an American playwright. Isaac Bashevis Singer wrote in Yiddish, but he is an American writer. We have included these to help us see the evolution of disabled characters over time.

Using data from medical interviews, literary criticisms, and critical readings of the works in question, we formulated the thesis for this work: that individuals with disabilities are rarely portrayed accurately, their disabilities exist to provide fear, loathing, or pathos, and that they are generally always the "other," no matter the vantage point.

With the passage of the Americans with Disabilities Act in 1990 and the efforts of disability-centered foundations, organizations, and rights groups, the way individuals with disabilities are perceived has been changing. This change is also slowly starting to be reflected in the literature. That we still have a long way to go is apparent. What is also apparent is that writers are becoming more inclusive, broadening their inventory of characters, and allowing individuals with disabilities to be the people they really are: us.

Definitions change, mores change, and cultures change. How we see and categorize the world around us is in constant flux. Embracing that change is how we retain our greatest sense of self. Our views on disabilities, be it a physical, cognitive, or emotional one, are making enormous strides for the better. But we will always have a ways to go for there is no end. There is no time when we can say, "There, the language and how we use it is complete." It will never be complete, but owning and directing the change can be enormously rewarding.

FOREWORD:
TEACHING DISABILITY AND DIVERSITY THROUGH LITERATURE

"What does this book have to do with disability?" This is a common question that my Spring Semester students at the University of Hawaii always ask halfway through reading Jeffrey Eugenides' *The Marriage Plot* (2011). The question is usually tinged with a subtle undertone of irritation: "I took this course to learn about disability and the instructor wants me to read a book about a lovesick Ivy League college graduate?" But when the character Leonard takes over the narrative, the connection becomes clear. Leonard is brilliant, charismatic, and manic-depressive. Soon the reader is deeply immersed in the world as experienced by Leonard, and the impact that his disability has on his life and the lives of those who are close to him. "What this book has to do with disability" is apparent and the class is soon engaged in a discussion of issues of mental illness, prompted by a work of literature that has deeply moved them.

I teach graduate level courses in Disability and Diversity Studies. One goal of my classes is to prompt students to think about disability as a diversity issue rather than an impairment issue. We discuss the stigma that people with disabilities face on a daily basis; and cover the Social Model of Disability (Barnes, Mercer & Shakespeare, 1999), which posits that the "problem of disability" is located within societal barriers and perceptions rather than in individual defects. We also study how disability studies fits into a range of disciplines outside of the "traditional" disability-focused fields of special education, rehabilitation and medicine. This range of disciplines includes the field of literature. Even though my courses are not literature courses, I find that literature is an excellent vehicle for discussing both past and current social justice issues such as disability.

I do assign academic texts, journal articles, and laws and regulations for my students to review. These readings provide them with excellent information about disability. But it is literature, including fiction, memoirs and poetry, that really moves my students to understand disability. Literature is crafted to engage the reader's imagination, thus my students are able to imagine what it is like to be someone other than themselves. Some of the literature that I use in my classes is written by people with disabilities, such as the poems of Kenny Fries, *Desert Walking* (2000) and Jim Ferris, *Facts of Life* (2005), or the lyrical memoirs of Simi Linton, *My Body Politic* (2006), and

Anne Finger, *Past Due: A Story of Disability, Pregnancy and Birth* (1990). But other useful literature is written by people without disabilities who just seem to "get" disability and difference, such as Jeffrey Eugenides in both *The Marriage Plot* (2011) and *Middlesex* (2002), Pat Wood in *Lottery* (2007), and even Alan Brennert in *Moloka'i* (2003). The latter is one that I suggest as supplemental reading for my students here in Hawaii, because it describes so well how Hansen's Disease (Leprosy) "patients" who were literally shipped off and imprisoned on the island of Moloka'i during the early part of the 20th Century formed a strong and vibrant community as the result of being ostracized for a stigmatizing condition.

As is the case with *Moloka'i* (2003), literature can help us to understand a particular issue within a historical context, whether it is the author's time period or one that s/he invites us to inhabit. *The Marriage Plot* (2011) takes place in the 1980's, when Lithium was the drug of choice for "controlling" mental illness, plunging many into a tug of war between the numbing side effects of the medicated state and the social repercussions of the non-medicated state.

John Steinbeck's *Of Mice and Men* (1937) is one of the many important works of American literature discussed in *Disabled Literature: A Critical Examination of the Portrayal of Individuals with Disabilities in Selected Works of Modern and Contemporary American Literature*. *Of Mice and Men* illustrates the extreme prejudice and fear felt by many in society about people of color and people with intellectual disabilities during the author's time. Steinbeck creates in the character Lenny - a man who is feeble of mind but strong of body, a gentle monster who does not know his own strength and must be put out of his misery like a dog who bites a child once-too-often. Though we feel that Steinbeck is sympathetic to Lenny, Lenny evokes in the reader feelings of pity, sympathy, and fear. At the end of the novel, we are convinced that shooting him in the head is the moral thing to do because it is a better alternative to seeing him violently hanged. This paradox of "the lesser of two evils" is one that is evoked even in the modern day to explain why the institutionalization and segregation of people with intellectual disabilities is "better than the alternative" (homelessness, prison, death).

The important role of literature in teasing out social justice issues, societal behaviors and ethical dilemmas is why *Disabled Literature* is such an important contribution to our scholarly understanding of both literature and disability studies. Literature is a mirror of our perceptions, and it is only through viewing our perceptions straight on that we will be able to change them.

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INTRODUCTION

> Handicapped people remain *outcasts* around the world, living in shame and squalor among populations lacking not only in resources to help them but also in understanding. And with their numbers growing rapidly, their plight is getting worse….
>
> The normal perception is that nothing can be done for disabled children. This has to do with prejudice and old fashioned thinking that this punishment comes from God, some evil spirits or magic…We have a catastrophic human rights situation…. They (disabled people) are a group without power.
>
> (Helander, 1993, UN press conference).

This statement was made in 1993 by Einar Helander at a press conference on the release of the UN report on *Human Rights and Disabled People*. Many years later, its authenticity remains true. The numbers of those with disabilities in the United States have risen over the years. The Americans with Disabilities Act (ADA) was established to ensure the rights of people with disabilities. Despite this, however, there still exists a pejorative attitude toward disability even as we progress into a 21st century society that enjoys the postulates of multiculturalism, and the excitement of embracing *difference*.

High levels of uncertainty continue to characterize the communication between the non-disabled and those with a disability despite the fact that persons with disabilities are now a large, vocal and dynamic group within the United States. Many individuals without disabilities harbor stereotypes of people with disabilities. This accounts for their discomfort when communicating with persons with disabilities. These stereotypes also facilitate the continued existence of disability oppression.

The authors argue that it is the confluence of societal conditions, circumstances and embedded cultural worldviews that creates an environment in which oppression of individuals with disabilities thrives. Using a culturally relativistic approach, they analyze this confluence to determine the potential role it can play in creating a changing perception of disability. In an attempt to do so, they approach the status of those with disabilities from a socio-cultural perspective, and the nature of the communication between the non-disabled and individuals with disabilities from an intercultural perspective. They posit that culture spawns institutionalized structures within which lies the society's proclivity toward disability oppression. It is a phenomenon that can be explained accurately only when we understand its systemic nature. We

must, therefore, understand the interplay of all the societal structures, including the political-economic and socio-cultural ones, and the systemic dynamics that ensure the longevity of the attitude toward disability.

The authors assert that disability is indeed a culture, and that those within it, a cultural group. They seek to uncover the powerful role culture plays in the continued existence of disability oppression and in the uncertainty that plagues the relationship between those with a disability and those without. More specifically, they are interested in how key manifestations of culture, like language and literature, act as powerful agents that entrench and perpetuate attitudes toward disability.

Disability as a socially constructed phenomenon

"Disability" is a socially constructed term and should be analyzed using a cultural relativistic approach. In other words, the phenomenon acquires its meaning from the culture within which it exists. To embrace this approach is to understand that the term "disability" is socially constructed and does not have a universal meaning.

Cultural relativism takes two forms, according to Whyte and Ingtad (1995); one being the "weak relativist" form which focuses on specific functions and tasks. It suggests that the disadvantage posed by a disability depends on the capacity that is valued or needed in a particular context. The middle-aged man who is unable to clear a hurdle in a highly-prized village relay competition will find that his age will be considered a disability in a culture that honors and values physical competition. In some cultures, according to Whyte and Ingstad, there is no word for "disability". In the Massai language the term used to translate the word "disabled" is actually a lizard with an awkward gait.

"Radical relativists," on the other hand, are concerned with the culture's worldviews and patterns which are at the very core of the society. They are interested in how these patterns impact the behaviors and attitudes of the population. In essence, they seek to find out what it is people are trying to achieve and how they define and view a person, and what kind of identities and values exist in specific social contexts. This approach questions the culture's philosophy or basic assumptions about identity and personhood in an attempt to explain the consequent cultural values and attitudes that underlie disability. Radical relativism underscores the need to understand cultural patterns which are, according to Samovar and Porter (2004), "the systems of beliefs and values that work in combination to provide a coherent, if not consistent, model for perceiving the world" (p.50). These patterns influence how people perceive and think about the world, and the manner in which they live in it.

Disability: A sociocultural phenomenon seen from a radical relativistic perspective

Of the essence is that despite how individuals with disabilities identify themselves, the society in which they exist gives them a negative identity. They are stigmatized and are in a constant battle against the negative image that society imposes on them. The fundamental beliefs and consequent attitudes of a culture are what define disability and what contribute to the continued existence of disability oppression. Cultural norms, signs and symbols, communication and behaviors, and salient institutions, among other things, are the external manifestations of the beliefs and attitudes, and are what reinforces the culture. In other words, individuals with disabilities are significantly affected by the way the culture explains the reasons for their disabilities.

Some cultures harbor the worldview that a disability is a punishment from God. Others see it as the negative karma from a past life that has 'caught up' with an individual. Yet others deem it a product of witchcraft or some other evil force. As a consequence of these deeply-held assumptions, disability evokes negative images of deformity, abnormality and suffering, and yields pejorative descriptions of disability that characterize the language of the culture. It is evident that the modern world still holds that those with disability are different, and are consequently inferior.

Personhood and equality: Assumptions that underlie disability

At the core of negative attitudes toward difference and perceived human deficiency are the cultural assumptions about identity and personhood. The culture that perceives the able-bodied individual as the quintessential "person" will also perceive individuals with disabilities as different, and ultimately subordinate, inferior and abnormal.

Western thinking on personhood suggests that the person has the innate abilities to compete on an equal basis with others for similar resources. It is these abilities that give you identity. The body, therefore, is the cherished manifestation of this capability and identity in the U.S. One only needs to observe the body images portrayed in literature, mass media and advertising to recognize the ubiquitous messages that emphasize fitness, self-improvement, and the physical characteristics of those who are successful in this culture. It is the strong and physically competent who have the potential to achieve the American ideals of equality, individualism, science and technology, progress and change, work and leisure, competition and materialism. (Samovar & Porter, 2007). Then, there is little or no value for those who do not have these necessary physical qualities.

At the core of the western society, more specifically the U.S., is the notion of equality. Whyte and Ingstad (1995) suggest that the term "disability" in the western world is derived from experiences of a struggle for equality. The term suggests the loss of a required competency or ability that makes it impossible to qualify equally for competition. In fact, the term "handicap,"

they say, was once used in a game in which unequal competitors were weighted in order to make the match more equal. Equality, one of the dominant American cultural patterns, has significantly influenced the values and the consequent attitudes toward disability.

Despite its history of immigration, for decades the U.S. embraced a worldview that to be equal is to be similar, and that all human difference should be "melted" down to achieve similarity in cultural philosophy and practices. It was not until the 1970's that this "melting pot" attitude was challenged in an attempt to introduce the "tossed salad" worldview that honors and values human differences. This is a worldview that gave birth to the concepts of multiculturalism and diversity, an evolving philosophy that assumes, according to Alex de Tocqueville, that where inequality reigns, there are as many distinct humanities as there are social categories (Ingstad, 1995).

However, the "melting pot" worldview still prevails in the US and continues to fertilize the pejorative cultural attitudes toward disability. Because individuals with disabilities are deemed physically or mentally unable to achieve the American Dream, their personhood is in question. Stiker (1982) aptly predicts that the possible consequence of the continued pursuit of equality is an intolerance of innate diversity and individualism. He posits that the love and value of difference leads to humane social life, while the love for similarity facilitates oppression and rejection.

Communication between individuals with disabilities and the non-disabled: Unsocial and unequal in the western world

Many persons with disabilities see themselves as belonging to a minority culture because they have experiences similar to those who belong to minority groups. The most common experience shared between these two cultures is the absence of status and power, and the discomfort that others experience because of the obvious differences. Thus, the communication between persons from the non-disabled and disabled cultures can be viewed from an intercultural perspective.

Communication between any two people is a negotiation, but it's particularly challenging when the communicators perceive themselves as different. This challenge is characteristic of the communication between persons from the dominant U.S. culture and ethnic minorities, specifically African Americans and Hispanics. In the same way, the able-bodied people experience fear and uneasiness when communicating with those with observable disabilities. As in the case of communication across ethnicity, this may be due to a lack of experience of interacting with people from the disability culture, which results in an uncertainty of how to interact. This is compounded by the negative disability stereotypes that the non-disabled often harbor.

To further complicate matters, communication across cultures in the U.S. takes place in a society that reinforces the ideal of equality. It is important to perceive the other as your equal, yet in the case of a disabled person he/she

belongs to a group that has been deemed as helpless, dependent, emotionally unstable and is "often presumed to differ from the non-disabled people in moral character, social skills and political orientation" (Coleman and DePaulo, 1991, p.69). This conundrum results in a communication climate wrath with uncertainty and discomfort, with the non-disabled people overcompensating for their prejudices by trying to offer more help than people with disabilities want or need. In most cases, the able-bodied person avoids this potentially dissonant situation by minimizing contact with persons with disabilities, or simply staying away.

People with disabilities are keenly aware of the discomfort that their able-bodied peers experience, and they have developed strategies for communication in these situations. For example, they might talk about topics that are common to everyone rather than focus on the disability, all in an effort to relieve the discomfort.

People with disabilities, in their attempt to navigate the social challenges they face, generate salient and distinctive cultural values and artifacts. According to Braithwaite and Braithwaite (2006), they develop distinctive speech codes, meanings, rules and ways of speaking that facilitate their existence and ensure their personhood. They have verbal and nonverbal symbols that are different from those that their able-bodied counterparts use. These symbols create a sense of identity for those who belong to the culture of disability. Interestingly, joining the culture of individuals with disabilities through injury or otherwise is like assimilating from a dominant culture into a minority culture. "The onset of a physical disability requires learning new ways of thinking and talking about oneself, and developing new ways of communicating with others." (Braithwaite & Braithwaite (2006, p. 188).

Interacting with individuals with disabilities in the western world: The fear of difference

The idea that people with disabilities are different feeds the prejudice which is then manifested in the forms of avoidance, fear and hostility. For example, there are accounts of people being ignored when dining out with their able-bodied friends or families. An articulate and intelligent young man who uses a wheelchair recounts his experience of inviting a non-disabled young lady to dinner. At the restaurant the waitperson, when taking their order, asked his date in a condescending tone, "And what would *he* like to eat for dinner?" At the end of the evening the waitperson also presented his date with the check (Braithwaite & Braithwaite, 2006, p.187).

Another kind of a common experience for many people with disabilities is when able-bodied people overcompensate for their discomfort, and enthusiastically rush to the assistance of those in wheelchairs or with walking aids by opening doors or actually pushing their wheelchairs. This continues to be a problem, as evident in this person's account: "A lot of people always come up and ask can they push my wheelchair. And, I can do it myself. They are

invading my space, concentration, doing what I wanted to do, which I enjoy doing; doing what I was doing *on my own……"* (Braithwaite & Braithwaite, 2006, p.187).

Many individuals with disabilities lament the way people avert their eyes and establish physical distance, suggesting that you can catch disability like a virus. Murphy (1995) claims that this avoidance is due to the resentment that the non-disabled feel toward people with disabilities because they are seen as "subverters of an American ideal like the American poor betrayed the American Dream." He further suggests that "to the extent that we depart from the ideal, we become ugly and repulsive to the able-bodied" (p. 143).

Disability and the political economy

The political economy is essentially concerned with issues of class, and "class positions groups of people in relation to economic production and exchange, political power and privilege" (Charlton, 1998, p 23). It generates and legitimizes the duality of domination/subordination; powerful/powerless and superiority/inferiority. It is, in essence, a system that thrives on power and hierarchy for its continued existence.

In the system, there are those who are in control and those who are controlled. This system is a byproduct of cultural ideals that yield the type of individuals who occupy the roles within it. In the U.S., for example, we embrace specific assumptions that in an ideal world there will be equality, individualism, materialism, science and technology, progress and change, work and leisure, and competition (Samovar & Porter, 2004). We also strongly believe that these ideals are possible to achieve by those who are able to maximize their potential. We have an image of the person who personifies our cultural ideal: white, tall, assertive, young, able-bodied man who is well-dressed and able to hone in all his faculties when necessary. He is the person who occupies the upper echelons of the political economic system because he personifies the American ideal, and he is able.

The political-economic structure of any society is unyielding. It determines the salience of the culture of the powerful, and consequently defines the status of individuals with disabilities. The characteristics of those in power and those who are not are legitimized by the system. Individuals with disabilities are thought of as not having power because they do not have the ability to compete on an equal basis for the goods and services of the economy; they are incapable of achieving the American Ideal. They are, in essence, part of the worldwide phenomenon that James O'Connor called the "surplus population". As Charlton (1998) laments, "Perhaps the most fitting characterization of the socioeconomic condition of people with disabilities is that they are outcasts. They are the poorest and most powerless people, not only in the US but in the world. They are typically unemployed, and the more severe the disability the higher the likelihood of unemployment." According to the U.S. Department of Labor, the current (2015) unemployment rate for

people with disabilities is 11.7 percent (compared to 5.3 percent for those without disabilities). However, that number is deceiving because only about 20 percent of people with disabilities are considered part of the labor force (compared to about 70 percent for people without disabilities).[1]

The implications of these conditions are astounding. Because of their political-economic status, people with disabilities are relegated to an under-class existence. So strong is the influence of our political economic impera-tives that we, as a society, are conditioned to uphold these worldviews. Our perceptions, attitudes and consequent actions reflect our entrenched belief in the able-bodied individuals, and our ambivalence about those who have disabilities. In one of the classic sociological experiments an able-bodied, young, well-dressed man approached subjects asking for money. He received money from a significant percent of them who later explained that they thought he was a successful businessman who had simply lost his wallet. This experiment highlights our innate attitudes toward those who represent the cultural ideal.

Cultural systems and disability oppression

"Nothing can be denounced if the denouncing is done within the system that belongs to the thing denounced." These insightful words of a Mexican novelist Julio Cortazar could be applied to describe the complexity of the struggle to eliminate disability oppression and purge the general negative attitudes toward people with disabilities.

Disability oppression requires a systemic approach to address its phe-nomenological structure. In other words, it is critical that we understand the interplay of the socio-cultural and politico-economic subsystems within which the oppression resides. These subsystems provide the overarching structures that support disability oppression. The negative attitude toward disability, therefore, is deeply embedded within the very structure of our society.

Embedded messages about disability in American literature

Disability evokes negative sentiments worldwide. However, the degree of this negativity varies across countries. Murphy (1996) has found that the reaction to the condition is quite extreme in Japan, probably because of a belief that the individual is to blame for his/her own misfortunes. He has also found that northern European countries generally have a more positive attitude toward disability, and they have a more advanced system of rehabilitation. However, in the western world the deeply entrenched value for physical and mental prowess renders disability undesirable. These values and attitudes are consequently reflected in the overt attributes of the culture, including its style of communication, mass communication, speeches, art forms, literature and staged events, among other things.

Literature uses cultural symbols, more specifically, language, to convey how we should react to disability. Therefore, there is a strong relationship between societal attitudes toward disability and the messages in the literature. The prevailing attitudes are both reflected in and significantly influenced by the literature.

A critical analysis of American literature reveals those powerful messages about individuals with disabilities. Persons with disabilities are often presented as crippled, invalid, retarded, among other things. Their disabilities are magnified, their personalities are characterized as abnormal, and they are unable to successfully socialize with the non-disabled. These messages generate an even more powerful sentiment that this group should be feared, pitied, ridiculed, or approached with caution.

The prevailing negative attitude toward disability extends into history. Reflecting on the treatment of individuals with disabilities at the Barnum and Bailey circus, now known as *Ringling Bros. and Barnum & Bailey*, we see a social legitimization of the disparagement of disability. Phineas T. Barnum, the great American showman, was able to capitalize on the hunger of the society to ridicule those who are physically or mentally different. The public was thrilled by the "human curiosities" that he presented. Included in his traveling circus, menagerie and museum of "freaks" was the little person (advertised at the time as a dwarf), General Tom Thumb, who became one of the sensations of the 1800s. He was two feet tall and 15 pounds, and he became a public relations sensation when he married another little person. Chang and Eng Bunker, born in Siam, were conjoined twins who also traveled with the circus, among others.

This type of disdain for individuals with disabilities characterizes American literature and other art forms, thus perpetuating the negative sentiments toward the group. Charlton (1998) aptly points out that "socialization works on simple symbols, simple repetition." (p.68). He posits an interesting formula for the socialization on disability based on very circular logic: "Over and over the myth as message is repeated: disability = sickness/deformation; sickness = helpless and deformation = abomination; helpless = protection and abomination = asexuality; asexuality = childlike; childlike = helpless/protection; helpless/protection = pity; pity = disability." He simplifies the message as disability = invalid; invalid = inferior; inferior = disability. Any attempt, therefore, to denounce the prevailing attitudes toward disability must first embrace this formula.

The disability oppression is strong, but there is a vocal minority of disability activists in the U.S. today committed to deconstructing the existing negative perception of disability through education and research. Since, as noted, language is a powerful cultural symbol, activists have addressed the use of language to talk about disability. The central idea is to identify and use terms that emphasize personhood rather than disability. For example, the term "person with disability" identifies the person first, and then describes

the condition, rather than "disabled person," which identifies the condition first.

The authors of this text continue the effort to redefine and socially reconstruct disability. They have embarked on a quest to uncover the ubiquitous and disdainful images of persons with disabilities that permeate the various genres of American literature, and they have embraced the cultural relativistic approach in this quest. The task ahead may seem daunting if we were to consider the systemic nature of the phenomenon. However, we can succeed if we were to engage authentically. With strong disability advocates in every sector of society, this dream to reverse the negative attitudes toward disability can eventually become a reality. One way to begin is with a critical and focused analysis of American literature.

CHAPTER 1
WHO DEFINES DISABILITY?

The best of American literature is infused with human genius, artistry, benevolence, curiosity, and imagination. Unfortunately, it has also been plagued by political and personal agendas, mistaken beliefs, error, cruelty, and a lack of vision. This genre, like any, is far too vast to examine individually, in one place, and with any semblance of depth. As a result, there are thousands of books on literary criticism that cover groups of writings like the traditional canon, feminist writing, Black studies, gay and lesbian literature, Chicano work, and even those with narrower foci, such as Hispanic feminist revolutionaries. Yet only within the past two decades or so has literary criticism started to focus on disability literature.

Research involving those who have physical disabilities show that the predominant feeling held by able-bodied persons toward individuals with a disability is sympathy; a reaction often accompanied by avoidance or patronization.[2] This is a good description of how individuals with disabilities are treated in modern American literature. That is, the subject of disability is either avoided or presented in a stereotypical and often negative manner. Individuals with disabilities are portrayed as helpless, or super-abled; pure and good, or evil monsters. While these portrayals may seem unimportant – after all, literature isn't real life – that is not the case.

As the actor Henry Holden says, "The attitudes of the public in terms of their perspective, can only be accomplished if the images portrayed are a true representation of the disabled population." His theme, "Don't DIS the ABILITY" is a catalyst for equality.[3] Dr. Harold D. Fishbein, professor of psychology at the University of Cincinnati, agrees, saying that stigmatizing and stereotyping of others:

> . . . is perhaps the most debasing form of prejudice and thus the most psychologically destructive for its targets. The physical consequences of stigmatization can also be enormous, as seen in the nearly total annihilation of European Jews by the Nazis during the Second World War.[4]

> One can incorporate the role of language itself in this process. One's vocabulary helps shape thought processes, the ability to have

ideas, and express them. Likewise, a society's literature helps shape those ideas.

Through our cumulative experience in reading, literature shapes our goals and values by clarifying our own identities. . . . It enables us to develop perspectives on events occurring locally and globally, and thereby it gives us understanding and control. It is one of the shaping influences of life.[5]

To understand the role of individuals with disabilities in literature that shapes cultural ideas, disability itself must first be defined. One definition is simply that it is a restriction or disadvantage, in this case physical. All too often this restriction or disadvantage is confused with impairment, which indicates something more universal: something completely damaged or spoiled. The link between impairment and disability, equating a mere disadvantage with the entire person being damaged, is automatic in our culture and informs most literature that includes characterizations of those with disabilities. Michael Oliver in "The Politics of Disablement" addresses many of the problems inherent in defining disabilities. For his text he preferred "disabled people" to "people with disabilities." He notes that,

It is sometimes argued, often by able bodied professionals and some disabled people, that 'people with disabilities' is the preferred term, for it asserts the value of the person first and the disability then becomes merely an appendage. The liberal and humanist view flies in the face of reality as it is experienced by disabled people themselves who argue that far from being appendage, disability is an essential part of itself. In this view it is nonsensical to talk about the person and the disability separately and consequently disabled people are demanding acceptance as they are, disabled people.[6]

Oliver then elaborates precisely what is meant by the term 'disabled people,'

Is mental handicap included, and blindness and deafness and non-visible disabilities like epilepsy? An adequate social theory of disability as social restriction must reject categories based upon medical or social scientific construction and divorced from the direct experience of disabled people. All disabled people experience disability as social restriction, whether those restrictions occur as a consequence or inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general population to use sign language, the lack of reading material in Braille or hostile attitudes to people with non- visible disabilities. (pg. xiii)

So, who should define disability? Individuals with disabilities? Simple logic, as well as activists like Mr. Oliver, dictate that those involved should certainly be consulted for the definition. Shouldn't we also have a complex definition that includes literary, film, and multimedia viewpoints? Since disability is, at least in modern Western society, centered on a medical model, then medical definitions should be included also. "As opposed to the medical model, the constructionist model sees disability as a social process in which no inherent meanings attach to physical difference other than those assigned by a community. This model condemns the medical establishment for its single-minded reliance on technology, institutionalization, and remediation."[7] Perhaps, a unified, universally accepted definition will eventually come about by a melding those of multiple disciplines and those most intimately involved with the issue. We have not yet reached that universal definition so for this work, Hahn's "Disability, in our society, is usually defined in terms of physical, emotional, or intellectual impairments rooted in the person that hinder normal function across a wide variety of settings" will do for now.[8]

Unfortunately, whether in literature, in social situations, or in the workplace, a person with a significant physical impairment (e.g., the loss of a leg) is often regarded as disabled *in all situations at all times.* Additionally, in *A Postmodern Disorder: Moral Encounters with Molecular Models of Disability*, author Jackie Leach Scully says: "In modern medicine, abnormality is *defined* in terms of deviation from the normal state. Consequently, in medical practice the problem of 'normality' has been reduced to agreeing on the *magnitude of deviation* from certain 'normal' ranges outside of which a person should be considered ill or disabled"[9] (Italics are those of Scully). The same is true of people with significant hearing, visual or neurological impairments that interfere with learning. From this conventional viewpoint, an impaired person is a disabled person regardless of time or place. This viewpoint may be a bit parochial. The man with one leg working at a computer has no bar to the use of his hands; the deaf person is probably able to read as well or better than anyone else; yet, the assumption of absolute disability is ever-present.

This certainly then fits in with Oliver's view, which states that

> disability has become medicalised, there can be no doubt. Doctors are centrally involved in the lives of disabled people from the determination of whether a foetus is handicapped or not through to the deaths of old people from a variety of disabling condition. Some of these involvements are, of course, entirely appropriate, as in the diagnosis of impairment, the stabilisation of medical condition after trauma, the treatment of illness occurring independent of disability and the provision of physical rehabilitation. But doctors are also involved in assessing driving ability, prescribing wheel chairs, determining the allocation of financial benefits, selecting educational provision and measuring work capabilities and potential; in none of these