

2011

Confronting the psychological and emotional effects of disability oppression

Ian R. Fagan
California State University, Monterey Bay

Follow this and additional works at: https://digitalcommons.csumb.edu/caps_thes

Recommended Citation

Fagan, Ian R., "Confronting the psychological and emotional effects of disability oppression" (2011).
Capstone Projects and Master's Theses. 393.
https://digitalcommons.csumb.edu/caps_thes/393

This Capstone Project is brought to you for free and open access by Digital Commons @ CSUMB. It has been accepted for inclusion in Capstone Projects and Master's Theses by an authorized administrator of Digital Commons @ CSUMB. Unless otherwise indicated, this project was conducted as practicum not subject to IRB review but conducted in keeping with applicable regulatory guidance for training purposes. For more information, please contact digitalcommons@csumb.edu.

Confronting the Psychological and Emotional

Effects of Disability Oppression

Ian R. Fagan

Advisor Dr. George Baldwin

Commencement taking place the twenty first of May, 2011

Abstract

This research project will administer the Rand 36-Item Health Survey to a subject pool of approximately twenty-one people to measure their quality of life. The results of this study will be compared to a similar population of subjects who were administered the Rand. The results are to help describe the forms of class struggles that exist for disabled Americans. I describe the different forms of discrimination and the struggles that disabled Americans face. Specifically, I describe how those with Multiple Sclerosis meet the challenges of surviving.

My research project is descriptive and the research question is, “what is the quality of life for clients of the Multiple Sclerosis Quality of Life Project in Monterey”? I administered The Rand 36-Item Health Survey over the phone. The study is not statistically valid due to the sample size of clients from MSQLP. Evaluating the 21 clients I administered the Rand-36 Item Health Survey to 17 of them were women and 4 were men. I scored each clients survey to discover their physical functioning, general health, and level of pain. I then calculated the mean for each area of all of the clients. I found that the mean for physical functioning is 40%, general health is at 73%, and the average level of pain is 12%.

Introduction

This research project administered the Rand 36-Item Health Survey to a subject pool of approximately 21 to measure their quality of life. The results of this study were compared to a similar population of subjects who were administered the Rand by Vickrey, Hays, Harooni, Myers, Ellison. The results were used to describe the quality of life that 21 MSQLP clients. The comprehensive literature review reports on the historical effect of the American with Disability Act.

My research project is descriptive, and the research question is, what is the quality of life for clients of the Multiple Sclerosis Quality of Life Project in Monterey? I am using quantitative research methods to analyze the data I collected from The Rand 36-Item Health Survey. This survey asks specific questions about quality of life. I use a convenience sample of thirty clients of MSQLP. I administered The Rand 36-Item Health Survey over the phone. The study is not statistically valid due to the sample size of clients from MSQLP.

There are three theories that I based my work on. I used Erving Goffman's theory of Stigma to explain negative social mores placed on the disabled, a Marxist frame perspective applied to disability theory, and I used Miliband's interpretation of Marx's conflict theory.

This topic of disability oppression is important to me because I want others to understand the many struggles that those with Multiple Sclerosis need to overcome to function in life. This includes having a meaningful and fulfilling life. I want to help make a difference in the world. I am a disabled American myself and have faced many barriers because of it. I am pursuing a career in social work. The methodologies I utilized are survey and case-study.

The theories that are used to interpret the results of the Rand and the findings of the literature review include Karl Marx's conflict theory; specifically (Class Struggle) and Erving Goffman's theory of stigma. Using a Marxist perspective I will show that there is discrimination due to the need to define and separate those who have a disability and those who do not.

I want others to understand the many struggles that need to be overcome for many of us to function in life. These struggles include pursuing a higher education and having the ability to support oneself in having a job, as well as being able to have a meaningful and fulfilling life. My values will affect the research in a positive way because I am a disabled American myself. I have had to go through many of the processes to get help in my recovery from cancer treatment and

the additional help to further my education. I know that in research and in writing there is no such thing as being objective, but I will do my best to look at the holistic picture by bringing in all perspectives.

Literature Review

In the following literature review, I describe the forms of class struggles that exist for disabled Americans. Secondly I discuss different forms of discrimination. Then move on to talk about effects of the ADA. I then, conclude with an explanation of two articles that talk about quality of life surveys. The topic of empowerment in the face of discrimination and adversity is the foundation of this thesis.

I) Class Struggles of Disabled Americans

Disability theory has been discussed in the past and will continue to be studied by many scholars in the field of sociology and social psychology. I found three books from scholars that relate directly to class struggle. Another three books that overview the over arching importance of the empowerment of the new civil rights movement by the disabled. One scholarly text book I choose to use is about the key importance of education to create free thinking as one of the greatest means to chance positions in life for the better. I have also found two journal articles that validates the Rand-36 Item Health Survey as an effective tool for measuring quality of life for Multiple Sclerosis patients.

Miliband brings to fruition the segregation or alienation that occurs within modern capitalism. Most notably there are still two main conflicting classes the Bourgeois and Proletarians. "Struggle in most of the countries of advanced capitalism has been waged in the context of Bourgeois democracy" (Miliband, p.74). The chapter continues by elaborating on Marx's thought that in a system of capitalism expression is fundamentally repressed in a social

aspect of individuality through private production. Miliband agrees that individuals function as instruments of capitalism and are not socially independent beings because they are functioning for the greater good of the Bourgeois and not themselves. "Within our own capitalist system the disabled are more isolated and are looked upon as instruments that represent a second class culture (Miliband, p.75)". According to Clarke a sub-culture can be defined as an ethnic, regional, economic, or social group exhibiting characteristic patterns of behavior sufficient to distinguish it from others within an embracing culture or society. These groups or sub-structures struggle to be distinctive groups within larger society. This even further supports my reflection that the underprivileged and disabled are a sub culture of their own.

Ralph Miliband was a leading contributor to the development of Marxist political theory in the late twentieth century, particularly on the state, democracy, class analysis and socialist politics. His life works are very heavily influenced by Karl Marx. Most importantly Miliband explores the many forms of class struggle within contemporary capitalism. In particular the struggle of the underprivileged and disabled, his writings remain highly influential in twenty-first century social and political theory.

Freire writing is of key importance to my research because it emphasizes the importance of education and the needed discourse that has to happen with free thinking in societies. Pedagogy of the Oppressed, relates directly back to my question on the application of a Marxist perspective to disability. The Pedagogy of the Oppressed is a book that is dedicated "to the oppressed, and to those who suffer with them and fight at their side," Freire includes a detailed Marxist class analysis in his exploration of the relationship between the colonizer and the colonized. Rooted in his experience helping Brazilian adults to read and write, the book remains

popular among educators in developing countries, and is one of the foundations of critical pedagogy.

II) Different Forms of Discrimination

In sociological theory, a stigma is an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted normal one (Eisenberg, p.3-4). Erving Goffman's theory of stigma provides a framework for better understanding the social dimension of the lives of disabled children and their families. This analysis highlights how a sociological framework can help advance our understanding of medical problems as social problems and shed light on socialization processes that can help resolve the discrediting, isolation and distress lived by disabled children and their families.

Erving Goffman's text *Stigma: Notes On The Management Of Spoiled Identity* has five sections where he discusses separate issues relating to identity. The first section of this text is on stigma and social identity, Goffman gives an outline of three types of stigma and the stigma of character traits, physical stigma and stigma of group identity. Goffman then goes onto distinguish between those who are stigmatized individuals discredited or discreditable depending on the perceptions of others and those who are not stigmatized. Issues of acceptance as well as behaviors that can emerge in stigmatized groups are also discussed.

There is a section on Information Control and Personal Identity, which Goffman writes about stigma symbols as opposed to status symbols. Stigma symbols label an individual as someone who is stigmatized and various examples are given. Goffman talks about the visibility of stigma and different concepts of identity. He then follows this with methods for controlling information relevant to stigma including covering and passing.

In another section on 'Group Alignment and Ego Identity', Goffman examines issues of how the stigmatized people perceive themselves both in terms of the stigma and in relation to others in their group who are stigmatized while in 'The Self and Its Other' he takes a closer look at the relationship between being stigmatized and not being stigmatized particularly in terms of perspectives. Goffman finishes with 'Deviations and Deviance' in which he looks at people who diverge from social norms without reaching the level of stigmatization.

The section on the self and its other discusses the cognitive and affective representation of one's identity or the subject of experience.

The final section on deviations and deviance is very insightful. Deviance in a sociological context describes actions or behaviors that violate cultural norms including formally-enacted rules such as laws. Crimes are informal and formal violations of social norms. Which include the rejection of folkways and social mores.

Irving Goffman has presented an important look into the stigmas of mental illness. Creating a bio-psycho-social model that explains society's views on those suffering from mental distress. Whose actions many times are not accepted within cultural norms and often labeled as deviant.

These behaviors are a disability associated with subjective distress disorders. The stigma and discrimination associated with an individual's disease often adds to the distress of those with these mental disorders. Professional treatment, social interventions, support systems, and medications are all positive interventions that offer a course back to feeling comfortable and accepted for who they are.

The Social Psychology of Stigma discusses the psychological effects of social stigma. Stigma directly affects the stigmatized through discrimination. These actions include directly

stereotyping individuals, and indirectly through threats to personal and social identity. Through theory and empirical research within an identity model of stigma we can understand the negative implications of stereotyping with a stigma attached.

Goffman's work on social interaction shows us that situational actions combined to represent one's stigma status, and or personal beliefs and motives shape expressions of the significance of stigma-relevant to situations for well-being. This conveys the fact that social interaction in any situation is influenced by personal beliefs or biases.

III) Effects of ADA

The books that I evaluated are *Voices from the Edge: Narratives about the Americans with Disabilities Act* by Rogers M. Smith, *No Pity: People With Disabilities Forging a New Civil Rights Movement* by Joseph P. Shapiro , *Nothing About US Without US: Disability Oppression and Empowerment* by James I. Charlton. These are the core texts that I will use in my capstone research.

These books give great historical background on the grassroots movement behind the Americans with Disability Act. The discussion within these text covers the sharing of information, such as how to access resources for education, job training, and how to be a productive citizen in society. I will also be referencing the text *Pedagogy of the Oppressed* which emphasizes the importance of education and the needed discourse that has to happen with free thinking in societies. In evaluating these four texts *Voices from the Edge: Narratives about the Americans with Disabilities Act* by Ruth O'Brien, *No Pity: People With Disabilities Forging a New Civil Rights Movement* by Joseph P. Shapiro, and *Nothing About US Without US: Disability Oppression and Empowerment* by James I. Charlton. I have come to find that they are all centered on the social grassroots movement for the rights of the disabled.

The only text that truly discussed the discrimination and the need for change in the educational system was *Disabled People as Second-Class Citizens* by Myron Eisenberg. It specifically attempts to show its readers about the discrimination, neglect, and contempt that the disabled face in our society, specifically within our educational systems. Many people who contributed to this book are disabled professionals; working within the US educational system. They describe prejudicial attitudes and malicious behaviors that are seen as examples of cultural, social, economic, and political oppression of disabled people. *People as Second-Class Citizens* is a text book that is meant to serve as an instructional text for educators.

This text is a clear concise telling of the beginnings and founding of the Americans Disability Act and presents an organized look at the disability literature within the Act. Fear, rage, courage, discrimination these are all facts of everyday life for many Americans with disabilities. The Americans with Disabilities Act (ADA), has made working, traveling, and communicating easier for many individuals. What recourse do individuals have when enforcement of the law is ambiguous or virtually nonexistent? How will its changing definition affect individuals' lives-as well as their legal actions in the future? What is life like in post-ADA America?

O'Brien seeks to challenge the mindset of those who would deny equal protection to the disabled, while providing informative analysis of the intent and application of the ADA for those who wish to learn more about disability rights. Giving voice to the many types of discrimination the disabled face while illustrating the personal stakes underlying legal disputes over the ADA, this collection of writings offers unparalleled insight into the lives behind the law.

Eisenberg explores the new perspective, of successfully coping with physical and mental disability necessitates more than just learning to live with pain and or frustration. It means

acquiring a whole new life-style where one has to actively work to confront and change dominant societal attitudes. This book is designed to assist the disabled to overcome widespread discrimination, enabling them to develop more rewarding and satisfying life-styles. A new social revolution is at hand, the disabled, are seeking full rights as citizens, through the passing of Americans with Disabilities Act. The Americans with Disabilities Act (ADA) gives civil rights protections to individuals with disabilities that are similar to those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, State and local government services, and telecommunications.

IV) Use of the Rand with MS patients

The first article by (Nortvedt, pp. 1022-1027) entitled *Performance of the SF-36, SF-12, and Rand-36 Summary Scales in a Multiple Sclerosis Population* explores how the Rand-36 Item Health Survey uses questions to evaluate the quality of life of a person living with Multiple Sclerosis in the areas of physical functioning and mental health. This survey is designed with a hypothesis that the physical and mental health factors are intertwined.

Nortvedt's article continues by comparing the effectiveness of the Rand-36 Item Health Survey, the SF-36, and SF-12. In evaluation of the scores on the three health surveys, the SF-36 and SF-12 had higher scores for patients living with Multiple Sclerosis. The higher scores indicate a higher quality of life. Two hundred and seven patients who participated in the Rand-36 Item Health Survey scored 10 points less on the mean for the overall survey. The data cannot truly be compared between the three surveys due to the fact that the Rand-36 Item Health Survey evaluates the overall well-being of a patient physically as well as mentally. The SF-36 and SF-12 take measures in the written questions that discriminate between physical and mental health

well-being.

The second article by (Vickrey, pp. 187-206) A Health-Related Quality of Life Measure for Multiple Sclerosis is written by medical doctors that specialize in Neurology. The article gives some basic information on Multiple Sclerosis including letting the reader know that it is an autoimmune disease that affects the brain and spinal cord. The body attacks its own central nervous system and has the potential to cause severe disability. Most studies of people with MS have not included a comprehensive measure of health-related quality of life questions or HRQOL, but have focused on either physiological outcome measures or on measures of physical disability only. The HRQOL measures multiple dimensions of functioning and well-being. These aspects are relevant to individuals with MS. The Rand-36 Item Health Survey is based on the SF-36 survey which is the product of several years of development. This article evaluates information that was collected from mailed Rand-36 Item Health Surveys in January of nineteen ninety three to one hundred and seventy-nine MS patients.

In conclusion, I believe that I have thoroughly given clear and concise information on the topics of class struggle, discrimination, the ADA, and the uses of the Rand. As stated above these four concepts are of vital importance to the theory and methodology I am using in my capstone.

Theory

The theoretical focus of my research on the macro level is confronting the psychological and emotional affects of disability oppression. More specifically, a micro focal point is on the quality of life of Multiple Sclerosis patients. The theories and theorists that I use include Erving Goffman's theory of stigma, Karl Marx's Conflict theory; specifically (Class Struggle), and I explore disability theory. Goffman believes that Stigma can positively or negatively affect one's perception of themselves. Those who have experienced negative stigma are more prone to

considerable and noticeable changes in social and psychological behaviors. Karl Marx's theory of Class Struggle sheds light on the reality that the disabled are a growing minority class that faces discrimination in our highly stratified country. The work of Goffman and Marx and their specific theories of Stigma and Conflict theory can be directly applied to my research as it is fundamentally applicable to the topic in which I have chosen. Based on all the other literature that I reviewed, Goffman's text on Stigma regarding the effects of negative stigma affect ones perception of them self. My argument is that there are many forms of discrimination toward the disabled because of the stigmas placed upon them. Class conflicts have resulted in the construction stigmas and the forms of stratification placed on society have resulted in inequalities within the United States.

The topic of disability theory has been discussed in the past and will continue to be researched by many scholars in the field of sociology and social psychology. I found three books from scholars that relate directly to class struggle; another text overviews the importance of empowerment within the civil rights movement of the disabled. One scholarly textbook I chose to use was about the key importance of education to create free thinking as one of the greatest means to change positions in life for the better.

There are three theories that I utilized use to support my work. The first one is a Marxist frame perspective applied to disability theory. I used Miliband's interpretation of Marx's conflict theory as scaffolding. I also utilized Erving Goffman's theory of Stigma to explain negative social mores placed on the disabled.

According to Clarke, a sub-culture can be defined as a group of people that have interrelated set of cultural factors such as class, age, sex, and even a commonalty between members. I use Clarke's work to define the clients of MSQLP as a sub-culture. By showing that

the Clients of MSQLP are a sub-culture, I am able to use Goffman and Marx's theories to give my research validity. Now that I have shown that the clients of MSQLP are a sub-culture of their own, it is easy to see the class struggles that they face. Using Goffman's work on stigma, I will show that there are negative social morays placed on the disabled, specifically in the case for my research with the clients of MSQLP.

The clients of MSQLP face class struggle through all the red tape that is placed in front of them by the government that inhibits their ability to obtain medical and living assistance. Many of the clients cannot handle the bureaucratic paper work and they come to MSQLP for assistance.

I strongly feel that because many of the clients have mobility issues and some have cognitive mental issues due to the fact that MS is an autoimmune disease. This can cause these individuals to not act accordingly along with societal norms. Due to this fact, some of these individuals are negatively stigmatized.

Methodology

In order to support my research question, "what is the quality of life for the clients of Multiple Sclerosis Quality of Life Project"? The Rand 36-Item Health Survey was administered. This survey measures the quality of life, see attachments. I administered this survey over the phone to a population of 21 clients of MSQLP. MSQLP is a nonprofit foundation that works with and advocates for Multiple Sclerosis patients to improve their quality of life.

Procedures:

I. Get list of client names and phone numbers with approval from the MSQLP foundation.

II. Call clients on list and record each time called until the survey is administered and

complete.

III. Tabulate the results, I will score each clients survey for physical functioning, general health, level of pain, & check for improvement or decline of health. With the information collected, I will evaluate the data with two parts. Part A) What does the Rand-36 Item Health Survey say the quality of life is for the client? Part B) How does the quality of life scores for MSQLP compare to those used in Nortvedt article Performance of the SF-36, SF-12, and Rand-36 Summary Scales in a Multiple Sclerosis Population.

Participant confidentiality:

I will keep client information undisclosed by assigning each person a number. After collecting the data, I will compare the data that I have collect with the data collected in Vickrey, G. B., Hays, D. R., Harooni, R., Myers, W. L., Ellison's study on quality of life.

Due to the nature of the capstone project and the instrument being used, I will have to obtain approval from the Human Subjects Board in order to get permission to administer my survey. Thus far, I have passed the required tests for certification and have begun filling out the necessary paperwork for the approval process.

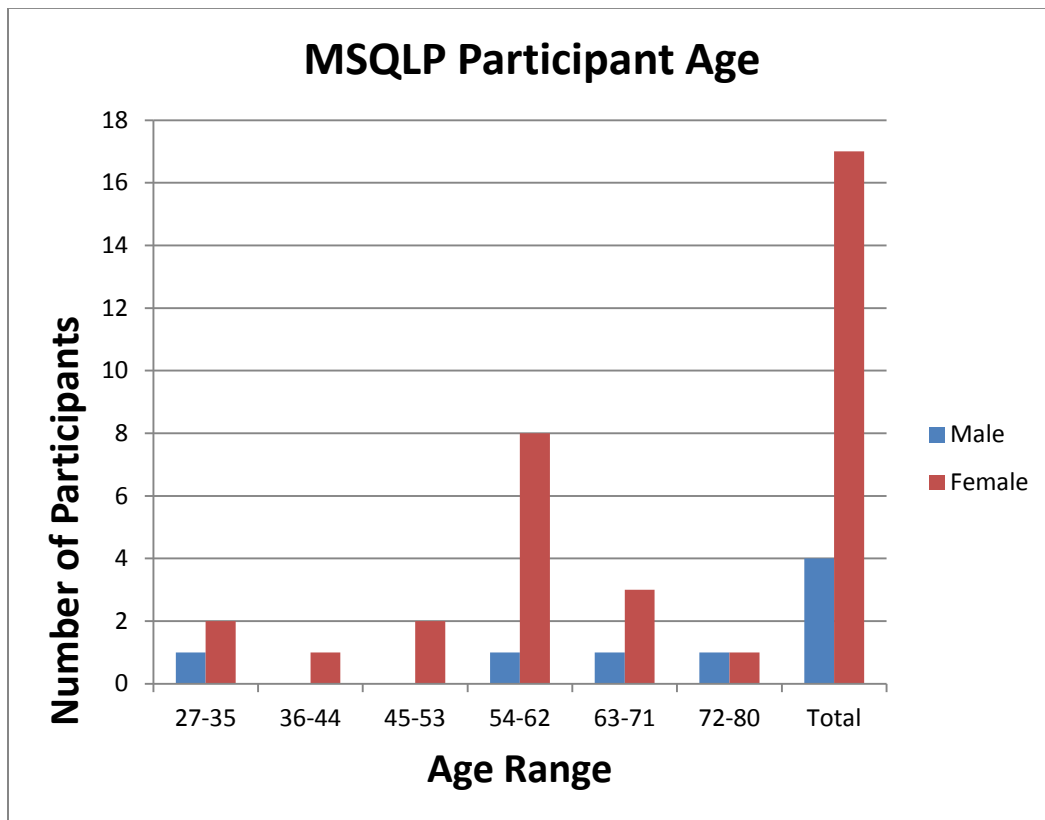
Analysis and Findings

In the following paragraphs I will discuss the data collected through the administration of the Rand 36-Item Health Survey over the phone. I also discuss how the Rand is scored and what function each question represents in a person's quality of life. I will compare and contrast my data with that from with the data collected in Vickrey, Hays, Harooni, Myers, Ellison's study on quality of life. In conclusion of this section I review and discuss the key points of information that are presented in this section.

When I began administering the Rand 36-Item Health Survey, I found that it took a good

deal of time to contact clients over the phone because they actually needed to answer the phone and be willing to participate in the answering of thirty six questions about their own quality of life. Many of the clients were pleased that someone would call them to see how they were doing overall mentally and physically. I always introduced myself, listened to what they had to say and responded with interest in the conversation. I had to stay focused myself and keep the person on the other end of the phone on topic with the survey. Due to the fact that it was a challenge to get a hold of clients who were will to participate in the survey, I was only able to complete 21 client surveys.

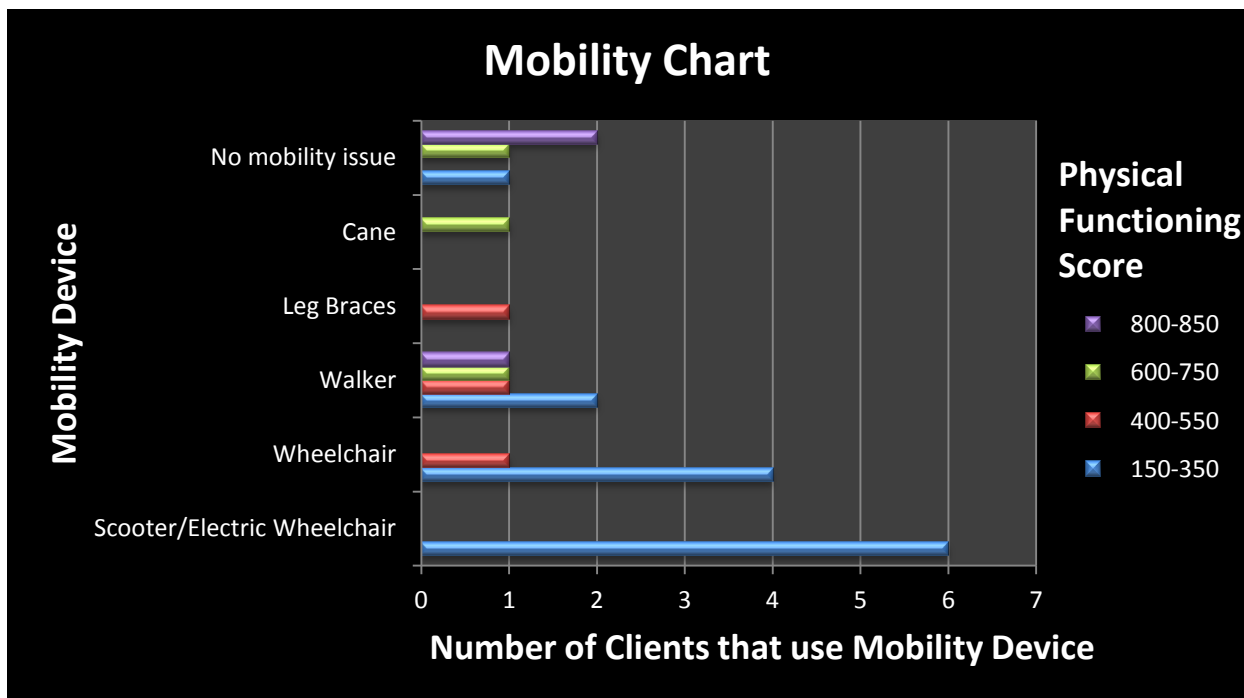
The chart below shows the number of participants that I administered the RAND-36 Item Health Survey to, the ratio of women to men, and the age range of participants.



The clients I spoke with had three different forms of mobility. Questions six through eleven on the survey were questions that dealt with getting up stairs and being able to walk or

roll more or less than a mile. Some clients were able to walk on their own, others needed the use of a cane or walker and some are wheelchair or scooter bound. In these questions I got different responses from clients over the phone saying that they were able to complete that such activity only with the assistance of a device. When answering the majority of the questions, many of the clients expressed that although the weather was not part of the survey, the outside weather had a good deal to do with how they felt and what they could accomplish on any given day.

The chart below shows the mobility scores of the 21 clients and it shows the device or devices used by clients to get around. The number of clients that use a mobility device may seem like it is indicating more than 21 clients but keep in mind that many of the clients use more than one mobile device as needed. For, example a person on a good day may not need a device at all and on another day they might not feel well and need the use of a walker. Or there are people that can walk upright with a walker when they have the energy and other times need the use of a wheelchair.



Scoring of the Rand 36-Item Item Health Survey is a two-step process. First, recorded

numerical values from each question are recorded per the scoring key in Table 1. All items are scored so that a high score defines a more favorable health state. In addition, each item is scored on a 0 to 100 range. Therefore, the lowest and highest possible scores are set at 0 and 100, respectively. Scores represent the percentage of the total possible score achieved. In step 2, items in the same scale are averaged together to create each scale.

Scoring Example

Questions 20 and 32 are used to score the measure of social functioning. Each question has 5 response choices. A response choice of 5 represents high functioning or high dysfunctioning depending on the question. A choice of 5 on item 20 indicates extreme limitations in social functioning. While a high score response to question 32 indicates the absence of limitations in social functioning. Table 1 shows that responses 1 through 5 for question 20 should be recorded as values of 100, 75, 50, 25, and 0 respectively. Responses 1 through 5 for question 32 should be recorded as values of 0, 25, 50, 75, and 100, respectively. Table 2 shows that these two recorded items should be averaged together to form the social functioning scale.

Table 1 Scoring Guide

Question numbers	Original response	recorded value
1,2,20,22,34,36	1 =	100
	2 =	75
	3 =	50
	4 =	25
	5 =	0
3,4,5,6,7,8,9,10,11,12	1 =	0
	2 =	50
	3 =	100
13,14,15,16,17,18,19	1 =	0
	2 =	100
21,23,26,27,30	1 =	100

	2 =	80
	3 =	60
	4 =	40
	5 =	20
	6 =	0
24,25,28,29,31	1 =	0
	2 =	20
	3 =	40
	4 =	60
	5 =	80
	6 =	100
32,33,35	1 =	0
	2 =	25
	3 =	50
	4 =	75
	5 =	100

Score response choices as printed in the survey

Table 2 Averaging Items to Form Scales

Scale	Number of items	Questions that correspond
Physical functioning	10	3,4,5,6,7,8,9,10,11,12
Role limitations due to physical health	4	13,14,15,16
Role limitations due to emotional problems	3	17,18,19
Energy / fatigue	4	23,27,29,31
Emotional well-being	5	24,25,26,28,30
Social functioning	2	20,32
Pain	2	21,22
General health	5	1,33,34,35,36
Improvement or decline of health	1	2

21 clients that completed the Rand 36-Item Health Survey had various physical abilities and limitations, but were able to function with the assistance of a scooter, wheelchair, crutches, walker or cane. When answering question 1, none of the clients felt that they had poor health. When answering the questions on physical functioning, the clients responded with a variety of answers regarding questions 3 through 12. In reviewing their responses and inspecting notes on the clients' explanations before answering the questions directly, one can see that the clients are content that their physical functioning is not worse.

A role limitation due to physical health refers to the kinds of activities that a person can or cannot do because of their physical health. It is clear to see that the clients of MSQLP that completed the survey have various role limitations due to their mobility. Some are scooter or wheelchair bound, some only need the assistance of a wheelchair when their MS symptoms are at their worst. Others may only need the use of crutches, a walker or cane. There are also some clients that can walk perfectly fine on their own. The issue of mobility has a good deal to do with role limitations due to physical health though, one's ability to stretch is also a factor. To help with role limitation those at MSQLP have found that many of the Clients have benefited from water aerobics and pool physical therapy. When I looked at role limitations due to the physical health of the clients on the surveys that I completed I noticed that there were various strengths and weaknesses when it came to physical role limitations. Some of the clients were able to stretch and move their arms and legs while others were not.

A role limitation due to emotional health refers to the kinds of activities that a person can or cannot perform because of how they feel emotionally. With questions 17-19 many of the clients I spoke with felt that they could not generalize their answer to just a yes or no. There are variables such as the weather many of the clients told me that the weather has a lot to do with

how they feel. Many said that during the past 4 weeks they had good as well as bad days where they felt energetic and happy or they felt depressed.

Questions 23, 27, 29, and 31 dealt with Energy / Fatigue. Client's responses over the phone ranged from having energy all of the time to none of the time. When asking question 23 regarding whether or not a client felt full of pep? Many of them said that the amount of energy they have varies throughout the day. Also their energy depended on what they were doing, if they were going out to lunch and a movie which gave them pep because they were going out and doing something with a friend or family member but they were tired by the end of the day, or if they were staying in and reading or playing a board game with their family. Question 27 asks if you have lot of energy. The answers I received ranged from most of the time to none of the time. Question 29 asks to what extent has someone felt worn out. The majority of clients when I asked this question wanted further elaboration, worn out at the end of the day or what they asked? I told them the question did mean at the end of the day or any other time as well. All of the answers ranged from a good bit of the time to a little of the time. When reviewing the answers on question 31 regarding if someone felt tired and to what degree. The responses ranged from most of the time to a little of the time.

Emotional well-being is a term that conveys mental health concerns such as stress, depression, and anxiety. These issues can contribute to ill-health such as digestive disorders, sleep disturbances, and general lack of energy. On the positive side, enhanced emotional well-being is seen to contribute to upward spirals in increasing coping ability, self-esteem, performance and productivity at work, and even longevity. Emotional well-being is also one of two aspects of personal well-being.

There are five questions that deal with emotional well-being on the Rand survey.

Questions 24, 25, 26, 28, and 30 cover issues in relationship to an individual's well-being.

Question 24 asks whether or not an individual feels as if they consider themselves to be a very nervous person. Of the 21 clients I interviewed 14 of the said that they were nervous none of the time and the other 7 said a little of the time. Question 25 asks whether a person has ever felt so down in the dumps that nothing could cheer them up. There were a range of answers from the 21 participants from some of the time to none of the time. These results show that from the clients I completed the survey with all of them have a good grasp on their individual emotions and only some or no of the time feel so depressed that they can't do anything about it. On the Rand 36-Item Health Survey question 26 asks if the person felt calm and peaceful in the past 4 weeks. All of the clients I completed the survey with responded by saying all of the time or most of the time. These answers indicate that of the 21 clients I surveyed they feel calm and at peace the majority of time. Question 28 is another question that asks about feeling depressed or blue. Again answers from the 21 clients I worked with ranged from some of the time none of the time. This was good to hear because not of the clients felt depressed all of the time or a majority of time. The last question dealing with emotional well-being is 30 which asks the question have you been a happy person? The answers of the 21 clients ranged from all of the time to a little of the time. I was pleased to hear that none of the clients responded by saying that they were happy none of the time.

Questions 20 and 32 dealt with social functioning. Social functioning can be seen as the ability of an individual to interact in society. Both questions ask to what extent or how often has your physical or emotional health interfered with normal social activities with friends or family. The responses varied between the 21 clients I completed the survey with. Again I was pleased to hear that not a single person felt that their physical health or emotions interfered extremely with

social activities. Nor did they feel that their physical health or emotions interfered with social activities all of the time.

Pain is a feeling triggered in the nervous system. Pain may be sharp or dull. It may come and go, or it may be constant. Pain can be felt in one area of the body, such as your back, abdomen or chest or one can feel pain all over, such as when muscles ache. Questions 21 and 22 address these problems. Question 1 asks how much bodily pain have you had in the past 4 weeks. Question 2 asks how much has pain interfered with normal activities in and outside of the home. It was very promising to hear that for question 21 no one had a very severe problem with pain. When responding to question 22, not a single person said pain extremely interfered with their normal activities in and outside of the home.

General health is a term that looks at the condition of a person in mind, body and spirit. Questions 1,33,34,35,36 examine ones overall health. The first question asks a person to rate their health as 1 excellent, 2 very good, 3 good, 4 fair, and 5 poor. None of the clients felt that they had poor overall health, this was great to hear.

Questions 33 through 36 asks the individual to rate his or her health on a sliding scale from 1-5, 1 meaning definitely true, 2 meaning mostly true, 3 meaning don't know, 4 meaning mostly false, and 5 meaning definitely false. Question 33 asks whether you seem to get sick a little easier than other people. I believe this question is inadvertently asking about a person's immune system. All of the 21 clients I administered the survey to answered with a 3 or 4 response. When it came to question 34 which gives the statement "I am as healthy as anybody I know", all of the clients I completed the survey with asked in regards to what, someone without MS or what? For this question because I am only working with a population of MS patients I said as healthy as anybody I know with MS. The majority of clients responded with a 2 or 3 as

an answer. Question 35 states I expect my health to get worse. At this point in the survey many of the clients spoke openly and said that they know things can get worse MS is an Autoimmune disease which is a form of an overactive immune response of the body against substances and tissues normally present in the body. In other words, the body attacks its own cells. It was a hard question to ask people on the spot. Many responded with either a 1, 2, or 3. The last question 32 states my health is excellent. The answers the clients I administered this survey to gave a range of answers from 2 to 4 in response.

In regards to the improvement or decline of health in the clients of MSQLP there was one question that examined an improvement or decline of health. The responses that the clients could choose from were 1 much better now than a year ago, 2 somewhat better than a year ago, 3 about the same, 4 somewhat worse than a year ago, and 5 much worse now than a year ago. The responses I got from the 21 clients I surveyed were answers 1 through 4. It was good to hear that nobody responded by saying their health was much worse now than a year ago.

The first article by I am using to compare the survey I administered is by Nortvedt and entitled *Performance of the SF-36, SF-12, and Rand-36 Summary Scales in a Multiple Sclerosis Population* explores how the Rand-36 Item Health Survey uses questions to evaluate the quality of life of a person living with Multiple Sclerosis in the areas of physical functioning and mental health. This survey is designed with a hypothesis that the physical and mental health factors are intertwined.

Nortvedt's continues by comparing the effectiveness of the Rand-36 Item Health Survey, the SF-36, and SF-12. In evaluation of the scores on the three health surveys, the SF-36 and SF-12 had higher scores for patients living with Multiple Sclerosis. The higher scores indicate a higher quality of life. Two hundred and seven patients who participated in the Rand-36 Item

Health Survey scored 10 points less on the mean for the overall survey. The data cannot truly be compared between the three surveys due to the fact that the Rand-36 Item Health Survey evaluates the overall well-being of a patient physically as well as mentally. The SF-36 and SF-12 take measures in the written questions that discriminate between physical and mental health well-being.

The second article by Vickrey, A Health-Related Quality of Life Measure for Multiple Sclerosis, is written by medical doctors that specialize in Neurology. The article gives some basic information on Multiple Sclerosis including letting the reader know that it is an autoimmune disease that affects the brain and spinal cord. The body attacks its own central nervous system and has the potential to cause severe disability. Most studies of people with MS have not included a comprehensive measure of health-related quality of life questions or HRQOL, but have focused on either physiological outcome measures or on measures of physical disability only. The HRQOL measures multiple dimensions of functioning and well-being. These aspects are relevant to individuals with MS. The Rand-36 Item Health Survey is based on the SF-36 survey which is the product of several years of development.

Evaluating the 21 clients I administered the Rand-36 Item Health Survey to 17 of them were women and 4 were men. I scored each clients survey to discover their physical functioning, general health, and level of pain. I then calculated the mean for each area of all of the clients. I found that the mean for physical functioning is 40%, general health is at 73%, and the average level of pain is 12%.

Reviewing the results for physical functioning, I consider 40% to be a strong representative number for the 21 clients I completed the survey with. 1 client is scooter bound and another is electric wheel-chair bound. Five others need the assistance of a manual wheel-

chair. 7 other clients use a walker. The remaining 6 clients are able to walk on their own and 3 of those clients said they use a cane when necessary. The range score for the general health of the 21 participants in the Rand-36 was 73%, this was great to see. General health looks at the condition of a person in mind, body and spirit. This statistical information shows that when looking at general health from a holistic point the 21 clients that I completed this survey with are doing well when considering their overall health. The resulting 12% as the average level of pain for the 21 clients I administered the health survey too was astonishing. In reviewing side notes on the surveys I feel that many of the client's pain levels fluctuate throughout the day. The clients are on various medications to control the pain and I feel that the majority of them have found ways to cope or ignore their pain by keeping their mind off of it.

Conclusions

In the conclusion to this Capstone project I echo my introduction, recapitulate my major ideas, and explain the significance of my project. I continue by explaining whether or not my research question had been answered, and show how my work is supported by the theories I used. I use a relevant quote and elaborate on its usefulness.

This research project administered the Rand 36-Item Health Survey to a subject pool of approximately 21 to measure their quality of life. The results of this study were compared to a similar population of subjects who were administered the Rand by Vickrey, Hays, Harooni, Myers, Ellison. The scored results from the 21 participants helped me describe their quality of life. The comprehensive literature review reports on the historical effect of the American with Disability Act.

The significance of my project has two focal points. The first is that it brings light to the fact that many quality of life surveys are not written to gather a patient or client's holistic well

being. I point to the fact that the SF-12 and SF-36 only evaluate physical or mental health and many of the questions are written from a medical perspective not the patient's. To gather meaningful quality of life questions the survey needs to look at both as the RAND-36 does. The second focal point is that after collecting and information through the RAND-36, scoring the results and finding the mean scores for physical functioning, general health, and level of pain I was able to answer my question "what is the quality of life for clients of the Multiple Sclerosis Quality of Life Project in Monterey"? The quality of life of the 21 clients that I administered the RAND-36 Item Health Survey to live good quality lives. There are variances in physical functioning and level of pain, though when individual scores for general health were evaluated all but one had 60% or a higher percentage for the well being of the mind, body and spirit.

The significance of my work was that I was able base my work off an effective quality of the survey the Rand 36. After talking with Andrea Dowdell, it seems that my work will have future impactions for the Multiple Sclerosis Quality of Life Project. The foundation is considering starting to evaluate the well being of its clients by administering the Rand 36-Item Health Survey to the other 200 plus Multiple Sclerosis patients that they work with.

I have sufficiently supported my findings and work with the works of Goffman, and Marx. Seeing the Clients of MSQLP as a sub culture I was able to incorporate the work of Goffman and Marx's. By showing that the clients of MSQLP are a sub culture of their own it is easy to see the class Struggles that they face. Using Goffman's work on Stigma I will show that there are negative social mores placed on the disabled specifically in the case for my research the clients of MSQLP.

The clients of MSQLP face class struggle through all the red tape that is placed in front of them by the government that inhibits their ability to obtain medical and living assistance.

Many of the clients cannot handle the bureaucratic paper work and they come to MSQLP for assistance.

I strongly feel that because many of the clients have mobility issues and some have cognitive mental issues due to the fact that MS is an autoimmune disease. Therefore, these individuals do not act accordingly along with societal norms. Due to this fact some are negatively stigmatized.

In completion of my work, I feel that I have shown the real-world implications of my research. I finish with a quote of my own to inspire the mind. "What does not destroy you, defines you." I learned this through my struggles with the world.

Bibliography

- Charlton, J. (2000). *Nothing About Us: Disability Oppression and Empowerment*. California University of California Press.
- Clarke, M. (1974). On the Concept of 'Sub-Culture'. *The British Journal of Sociology*, 25, 428-441.
- Eisenberg, M. (1982). *Disabled People as Second-Class Citizens*. New York Springer Publishing Company, Inc.
- Freire, P. (1970). *Pedagogy of the Oppressed*. Reprint (2000) New York Continuum Publishing
- Goffman, E. (1963). *Stigma: Notes On The Management Of Spoiled Identity*. New York Published by Simon & Schuster, Inc
- Heatherton F. T. (200). *The Social Psychology of Stigma*. New York, NY: Guilford Press.
- Mackelprang W. R. and O. Salsgiver (2009) *Disability: A Diversity Model Approach in Human Services Practice*. Chicago, Illinois Lyceum Books, Inc.
- Miliband, R. (1990). *Divided Societies: Class struggle in contemporary capitalism*. New York Oxford University Press.
- Nortvedt, W. M., Riise, T., Myhr, K., Nyland, I. H. (2000). Performance of the SF-36, SF-12, and Rand-36 Summary Scales in a Multiple Sclerosis Population. *Medical Care*, 38, 1022-1027.
- Shapiro, J. (1993). *No Pity: People With Disabilities Forging a New Civil Rights Movement*. Toronto, Candia: Three Rivers Press.
- Smith, R. (2004). *Voices from the Edge: Narratives about the Americans with Disabilities Act*. New York Oxford University Press.
- Vickrey, G. B., Hays, D. R., Harooni, R., Myers, W. L., Ellison, W. G. (1995). A Health-Related Quality of Life Measure for Multiple Sclerosis. *Quality of Life Research*, 4, 187-206.

Annotated Bibliography

Charlton, J. (2000). *Nothing About Us: Disability Oppression and Empowerment*. California University of California Press. pp. 200-225

In this book, James Charlton has produced a reflection of disability oppression. Where he says, is rooted in degradation, dependency, and powerlessness and is experienced in some form by five hundred million persons throughout the world who have physical, sensory, cognitive, or developmental disabilities. *Nothing About Us Without Us* is the first book on disability to provide a theoretical overview of disability oppression, which shows its similarities to, and differences from, racism, sexism, and colonialism. The analysis given by Charlton is illuminated by interviews he conducted over a ten-year period with disability rights activists in the United States.

Charlton found that there was an antidote for dependency and powerlessness in the resistance to disability oppression that is emerging worldwide. His interviews contain striking stories of self-reliance and empowerment evoking the new awareness of disability rights activists. As a latecomer among the world's liberation movements, the disability rights movement will gain visibility and momentum from Charlton's elucidation of its history and its political philosophy of self-determination, which is captured in the title of his book.

Nothing About Us Without Us expresses the conviction of people with disabilities that they know what is best for them. Charlton's combination of personal involvement and theoretical awareness assures greater understanding of the disability rights movement.

Eisenberg, M. (1982). *Disabled People as Second-Class Citizens*. New York Springer Publishing Company, Inc. pp. 100-132

This book, explores the new perspective, of successfully coping with physical and mental

disability necessitates more than just learning to live with pain and or frustration. It means acquiring a whole new life-style where one has to actively work to confront and change dominant societal attitudes.

This book is designed to assist the disabled to overcome widespread discrimination, enabling them to develop more rewarding and satisfying life-styles. A new social revolution is at hand, the disabled, are seeking full rights as citizens, through the passing of the Rehabilitation Act.

Freire, P. (1970). *Pedagogy of the Oppressed*. Reprint (2000) New York Continuum Publishing pp.126-156

The *Pedagogy of the Oppressed* is a book that Dedicated "to the oppressed, and to those who suffer with them and fight at their side," Freire includes a detailed Marxist class analysis in his exploration of the relationship between the colonizer and the colonized. Rooted in his experience helping Brazilian adults to read and write, the book remains popular among educators in developing countries, and is one of the foundations of critical pedagogy

Goffman, E. (1963). *Stigma: Notes On The Management Of Spoiled Identity*. New York Published by Simon & Schuster, Inc.

The first section of this text is on stigma and social identity, Goffman gives an outline of three types of stigma and the stigma of character traits, physical stigma and stigma of group identity. Goffman then goes onto distinguish between those who are stigmatized individuals discredited or discreditable depending on the perceptions of others and those who are not stigmatized. Issues of acceptance as well as behaviors that can emerge in stigmatized groups are also discussed.

There is a section on Information Control and Personal Identity, which Goffman writes about stigma symbols as opposed to status symbols. Stigma symbols label an individual as

someone who is stigmatized and various examples are given. Goffman talks about the visibility of stigma and different concepts of identity. He then follows this with methods for controlling information relevant to stigma including covering and passing.

In another section on ‘Group Alignment and Ego Identity’, Goffman examines issues of how the stigmatized people perceive themselves both in terms of the stigma and in relation to others in their group who are stigmatized while in ‘The Self and Its Other’ he takes a closer look at the relationship between being stigmatized and not being stigmatized particularly in terms of perspectives. Goffman finishes with ‘Deviations and Deviance’ in which he looks at people who diverge from social norms without reaching the level of stigmatization.

Goffman’s work is thought-provoking. There is a need to reduce the stigma that those with mental illness may face in society and there are many people that emphasize the importance of what Goffman has written about. Goffman’s work shows the complexity of stigma which involves interplay between society and the individual which is multilayered and in a state of flux. This is a difficult phenomenon to examine as it is a property of the group which is manifest both in actions and inactions which is why this level of analysis is perhaps the most meaningful.

Heatherton F. T. (2003). *The Social Psychology of Stigma*. New York, NY: Guilford Press.

This book addresses the psychological effects of social stigma. Stigma directly affects the stigmatized through discrimination. These actions include directly stereotyping individuals, and indirectly through threats to personal and social identity. Through theory and empirical research within an identity model of stigma we can understand the negative implications of stereotyping with a stigma attached. Goffman’s work on social interaction shows us that situational actions combined to represent one's stigma status, and or personal beliefs and motives shape expressions of the significance of stigma-relevant to situations for well-being. This conveys the fact that

social interaction in any situation is influenced by personal beliefs or biases.

Identity intimidation results when stigma-relevant stressors are valued as potentially harmful to one's social identity and as exceeding one's coping ability. Identity threat creates involuntary stress responses and motivates attempts at threat reduction through coping strategies. Stress responses and coping efforts affect important outcomes such as self-esteem, academic achievement, and health. Identity threat perspectives help to explain the tremendous variability across people, groups, and situations in responses to stigma.

Miliband, R. (1990). *Divided Societies: Class struggle in contemporary capitalism*. New York, NY: Oxford University Press. pp. 73-74

In Miliband's text he brings to fruition the segregation or alienation that occurs within modern capitalism. Most notably there is still the two main conflicting classes the Bourgeois and Proletarians. "Struggle in most of the countries of advanced capitalism has been waged in the context of Bourgeois democracy.

Shapiro, J. (1993). *No Pity: People With Disabilities Forging a New Civil Rights Movement*. Toronto, Canada: Three Rivers Press.

This book follows the movement of the Americans with disabilities act and all of its implications upon education. Getting, and giving the educational assistance to the learning disabled that they need to succeed in their educational pursuits. *No Pity: People with Disabilities Forging a New Civil Rights Movement* is a riveting account of the personalities and process leading to the passage of the Americans with Disabilities Act. Not since Branch Taylor's *Parting the Waters* have I been so involved with a work of non-fiction. Perhaps it was because *No Pity's* subject matter involved my professional work or perhaps it was because I am familiar with so many of the names. More likely, it was due to the fact that *No Pity* was so well written that I found the book difficult to put down once I started.

Joseph Shapiro, author of *No Pity*, points out that it is very difficult for persons who are temporarily able-bodied to really understand persons who have disabilities, just as it is for persons who are not of minority ethnic/racial background to fathom the perspectives of those who are. But understand we must as persons with disabilities, as professionals in rehabilitation, and as part of a nation dedicated to justice and equality of its citizenry. *No Pity* helps us to understand. *No Pity* documents a change in the way that persons with disabilities perceive themselves and by extension, the world about them. It is a change in "mindset" and identity that will revolutionize America and the world. Shapiro calls this change a "radical transformation" which has yet to manifest itself fully in American life.

No Pity is immensely readable because it intertwines the personal with the public. These are the stories of Marilyn Hamilton, Ed Roberts, and Larry McAfee, but also the stories of major events such as the protests at Gallaudet and the demonstrations of ADAPT. There are vignettes of history with Alexander Graham Bell and how the Jacuzzi was invented as an attempt to provide relief from the pain of arthritis. The ten chapters document the personal and public struggle of self determination, frustration, anger, and victory.

This is a book for persons who may have disabilities and for those of us who work with persons with disabilities. Practitioner, consumer, administrator, or educator will benefit from reading *No Pity*.

No Pity is far from perfect. I'm sure that every individual reading it may have heard or observed something a little different from the account in the book. I suppose that each of us can quibble some about personalities and the events and their interpretation, but these are minor.

No Pity as an important resource for anyone that has a disability or is interested in the movement. *No Pity* provides a basis for understanding the personal and societal context of

persons with disabilities. As Shapiro explains in the introduction, *No Pity* is an attempt to explain, to nondisabled people as well as to many disabled ones, how the world and self perceptions of disabled people are changing. It looks at the rise of "the new thinking by disabled people that there is no pity or tragedy in disability, and that it is society's myths, and fears.

Smith, R. (2004). *Voices from the Edge: Narratives about the Americans with Disabilities Act*. New York Oxford University Press. pp.

This text is a clear concise telling of the beginnings and founding of the Americans Disability Act. *Voices from the Edge* presents a refreshing and innovatively organized look at the disability literature in the context of the 1990 Americans with Disabilities Act. The text is filled with collections of personal narratives of the experience of disability, and, though fewer, with legal analyses of court cases, the ADA, and American disability rights history.