

AUDIENCE RESPONSE & DISABILITY REPRESENTATION IN FOUR
FILM AND TELEVISION DRAMAS: A QUALITATIVE AUDIENCE STUDY

By

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Ph.D. University of Kansas, 2008

Submitted to the graduate degree program in Theatre
and Film and the Faculty of the Graduate School of the
University of Kansas
in partial fulfillment of the requirements for the degree
of Doctor of Philosophy.

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Acknowledgements

There are many people to thank for their support over the years that I have been working on this project, but I will only name a few whose help has been crucial at one time or another. The rest know who they are and they also have my deep gratitude; first among them, the participants in my study.

I thank the members of my committee, professors Catherine Preston, Edward Small, John Tibbetts, William Staples, chair of the Sociology Department at KU, who graciously accepted to help me even though I had never been in one of his classes; Dr. Chuck Berg, whose unexpected absence led to the inclusion of Dr. Michael Baskett, who providentially was willing to take his place. Especial mention is deserved by Dr. Carol Warren, from Sociology, who guided me through the first sketches of this project and suggested to me the use of the focus group methodology.

Among the Lawrence KS, community I would like to especially thank Ms. Dot Nary, M.S., whose guidance and suggestions were invaluable in helping me recruit volunteers, as well as the staff from Independence Inc. I also would like to leave notice of my gratitude to my KU friends Jae Yoon Park, Sam Joshi, Nohchool Park, Novotny Lawrence, Chris Meissner, Rodney Hill, Victor Andrade, Manuel Pérez-Tejada, Faye Riley, Mark von Schlemmer, Jason Cole, and Robert Sokol for lending me help and support intellectually, emotionally and at times physically in a myriad ways.

Thanks to Sharon Carr, for her expert typing and transcription services, and to the staff at Oldfather Studios, for their great cooperation and helpfulness over the years. Thanks also to my colleagues and friends at The School of Literature, Communication and Culture, at Georgia Tech, for their help in the last year of this work.

Finally, a word in memory of my father, Gustavo Arenas Reyes, who passed away while I was still in the middle of the project and could not share with me the happiness of its conclusion. Thanks to my brother, Andrés, for his patience over many years. And thanks to Savannah. Wherever you are, you are never forgotten!

Fernando Arenas Vélez, Jan. 30, 2008

Abstract

This dissertation examines the audiovisual representation of physical disability in a group of films produced for theatrical and television distribution. The films under study are: Prelude to Happiness (USA, 1974), Passion Fish (USA, 1992), The Sea Inside (Mar Adentro, Spain, 2004), and The Brooke Ellison Story (USA, 2004/TV).

The study challenges the critique of media representations of disability as predominantly carriers of stereotypes and producers of harmful effects in the audience --a view emanating from a number of media and disability studies scholars-- with a more personal, hermeneutic approach based on the focus group methodology. It concludes with a discussion of the strategies of interpretation used by these viewers with disabilities to make sense of disability centered films, in the context of a cultural studies model of audience reception theory.

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Chapter 1

Introduction

Where am I, as a disabled woman, in the general culture that surrounds me? Generally, I'm not there. I could watch television for years, possibly a lifetime, without seeing my experience reflected in its dramas, documentaries, and news stories. I could spend a lifetime going to theatres, libraries, bookshops, reading newspapers, without finding any portrayal of a disabled woman's life which speaks to my experience... (Morris, 1991, 84)

When discussing cultural representations of people with disabilities, the lives of these individuals, their concerns, views, and experiences are missing from mainstream media products such as films and television programs. This is the charge that Jenny Morris, a British activist and author articulates. And she is not alone. A number of authors from the disability studies field argue that instead of producing images of disability that people with disabilities can recognize as their own, consonant with their perceptions and life experiences, media products often re-circulate a host of negative stereotypes that promote the oppression and misunderstanding of disabled people. (Klobas, xi; Norden, 3; Longmore, 3; Morris, 84 ff. Darke, 9)

I understand the concept of representation as employed by Stuart Hall: The "production of meaning through language." (Hall, Stuart, 2000, 16) Film and video are audio-visual languages because they allow a signifying practice through the use of their shared matter of expression (the photographic image, several sound tracks and written materials such as credits). Though film is not a language in the Saussurian sense of "langage," or sign system, it is a language in the sense of "langage." (Metz 1974, Stam 2000). The concept of representation is a complex one, involving religion, aesthetics, politics and semiotic dimensions (Shohat and Stam 1994 182ff). Leaving aside the religious connotation of the term, which involves fights over the right to produce "graven images," a contentious issue in many Muslim countries today as it was also for Jewish religious leaders and for the Christian Byzantine empire, we can briefly mention the aesthetic and political implications of representation. For Ella Shohat and Robert Stam,

The narrative and mimetic arts, to the extent that they represent ethos (character) and ethnos (peoples) are considered representative not only of the human figure but also of anthropomorphic vision" (1994 182)

This gives an idea of how important it is to be portrayed in the arts for the recognition of a group's humanity, of its values and distinctiveness. Additionally, it explains the urgency of minority groups in a given society to control and correct the prejudicial representations of them produced by a dominant group. The struggle over representation has been played out historically whenever a minority ethnic or religious, or gender group has sought to redress some injustice in the public sphere. After all, the word representation evokes also the political rights of citizens in a democratic government, as in the famous "no taxation without representation" from American revolutionary times.

As for the other expression that is central to my project, Simi Linton's *Claiming Disability, Knowledge and Identity* (1998) provides a detailed examination of the linguistic subtleties involved in the use of expressions like "disabled people" or "person with a disability", and others traditionally used to refer to persons with physical or psychological impairments. In this dissertation, I strived to use the currently preferred "people first" language, occasionally reverting to more traditional usage for reasons of linguistic variety and

economy. It is worth considering that from the viewpoint of a social model of disability an impaired person can be effectively "disabled" by social and environmental barriers. Thus, using "disabled person" instead of "person with a disability" could be justified depending on the model we employ to define disability and its causes. Later in this chapter, I discuss several ways to define and understand disability.

Statement of Purpose

This dissertation examines the audiovisual representation of disability, specifically physical disability in a group of films produced for theatrical and television distribution. I searched for the ways that these films contributed either to perpetuate or challenge dominant stereotypes and prejudices towards disability and people with disabilities. And, unlike most other previous studies, I took into account an empirical audience's response to such audio-visual depictions of physical disability. I conducted focus groups with people with disabilities, which included screening films and discussing them.

I wanted to contrast the critique of media representations of disability emanating from the Social

Model of Disability scholars, cited above, with a more personal, hermeneutic approach based on the focus group methodology. At the same time, I considered the reservations and cautions of feminist and phenomenological authors, critical of the Social Model, who counseled to "stay close" to the experience of disability in order to illuminate culture (Morris, Titchkosky). Therefore, I decided to interrogate those who experience disability in their daily lives, members of an audience who I thought could provide a unique perspective on the reception of disability centered films and television programs, specifically dramas.

Value and Significance

Regarding the significance and value of this study, it is important to consider various dimensions:

1. The United States media, with its considerable domestic market and its global reach, consistently disseminates not only stories, but ways of life, ideologies embedded in them. The images of various social groups, including people with disabilities, that are presented through the media in general, and specifically through powerful audiovisual media such as television and film are available to millions of people the world over.

Therefore, it is important to consider what kinds of representations of people with disabilities, of their potential, of their place in society, their relative integration or marginalization these films and television programs are showing, as they form part of the circulating discourses about disability and society at any given time.

2. The matter of how people with physical disabilities are being portrayed in film productions is also important for people without disabilities in other ways, as it constitutes an analog to similar processes involving the marginalization or integration of different groups within culture and society. Therefore, the processes of stigmatization, circulation of stereotypes, or conversely their criticism, and the dismantling of prejudicial ideologies through media messages that can occur in the case of physical disability representation can be compared to those processes involving the civil rights struggles of ethnic, gender or class minorities.

3. The very experiences of people with disabilities can be powerful stories to learn from for other members of society, with or without disabilities. Among these, in particular, there is a sense of community across physical

differences that allows a person born blind to share experiences with someone who lives with a mobility impairment or a learning disability. Reflection on the lives of people with disabilities can in turn illuminate the larger organization of society and, on a personal level, it can help us all gain in knowledge, experience and awareness of the common human bonds that can be formed beyond superficial appearances.

Personal Background

A more personal reason for initiating this study resides in my experience of a relationship with a woman with a disability, who used a wheelchair. My conversations with her, where she would say that people like her were nowhere to be found in the television programs and films that we would discuss in our everyday conversations, were the initial sparks for my desire to study films about disability. To this I should add also the long-standing interest that disability related films and television shows had for me since I was a small child watching television in my native Colombia. I remember being drawn to depictions of blindness in a Venezuelan telenovela called Esmeralda (Dir. Grazio D'Angelo, 1970), as early as 1972 or 1972. Later came Michael Landon's The

Little House on the Prairie and its depiction of Mary Ingalls' blindness, and Audrey Hepburn's portrayal of another blind woman in mortal danger, in the film Wait Until Dark (Dir. Terence Young, 1967), a film produced the year when I was born, but which I saw for the first time as a teenager. I remember as well the very intimate memory of watching an anonymous American thriller late at night, on television, when I was still a young child. The protagonist was a young woman, a kindergarten teacher, who was a similar predicament to that of Hepburn's in Wait Until Dark, except that in this case she was paralyzed, in a wheelchair, as the criminals threatened to invade her home. Watching this film was a riveting emotional experience, which I keep in my memory even though I never could find the title of the film in question. All of these examples and many others whose recollection escapes me now, form the personal background of this research.

Disability: Contested definitions, changing views

Michael Berubé notes that disability

...is the most labile and pliable of categories: it names thousands of human conditions and varieties of impairment, from the slight to the severe, from imperceptible

physical incapacity to inexplicable developmental delay. (Linton, vii, viii).

Various authors in the disability studies field remind us that disability is not a direct result from a physical impairment, but it arises from the prevailing social meanings, values and norms governing how that impairment is interpreted. (Morris, 9ff, Pointon & Davies, 1-3) Those social meanings of disability can be described briefly in adjectives such as "worthless," "abnormal," "tragic," "dependent," "bitter," "brave", "inspirational" and a whole range in between. According to David T. Mitchell and Sharon L. Snyder, "Disability acts as a loose rubric and as an amalgam of dissimilar physical and cognitive traits that often have little in common other than the social stigma¹ of limitation, deviance and inability." (1997, 7)

Canadian sociologist Tanya Titchkosky defines Disability in this everyday sense as "an inability to do things as they are ordinarily expected to be done and be seen to be done." She states that this "is one of society's primary definitions of disability." (14)

¹ The concept of *stigma* was developed by sociologist Erving Goffman in his book Stigma, Notes on the Management of Spoiled Identity (1963).

The medical and legal communities traditionally distinguished between the terms *disability* and *disablement* in one crucial economic aspect, according to *Steadman's Medical Dictionary* (1976): While disability is understood as loss of function and earning power, disablement refers only to loss of function without the loss in earning power. (Linton, 11).

The World Health Organization's *International Classification of Impairment, Disabilities and Handicaps* is a commonly used document among governments and international organizations working with disability. (Titchkosky, 14; Darke, 3) This international organism provides the following tripartite definitions:

Impairment: 'Any loss or abnormality of a psychological or anatomical structure or function.'
Resulting in

Disability: 'Any restriction or inability to perform an activity in the manner or within the range considered normal for a human being.'

This may lead to:

Handicap: 'Any disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal for that individual.' (Unison, 1998:33)

The Medical Model vs. the Social Model of Disability

These definitions belong to a conception of disability as pathology, which traditionally dominated all knowledge and activity towards disability in the medical and social sciences. Critics of dominant understanding of disability dubbed it the "Medical Model of Disability." In opposition to it, they proposed an alternative conception that considers disability a socially constructed identity. Instead of the catastrophic and tragic associations of the medical model, the Social Model scholars and/or activists proposed visions of people with disabilities as an oppressed minority, thus taking the focus away from biological conditions to social structures and civil rights struggles.

According to Paul Darke, the medical model of disability emerged with particular strength during the Enlightenment. Needing to rationalize work and the administration of charity and state benefits, medical authorities enforced definitions and practices destined to separate people into productive and unproductive groups. As Darke notes, the imperative of economic

rationalization made salient what had been formerly irrelevant impairments. (Darke, 3)

In Discipline and Punish, Michel Foucault detailed this evolution, which did not occurred suddenly but was "a multiplicity of often minute processes, of different origin and scattered location which ... converge and gradually produce the blueprint of a general method" (Foucault 1995 138) As he noted, European governments took the methods of disciplining bodies that had succeeded in the armies of Europe and subsequently transferred them to such spaces as schools, factories and hospitals, in a process parallel to the growth of Capitalism on the European continent, as we can see from this passage about the reorganization of a naval hospital at Rochefort:

The medical supervision of diseases and contagions is inseparable from a whole series of other controls: the military control over deserters, fiscal control over commodities, administrative control over remedies, rations, disappearances, cures, deaths, simulations. Hence the need to distribute and partition off space in a rigorous manner (Foucault, 1995 144)

The Medical Model and the Human/Social Sciences

Following Foucault's lead, a number of authors have examined the development of the medicalization of

disability and the influence this medical model has had on other forms of knowledge. Michael Oliver, a leading proponent of the Social Model of disability, writes:

A sociologist having either a personal or a professional interest in disability will not find disability occupies a central or even a marginal place on the sociological agenda. And even where it does appear, sociology has done little except reproduce the medical approach to this issue. (Oliver, 1990, x-xi)

In reviewing the various claims for the emergence of a new kind of disability studies in the 1990s, Titchkosky underscores the dominance -only challenged in recent decades- of the medical model in discussions of disability, including academic discourse:

Disabled people speak and engage in sociopolitical action, and have done so for a very long time. Nonetheless, normate culture² has easily and readily regarded all such speech and action as a kind of symptomatology, as signs of adjustment to, coping with, management of, or acceptance of disability.... Under the hegemonic control of the medical model, disabled persons are deciphered but not understood. Starting from the taken-for-granted singular sense that disability is a bodily condition of lack and inability unchosen and

² Normate culture is a term introduced by disability scholar Rosemarie Garland-Thompson, by which she highlights the ideological nature of the notion of "normality" used to isolate and marginalize people with disabilities. The idea of normalcy that "normate culture" seeks to impose is, of course, a fictional, idealized notion that no 'normal' person completely embodies in actuality.

despised, all speech and action can be regarded as merely symptomatic of the disabled person's healthy or ill relation to such a 'condition.' (162-163).

One important, but often overlooked dimension of the medical model is the power it bestows on those professional and academic disciplines entrusted to keep the boundaries of disability and its place in social life. Those gatekeepers of disability include doctors, health administrators, charities, insurance companies, and the 'caring professionals' (Russell, 96-108). In the words of David T. Mitchell and Sharon Snyder,

We rarely consider that the continued circulation of professionally sponsored stories about disabled people's limitations, dependencies, and abnormalities proves necessary to the continuing existence of these professional fields of study. (1997 1)

The importance of considering the role of these professionals and the institutions where they work is that their influence over the representations of disability in the media traditionally drowned the voices of the people they were caring for. Privileging the figures of doctors, nurses and other non-disabled caregivers created a world where the only authoritative voices to be heard concerning people with disabilities

were those of the medical establishment and its institutions, as they were considered the experts. Against this state of affairs, people with disabilities themselves started to claim for their own representation, in all senses of the term; hence the birth of the social model of disability.

Disability representation in American Culture

Woody Allen's Alvy Singer, protagonist of his film Annie Hall (1974), echoes the popular view of disability that is reinforced through the medical model:

I feel that life is divided up into the horrible and the miserable; those are the two categories, you know: the horrible would be like - um - I don't know, terminal cases, blind people, cripples. I don't know how they get through life, it's amazing to me. The miserable is everybody else. So when you go through life you should be grateful that you're miserable; you're very lucky to be miserable³.

The excerpt from Allen's film is just one stark example among many from film and television, which illustrates how the mass media are major venues for the circulation of prejudicial stories and images of people with disabilities. In this light, it became important to identify the ideological messages embedded in films which act as relays for the circulation of oppression and the

³ Thanks to Paul Darke for reminding me of this quote.

denial of civil rights to millions of people with disabilities. The importance of doing this kind of work is even larger when considering the U.S. media, since its influence is not circumscribed to the United States' already large domestic market, but extends to every other country within reach of its global distribution network.

Precedents in other media

Before the appearance of film, disability imagery was circulated through older media such as literature and theatre. Rosemarie Garland Thomson remarks that the disabled figures found in popular literature are "informed more by received attitudes than by people's actual experience of disability." (1997 9) How have these attitudes and images been transmitted?

The use of disability as metaphor has been a mainstay of Western cultural representation across time from the age of classic theatre (Oedipus) to modern films, television and newer media. For classical authors like Shakespeare the visibly disabled character presented an easy way to solve the difficulties of representing in tangible form an invisible moral flaw. Therefore, he made the purportedly greedy and unscrupulous King Richard III

appear as a lame character with an arched spine.

(Sandahl, 14, 15)

These traditional attaching of a moral flaw to characters with a physical disability passed from literature to film, as several scholars illustrate. (Klobas, Longmore, Norden). Even if a large number of characters with various disabilities can be identified in the history of film and television productions, these representations often owe more to the imaginary fears and desires of the majority of non-disabled people than to any actual experiences of meeting and relating to people with disabilities. This situation is the "paradoxical invisibility" of people with disabilities described in Paul K. Longmore (2001).

The majority of the representations thus conceived - under the dominance of the medical model- tend to present images of disabled people as deviant, pitiful, sad, and a host of other negative traits that we could encompass under the general category of stigma. Further, this stigma is understood as a "natural" consequence of the person's impairment, so that stigmatizing representations logically justify the isolation and social

marginalization of disabled characters by virtue of their suspected moral failings.

Research Problem

Given these premises, disabled activists and scholars in the disability studies field have devoted considerable attention to the critique of negative representations of disability in cultural products. This critique has often taken the form of a call for more "positive images." This has been especially urgent for organizations of disability advocates and later by specialized scholars in the emerging field of disability studies. (Mitchell and Snyder 1997 16, 17)

Some of the studies arising from the disability studies and advocacy field have produced a binary opposition among representations of disability in films, which are assumed to be wholly positive or negative. Further, certain authors seem to subscribe to a "hypodermic model of communication" which assumes a high degree of power on the part of message producers over its receivers (viewers) in order to achieve a given effect.

The preceding picture of negative images in circulation through the media, as presented by scholars such as Longmore, Klobas, Norden, et al. prompted me to

explore whether the critics were perhaps overstating their case. Further, I wondered whether a group of citizens with disabilities would confirm the fears and alarms raised by these authors. These questions gave rise to the present study, which sought to investigate how a group of films represented disability and what kinds of responses would those representations elicit from a specific audience of people with disabilities.

There were the following questions to consider:

Research Questions

- 1) How do disabled audience members respond to the representations of their disabilities or disabilities in general in the movies they see? Do their responses show any evidence of a strategy of rejection, negotiation or subversion of these images in their interpretation of the movies?
- 2) To what extent do they consider these representations harmful or positive to the advancement of their interests in society?
- 3) If disabled audience members are dissatisfied by the dominant representations of their lives in movies, do they identify any exceptions to this rule? What would constitute such exceptions? What kinds of representations would they want to see in place of the existing ones?

These research questions grew out of other ideas that I pondered on when I first conceived of the project.

Among them, for example: in which ways would a group of audience members with a disability use those films that closely attempted to depict their lives, stories and experiences? Would they use these "films about disability" in order to relate to other people with disabilities and to learn how to navigate potentially difficult interactions with non-disabled people? Would they use these films as "inspiration" sources? Would they rather ignore them and dismiss them as uninformed products of a dominant prejudiced view? Would they, as the common paradigm of the British Cultural Studies analysts predicted, take up a "dominant", "negotiated" or "oppositional" reading of these cultural products? (Hall, 1980) It might be that, like Jenny Morris, disabled viewers (or viewers with disabilities, as the currently preferred language in The United States prescribes), would feel betrayed and ignored by the mainstream cultural producers. It might be that they would feel the need to take control of production and create their own films. Or maybe they did not share the misgivings of the scholars and activists and wholly embraced these images un-critically. This work is an attempt, informed both by

current problems in disability studies and in audience reception studies, to answer to all of these questions.

Limits and scope

The scope of my study is restricted to the representation of physical disability in movies and the disabled audience's responses to it. Why physical disability? First, because it is the area of disability that particularly holds a personal interest for me. And second, because, as Martin F. Norden points out, the definitions of disability that is included, for example in the Americans with Disabilities Act of 1999, and the Rehabilitation act of 1973, "are so broad that they proved an untenable basis on which to build a single book" (Norden, xi)

I decided to limit myself to representations of people with physical disability, understood here in its everyday sense as related to visual, auditory or musculo-skeletal impairments. The selection of the films was strongly skewed towards the last kind of impairments, both because paralysis and amputation are readily represented in visual terms (thus, for example, the international symbol for disability is a stylized image of a person in a wheelchair), and because this kind of

impairment was closer to the experience of the group of participants who responded to my call in this study. Additionally, trying to recruit participants who were deaf or blind would have complicated the logistics of communication about films in my focus groups and for practical reasons related to time and finances, I decided against that possibility. That is then a further limit on the scope of the study, although similarities exist in the cinematic representations of other physical disabilities with those of paralysis, amputation or skeletal deformations.

As I explain in the literature review section of this dissertation, a strong tendency in authors who study the cultural representation of people with disabilities is to impute to these representations a notable, and at times alarming ability to affect the lives of the viewers with disabilities, either directly by diminishing their self-esteem or indirectly by fostering prejudices and oppression of people with disabilities. What is missing from much of that literature thus far, however, is direct empirical evidence to support or contradict those claims. The significance of my study lies in its providing a

methodology only rarely⁴ deployed for the understanding of this particular research problem. In addition to the experts' voices represented by the scholars and activists from the disability studies movement, my study offers a sample of the views of a group of members of the audience which could confirm, complement or modify what those scholars/activists have written.

In the context of film studies, this project's value also resides in contributing to a relatively scarce number of works in the area of disability within film studies⁵, with the intention to complement the scholarly publications produced by authors such as Klobas, Norden, and the University of Iowa group headed by Enns, Smit and their colleagues. In addition to that, it continues the relatively recent tradition of 'ethnographic' audience

⁴ See Chapter 2, literature review, for a discussion of the studies that precede me in the use of this approach to the study of disability representations in media.

⁵ At the time of this writing there were only a few books within film studies devoted to the representation of people with disabilities. These are the single volumes by Klobas, Norden and the duo of Enns and Smit, and their contributors. Other than these, there have been many references and articles published within disability studies, but these often have not taken into account any film studies perspectives and have assumed an "idea of passive spectatorship." See Thomas B. Hoeksema and Christopher R. Smit, "The Fusion of Film Studies and Disability Studies," in Anthony Enns and Christopher R. Smit (Eds.) Screening Disabilities, p.36-37.

research advocated in the last two decades by authors such as Morley, Ang, Radway, Katz and Shohat, Hermes, Staiger, and others within communication and film studies.

Methodology

In order to find a suitable methodology to questions of audience interpretations of film and television movies, I have relied on literature on audience research, particularly to the qualitative or ethnographic methodologies employed in film and media studies under the influence of the British Cultural Studies tradition.

The Cultural Studies tradition of media scholarship has been particularly strong in employing qualitative approaches to social research in their attempts to understand media and its relation to its viewers. Among my predecessors and models for this study I found Jacqueline Bobo's dissertation particularly relevant since her problem and methodology could offer me a useful model for my own study. She utilized the focus group methodology in studying the audience responses of black women viewers of The Color Purple.

Bobo's research question arose from the differences she noticed in the responses of male and female audiences

to the Steven Spielberg film based on the similarly titled Alice Walker novel. She specifically wished to answer the question of how a specific audience (black female viewers) used a mainstream text to empower themselves and their social group. In opposition to the mostly negative reactions of male critics and commentators who constructed the book and film as controversial in its depiction of black ethnicity, Bobo wondered why women expressed positive responses to the film since, according to the then dominant view of film theory, it would be encoded with a dominant ideology. She used the Cultural Studies theory of communication in order to explain Spielberg's position, not as a member of a dominant class engaged in a conspiracy against the audience, but as someone subject to an "ideological pressure to reproduce the familiar," in spite of his best intentions to avoid reproducing negative stereotypes.

(20-21) Similarly, Bobo sought to understand the complexity of the responses to the picture from her female audience members. In doing this, she works against the notion of "false consciousness" on the part of female viewers who react positively to the film. Instead, she refers to the "cultural competencies" that a marginalized

viewer can bring to her encounter with a cultural work: one is a positive response "where the viewer constructs something useful from the work by negotiating his or her response, and/or gives a subversive reading to the work," and the other "is a negative response in which the viewer rejects the work." (32-33) In particular, she explains the positive reactions of the viewers she interviewed as instances of intertextuality, since her participants have an experience of creative cultural products by black women. (33)

The similarity between Bobo's project and mine resides in that I too am seeking to explore the complexity of responses to a film (in my case a group of films), from a particular marginalized audience. I also started from the premise that media reception is not a uni-directional process and that media products do not simply have a negative, overpowering influence on their viewers, but that these viewers, according to those cultural competencies described above, can respond variably to the different ideologies present in the film texts.

Similarly to Bobo, I chose to use a focus group methodology to carry out my study. In defining Focus Group, I followed Martha Ann Carey, who writes:

Although the term *focus group* has been used to include a range of techniques, the general field of social science research has come to broadly conceptualize this technique as follows: using a semi-structured group session, moderated by a group leader, held in an informal setting, with the purpose of collecting information on a designated topic....the collection of personal experiences and beliefs related to the designated topic is the purpose of the focus group. (Carey, 226-227)

In researching the uses and benefits of the focus group method, I have followed Carey's insights along with those of David Morgan and Richard A. Krueger, authors of the six volume Focus Group Kit the aforementioned Bobo, and the team of researchers from Yeshiva University who authored Qualitative Data, An Introduction to Coding and Analysis, Carl Auerbach and Louise B. Silverstein. In addition, I consulted books by other well known authors in the field of qualitative studies, such as Lyn Richards and Janice S. Morse, in their book Read Me First for a User's Guide to Qualitative Methods (2002), and Morse's edited volume Critical Issues in Qualitative Research Methods (1994). Additionally, I have read the chapters

pertinent to focus group planning in Martin W. Bauer and George Gaskell's edited text Qualitative Research with Text, Image and Sound: A Practical Handbook (2000). All of these provide excellent advice for the practitioner of media audience research using qualitative studies techniques, particularly in terms of the logistics of putting together a focus group and analyzing its results.

In addition to the focus group methodology for collecting and analyzing data from viewers, I have complemented the interview results with a more traditional textual analysis of the films under study. In the next section I offer an overview of the organization of the project, before moving on to the chapters on literature review, methodology and results of my study. issues in Chapter 3.

Organization

Chapter 1 Introduces the subject of disability representation in cultural products, with particular emphasis on the problematic nature of its representation in film and television and the attempts by media scholars and disability activists to find a solution to the negative images of disabled people carried through the media. It also offers a general discussion of the

research questions, scope and limitations, and the motivations for this study.

Chapter 2 offers a review of the literature on disability representation as well as on the theoretical problems surrounding the study of media effects and audience reception, with a view to explain how this study fits into a larger academic discussion about the importance and degree of activity of viewers in the communication process, and also how it contributes to the literature on disability representation in media.

Chapter 3 offers a summary of the methodological design of the present study, including especially the procedures followed for collecting and analyzing data from the focus group interviews with a group of viewers with physical disabilities. In this chapter the global results of the study are discussed.

Chapter 4 discusses the reception of two independent films from the United States. The first one is Prelude to Happiness (1974), starring Rose Petra. This is a melodrama produced in Texas, outside of the mainstream American industry, devoted to telling a love story between a successful doctor and a young nurse who suffers the traumatic amputation of her leg in a road accident.

The second, more recent example of the depiction of physical disability and traumatic injury in American independent cinema is Passion Fish (1992), directed by John Sayles, starring Mary McDonnell and Alfre Woodard.

Chapter 5 studies an international film, the Spanish production Mar Adentro, known in the United States by its English title, The Sea Inside (2004). This film, directed by Alejandro Amenábar, starring Javier Bardem, depicts a story based on the real-life struggles of Ramon Sampedro, a Spanish man who, after living for thirty years with quadriplegia, obtained his desire of dying through the help of an anonymous group of friends. The debates over euthanasia and the "right to die" regarding the lives of people with disability are prominently featured in this movie, as they were in its contemporary winner of the 2004 Academy Awards, Clint Eastwood's Million Dollar Baby. The chapter also focuses on a second recent film about a quadriplegic character. Like the Spanish film, The Brooke Ellison Story (2004) is also based on the actual life of an actual person, Brooke Ellison. She is a young woman whose life was dramatized in the film by director Christopher Reeve. Starting from the day of the accident that left her with paralysis of all extremities

at the age of 11, Reeve examined a story close to his own, after his paralyzing accident from 1995. This chapter explores the barriers to social acceptance and the institutional hurdles that threaten to hinder people with severe physical disabilities in contemporary American society. In addition, we examine the viewers' reactions to the televisual depiction of Ms. Ellison's life and the participants' changing attitudes towards the figure of Christopher Reeve, a famous film star turned celebrity activist for the cure to paralysis.

Chapter 6 presents this dissertation's conclusions, with an evaluation of its results and an indication of further areas of interest for research.

Chapter 2

Literature Review

In this chapter I discuss the literature on representation of disability in film, and I trace the development of audience research in film and television.

There is a varied and growing literature on disability in the United States, The United Kingdom and Canada. The authors of this literature are in many cases people who live with a disability or they can be non-disabled ones who are allied to the aims and objectives of the disability movement. Specifically considering the United Kingdom and Canada, authors such as Jenny Morris, Michael Oliver, Paul Darke, Tanya Titchkosky, and many others have given rise to a view of disability as a question of social and political rights rather than as a medical problem. Collectively, along twenty or thirty years, the writers in this movement (of which the ones I cite are only a few outstanding examples) gave birth to what has been termed the "Social Model of Disability", an influential new way of conceptualizing the issue.

In The United States, meanwhile, authors such as Rose Marie Garland-Thomson, Simi Linton, Paul Longmore, among others, exemplify the point of view of disability

activists and scholars united in a multi-disciplinary field known as "new disability studies"⁶. In the following section I discuss the most influential authors dealing with the representation of disability in culture and those that have conducted audience studies on disability representation.

First, there is the important work being carried out by Rosemarie Garland-Thomson in the field of literary and photographic representation. This is exemplified in her book Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature. (1997) In addition to this, Thomson has made an important contribution to the study of visual representation of disabilities through her article, "Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography." (2001)

In the first part of Extraordinary Bodies, Thomson defamiliarizes the notions of "able-bodied" and "disabled" as physically given conditions, in order to highlight the socially constructed conventions that underpin these familiar notions. As she puts it:

⁶ in order to distinguish it from the older writings about disability from a medical perspective produced by members of the "healing professions"

Invested with meanings that far outstrip their biological bases, figures such as the cripple, the quadron, the queer, the outsider, the whore, are taxonomical, ideological products marked by socially determined stigmata, defined through representation, and excluded from social power and status. Thus, the cultural other and the cultural self operate together as opposing twin figures that legitimate a system of social, economic, and political empowerment justified by psychological differences. (1997 8)

The opposition between "able-bodied"⁷ and "disabled" thus constituted is the target of Thomson's deconstruction in this book, under the neologism of the "normate", which she defines as "a social figure through which people can identify themselves as definitive human beings." The irony of the operation of this figure in culture is that after excluding all the markers of otherness and deviancy signified by the figures mentioned in the preceding quote, what is left is a small minority of people. In other words, the normate is not normal.

Thomson states in her discussion of the literary representation of disabled figures:

The discursive construction of the disabled figure, informed more by received attitudes than by people's actual experiences of disability, circulates in culture and finds a

⁷ In this dissertation I am using "non-disabled," in an attempt to destabilize the unmarked status of the more usual term "able-bodied."

home within the conventions and codes of literary representation. (9)

This disparity between the literary figures of disability (or its cinematic images) and the experiences of people with disabilities gives rise to Thomson's study, where she analyzes representations of disabled figures in literary works from a feminist, social constructionist perspective. My own study arose as an attempt to verify whether there was such a distance, as Thomson(1997) or Klobas(1988) posited, between the representations of disability and the lives of people with disabilities who view them in film and television.

Thomson appropriates the theories of Ervin Goffman, with his notion of Stigma discussed above, Mary Douglas, who studied cultural conceptions of dirt and pollution, and Michel Foucault's writings about *docile bodies* from Discipline and Punish. (Thomson 1997 16) Using these authors theories, she explains how the ideology of the normate manages the existence of anomalous bodies (those to whom Goffman referred to as having a "spoiled identity".) For instance, according to Douglas, there are five cultural responses to "dirt," which Thomson extends to the disabled body: 1. reducing ambiguity by assigning

to the anomalous body an absolute category (such as the label "disabled"); 2. eliminating or destroying the anomaly: such would be the solution of the eugenics movement and of people such as Dr. Kevorkian, who advocate suicide of people with disabilities and chronically ill people. 3. avoiding the anomaly. This is also exemplified in regulations that seek to segregate and enclose people with disabilities within special institutions. 4. Labeling the anomaly as dangerous. This type of response may lead in itself to solution number 2, elimination. But it can also serve to justify other repressive measures. Finally, 5. incorporating the anomaly into ritual. (Thomson, 33-38)

Thomson discusses the possibility of using this fifth response in a more constructive way by interpreting disability as the bearer of a fresh view, a different category that transgresses established borders, akin to the carnivalesque of Bakhtin's theory. (1997, 38)

Finally, from Michel Foucault's historical explanation of the rise of the norm, which traces the creation of rigid schemes to classify people into discrete and hierarchical relations, she takes the impulse to highlight the constructed nature of such classifications. (Thomson, 39)

In addition to her contribution to disability theory in Extraordinary Bodies, Thomson's 2001 article offers an alternative model of visual representation of disability that is designed to go beyond the simple dichotomy of negative versus positive images. (2001, 339) Although her theorizing is specifically referred to photographic images rather than film, it is still relevant as a model for analyzing the cultural assumptions that inform the representation of disabled people in moving image productions. As she puts it,

The images we see seem to ensnare truth. Even though photographic images appear to capture the genuine, at the same time this representational medium arrests time, freezes motion, and prunes away space, which are the coordinates and the context of 'real' life (2001 336).

Thomson proposes a fourfold model of visual rhetoric of disability, which allow her to illuminate the content, conventions and context of the photographs under analysis, as well as the relationship that they seek to establish with the viewer. The four visual rhetorics that she describes are the wondrous, the sentimental, the exotic and the realistic. (2001 339)

By 'the wondrous', Thomson refers to those images that seek to place the disabled in a position of mastery and super-human ability, whereby the non-disabled viewer may be awed in witnessing the "incredible feats" or the noteworthy endurance of the disabled persons portrayed in the images. Historically, this is the oldest visual rhetoric about the disabled, and it mingles with the traditional views of archaic cultures which looked at them as monsters and were stricken with both awe and terror as they beheld them. In Thomson's words, "their different bodies were thought to augur the future or encode enigmatic omens from the gods." (2001 340) Using a spatial metaphor, she explains how this mode of representation situates the viewers at the level of "undistinguished commoners", while the disabled figure is "elevated to a position of eminence." (2001 340)

In the second mode of representation, the rhetoric of the sentimental, the disabled person is seen "from above," as an object of pity, needing protection and help from the viewer. In its power to evoke feelings of sadness and pity, the "poster child" is the typical example of this rhetoric at work. It becomes a signifier of suffering, as the reality of suffering is difficult to

represent. As Thomson states, "such a model infantilizes the disabled figure -literally, in the case of the poster boy-and bestows authority and agency on the spectator. Thomson's eloquent example is a poster produced for the *National Foundation for Infantile Paralysis*, announcing the "March of Dimes." The message is expressed through the comparison of two images. The first one shows a little boy of 7 or 8 years of age that is restrained with a belt around its neck, inside a crib. The bars in the crib resemble cell bars in prison or perhaps the rugged construction of old hospital beds. In contrast to this image, the second one shows the little boy walking towards the viewer with an attitude of purposefulness. Presumably, the stark difference between the two images represents the intervention of the charity that sponsors the poster, and at the same time, it is the fruit of the viewer's positive decision to help the child by joining the March of Dimes. This way, a relationship between mastery and helplessness is clearly established by this mode of representation.

The rhetoric of the 'exotic' is Thomson's third mode of representation. Instead of emphasizing a vertical

relationship of above/below, superior/inferior between the disabled subject and the viewer, it creates a sense of distance as its main rhetorical effect. The exotic representation can view its subject as either specially noteworthy or debased, but it always strives to separate it from the common experiences of the presumably non-disabled viewer. In the author's telling example, a photograph of a group of "spotted boys" presented them as "freaks" in order to create ethnographic interest out of a medical condition known as vitiligo. (2001 343) More recent examples of the exotic mode are the fashion pictures that use disabled models in order to present them as chic and to exoticize their difference. One example of this is the work of British fashion designer Alexander McQueen, in his collaboration with double leg amputee athlete Aimee Mullins, which rather than conceal her prosthetic legs, showcases them in his fashion shows and photographs. (2001 360, 362-363)

Thomson's fourth and final rhetoric, the 'realistic', attempts to erase the distance between the disabled subject and the viewer, while avoiding also to position either of them in a relation of master to

victim. Recent news and documentary photographs that frame the subject usually at eye level and may or may not foreground her difference exemplify it. When these pictures call attention to physical difference, it is to encourage identification between subject and viewer, instead of exoticizing or sensationalizing such physical difference. (2001 344 -346) As she points out, calling this rhetoric realistic does not imply that it is less bound by conventions or less constructed than the other three modes of representation. It is simply designed to create an illusion of reality, for the sake of the commercial or journalistic ends that inspire the construction of its images. (Thomson, 2001 344)

Literature on Disability in Films and Television

Until recently, there has been a dearth of scholarly books dealing with the representations of disability from the standpoint of film and media studies.

One of the first book-length studies to appear was Lauri Klobas' Disability Drama in Television and Film (1988). In the course of nearly 500 pages, Klobas' analyzes numerous examples of television programs and films that have dealt with disability, in search of recognizable patterns, repetitions, and especially

hunting for manifest inaccuracies in the depiction of details from the lives of disabled people. For instance, she cites the familiar scene of a blind character touching another character's face in order to 'see' it with his/her fingers. This commonplace image from movies and television programs, Klobas explains, exists only in the minds of the writers and directors, and it is continually re-created and reformulated by a dramatic tradition that ignores the real-life behaviors of blind people.

Klobas, who wrote her book in 1988, was following the example of a leading disability critic, Paul K. Longmore, the author of a seminal 1985 essay *entitled "Screening Stereotypes: Images of Disabled People."* As Longmore had done, Klobas compiles a list of familiar stereotypes that she identifies in a large number of audiovisual productions in the span of several decades. Her book is organized by reference to particular disabilities and how they have been portrayed in films and television.

The resulting work, while important as a pioneering effort, is largely a reference book, listing a long list of examples of the treatment of particular disabilities

in the media. She specifically warns the reader about the spontaneous character of her selection, as she has collected her specimens over a little over a decade of watching films and television. But she endeavors to identify the most common characteristics and stereotypes associated with the depiction of blindness, wheelchair users, deafness, amputation, developmental disabilities, small stature, multiple disabilities and a general section for "other disabilities".

Klobas criticizes the depictions of people with disabilities in movies and television programs for being narrow and "in some cases damaging to the lives of actual citizens with limitations⁸" (xi). In her view, the constant screen repetition of such reductive or narrow images creates a gap between reality and representation similar to the one that Thomson identifies. The question becomes, for Klobas one of the relative adequacy or inadequacy of the images created by "Hollywood" to "the real-life counterparts" of those images. (xi)

⁸ The question arises of how she knows that those representations do actual damage to people with disabilities. Since the only logical way to answer such a question seems to be to ask the people concerned, this is further impetus for a study such as mine.

The solution to the problem would seem, for Klobas, to produce more positive images. This straightforward formulation, however, is parallel to one that has been proposed also in other areas of cultural criticism and social life, such as in the struggles over the images of women, African-Americans and other ethnic minorities. This formulation was used in those other civil rights struggles, but then it was discarded as too simplistic, or at least revised and complicated by successive scholars, for example, Ella Shohat and Robert Stam, who write:

The facile, catch-all invocation of "stereotypes" elides a crucial distinction: stereotypes of some communities merely make the target group uncomfortable, but the community has the social power to combat and resist them; stereotypes of other communities participate in a continuum of prejudicial social policy and actual violence against disempowered people, placing the very body of the accused in jeopardy." (183)

Taking Shohat and Stam's distinction into consideration, it is clear that stereotypes of people with disability, such as those studied by Longmore and Klobas, for example, belong to the second category. However Klobas' premise is open to question. She assumes a very direct link between 'negative images' and negative

treatment of disabled people in society, and therefore she assumes a passive viewer who simply accepts whatever negative images or stereotypes are carried by the films and television shows. This picture of the communication process is too simple and it raises the vexing question of how to create positive images.

A similar situation occurs with the next author, Martin F. Norden, in his book The Cinema of Isolation (1994). In this historical overview of the representation of disabled characters in Hollywood cinema, he covers the entire history of the medium from the 1890s to the early 1990s. In that year, the U.S. Congress passed the *Americans with Disabilities Act*, in an act which political commentator George Will called "the last great inclusion," or the seeming culmination of the civil rights era. (Longmore and Umansky, 2) Norden's is a polemical work that sees a pattern of exclusion and isolation of the disabled characters "from their able-bodied peers as well as from each other" (Norden, 1). This is accomplished not only through the plots of the films but through their use of the medium's expressive techniques -framing, lighting, camera movement, editing and so on. Norden traces this overarching theme of

isolation, both physical and symbolic, through the twin lenses of feminism and psychoanalysis. He acknowledges a debt to feminist film theorists Mary Ann Doane, Patricia Mellencamp, and Linda Williams, and to historians Douglas Gomery and Robert Allen, for their descriptions of his methodology, labeled by Doane et al. as "the image of approach." He describes this approach briefly as a sociologically inspired framework that he deems particularly useful for dealing with large quantities of films while charting their associated historical currents. Norden, ix)

To this historical and feminist methodological approach, Norden adds his own interest in subject position theory and "commodification issues." He develops the argument that films are primarily positioning audience members as consumers, and that what they are selling are the dominant views of a "paternalistic, phallogocentric society." (Norden x)

While Norden's approach is useful, it is also problematic for various reasons. First, Norden's approach tends to produce a catalog of static stereotypes, which is the reason why it was abandoned by

earlier practitioners in the feminist analysis of films as well as in studies of ethnic representation⁹.

Although this type of study has an undeniable value in identifying the gross simplifications and exaggerations that often mark the representation of minority subjects, film analyses based only on an "image of" approach tended towards the construction of a more or less small and static range of stereotypical images: "the sweet innocent," the "obsessive avenger" or the "civilian superstar," to use Norden's terminology. (Norden, 33, 52, 28) Other publications in this tradition of denouncing negative representations of disability are Leonard Kriegel's "Disability as Metaphor in Literature," (1988) and the aforementioned article by Paul Longmore: "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures." (2001 1-17)

As stated above, after the charge is made that Hollywood creates and perpetuates negative images of women or of disabled characters, the question immediately

⁹ A discussion of the history of the "image of" approach within feminist criticism can be found in Christine Gledhill's article "Developments in Feminist Film Criticism." For a similar discussion regarding ethnic stereotypes see also Shohat and Stam (1994)

follows of "what would constitute a positive image?" Two authors from the United Kingdom, Ann Pointon and Chris Davies (1997) assert that reducing disability representation to a scheme of positive versus negative images is too simplistic, given the difficulty of defining a positive image unambiguously. As Paul Darke has pointed out, in his Ph.D. dissertation, even superficially positive images can be misleading:

The positive images, so admired by Morris and Longmore, marginalize those with severe impairments even further because the latter are unable to imitate any semblance of normality or benefit from the attempt to normalize them. (Darke, 13)

The difficulties in distinguishing a negative image and a positive one probably stem from the nature of the notion of stereotype, which is often used in discussions of representation of oppressed minority groups, such as women, disabled people or ethnic minorities.

According to Michael Pickering, the word *stereotype* was coined in the 1920s by Walter Lipmann. As with the word *cliché*, the term was applied metaphorically, taking it from the world of printing and typography, where a stereotype was a text cast into a rigid form for purposes of repetitive use. (Pickering 9)

The "classical view of stereotyping" sees them as intrinsically negative concepts in the sense that they are rigid, erroneous and simplistic ideas, based on discriminatory values. They are seen as distorting the perception of social groups or individuals, as reducing the complex traits of people under "overarching group-signifiers" and as encouraging negative and hostile judgements, thus justifying oppression and injustice.

Given this theory of the work and functioning of stereotyping, some people have proposed to provide more accurate information and a more positive representation, in response to a negative stereotype. As Pickering explains it, many critiques of stereotyping in the media are based on an implicit model of communication which sees it as a linear process, "with an active sender providing a powerful message and a passive receiver reacting dumbly to what was transmitted." (22) The media in this model are seen as manipulating and seducing an inert and tractable audience, easily swayed by propaganda, stereotyping and social myth. (Pickering 22) Other researchers, such as Goffman, doubt that the solution to the problem of stereotyping resides in an increased familiarity or contact. He points out that

"normals who live adjacent to settlements of the tribally stigmatized often manage quite handily to sustain their prejudices." (Goffman 53) In Goffman's view, the difference between treating someone as an individual, with particular characteristics, or treating him/her as just an example in a category (that is, stereotyping), depends in crucial ways on a set of "standardized anticipations" or "standard expectations" which people learn in society regarding the different roles people play and types of encounter. So, for Goffman, "various structures in which contact occurs and is stabilized -public streets and their strangers, perfunctory service relations, the workplace, the neighborhood, the domestic scene," (55) and the expectations we learn regarding what takes place in such contacts, are the primary determinants of whether we treat somebody openly or we stereotype that person.

Taking into consideration the lessons from Pickering and Goffman would lead us to doubt that the media by themselves can be so strong in their influence on viewer's attitudes towards people with disabilities. However, this does not mean that stereotypes are not an important issue in the study of media such as television

and film. After all, remembering the quote from Shohat and Stam(1994)mentioned above, not all stereotypes are created equal, and even if the media alone cannot hope to effect a drastic social change, this does not mean that they have no part to play in this process. The crucial question, in the end, is that we need to understand better the communication process that happens between a film and its viewers, and this study hopes to be a contribution in that direction.

Audience Research Literature

In my discussion of audience research, I have been particularly influenced by Professor Janet Staiger, of the University of Texas, at Austin, whose books on the subject, Interpreting Films (1992), Perverse Spectators (2000), and Media Reception Studies (2005) provide a comprehensive, clear and immensely perceptive overview of the history and possibilities of studies centered on the spectators or audience members¹⁰ of film and television.

¹⁰ In this dissertation I prefer to use the terms "viewers," to emphasize the visual character of the media under study, "participants," and "audience members" or "audiences," instead of the classical "spectator," because I wish to avoid the connotations of passivity that the latter term often implies.

Film theory before the 1980s frequently viewed film audiences in terms of individual spectators who would submit unquestioningly to the power of the film narration. In 1970s theory's vocabulary, words such as "apparatus," and "subject positioning" assigned viewers a role of passive subjects of the effects created by the text. The whole activity of film theory and criticism was viewed as one of unmasking the operations of the text on the viewers and how those operations hid an ideological charge that was often taken for granted as impossible for the viewers to counteract or resist. (1992 49-57, 59-68)

The impulse to give primary attention to textual analysis and to consider only the ideal viewers addressed by the text instead of empirical audiences is perhaps one of the few areas where classical film theory, with its competing schools of 'formalism' and 'realism' could be in agreement. The film itself and its careful formal construction were the focus of attention for both theoretical tendencies. For Sergei Eisenstein, Formalist theory was the study of how the work of art could plough "over the audience's psyche, in a particular class context," (Staiger, 1992, 53) The mention of class context, however, provides an opening for the

consideration of possible variable responses from audience members. Eisenstein's contemporary, American psychologist and critic Hugo Münsterberg, also saw the importance of the audience's imagination and "earlier experiences" in order to create meaning from films.

(Staiger 1992, 56)

The most significant challenge to the dual paradigm of formalism and realism to appear in film theory, which signaled the triumph of formalism, was the emergence of "screen theory," a body of work that took its name from its most influential disseminator, the British journal of that name, during the early 1970s. Screen theory introduced a politicized brand of psychoanalysis under the influences of Jacques Lacan, Louis Althusser and Roland Barthes.

But although this new way of theorizing film challenged many assumptions of earlier film theory, it only reinforced the idea of a passive viewer under the total sway of the film's ideology. Screen authors studied the formal structures of representation in film with a view to describe and explain how they construct for spectators "certain ways of viewing and looking."

(Moore, 12) Following Louis Althusser's (Essays, 24)

exposition of the existence of Ideological State Apparatuses, including the media, religion, the family etc, they considered films as vehicles through which ideology hails, or "interpellates" the viewers as subjects. Lacan's reformulations of Freud's theories within the frame of a structuralist theory of language gave these and other screen theorists a notion of the subject as a de-centered, provisional construction, produced within an external system of signs. (Stam 2000 158ff)

In applying Lacanian theory to film, Colin MacCabe posited a "classical realist text" (2000) which creates an illusory transparency by which the audience members imagine themselves gazing directly into a real scene, instead of watching a movie. Hollywood films thus would seem to constitute this fiction of a unified subject position where the viewer would be hailed in an althusserian fashion and he or she would believe to be "the source of the look," as Jean-Louis Baudry put it, when in actuality their look is being subjected and

controlled by the camera. This was what came to be known as the Cinematic Apparatus¹¹. As Robert Stam puts it:

Apparatus theory at times imbued the cinematic machine with an abstract and malevolent intentionality, falling into a kind of neo-Platonic condemnation of emotional manipulation. But real-life spectators were never the pathetically deluded, shackled captives of a high-tech version of Plato's cave decreed by apparatus theorists. (Stam 2000 139)

Screen theorists preferred type of film, in opposition to Hollywood cinema, was the so-called "Brechtian," avant-garde films which "foreground[ed] the machinery of representation," disrupting the bourgeois ideology's "security of vision" promoted by Hollywood film. In this way, as other authors point out, the subject created by screen theory was a "kind of phantom," an "implied spectator . . . not to be confused with real viewers," in the words of Judith Mayne (30). As she points out, however,

It is one thing to assume that cinema is a discourse (or a variety of discourses) . . . that the various institutions of the cinema do project an ideal viewer, and another thing to assume that those projections work. (Mayne, 30)

¹¹ This process of creating "subject-effects" on a spectator was explained by Jean-Louis Baudry in "Ideological Effects of the Basic Cinematographic Apparatus" (1970).

To summarize the relevance of this discussion to an analysis of disability representation in film, what I argue here is that the same flawed assumptions that governed apparatus or screen theory are at work in the denunciations of disability representation by authors such as Klobas, Norden, Morris or Longmore. Even accepting the existence of prejudicial stereotypes in films and the need for images of disability that escape the positive/negative dichotomy, it is important to recognize that the process of reception of a film is more complex than either the apparatus theorists of film studies or the 'negative images' school of disability studies would like to believe. But how then can the relationship between films and viewers be conceptualized? A key insight towards understanding the complexity of reception moment in the process of communication, and particularly in the reception of television [and film] messages, came with the work of a group of researchers in the United Kingdom, at the University of Birmingham.

Cultural Studies: The Birmingham School

The dissatisfaction with the assumption that the ideology implied in the film "text," grew particularly strong in the U.K., where another group of politically

inflected theoreticians worked at the University of Birmingham's *Centre for Contemporary Cultural Studies*. The CCCS researchers, whose main focus of interest was popular culture, were dismayed by the ease with which the then dominant screen theories lay aside all types of commercial cinema and television programs, as irremediably infected by "bourgeois ideology."¹²

In 1980 Stuart Hall, one of the leading figures at the CCCS, published "Encoding/Decoding," which was based on a 1973 paper entitled "Encoding and Decoding in the Television Message" (Moore 17)¹³, where he set out to combine semiotic and sociological concerns regarding the activity of viewers of television programs. The point of departure for Hall's argument is that media 'language' is not simply a "circulation circuit or loop," but it is instead a

complex structure in dominance, sustained
through the articulation of connected

¹² See for examples of that tendency Jean Louis-Baudry's works cited above, Colin MacCabe's "Realism and the Cinema: Notes on Some Brechtian Theses" (1974) and Brian Henderson's "Towards a non-bourgeois camera style." (1970-71)

¹³ Note the emphasis on television as opposed to film, which is relevant, as film studies would struggle for about a decade and a half under the dominance of "subject positioning theory," with little attention paid to empirical spectators

practices, each of which, however, retains its distinctiveness and has its own specific modality, its own forms and conditions of existence (Hall 1980 167)

Both the producers of a media message, and the viewers of it, are engaged in the work of making things mean by appealing to "codes" or conventional rules of message construction and reading. An important conclusion Hall extracted from this was that "the codes of encoding and decoding may not be perfectly symmetrical," in other words, that there is an activity from viewers that is not pre-inscribed in the text (Hall 1980 169). Hall wrote: "what are called 'distortions' and 'misunderstandings' arise precisely from the *lack of equivalence* between the two sides in the communicative exchange." (169)

Following the precedent of Valentin Volosinov (Moore, 19) Hall, and his successors in "British Cultural Studies" championed a type of research that would be centered not exclusively on the 'text', or on the 'author' or producer of it, as in earlier literary and film theory, but on the context of that encounter between the media product (film, television program) and its socially, historically situated viewers.

Three particular "hypothetical positions" for viewers' reactions were identified in Hall's Encoding/Decoding paper: a "dominant code,"¹⁴ a "negotiated code, or position" and an "oppositional code"¹⁵ (Hall, 174-176) that differently situated viewers could adopt when faced with the same media text. In the first case, the viewer is aligned with the hegemonic ideology favored by the producers of the text; in the second option, he/she will acknowledge the general legitimacy of the ideology presented in the text, but will make certain exceptions according with his/her local situation; in the final possibility, the viewer may completely reject the preferred meanings from the text and re-interpret it in a resistant way. This final hypothetical position is often congruent with a political form of class consciousness, as implied by Parkin's correspondent category of "radical meaning system."

(Moore 19)

¹⁴ Hall included the study of the program's producers under what he called "the professional code," which was a subset of the "dominant code", that was "relatively independent" of it but operated "within the hegemony" of the dominant code. (Hall, 174)

¹⁵ Hall was following sociologist Frank Parkin's notion of 'meaning systems', which that author had employed in his study of social class and political order, in 1972. (Moore, 18)

Among the studies conducted at the CCCS, under the influence of Hall's model, the first one to have a decisive importance for the development of audience research was David Morley's The Nationwide Audience. This project started in 1975-76, when members of the CCCS took an interest in studying the encoding-decoding of Television discourse in the case of *Nationwide*, a BBC political show that aired in between the national news and the peak-viewing time for family entertainment. (Moore, 19) The show's approach was to present how an important political topic affected the daily life of "ordinary" people in the different regions of the U.K. The emphasis in the program's presentation was on ordinary affairs presented in a regional context.

The first stage in the *Nationwide* study was a monograph written by Charlotte Brunson and David Morley, in 1978, under the title: Everyday Television: Nationwide. The audience study that followed two years later was intended to explore the degree of acceptance or rejection of the preferred reading of the program as identified in the earlier monograph.

Twenty-nine pre-existent groups of viewers participated in the study by commenting on selected

Nationwide shows. They were either members of trade unions, students, apprentices or managers who were shown video recordings of *Nationwide* and were then invited to discuss it. Morley looked for patterns in the group's responses to the text's ideology and to the show's mode of address. (Moore, 21)

Pioneering as it was, the *Nationwide* study has been criticized on some theoretical and methodological points by later writers. Morley would later warn that the reduction of reader's interpretative positions to the triad of hegemonic, negotiated and oppositional can be overly simplistic and as guilty of essentialism as the earlier models of the screen theoreticians ("Texts, Readers, Systems", 172) And Janet Staiger criticizes two basic assumptions of the British Cultural Studies model: The first is that even though texts are said to be polysemic, in practice they are treated as unified vessels of hegemonic ideology¹⁶. The second is that, in

¹⁶ Judith Mayne agrees with Staiger when she writes:

...in order to foreground the activity of reading, viewing and consuming mass culture, what Hall's model leaves relatively intact is the notion of a text's dominant ideology. This is peculiar insofar as the activity/passivity of the apparatus model appears to be reversed

Staiger's terms, "readers are reducible to socioeconomic categories," and, she adds: "such a proposition produces ideal readers." (2005 63; 1992 73) In other words, Staiger criticizes the practice of choosing study participants on the basis of their previous classification according to social class status. It was very important for the critical project of the CCCS members to correlate the variations in viewer responses to *Nationwide* with a political context of class struggle and resistance to hegemonic discourses. However, as Staiger points out, "a socioeconomic class member is not all that a reader might be ... gender, ethnicity, and so forth are also identities in which power differentials affect individuals (1992 74).

I agree with Staiger that the identity of viewers is not fully covered by their belonging to a social class. Taking into consideration those other categories is helpful in order to better describe and explain the richness and variability of reception processes, as illustrated for example by Bobo's work among black female

in favor of an active reader/viewer and a relatively stable, if not completely passive text. (Mayne, 39)

audiences. Adding disability to such categories as gender, ethnicity and class is another way to address the complexity of identifications that influence the reception of cultural texts. As we have seen before, through the work of Thomson, for example, and others, the study of disability in society can teach us about the imposition of hegemonic constructions of normality that would seem to fit only a minority of people, if any at all, yet are usually considered "natural."

Following the *Nationwide* study, other investigators used and expanded the encoding/decoding model to research the reading of media products among viewing groups as diverse as soap opera female fans, romance readers, and marginalized punk-rock youths. Ien Ang studied *Dallas* watchers in the Netherlands, at the peak of the show's popularity, in the early 1980s. Respondents would communicate with her via letters, after she published an ad in a widely read woman's magazine called *Viva*. (Ang, Watching Dallas, 10) Her interest was on the intersection between pleasure and ideology. According to Ang, in order to account for their feelings towards *Dallas*, audience members have to "call on socially available ideologies and images, which channel the way in which

such a television serial attains its meanings." She proposed to trace "those ideologies and images in the letters," as a way to find out "what textual characteristics of *Dallas* organize that experience and in which ideological context it acquires social and cultural meaning." (Ang, 11) Another team of researchers, Tamar Liebes and Elihu Katz, (1985, 1990) analyzed the same television program in terms of its cross-cultural reception by different ethnic and cultural groups (Arabs, Russian Immigrants, Moroccan-Jews, Japanese and Americans). An important result of this study was that viewers "use the program as a "forum" to reflect on their identities." The researchers distinguished four kinds of responses amongst their participants: 1. a *moral* response (comparing "them" and "us"), 2. a *playful response*, which involved trying on unfamiliar roles, 3. an *ideological* one where they looked for manipulative messages, and 4. an *aesthetic* one where they identified the formulas from which the program was constructed (Liebes & Katz 1985 45)

Of special importance for the present study is the tradition of research linking minority status in society to specific responses to cultural products. Within the CCCS tradition, as early as 1976, researchers such as

Angela McRobbie and Jenny Garber wrote of the bias favoring male working-class youth among the people being studied. (Staiger, 2005, 86) Other authors, such as Joke Hermes (2005), have invited researchers to examine our motivations for undertaking these studies.

An important precedent for the present study was the research by Jaqueline Bobo's on the reception of the film The Color Purple (directed by Steven Spielberg, 1979) among a group of African American women. This study, which she presented as her doctoral dissertation to The University of Oregon in 1989, later became the book Black Women as Cultural Readers (1995). In her dissertation, Bobo's argument starts from the premise that Spielberg's film expresses society's the dominant ideology concerning the proper place of women of color. She acknowledges that Spielberg himself, as the artist responsible for the film, is subject to an "ideological pressure to reproduce the familiar," even though he is not in a conspiracy against his audience. (Bobo 1989 20) In fact, she quotes Spielberg regarding his deliberate intention not to reproduce negative stereotypes through his casting process (Bobo 1989 21)

As Bobo explains it at the beginning of her text, the aim of her dissertation is to examine a specific audiences' use of mainstream text to empower themselves and their social group. I find her decision to center her discussion on the reaction from a specific social group (black women writers) especially interesting in relation to my own project. Bobo was intrigued by the black woman's audience's "positive engagement" with the film, in the face of an overwhelmingly negative critical response from male African-American critics and cultural commentators. According to Bobo, her dissertation was among the first studies to look at the intersection of class and gender, instead of looking at those two dimensions separately. (Bobo, 1989, 8-9)

For Bobo, there are two aspects of cultural competency that a marginalized viewer can bring to a cultural work: a positive response "where the viewer constructs something useful from the work by negotiating his or her response, and/or gives a subversive reading to the work," and "a negative response in which the viewer rejects the work." (1989 33) Bobo explains that the negative and subversive reading are types of oppositional reading that are prompted by the negative images from the

story of Hollywood films in the case of black viewers, while the positive female response to The Color Purple can be explained as an incidence of intertextuality, given the contemporary proliferation of creative works by black women.

The concept of articulation, which Bobo introduces in her discussion of black women's responses to the Spielberg film, is particularly interesting for my own study. After tracing a lineage of black female writers, whose work in her view influences the positive responses of her specific group of viewers of The Color Purple, Bobo explains that articulation, as advanced by Ernesto Laclau and commented upon by Stuart Hall, is the process by which "individuals within a particular society at a specific historical moment wrest control away from the dominant forces in a culture and attain authority over their lives for themselves and for others within their social group." (Bobo 1989 36)

She adds that the word articulation means "a connection, a linkage that can establish a unity among different elements within a culture under certain conditions." (1989 36) Bobo also explains that the meaning of articulation can be taken in two different

senses: that of a "joint" as in between the limbs of the body, or that of "giving expression to." As she explains it, Stuart Hall objects to the second sense because for him there can be no unity in a social group. The structure between the social group and the signifying text is not identical, the articulation being more the result of a social alliance in a political context which makes it useful for a time and a purpose so that the members of the group make it a cohesive one.

The importance of an articulation is that it allows for cultural transformation, as the articulation disrupts old ideologies and helps the group realize that they are in the midst of a moment of change. For Bobo, the union of a positive response from women to The Color Purple, and a Black women's writer's tradition makes up an articulation which "solidified a gestating social movement of black women." (1989 38) Likewise, my study aimed at showing whether (and if so how) the responses from my group of disabled viewers evidenced a degree of articulation between their encounter with the films under study and the disability movement's struggle for influence over the media representations of disability.

Other Empirical Studies of Disability Reception

Only four prior studies have attempted to research into the reception of disabled audience members to their representation in cultural products. These are: a small-scale study of the reception of the BBC drama *Scallagrigg*, performed by the British Broadcasting Standards Council in 1997; two reception studies (1997, 2001) conducted by Karen Ross, from Coventry University, and an Israeli study in 2004 conducted by Amit Kama.

The first study, on a drama about a teenager with cerebral palsy concluded with the following findings: 1. viewers sharply criticized heroic depictions of individuals as "overcomers" of disability. 2. Viewers required primarily positive images of disabled characters. 3. Finding programs about disability is difficult, as they are confined to unattractive and unpopular programming slots. (Broadcasting Standards Council, 193-205)

The second and third studies, by Karen Ross, employed focus groups (33 in the first study) and postal questionnaires in the second study. Echoing the complaints of Klobas or Morris, participants in those studies complained about the absence of "real-life

experiences" or living with disability in an ordinary, everyday life. The emphasis on ordinariness was notable, as opposed as being represented as "disabled." Ross's second study was particularly geared towards the reception of radio programming (BBC) by audience members who identified as disabled. This was a large study with "469 people with a disability ... including 82 participants in 15 group interviews, 85 individuals who completed questionnaires and 372 people who took part in a telephone interview." (Ross 2001 424) Her results include the following conclusions:

1. Participants continued to decry the appearance of people with disabilities as "tragic but brave," "dependent but helpless," "bitter and twisted," "sexless and isolated" and other stereotypical images.

2. Participants were irritated that whenever a person with a disability was presented as brave and able to "overcome," that story became a "benchmark" for others with the same impairment.

3. Participants decried the practice of "sanitizing" the presence of disabilities for the tastes of a non-disabled audience. This was linked to concerns about "acceptability" on the part of a wider audience as well

as with the ignorance and lack of concern about disabilities among program producers. Additionally, listeners noted the preference routinely given to portrayals of blind and wheelchair using characters.

4. Listeners also criticized the use of offensive language, for example expressions such as: "wheelchair-bound," "crippled," "handicapped," or the use of the generic "the disabled," which are often inaccurate (wheelchair-bound) but also which many people with disabilities consider derogatory. (Ross, 2001 425-429).

Amit Kama's study, finally, is the closest one to my own project, but it differs from it in terms of its scope. Kama's study interviewed 30 Israeli people with disabilities who participated in focus group interviews (each lasting about 45 minutes). Kama's interests, like those of my study centered on the relation between films and the psychological and sociological processes of identity construction. However, Kama's scope, at least as far as the published study results show, is restricted to the examination of only two stereotypical images: the "supercrip" and the "pitiful handicapped." (Kama, 447) That study concluded that the Israeli participants feel an intense antipathy towards depictions of the "pitiful

handicapped," but, interestingly, they do not seem to harbor negative feelings towards depictions of the "supercrip." Instead, Kama explains: "Highly regarded supercrips embody one example as 'regular' supercrips (i.e. 'someone like me') people are especially coveted" (447). And further,

This sort of triumph is used to validate the disabled individual ('I can do it') and to alter societal perceptions ('The disabled can be like everyone else'). Consequently, the wish to see disabled people who 'have done it' is particularly intense, while the pitiful disabled trigger antipathy because they reproduce and reinforce the cultural status quo (464)

It is noticeable that Kama's conception of the representation of people with disabilities as 'regular people' is still framed by the category of the "supercrip." This is an inclusion that I reject. In Kama's view, in spite of the author's intentions to avoid a polarization between negative versus positive images, the middle point in the spectrum is still assimilated to the "Super Crip" stereotype. This runs contrary to the views expressed by Ross' listeners, above, who decried the imposition of a need to live up to an excessively perfect 'benchmark' represented by the "Super cripp" ideal. This is one way in which my own American

respondents also differed sharply from Kama's, as the following chapters show.

Chapter 3

Methodology and Research Design

I conducted five focus group interviews over the course of five months between November 2004 and April 2005. Prior to this, a preliminary stage had to be completed, in order to be able to work with participants for the study. In February 2004 I presented a project to the University of Kansas Human Subject Research Committee for the Lawrence Campus. In September of that year, after my prospectus for the study had been approved by my Dissertation Committee, I completed a mandatory online tutorial with HSCL, on the subject of ethics of research with human subjects, as did my advisor. Finally, on November 11, 2004, the study was approved by HSCL, under "approval stamp HSCL #14955." This approval was subject to the drafting of an "Informed consent form" to be supplied to all participants. In essence, this document outlined the regulations under which the study was to be conducted and informed participants of their right to withdraw at any time they deemed necessary or convenient.

Data collection

I was looking for a group of adults with physical disabilities from the Lawrence, KS and the greater Kansas

City area, who would be willing to volunteer to participate in the study. They would not receive any monetary compensation in exchange for their participation. Initially, a double strategy was attempted in order to publicize the study and recruit interested individuals. First, I attempted to look for volunteers for the focus groups in the area of Lawrence and adjacent municipalities, including several suburbs of Kansas City. Secondly, at the same time, I tried to call for participants who would be willing to send me written accounts of their experiences with films that depicted physical disability, by issuing a call to that effect through *New Mobility Magazine* (a paper and online publication specializing in disability issues). Even though the editors of *New Mobility* agreed to publish my call for volunteers, this initiative did not achieve any positive results whatsoever.

On the other side, the call for participants in the focus groups, which was expected initially to draw a fairly large number of possible participants (my hoped for number initially ranged around 20 to 25 people in total), was not going much better.

In the fall of 2004 I sent a request to a non-profit disability organization in the Lawrence (KS) area to publish an announcement in their bulletins and other communications to their constituents. By September 14, with the help of Ms. Dorothy Nary, M.A. (Director of the Independent Living Center at the University of Kansas, in Lawrence), I made a personal contact with a member of a local Independent Living Center and with their assistance I could finally secure the participation of a group of seven (five male, two female) participants. They all ranged in ages from 20 to 54. There were two participants in their thirties, one in her forties and three in their fifties. In the next five months, their number would fluctuate between three and four actually attending each focus group interview. Although this was a much reduced number of participants than I initially desired, it nevertheless allowed me to successfully probe the responses to disability representation in films as required by my study goals. A schedule of focus groups with their topic dates and locations can be seen here, together with a list of the participants:

FOCUS GROUP #	DATE	PARTICIPANTS	TOPIC
Focus Group 1	Nov. 12, 2004	4. CR (36,M) RI (51,M) RA (54,M) LO (36,F)	GENERAL DISABILITY REPRESENTATION IN FILMS & MEDIA.
Focus group 2	Dec. 10, 2004	3. BO (53,M) SH (43,F) CR (36,F)	THE BROOKE ELLISON STORY
Focus group 3	Mar. 18, 2005	3. BO (53,M) RA (54,M) RI (51,M)	THE SEA INSIDE
Focus group 4	Apr. 18, 2005	4. ZA (20,M) RI (51,M) BO (53,M) RA (54,M)	PRELUDE TO HAPPINESS
Focus group 5	Apr. 24, 2005	3. BO (53,M) RA (54,M) RI (51,M)	PASSION FISH.

TABLE 1 - SCHEDULE OF FOCUS GROUPS

Name	Age	Gender	Education/Professional Background
L0	36	Female	Disability Sensitivity trainer.
SH	43	Female	Office Worker, Mother.
ZA	20	Male	College Student
CR	36	Male	Psychologist, Disability Counselor, Photographer
RI	51	Male	Psychologist, Disability Counselor.
BO	53	Male	Disability Services Administrator
RA	54	Male	Psychologist, Disability Counselor.

TABLE 2. FOCUS GROUP PARTICIPANTS

Selection of the Films Under Study

Trying to be faithful to the philosophy of qualitative research, I initially planned to elicit from participants the titles of those films that they might spontaneously consider relevant to the discussion of how disabilities are represented in film and television. Therefore, the first focus group interview was open-ended, with a number of general questions and a fairly wide variety of clips sampled from film history, all of which dealt with physical disability, and particularly with mobility impairments, which were also prevalent among the study participants.

My original design of eliciting "spontaneous memories of mass mediated images" (Kama, 452) from the group of respondents afforded me an early surprise. In my initial questioning, during focus group # 1, participants only suggested the title of the Christopher Reeve television movie, The Brooke Ellison Story, which had recently appeared on television (broadcast by the A&E cable channel) and was therefore topical. I could equally have chosen Reeve's television version of Hitchcock's Rear Window (Dir. Jeff Bleckner, USA, 1998), but I selected The Brooke Ellison Story, based on its

topicality and interest to the participants, one of whom had praised it during the first focus group. Other films mentioned that day were older titles which I judged sufficiently studied in the pre-existing literature, such as The Best Years of Our Lives (Dir. William Wyler, USA, 1946) and Coming Home (Dir. Hal Ashby, USA, 1978).

After my first focus group and under the pressure of time to start planning and executing the remaining interviews, I took the initiative of choosing a number of films that I considered especially relevant to the discussion of different physical impairments or different ways of dealing with the same impairment (for example, quadriplegia in The Sea Inside and The Brooke Ellison Story). I considered variety as one of my criteria, but I was also trying to discuss films that were either recent, as the two aforementioned ones, or ones that were not as much discussed in the literature, such as Passion Fish and Prelude to Happiness. Participants could then respond, interpret and discuss these films in front of a video camera. The list of films chosen is as follows:

1. The Brooke Ellison Story, (2004) a 'made for television' film depicting the life story of an actual quadriplegic young woman, from the time prior to her

accident (at age 11) to her graduation with academic honors from Harvard University. This film was the last one directed by the late Christopher Reeve shortly before his death. It exemplifies the genre of the made-for-television movies and it is a story based on real-life. I chose it as well, as explained above, because it had come up in my initial focus group discussion, in connection to its director's controversial role in the field of disability activism and representation.

2. The Sea Inside (2004). Directed by Spanish filmmaker Alejandro Amenábar, it is the only foreign film included in the study. It became prominent in 2004, as the winner of the Academy Award for Best Film in a Foreign Language. It depicts the struggles of another real-life character, Ramón Sampedro, who waged a 30 year public campaign to obtain the right to die, after becoming paralyzed from the neck down in a diving accident. The film, although not originated in the U.S., achieved wide exhibition due to its success in the Academy Awards.

3. Prelude to Happiness (1974). An independent, low-budget production, made in Texas, and starring Rose Petra, an amputee actress and model who sells the video

through the internet. This film allowed us to discuss a different disability, amputation, as well as other modes of production, from the slick, multi-million dollar productions of the mainstream industry, to the independent scene. The fact that the film is a melodrama also allowed me to inquire about participant's responses related to issues of intimacy and love between partners with and without disabilities. This aspect, although present in all of the films studied, was especially salient in this one.

4. Passion Fish (1992). Written and directed by a well known independent filmmaker, John Sayles, this feature film achieved two Academy Award nominations (Best Actress, Mary McDonnell, and Best Screenplay, Sayles) in 1993. The story concerns the recovery of a successful soap-opera star who becomes paralyzed from the waist down (paraplegic) after a traffic accident in New York City, and subsequently moves back to her ancestral home in the Louisiana Bayou.

Conducting the Focus Group Interviews

Several scholarly sources were useful regarding the procedures and nature of the focus group interview process. Among these, a chapter by George Gaskell,

entitled "Individual and Group Interviewing," (Bauer and Gaskell 2000) was most helpful, together with the series of manuals on focus groups written by David L. Morgan and Richard A. Krueger (Focus Group Kit), and a chapter by Martha Ann Carey, entitled "The Group Effect in Focus Groups: Planning, Implementing, and Interpreting Focus Groups." Carey gives the following definition of this type of interview:

Using a semi structured group session, moderated by a group leader, held in an informal setting, with the purpose of collecting information on a designated topic....the collection of personal experiences and beliefs related to the designated topic is the purpose of the focus group. (226-227)

I initially approached a local disability advocate, whom I had met in the course of a previous class project, in order to be the moderator of the first focus group. Eventually, because of the unexpectedly low number of participants who responded to my recruitment efforts, he became one of the study participants (identified in the table above as RI), and I continued moderating the discussions.

Previous to any focus group meeting, I would draft a short number of questions (approximately 5-6) related to the depiction of disability in the film under study. I

would then ask the group and then I would strive to not interrupt or unduly influence their answers. Although I did not achieve that ideal unobtrusiveness all of the time, I think I was mostly successful in this regard. With one exception, the meetings took place immediately after watching the films, so that their details would be fresh in the minds of questioner and participants alike. The exception was focus group # 2, where a different strategy was tried: distributing the film on video-cassette to all participants for their private viewing, prior to the common interview. Although the logistics of this arrangement meant a shorter time commitment for participants, I deemed it less useful in terms of the ability of the discussion to take place shortly after viewing the film. It also tended to undermine the communal aspect of film viewing, which proved to be an interesting feature of the response to at least one of the films (Prelude to Happiness) and which would have been missed under the alternative arrangement. Therefore, after this experiment on focus group 2, we returned to the regular practice of watching the films and discussing them subsequently.

All focus group discussions took place in wheelchair-accessible rooms, and they were recorded on videotape by ad-hoc technical assistants or by me directly. The tapes were then transcribed (a long and laborious process), and finally analyzed, or 'coded', in the qualitative research terminology.

The Issue of Validity

According to Carey, "a group has a chemistry and a dynamic that are greater than the sum of the members. In a different mix of members, the data collected could, and likely would, be different." (233) She also emphasizes that "specific data are not readily comparable across groups ... it is more appropriate to examine broad themes across sessions." (233) Even acknowledging the fact that "psychosocial factors" intervene in the data obtained in focus groups, she states that the data are nevertheless valid because "What is collected, though possibly subject to some constraints, represents the reality of the experiences of the group members." (233)

Coding Methodology

My coding methodology is derived from the model provided by Carl F. Auerbach and Louise B. Silverstein in Qualitative Data: an Introduction to Coding and Analysis.

In that volume, these psychologists describe their work at the Yeshiva University Fatherhood Project, a long-term study of fatherhood across diverse communities in the United States, especially including a study on Haitian fathers which forms the substance of the book. By reconstructing the genesis of their Haitian fathers project and describing the methodology that they, and their graduate students, used for this study, they provide a blueprint for the design of grounded theory studies using the focus group method to collect information. Given the fact that I had previously decided to use focus groups as my primary source of information for my own project, I adopted this book as my main guide to coding and analysis.

Auerbach and Silverstein propose their method of coding and analysis as a means to achieve a number of theoretical constructs derived from the focus group data, in a process they call "hypothesis generating research," as opposed to more traditional social science methodologies aimed at "hypothesis testing." (4-9, 14-21) Their book seeks to provide beginning researchers with a methodological toolbox that will allow them to conduct grounded theory research as a way to develop hypotheses.

The first step in Auerbach and Silverstein's method is the selection of "relevant data" among the mass of information produced in the focus group interviews. After transcribing the raw data and reading and re-reading it, a number of relevant passages capture the attention of the researchers. These are marked, often through the use of underlining in several colors. I have used this procedure through the electronic underlining function of the Microsoft Word software in which the interviews were transcribed.

After having a number of relevant text passages selected, researchers proceed to extract the "repeating ideas" or "text-based categories" included in the selected relevant text. An example of a "repeating idea" (the more user-friendly term, according to the authors, an opinion with which I agree) in their study is this: "My father never said I love you." This is a statement that they found in different forms throughout their conversations with Haitian immigrant fathers interviewed in the State of Florida. I have so far followed their lead to identify a number of such statements made by the participants in my focus groups which contain important ideas that came up in conversation several times while

discussing the movies sampled. I have tried to select direct quotes from the focus group transcripts to name these categories, whenever possible. For example, a repeated idea I have found is this one: "*I think a lot of us didn't trust Christopher Reeve for a long time.*" This direct quote from a participant in focus group one (a general discussion before concentrating on any particular feature film) was repeated and expanded in several other conversations. The figure of Christopher Reeve as a disabled celebrity in recent years became a point of contention and the focus of a distinctly divergent interpretation among people with disabilities as compared to the general media audience. His post-accident life and his subsequent fame as a crusader for a cure to paralysis touch on issues of activism of disabled people in society, celebrity, controversies over the medical model vs. the social model of disability, and the creation of motion pictures focused on disability issues. Therefore, Reeve's presence looms large in the course of my study, as his example was often referred to in the discussion of other films.

After finding the "repeating ideas" or "text based categories" in the transcripts, the researchers proceed

to group them into larger units that Auerbach and Silverstein term "themes," or, in their more arcane original language, "sensitizing concepts." (36) These themes are implicit topics shared by a group of repeating ideas.

In their example of their Haitian fathers study, Auerbach and Silverstein found the following theme, with its corresponding sub-groups of repeating ideas

Theme: A. Praising aspects of the traditional Haitian father.

This theme included these repeating ideas:

1. "My dream was to look like my father."
2. "There is no inch of laziness in my father."
- 3 "I love the way my father treated my mother." (Auerbach & Silverstein, 36)

In my own grouping of repeating ideas and themes, I found correlations between several repeating ideas, so that I was led to group them into unifying themes. This process is still on-going as I write this and no doubt I will have to revise and refine it as I go along. For example, the following repeating ideas from my transcripts share a common theme that I have called, "acceptance versus prejudice in non-disabled interactions with people with disabilities."

1. "People have a curiosity about it"... "Some people chose to be up front about it."

2. "Being around my grandparents was kind of weird."

3. "It seems to be more accepted to have had an accident."

My coding proceeded along the lines of Auerbach and Silverstein's examples. After completing my list of repeating ideas and themes, I was able to move on to the third step in the process, the creation of higher level interpretations that Auerbach & Silverstein call "theoretical constructs" and "theoretical narratives." A theoretical construct is a larger idea that encompasses several themes and relates these to the existing literature in the field in question. For Auerbach and Silverstein, the relevant field is psychological literature and theory (39), while for me the two relevant fields would be film studies and disability studies. Already at the level of repeating ideas and themes I have found echoes of discussions seen in the corresponding literature, but a firmer correlation is presented later in this manuscript when I discuss the stage of "theoretical constructs." Finally, a "theoretical

narrative" is a kind of summary of the conclusions of the study that links the theoretical constructs found through the process of coding, specifying "what we ha[ve] learned about our research concerns." (40)

I have found the method of analysis advocated here to be quite clear, user-friendly and fruitful in organizing and understanding my findings. On the next page, Table # 3 describes the repeating ideas and themes I identified in the five focus groups. I then discuss these in more detail in the remainder of this chapter.

APPEAL (Or LACK THEREOF) OF DISABILITY CENTERED MOVIES.
<i>"I don't watch those kinds of movies"</i>
DRAMA VS. REALISM
<ul style="list-style-type: none"> • "Movies do not show all the hassle."
<ul style="list-style-type: none"> • "You always wonder how much is based on real life and how much do they choose to use drama to embellish for the sake of entertainment."
<ul style="list-style-type: none"> • "If you really want to capture what's going on in the culture, look at what's going on with the minor characters"
CELEBRITY AND DISABILITY
<ul style="list-style-type: none"> • "Those people in that age really were <i>champions</i>"
<ul style="list-style-type: none"> • "I think a lot of us didn't trust Christopher Reeve for a long time."
<ul style="list-style-type: none"> • "My family and friends [...] They wouldn't watch the Telethon!"
ACCEPTANCE VS PREJUDICE IN NON-DISABLED PEOPLE'S INTERACTIONS WITH PEOPLE WITH DISABILITIES.
<ul style="list-style-type: none"> • "People have a curiosity about it". "Some people chose to be up front about it."
<ul style="list-style-type: none"> • "Being around my grandparents was kind of weird."
<ul style="list-style-type: none"> • "It seems to be more accepted to have had an accident."
<ul style="list-style-type: none"> • "You gotta stick to your own kind."
<ul style="list-style-type: none"> • "The mother actually did an awful lot."

Table 3. FOCUS GROUPS – REPEATING IDEAS AND THEMES

Global Results of the Group Discussions

Appeal (Or lack Thereof) of Disability Centered Movies

"I don't watch those kinds of movies"

I suppose speaking as a person in a wheelchair it's a main issue with me. But at the same time, I don't like to watch hospital movies, because, 'been there, done that' you know [...] speaking for example of the clips that we just watched, it kind of like brought me back a little bit to when it was a first ordeal for me, you know? and it's like: "oh, no, I remember feeling like that..." (CR, FG1, 36)

Participants point out that they sometimes shy away from movies that depict disability, not only because they have the potential to bring back painful memories, but because they oppose the general practice of focusing on the medical aspects of disability (impairment), viewed as a tragedy.

Regarding the portrayal of different kinds of disabilities in film and television, it is clear that the emphasis on visible sources of disability, such as mobility impairments is only a matter of methodological expediency. In practice, many of the observations made here apropos physical disability can also be extended to psychological impairments or learning disabilities. Members of the disability community in fact express a will to think and act in a united way, and some, like LO

(F, 36), express having "a hard time, separating disability." As she says: "when I was asked to come up with five movies portraying people with physical disabilities, what I kept coming up with was things like Rainman, Radio, but those aren't [...] physical disabilities. (FG1, 37) On the other hand, they confess to the same kinds of questions and lack of knowledge as the general public as to the specific details of disabilities other than their own:

Well it's always instructive to see Daniel Day-Lewis or Deaf culture being portrayed in some manner... I know very little about it. Obviously this world is important to me, but there's so much of it that I don't know, so, movies have an important role, at least to me, for that reason [....] But by the same token I get really scared that they're getting it all wrong. (RI, FG1, 37-38)

RA expresses a positive side of living with a disability and having a sense of community: "it makes for a more, if you will, human rights perspective to be a natural inclination," and fosters an "appreciation for people that are making it with obstacles." (FG1, 16).

"Drama" vs. "Realism"

The same person remarks the following, regarding his general attitude towards depictions of disability in film and television:

I can't remember watching a movie or TV show and saying: That was so unreal because there was nobody with a disability in it. But I certainly can remember one where there was some incident related to disability and it was done ineptly. And I think: 'Oh, man, those people don't have a clue.' (RA, FG1, 50)

"Movies do not show all the hassle" (fg2, p.2, 24, 25).

Dangers and difficulties of daily care for a person with a disability (such as aspirations of mucus from a quadriplegic person's respiratory system, use of catheters, etc.) are reduced in film portrayals. Focus group participants explained this fact as a result of such portrayals being "too disturbing" (to non-disabled audiences) and not marketable¹⁷. Further, participants showed ambivalence about their desire to see the true difficulties of daily life as a disabled person portrayed accurately, and the recognition of the discomfort in watching those kinds of scenes. SH expressed it this way during focus group 2, regarding The Brooke Ellison Story: "Who wants to see all that hard stuff?"

"You always wonder how much is based on real life and how much do they choose to use drama to embellish for the sake of entertainment" (fg1, p. 5, 15; fg2, p. 5, 22).

¹⁷ Recall a similar line of reasoning from Ross' radio listeners, discussed in Chapter 2.

This idea, which could also be abstracted as part of the conflict between "Drama" vs. "Realism" reoccurred in the different discussions. It was particularly important to one of the participants in his appraisal of every movie in question, but it is also mentioned by others. The criterion of *realism*, despite being a problematic category for film theoreticians, was still held as an important yardstick by participants, who often wondered whether a certain detail in a film is "what really happened" or whether it came about "for the sake of drama or audience attraction." Participants were particularly critical of dramatic portrayals of disabled characters as tragic figures or, on the opposite pole of the spectrum, as super-human beings. As one of the focus group participants (B0) characterizes it, portrayals of disability in movies usually fall in two categories: "Tragedy or Super Crip." (FG3, 45) This is also a common complaint in the literature on stereotypical representations. (E.g. Norden, Longmore, Klobas etc.)

"If you really want to capture what's going on in the culture, look at what's going on with the minor characters."

As CR observed, taking the 'drama' approach to a story about disability can make sense from the point of

view of the writers, even if it does not satisfy the expectations of audiences with a direct knowledge of the issues involved:

...most of [the stories are set] early [...]from the onset of disability, which I can see why, storytelling-wise, I mean that is probably the most dramatic time, when you have a disability, it's when the change first occurs, [...]it's the most emotional time and stuff, so it's probably, might be better storytelling, but[...]it doesn't seem like there's [...] just a guy who happens to be in a wheelchair situation...(CR, FG1, 8)

RA echoed CR's feelings:

...whether a movie, or film or whatever is about a particular disability or person or whether [...] there's people that wind up being in a certain scene or in a certain movie or television show, that's not about them, they're just there, I guess my own feeling is that over the long haul you get less of the former and more of the latter, is really more influential on the culture, in terms of, you know, not just having to see another *Helen Keller Story*. (RA, FG1, 38)

CR and RI agreed too that when characters with disabilities are included in secondary roles, not as the center of attention, that inclusion is "bringing it to consciousness without shoving it into your face. You know. 'This is the story. This is what it's about. It's just there.'" And RI stated: "That's more of a reflection of the society and the culture. What do you do with the

minor, minor characters in Hollywood productions of a given year or decade. You know.”

The importance of television and its pioneering role in this sort of integration through the inclusion of minor characters was pointed out by RA, in turn: “...you got these cartoon characters being integrated in this mad world of *South Park*, Colorado, and I think that’s just as much in the background of what they’re doing, as somebody in a wheelchair would be in some office scene.” (FG1, 48)

LO raised a critical voice, even when recognizing that the Industry is attempting to correct the problems traditionally observed with regards to disability representation:

I think Hollywood is doing a better job than it used to, of portraying people with disabilities, but at the same time we have things like The Jerry Lewis Telethon every year, which I think skew the view of what real disability is like. And so, I’m not sure, you know. I ‘m not sure that the ‘overcomer story’ of “look, I’ve, I’ve conquered my disability” is any better. (FG1, 29)

Celebrity and Disability

“Those people in that age really were champions”

Participants identified a few historically important films in portrayal of disabled “average guy,” especially in the context of war and its aftermath. In particular,

they mentioned The Best Years of Our Lives (Dir. William Wyler, 1946), and Coming Home (Dir. Hal Ashby, 1970). Regarding The Best Years of Our Lives, they connected the film's depiction of disability with the existence of a few well known celebrities with disabilities in the 1940s era. Among these, the outstanding figures were Franklin Delano Roosevelt, the President, and writer and advocate Helen Keller, whose lives have made it to the screen. Also, Harold Russell, a combat veteran who came back from World War II having lost his hands in a naval explosion and who starred in the Wyler film. One focus group participant (RA) remembered him as "this guy who was for a long time, chairman of the President's Committee on, what it used to be "Employment of the Handicapped." These earlier disabled celebrities were remembered with respect, as pioneers of the integration of people with disabilities in society. They were seen as "Champions" for disability awareness in an era where only a few people with disabilities were visible in the public sphere.

"Because, I think they were made, I don't want to say they were made into celebrities, but their celebrity status was *enhanced*, and it was built around their disability, perhaps their *uniqueness* and the fact that they were

accomplishing some things, even though they had a disability. So, those stories I think were few and far, farther between, when you think about now for example, Children for a Lesser God, from that comes Marlee Matlin, then becoming a TV attorney, and other roles where she sort of more blends in, it's not about being deaf." (RA, FG1, 21)

"I think a lot of us didn't trust Christopher Reeve for a long time" (fg.1, pg.15).

Actor/director Christopher Reeve, who became a quadriplegic after a horse riding accident and lead a widely publicized campaign to find a cure for paralysis, was the focus of mixed feelings among participants. Reeve's concentration on medical issues ("search for a cure") created controversy among the disability community because of the perceived lack of a social, civil rights emphasis. (FG1, 15-18; FG2, 3, 15-17). As an example of a lack of clarity regarding social and historical context in Reeve's film The Brooke Ellison Story, BO cited the school board's initial refusal to accept Brooke's return to classes after her accident, in seeming violation of Federal Law. Participants mentioned the existence of various legal and institutional barriers to integration of people with disabilities, which are did not seem to be as emphasized enough in films, especially in The Brooke

Ellison Story, for example, insurance companies and Social Security Administration rules, school board decisions, etc. (fg2, p.13, 14).

Christopher Reeve's celebrity and the media's attention to his every minute physical progress were seen as "hoopla." His media figuration was considered as the latest in a line of stereotypical "super-crip" media depictions, including those of Helen Keller and Franklin Delano Roosevelt with implicit connotations of condescension and pity from non-disabled people towards people with disabilities (FG.1, pg.14, 15, 18; fg.2 pg. 22).

RA: [Christopher Reeve] has got to go, oh it's terrible, he's got to make you feel like oh how terrible and pitiful these people are in order to get, you know, the appeal for money.

RI: Superman can fly again if you give him a little bit of money.

RA: Yeah.

BO: Yeah, I mean that's the whole approach.

RA: And so that correlates with the same kind of drama thing, I mean, we're back to the drama thing. (FG3, 43)

After acknowledging a certain prevalence of hostility towards Christopher Reeve's celebrity, participants sought to explain his attitude or to exculpate him for his emphasis on the cure, stating that it could be explained by his level of injury

(quadriplegic) and relative difficulty to lead an active life on his own (FG2. pg.16). However, among positive consequences of Reeve's work, his remake of Hitchcock's Rear Window is seen with curiosity as a celebration of assistive technology. Respondents perceive an instructional value in films of that kind (fg.1, pg.17).

"My family and friends [...] They wouldn't watch the Telethon!"

There is among participants a marked suspicion of charity initiatives featuring prominent celebrities, ostensibly for the purpose of helping people with disabilities. Part of the same doubts raised by Christopher Reeve and his campaign for the cure to paralysis are elicited by the figure of comedian Jerry Lewis, organizer of the famous *Telethon*. He is charged with manipulating audiences by presenting people with disabilities as dependent and pitiful figures, worthy only of the paternalistic aid from the non-disabled community. His private attitudes are exposed as hypocritical and damaging to the disability rights cause, although there is a certain pragmatic acceptance that his tactics may be effective in raising money. The subject showed a certain ambivalence on the part of the

participants, who nevertheless seemed to be generally against the use of those pitiful images that Lewis' and other Charities promote:

I wonder if it's the same audience for both things [*Coming Home* and *The Jerry Lewis Telethon*]. The people who would be interested, ok, the people in my life that I would wind up talking with about *Coming Home* or something else, my family and friends, most of whom don't have disabilities... They wouldn't watch the Telethon! [...] I'm wondering, do the people who watch the *Telethon* have any clue about what we would be saying about the Telethon, and I think the answer is No! (RA, FG1, 30)

A younger participant, CR, counters RA's argument on practical grounds:

CR: If I stay back from just the outside and not watching it, and going, nobody really tells me about it but somebody says: "Jerry Lewis Telethon has raised 45 million dollars for, for research in disability, I would say: "that's a good thing".

RA: But the outside is, at the expense of what? Or whom? (FG1, 31)

Acceptance vs. Prejudice in Non-Disabled People's Interactions with People with Disabilities

"People have a curiosity about it". "Some people chose to be up front about it."

Non-disabled people are interested in knowing about people with disabilities, but their attitudes in social contacts can be sometimes inadvertently condescending or rude. For example, a female respondent SH, who uses a

power chair for mobility, recounted the following story, in our focus group # 2:

SH: I was writing a check in a department store one time, and a woman said to me, just exactly what is that is wrong with you. And I said: I didn't realize we knew each other that well. And then she goes, oh, I'm sorry. I was in a bad mood that day, so see, I thought.
AF: How often does that happen that people are rude like that?
SH: Well, I mean, she didn't think she was being rude. *She thought she was carrying on a conversation with the village idiot, I guess, I don't know.* But, I mean, she thought that and then she realized that she was rude. I mean, she said, I'm sorry and I said, and you should be. (FG2 19, my italics)

People with disabilities, in turn, adopt different strategies to respond to these situations. Brooke Ellison, for example, announces to her peers the reason of her using a wheelchair on the first day of classes, just as she introduces herself. Participants said that they sometimes can be more open to children's questions. In fact, the degree of acceptance or prejudice they experience in their encounters with non-disabled people seem to be linked to age and life experiences, which is our next theme:

"Being around my grandparents was kind of weird."

School children are quick to accept a newly disabled person. Older adults have the most difficulty (FG1, 10;

FG2, 12, 20). Some respondents expressed a certain "forgiveness" of older generations' entrenched prejudices, while at the same time not feeling happy about them. They emphasized that there is no single right way to approach these contacts, but each person develops a distinct strategy or strategies with which he or she feels more comfortable (FG 2, 18, 19, 20, 21, 22).

Participants were also aware of the gains made in terms of accessibility of public spaces, visibility in the media, etc, through the efforts of the disability rights movement, even when they decried the lack of emphasis on those social and political aspects in some media productions. Comparing the current social environment to the one a paralyzed veteran (Marlon Brando) encounters in Stanley Kramer's The Men (1950), when he takes a date to a restaurant, participants commented that "then [in the 1950s] he couldn't have gotten into the damn restaurant," had he been an actual wheelchair user. (RA, CR, LO, FG1, 13-14) RA reflects:

When I went to school, I was the only kid with a disability in an elementary school in Dallas. My daughter went to school here. There were kids with walkers and kids in chairs, I mean, there was not a huge number of them but there were kids with different disabilities, and plus the fact that she knew I guess all my friends,

cause I was in the disability rights movement, where people would be using chairs and she rode around in a chair when she was four, and her view of the world was totally different, than that. (RA, FG1, 14)

Another participant, CR, points out the influence of 1990's *Americans With Disability Act* (ADA) in making disabilities more visible in public life, so in the future "it should become easier to get access to restaurants and other public places." (FG1, 18)

"It seems to be more accepted to have had an accident."

Participants perceive that non-disabled people are more likely to accept a person with a disability when the disability has been accidentally, instead of congenitally acquired (FG2, 17, FG3, 10-11). Some participants associate this to the casting of the leading actors in films. One of them speculates on how differently The Sea Inside would have been received by non-disabled audiences if the leading man had not been portrayed as a handsome man (Javier Bardem) but as someone whose body is misshapen by illness (such as scientist Stephen Hawking).
"You gotta stick to your own kind."

Participants recount an attitude sometimes found in parents, especially of an older generation, whereby a person with a disability is supposed to only form

romantic relationships with "his or her own kind." This belief that "We're made for each other" is coupled with "assumptions that people are making that [for someone with a disability] having a relationship with a non-disabled individual is anathema." (RI, FG1, 12) These isolationist social attitudes ("stick to your own kind," "learn to settle...") may be reinforced by parents of children with disabilities as a way to protect them from prevalent prejudices in the outside world. As such, they possibly might not affect so much that who have been disabled in adult life.

An expression of the existence of curiosity, mixed with prejudice, in the relations between people with and without disabilities, is provided by a clip from a film shown in our first focus group. Participant uniformly reject the self-devaluating attitude portrayed by an attractive young woman who is a wheelchair user in the movie Persons Unknown. (Dir. George Hickenlooper, 1996, USA).

Soon after meeting the story's leading man, (Joe Mantegna), Molly (played by Naomi Watts), informs him that she has learned a lot about men since the accident that left her paralyzed. This includes the notion that

for a man to be attracted to a paraplegic woman, this constitutes "one step up from necrophilia." One of the focus group participants declares himself puzzled by "a particularly bizarre thing that never occurred to me." (RA, FG1, 11). Another one explains it as a symptom of the character's insecurities and "self esteem issues," but a perhaps deeper question they pose is whether the expression of this idea on film is the result of informed criticism from a person with a disability, or a "projection of a world's view of how a [non-disabled] person might feel in those circumstances," in other words, an instance of the prejudices of the non-disabled majority as expressed by the film producers¹⁸.

In connection to the possibility of frank and illuminating portrayals of romantic, and sexual, relationships between disabled and non-disabled partners, participants point to a film that one of them considers "a classic" (FG1, 10), Hal Ashby's 1970 Coming Home, where Jon Voight plays a paralyzed Vietnam veteran and Jane Fonda becomes his love interest. This film

¹⁸ It should be noted here that the suspicious attitude expressed by this character early in the film is later alleviated by the establishment of a romantic relationship between her and the Mantegna character.

constitutes for participants a breakthrough film where, at least one of them for the first time, found satisfactory answers to common questions and misconceptions that non-disabled people often have about people with disabilities: "How do they Do it?" or "they can't have children."¹⁹ In this respect, notes this participant, "movies provide a snapshot... something good that comes out of that." The same man, who now lives with sequels from polio contracted as a child, recounts the impact Coming Home had on him as a young viewer, during that tumultuous Vietnam era: "The thing I remember about Coming Home was that it, I think it was really the first time I ever saw some new movie that really tried to be relevant to me." (FG1, 9) With Coming Home, disability was presented as an average world occurrence. "No more "Quasimodo" or "mass murderer on the lam" and other fringe characters." (RI, FG1, 13)

On the other hand, participants criticize films where characters with disabilities were shown as unable

¹⁹ RA mentions the existence of a disability attraction for an "underworld culture of kinkiness." While he is quick to emphasize that he's "not a member of any such club," he points out the strangeness of the idea that being attracted to someone with a disability can be considered akin to a perversion (necrophilia).

to form lasting relationships. One of the participants sees this as part of the larger "victimhood" portrayal of people with disabilities as tragic figures. Here is BO (M, 53), Speaking of Christopher Reeve's The Brooke Ellison Story, for example:

...showing a failed relationship as if that's the only boyfriend that she'll ever have in her life, which is not a very accurate, I think, depiction of what her life is. Maybe she's probably already had more than one boyfriend. That's the part that still is a little bothersome to me and, you know, I think it's a reflection of where movies that are based on a true story start departing from the true story for sake of dramatic depiction. (BO, FG3, 41)

"The mother actually did an awful lot" (FG2, 1-3, 9, 10.)

Participants perceive that family members as primary caregivers are more dependable than strangers, but they have to sacrifice a lot. In real life, one participant observes, this often takes a toll: marriages are dissolved, spouses leave, etc.

..having a family member like a tough parent, and I know other people with disabilities that in the early part especially of their rehabilitation that family members provide a lot of assistance because it [is] dependable and reliable [...] I've heard some people criticize that, but that's just their own outside opinion, I think. You know thinking, you know, they shouldn't rely on family, they should make their own way, but it's really nobody else's business. It's for that

individual to choose how they work that out.
(BO, FG2, 12)

In conclusion to this chapter, I want to quote the words of one of the focus group participants, who very neatly summarizes the general tenor of the aspirations of many people with disabilities with regards to their depiction in film and television:

My concern is that the general public has the opportunity to have insight to other people in the same circumstance and understand that not everyone has the same perception [...] this does not mean that all people with disabilities or all people who are quadriplegic have that same view of life and that's what I would like to see more exposure of in stories that can be equally entertaining, creative, interesting. [...] If cinema is for the sake of entertainment in large part, it's also information education [...] I would like to see them cover the whole spectrum, not just the most dramatic, most difficult, negative, suffering and, you know. (BO, FG3, 8-9)

After this global presentation of my findings in terms of themes and repeating ideas, my discussion moves on to chapters 4 and 5, where I correlate the responses to each individual film with a more traditional textual analysis that will allow me to complement the participant's responses with the insights from film and disability studies scholarship. Finally, in the conclusion to this dissertation (Chapter 6), I establish

what this study has contributed, and what avenues are open for further study.

Chapter 4

Camp and Irony: Two Independent Films' Views on Melodramatic Portrayals

In 1994, when Martin F. Norden published his comprehensive history of the American Film Industry's portrayal of disability in the 20th Century, his title The Cinema of Isolation, underscored a prominent theme in the mass of footage he had viewed in his research. "most movies have tended to isolate disabled characters from their able-bodied peers as well as from each other." (1) In this chapter, I turn to an examination of two movies that have deliberately gone in the opposite direction, centering on the forging of relationships and domestic life of characters with disabilities, specifically on women with disabilities and the people around them. The films in question are Prelude to Happiness, (Directed by Gidney Talley Jr, USA, 1974) and Passion Fish (Directed by John Sayles, USA, 1992).

Both films have in common their origins outside of the mainstream American film industry, as independent productions. Both too share the fact that their protagonists are women and the sphere of their actions is the domestic realm, which places them both in what is

generally considered "melodrama." I intend to clarify, however, that these films represent divergent attitudes towards melodrama, both at the level of each film's text, and at the moment of their reception by the particular audience of my focus group participants.

Disability Melodrama and Camp Reading.

Prelude to Happiness is a rather obscure work. It came about through the independent efforts of its producer, Robert Pinkerton, in the Summer of 1974. Its director, Gidney Talley Jr. and cast were active in the film industry and theatre at the regional level. All of them, that is, with the exception of Rose Petra, the protagonist, then a young Psychology student at Florida International University who had lost her leg to cancer five years previously.

According to Petra, Prelude to Happiness was never theatrically distributed. Once production finished, Pinkerton sold the movie's rights to a Florida distributor, who then provided Rose with a non-color-corrected print, from which most of the extant subsequent copies were derived²⁰.

²⁰ Petra, Rose, phone interview, 08/07

The film tells the story of a young and beautiful nurse, Susan Imes (played by actual amputee model and actress Rose Petra), whose left leg is removed, eight inches above her knee, after a road accident. The film traces her life from the day just before the traumatic event, to the beginning of a promising love life with a young, talented physician, Dr. Steve Hartman. The film shows the challenges of returning to a working life as an amputee, and especially the self-doubt and inner conflicts assailing Susan as she faces the competition of a seemingly powerful rival for Steve's love.

At the start of Prelude to Happiness, Susan is enjoying a day at the beach, in the company of her fiancé, Joe. The two are shown playfully flirting, running around, bathing and taking leisurely walks by the sea shore in the warm Summer evening. The camera follows their movements while in the background a soft, romantic instrumental melody plays. The shots describing this pleasant outing, however, present what might seem like a curious insistence on the legs of both characters. Their lower extremities are pointedly isolated in various close-ups, as they pose in flirtatious attitudes, run along the beach or, walk together in romantic embrace.

These shots, made with a stand-in for Rose Petra are an early foreshadowing of the traumatic event to come.

As the lovers return to the city, an importune flat tire forces them to get out of their car, in the middle of a back road. They have just finished fixing the tire, when a speedy car approaches them, seemingly out of nowhere, and sideswipes Joe's car, throwing Susan back into the vehicle. After the collision, a terrified Joe grimaces, as he notices the blood on his fiancé's leg. "Oh, God!," he exclaims in desperation.

The next scene takes place at the Hospital, in San Antonio, Texas, where Susan wakes up after an emergency operation. Joe is nowhere to be found. He only reappears a few days later, carrying a small bunch of flowers, nervously stammering an apology and quickly announcing that he is breaking up with the now amputee Susan. The sudden news throws her in a deep despair, from which she will only emerge with the help of Steve Hartman, a sympathetic young doctor. The situation is thus set for the central conflict in the movie, involving the obstructions to the romantic union between Susan and Steve.

Two primary arenas of conflict shape the action dramatized in Prelude to Happiness: Susan's work as a nurse, and her love relationships. The narration solves the first conflict, that is, the challenge that Susan's amputation presents to her ability to lead a self-sustaining life when the principal male characters around Susan, doctors Hartman and Detweiler, exercise their influence to get her a job as a nurse in the same hospital where she has been treated. Thus, a very real and pressing problem for anyone suddenly impaired, is annulled by a 'deus ex-machina' device characteristic of melodramatic plots.

This feature of Prelude to Happiness recalls the imaginary solution to real social conflicts in the family and personal relationships that is typical to melodrama (Gledhill, 13). However implausible the resolution of the challenge to her livelihood can seem, it was something that at least one of the focus group participants considered positive, in the film's portrayal of Susan:

BO: "But that was the other good thing, I thought, it showed she was able to go back to work and get a full-time job and that's true for a lot of people."

The sudden break-up of the previously secure bond of love and prospects of marriage to Joe, motivates Susan's depression. The sheer excessiveness of Joe's rigidity in his rejection of Susan -he goes as far as dressing in mourning when he goes to visit her-- is designed to elicit the audience's sympathy. In the wake of their break-up she struggles with her self-image. She fears that nobody will want to marry her, or worse, that if someone does, it will not be a fair match, and therefore it is something she cannot accept.

The tension between the growing love between Susan and Dr. Hartman, and her hesitation to accept his romantic interest provides an important axis of conflict in the story. Towards the end of the film, after being rebuffed by Susan and trying half-heartedly to formalize an engagement to the wealthy Tiffany (Susan's antagonist), Doctor Hartman suffers a car accident and lands in the hospital, where Susan finally reunites with him, having changed her mind through his tribulations.

Prelude to Happiness' story arc conforms very well to the outlines of melodrama that Ben Singer provides when he refers to melodrama as a "cluster concept," encompassing the dimensions of pathos, overwrought

emotion, moral polarization, a non-classical plot construction, and sensationalism²¹.

The scenes alluded to up to this point neatly fall into Singer's categories of "pathos," "overwrought

²¹ Ben Singer defines melodrama as a "cluster concept" containing the following elements in different combinatory possibilities:

1. Pathos, that is, "the eliciting of a powerful feeling of pity."
2. Overwrought Emotion. The uncontrolled, excessive or intense expression of emotional states, characterized by urgency, and tension. This can include pathos, but also other emotions such as jealousy, greed, hatred, lust, compassion etc.
3. Moral Polarization. Referring to the presentation of conflicts in stark oppositions of good and evil, light and dark, black and white, without any possible nuances or gray areas. Characters embody moral principles, instead of conflicted, multi-dimensional personalities.
4. Non-Classical Narrative Structure. Instead of the carefully constructed plots united by cause-and-effect relationships that characterized classical theatre, and, according to some authors, also "classical Hollywood cinema" narration (Bordwell, 1985), melodrama stories are mostly episodic, more interested in a vivid recreation of sensational moments than in the logical progression of events.
5. Sensationalism. It is an emphasis on extravagance, action, adventure, unusual situations with violent, sordid or gory elements as the basis of the spectacle. As Singer explains it, central to classical melodrama is the combination of "amazing sights with credible diegetic realism." (Singer, 44-49)

emotion" and "sensationalism," especially in the graphic presentation of Susan and Joe's violent accident.

The presentation of Susan's accident with her consequent impairment opens the possibility for viewers to react with feelings of pity towards her, as the *tragic victim* of such an accident. The start of the dramatic action by portraying the accident places Susan's story, at least potentially, in the same genre as well known melodramas such as Sirk's Magnificent Obsession (1954), where the female protagonist is blinded, or Leo McCarey's Love Affair (1939) and its remake An Affair to Remember (1957), where the female protagonist becomes paralyzed. In those three films, the emotional appeal results from the self-sacrifice of the heroine, who is reluctant to let her lover find out about her accident, and to therefore enter into a committed relationship with him. In Prelude to Happiness, although Susan's amputation is a universally known fact, and she openly declares her love for Dr. Hartman, we nevertheless find a similar reluctance to marry him. When Steve proposes to Susan, she emphatically rejects him, presumably on the grounds of that self-sacrificing nature of the melodramatic heroine.

Participants in the focus group on Prelude to Happiness referred to another salient trait of melodrama in relation to the film, that of excessive or overwrought emotion:

RI: It was just over the top.

BO: Yeah.

RA: Or under the bottom or something.

RI: I mean it's such a campy, melodrama...

RA: Yeah.

RI: It's fun to watch for that reason. (FG4 22)

Finally, the remaining characteristics of melodrama, following Singer, are sensationalism, moral polarization, and a non-classical plot construction. In Prelude to Happiness the main instance of "sensationalism" is the accident itself when Susan loses her leg. Without being too graphic in its depiction, the narrative does attempt to convey in very stark terms the dramatic situation by a cut to Joe's horrified reaction.

The trait of moral polarization is most visible in the depiction of Susan's antagonist in the story, Tiffany (Carol Sowa). Physically she is brunette, petite, and very beautiful, while Susan (Rose Petra) is blonde, blue-eyed and very attractive as well. Psychologically, Tiffany is selfish, domineering and nagging. As her name would indicate, she is like a precious jewel on display.

In opposition to the industrious Susan, Tiffany does not work at all, presumably due to her father's great wealth. Her only occupation seems to be to wait for Steve's arrival from work so that they can attend one of numerous social events. Her character is marked as shallow and spoiled, the representative of a life of idleness, hollow appearance and the prospect of a useless, if comfortable, existence for Steve.

This binary opposition between Susan and Tiffany falls well within the generic mandates of the melodrama, where class relations are interpreted in terms of a Manichean dichotomy of good vs. evil. Christine Gledhill explains, Melodrama invariably takes the side of the non-competitive, selfless protagonist, who nevertheless defeats the logic of capitalism. (21) The seemingly powerless thus triumphs. Prelude to Happiness conforms to this manner of ideological operation, as it is clear in the way that the silently persevering Susan keeps her love for Steve a secret for much of the film —while it is wholly transparent to the audience— and never directly confronts her wealthy socialite rival. Yet, in the end, it is Susan who retains Steve's love.

For my focus group audience, the choice was clear:

RA: Well, compare and contrast. A pretty good looking amputee that's decent and interesting to be around, and this snooty, upper rich bitch...when you think, I mean...

BO: That was a good contrast, I thought.

RA: Well, yeah, I guess.

BO: To show that people with disabilities can still be desirable, decent people that you want to marry and be with. (FG4 30)

Finally, regarding its plot construction, Prelude to Happiness also conforms to the episodic character of melodramatic plotting (Singer, 46-47), since its storyline is not developed according to a tightly linked chain of cause and effect. Instead, the narrative of Prelude to Happiness is built around a reduced number of encounters between Susan and Dr. Hartman, which the narration singles out according to their appeals to sensationalism:

1. The accident;

2. A potential night mugging where Dr. Hartman comes to Susan's rescue against two suspect characters who approach her on the street;

3. A critical situation at the hospital, when Susan stands up frozen at the sight of a trauma patient, while a frantic Dr. Detweiler shouts at her to apply an injection, and so on.

The story of Prelude to Happiness relies heavily on generic character conventions. In addition to the stark dichotomy between the good Susan and the bad Tiffany, for example, the narrative presents us, embodied in Susan and Steve, with two generic archetypes, as exemplified by the scene where a distressed Susan is rescued by her "knight," Dr. Hartman, in a dark alley. Similar conventions are echoed at the very start of the film, where Susan and her then fiancé, Joe, playfully enact a scene from an imaginary science-fiction or fantasy movie, in which an alien sea-creature (Joe) is abducting the defenseless female, who protests that her children need her, back home.

In addition to the conventional characters, the acting was excessively conventional for the taste of some of the focus group participants:

ZA: "...if you can get past the shoddy acting [...]it does go through some real issues and it does show that life goes on and [...] it's not just downhill afterwards [as] her old fiancé would have you think. Just walking in the room and not looking at her and dressed all in a black suit like she's dead!" (FG 4, 10)

So, while this quote evinces a clear awareness of the over-conventionality of the production, yet it balances its critique with an appreciation for the film's

attempt to address valid issues of self-image, recovery and adjustment to a traumatic mutilation. The ambivalent response echoes the words of another participant, RA: "it really didn't make you want to gag, it was just that you really had to kind of help it out," where an almost apologetic note appears, as he justifies his camp reading of the film.

As with the overconventionalized portrayals, the gender portrayals in the film were noticeably outdated for the focus group participants. They noted that the film seemed to belong to an era prior to the famously liberated 1970s:

RA: Now that I think about it, this was the 70s, right?

RA: So, they didn't have sex or something, was this like, I don't understand, they're . . . right, they're in their twenties.

BO: The implication was that they had not because she was not comfortable, I guess, with her body, and not to think that she could be desirable in that way. At least, in the beginning, you know, when they first became known that they...

RA: So they're gripping on the sofa and he goes, oh I got to go because of his girlfriend or whatever, the fiancé to be or whatever.

RI: But later on she says well you can stay, or was that only for the coffee?

RA: Another interesting aspect, I guess, I felt like this, you know, he asked...he says he loves her and she loves him and he asks her to marry him, then at that point, I'm kind of not

buying the *oh, no I can't, I can't*. That's like back to the beginning.

This type of implausible emotional development might point to a portrayal of disabled people as nonsexual beings, a recurrent topic in discussions of disability representation, but it could also correspond to another expression of the self-sacrificing, conventional nature of the heroine in a melodramatic film. The disconnect between the puritanical, non-sexual representation of love in the film, and the historical developments in this area since the 1970s may be understood as part of what compels participants to resort to a camp reading of the film.

Another important factor in prompting the camp reading were the traditional (and by 2004 outdated) gender roles portrayed in the film. Female characters in the story, other than the main roles of Susan and Tiffany are seen at work (nurses) and at home (Susan's sister), but invariably they act in subordinate roles, always deferring to the authoritative male doctors. Women in the film can live successful professional lives, and can hold positions of authority to some extent (as is the case with the African-American head nurse, who becomes Susan's

boss). But they only work in traditionally female occupations, such as caring for patients and supporting the male doctors who oversee them.

The physicians, Dr. Detweiler and Dr. Hartman, on the other hand, represent the power and authority of the medical profession in American Society. Beyond their ability to mend broken bodies, these fictional doctors provide a model of care for the whole person of their patients, evidenced, for instance, when they find a job for Susan in the hospital. They offer an idealized version of the medical professionals as disinterested, generous, caring healers. In a later scene, when tempted by the possibility of a life of luxury performing trivial, cosmetic procedures in a well-appointed New York office, Dr. Hartman contrasts this prospect with the image of a country doctor who applies measles vaccines day in and day out.

The dichotomy here complements the choice he has to make between Susan and Tiffany, adding a socially relevant dimension to Steve's personal dilemma. When questioned about the class differences implied in the choice given to Dr. Hartman - "poor country doctor vs. rich city doctor,"- as well as in the opposition between

Susan and Tiffany, my respondents refused to see it as a significant factor in the film²². To me, the portrayal of the doctors in Prelude to Happiness falls clearly in line with the prevailing medical model of disability, where the figure of the professional healer is paramount in the exercise of knowledge and power over people with disabilities. Doctors Hartman and Detweiler represent potent figures who open all the doors to Susan's re-integration to society. However, the film producers intend to present a positive image of disability in the integration of Susan to a work-life in the Hospital, as a productive and respected member of the staff.

Camp reading of Prelude to Happiness

One of the most surprising and uncharacteristic reactions of the group of participants to any of the films screened during the study happened with Prelude to Happiness. While watching the film, participants became visibly excited, with some of them going as far as shouting to the screen, and cheering on Susan's successes in her quest for Steve's love. And yet, once the focus

²² This response might be an instance of the pervasive attitude of denying class differences in American society. Unfortunately, I did not have the foresight to press the issue further with the participants.

group interview started, participants also expressed a disdain for the film's overall production quality, its acting, and some of its outdated traits.

In general, I characterize the participant's response as ambivalent. Respondents seemed to like the film yet feel a certain shame about it. Or conversely, they saw all its flaws, yet they were affected by it on an emotional, visceral level. Most of their criticism of the film was grounded in aesthetic factors, such as the shoddy acting, the presence of the boom microphone on the screen, and so on. Their reactions to the film's portrayal of disability were generally positive. They considered it a progressive film in the sense that it showed Susan's integration in society and portrayed her as a hard-working, lovable and desirable person.

Next, I discuss further this conflict between the enjoyment of the movie, expressed in visible and audible terms as the screening progressed, and the distance that participants felt the need to create between themselves and the story.

One of the first responses to emerge in the focus group around this picture was that one of the participants described it as "camp." This word refers, in

Barbara Klinger's words, as a "willful misreading," or a "counter-taste that vies brashly with truisms about good taste to establish the validity and special worth of that which appears to be vulgar." (134) This way of understanding camp, as an instance of what Stuart Hall might call a "resistant reading," illuminates the spontaneous reaction of one of the focus group participants, who, upon finishing the screening of Prelude to Happiness, immediately got the discussion started with the following rhetorical question: "'Did you know it was a comedy?'" Later he would suggest to submit the film to a kind of *Mystery Science Theatre 3000* performance²³. So, from the very beginning, it was clear that the reading of the film as "camp" would be a salient feature of this particular reception situation, as opposed to the others in the study.

RI: You can imagine everybody, you know, our sons watching this thing and being caught by, God, they're really doing that on television,

²³ *Mystery Science Theater 3000*, an American television show which ran for ten years, 1984-2004, worked on the premise of a scientific experiment trying to test the responses of the protagonist, an "unsuspecting clerk," to "cheesy movies." The clerk is sent to space in the company of two robots, Tom Servo and Crow, who accompany him through the experience of watching a mass of uniformly bad movies, which provokes their humorous remarks. (Taylor, 1999 3).

shown in home movie and, you know, we've seen it before and we can really get caught up by the campiness of the production. I think most people wouldn't see that or wouldn't respond to it initially.

RA: Well, we enjoyed it, because it just, *I think if I showed this to my daughter, I think she would immediately go mystery science theater and there would be all this, kind of interrupted scripting like we were doing. It just begged to be [interrupted], and it's not to make fun of the movie at all, it's just to kind of make fun of the way it was put together.* It's not the storyline and it really didn't make you want to gag, it was just that you really had to kind of help it out. So ask Susie if she wants to re-script this, because I really think, it would be hilarious..." (FG 4, 23, my italics)

The participants' near unanimous response to the film was to decry the quality of its mise-en-scene, while simultaneously enjoying the experience of watching it. Their use of expressions like "camp" or "over the top" to describe the film is a sign of their wish to distance themselves, as discerning viewers, from the seriousness of the dramatic portrayal of Susan's travails, while asserting that the film is enjoyable at least as humor. This type of response, while unusually animated, and for that reason novel to me as I conducted the focus group, turned out to fit well with some of the literature on

melodrama and its reception, as authors such as Greg Taylor, and Barbara Klinger explain.

For Greg Taylor, shows such as *Mystery Science Theater 3000* are instances of a particular type of viewer attitude, which seeks to "celebrate their own triumphant power as active, creative spectators. They are not simply making fun of junk; they are making fun out of junk." (3) Klinger, in turn, points out the existence of a tradition of camp readings of films which moved from sub-cultural expressions of resistance to the mass media, among minorities such as gays and lesbians, to become a mass phenomenon during the 1960s to 1980s. She cites television shows such as *The Tonight Show* (1962-), *The Carol Burnett Show* (1967-1979), *Saturday Night Live* (1975-), *Second City TV* (1977-1981), along with the already cited *Mystery Science Theatre 3000*, as examples of the kind of vehicle that made it possible for a mass audience to assimilate the parodic attitudes of camp reading (133).

According to Klinger, this newly developed "mass camp" reading was applied to Hollywood productions from earlier decades, as it allowed viewers to "adore the mediocre, laugh at the overconventionalized, and critique

archaic sex roles.” (139) This observation fits very well my observations of the participant’s reactions to Prelude to Happiness, since much of their commentary evidenced a disbelief and critical distance from the conventional representation of the film’s characters and conflicts, in addition to the outdated quality they pointed out in the mores the film depicted.

An interesting aspect of this response from participants, who in this instance were all male, concerns their clear attempt to distance themselves from the ‘corny,’ emotional traits of the drama on the screen. Perhaps in this aspect of their response there may be an echo of the words of Jane Tompkins, who writes of a long tradition by which,

Twenty century critics have taught generations of students to equate popularity with debasement, emotionality with ineffectiveness, religiosity with fakery, domesticity with triviality, and all of these, implicitly, with womanly inferiority (Tompkins, 1985 123).

What I characterize here as ambivalence in the response of my focus group participants is evident in the fact that they unanimously made fun of the ‘campy’ aspects of the film, yet they were invested enough in the

story and its protagonists to yell to the screen, as exemplified by this exchange:

RA: There was so much...well there was so much opportunity to really jump in. I mean, it was just begging...

BO: Did you notice that some of the times we jumped in, we were like rooting for her when we were...there were comments made about the bitch [Tiffany] that was...

RA: Well you wanted...you know...

/OVERLAPPING CONVERSATIONS/

RA: [to] slap the bitch, I mean.

[LAUGHING]

BO: Something like pop-up video.

The participants in the focus group reacted to the perceived implausibilities of the story and the acting in the movie by resorting to a camp reading. However, as they decried the "shoddy acting" and the presence of clichéd attitudes in Prelude to Happiness, they also strove to rescue in it some valuable traits, from the point of view of people with disabilities. I now turn to a review of these.

Finding valuable traits in Prelude to Happiness

Among the general merriment the film generated, one participant took a more serious approach and tried to find a more transcendent value in the movie:

I think they made an attempt to cover the stages of, you know, the mild trauma involved and how it affects you psychology and it takes a lot before you can really accept it and try

to deal with the relationship issues..." (BO, FG4, 3)

Bo's positive appraisal continues, regarding the film's effort to deal with serious issues:

BO: I can see that they were making an attempt to cover, you know, those relationship issues and acceptance issues that are, I think, are a part of adjusting to it. (FG4 4)

They praise the film's attitude towards independent work for people with disabilities. In the words of RA, the head nurse who supervises Susan at the hospital is "ahead of [her] time, basically making reasonable accommodations to this person's disabilities," as evidenced in the scene when Susan is first hired. (FG4, 16) Other participants also reacted with approval to this scene:

ZA: I thought it was pretty compelling like when the nurse, the head nurse first met Susie and was, like, yeah, I mean, anything, I'm not going to require you to do anything you physically cannot do, but I'm not going to let you [...] cop out [because of] your disability. (FG4, 16)

In addition to its positive portrayal of the ability of people with disabilities to work, the film fulfills an educational function regarding common questions, curiosities and/or misunderstandings about disability. It addresses these either through the dialog or the image;

for instance, during the early phase of Susan's recovery, the film dramatizes the phenomenon of the phantom pain, as Susan repeatedly asks her sister to help her with her foot, which seems to be placed in an uncomfortable position, without realizing yet that her whole leg is missing. Dr. Detweiler then provides a succinct explanation of the phenomenon. Soon thereafter, he informs Susan's brother in law, and with him the audience, that it takes three or four days for the nerve endings of a residual limb, or stump, to heal, so that the pain in the limb subsides. Later, Susan demonstrates the act of putting on her above-knee prosthesis. As she is hastily preparing to go look for an apartment with Dr. Hartman, Susan complains of the difficulty in putting on the leg when she is in a hurry. This way, a bit of instructive information, no doubt from Rose Petra's "real" life, is effectively embedded into the dramatic story line. Participants received this kind of demonstration enthusiastically, for its potentially instructive, demystifying function in relation to assistive technology:

RI: I think those are super. I think the more of that there was, the more demystifying it.

RA: Pretty real, I mean that's right.

RI: That's great.

RA: What they were doing was right, and people do have trouble with the stockings and the slipping off and pressure sores and, you know, everything..."

Along the same theme, participants valued the fact that Prelude to Happiness did not make the type of factual mistakes that they had seen in other disability films, that is, having the actor portraying the disabled person use the wrong type of wheelchair for daily life activities, or showing an audience of deaf people clapping in appreciation of an artistic performance, etc. As BO said, "To their credit, they really exposed and made an effort to show that reality for an amputee." He adds:

"Yeah, it was a little campy in the way it was acted, but they did ... I think they communicated the types of things that the medical profession tells you. Your life is not over. Get off your lazy butt and go to physical therapy, because you're going to be able to return to work and life." (FG4, 29)

BO found it strange that Dr. Detweiler would be so liberal in his supplying of pain medications:

BO: The only thing about the pain medication is when she came in to the see the doctor that she was dating, the guy says, here I'll give you some pain medication, I thought, she's just coming here to visit somebody in the hospital and you're going to give her pain medicine. (FG4 30)

But even some of the less plausible moments in the film, like the scene where Susan rejects Dr. Hartman's marriage proposal, which RA rejected as unbelievable and "campy," provided some chance for other interpretations.

BO: But it didn't have to be a total rejection of the possibility to still make the point in a realistic way to people, you know, that it would be natural that they would want to check in to be sure that they were really comfortable with [her disability]. (FG4 38)

Participants found puzzling and less-than-perfectly developed the film's allusion to prejudiced attitudes against people with disabilities among the non-disabled population. There is a scene in the film where Susan and Doctor Hartman attend a poolside party at one of Susan's old friends' home. Among the guests at the party, a teenage boy looks intently at Susan as she walks with her crutches towards the pool. The camera cuts to him in particular, calling attention to his presence.

Participants in the focus group singled out this scene for discussion:

RI: "The thing that, I think, looked kind of fishy to me, pardon the pun, was the guy that kept going in and out of her swimming pool. You know, what was that? I mean, was that a story line that they dropped all together?"²⁴ (FG4 10)

²⁴ Interestingly, Rose Petra confirms RI's guess, that this incident was included in the film as an attempt to

RI: You know, it looked like he was going to...I really expected that we're going to see [BACKGROUND CONVERSATION]
RI: See a piece that was going to deal with friends ostracizing her [...] Or friends, you know...
RA: "Or him leaving the party, I can't deal with this."
RI: "I can't be in the same water with her."
(FG4, 13)

As a direct response to this scene, one of the participants, RI, recounted an experience from childhood, when he proudly rejected an attempt to treat him as the mascot for a sports team: RI: "You know, I said, screw that, I ain't playing no mascot. Sorry, I'll see you."

Discussion of discrimination prompted some attention to the use of terminology to designate people with disabilities within the film, a subject to which people with disabilities are particularly sensitive, thanks to the work of numerous activists and scholars.²⁵ Even though the characters in the film occasionally use the term "crippled," participants did not object, given the context of its use, as Dr. Hartman attempts to rouse Susan to action in the midst of her depression:

add conflict to the drama, but it was not sufficiently developed (Petra, Rose, phone interview, 08/07).

²⁵ See Simi Linton, Claiming Disability. Chapter. 2.

Dr. Hartman: ... I want you to do those things that are best for you. And that includes practicing your walking on crutches.

Susan: What's the use?!

Dr. Hartman: The use is you're going to be given an artificial leg that will let you get out of that bed, walk around and do whatever you wanna do. Now, if you insist on lying there and feeling sorry for yourself, you're never going to be anything but a hopeless cripple, instead of an attractive young lady with her whole life ahead of her. (Prelude)

On a related note, comparing the film to the participant's own lives, RA found that the hospital where part of the story is set is the same actual hospital where his daughter was going to be born (FG4 3). During the course of the focus group, he referred to this familiarity to the setting of the film. This factor, and the protagonist's closeness in age to himself, seemed to be strong motivators to take an interest in the film.

Regarding the star, Rose Petra, participants found valuable the fact that an actress with a disability was employed to portray the central character in the film, and they showed an interest in the actress' life and personality, even going as far as suggesting that I invite her to visit Lawrence. "ZA: 'Fernando, invite her'". RA:

"Fernando, get her over here. Iowa is not that far." (FG4
18)

In concluding this I wish to stress the fact that participants enjoyed the film and engaged with its story in a particularly strong way, even while asserting their critical distance from the conventions of melodrama that they considered dated or misapplied. The encounter of this group of viewers with Prelude to Happiness illustrates the phenomenon of mass camp, and shows the participants as "resistant readers" who pick and choose from the film text what they consider valuable and contrast the fictional world of the film with their own life experiences in order to ascertain its value.

The next film in consideration did not attempt to be a straight melodrama, as Prelude to Happiness, but instead opted for an ironic approach to the genre. It is John Sayle's Passion Fish, a 1992 feature starring Mary McDonnell and Alfre Woodard. Discussing the films side by side allows us to understand the different responses to potentially similar material on the part of the focus group viewers.

Passion Fish: An Ironic Look at Disability Melodrama

In Passion Fish, John Sayles tells the story of a soap opera actress whose life changes radically in an instant as she takes a cab on her way to having her legs waxed, and she is hit by a car. The accident leaves May-Alice Culhane (Mary McDonnell) paralyzed from the waist down. Soon after her accident, May-Alice goes to rehabilitation but soon, a victim of her own brashness, nervousness and impatience, she quits and seeks refuge in her ancestral home in the Louisiana Bayou.

From the very first shots of the film, Sayles is inviting his audience to compare the melodramatic treatment of stories that is standard in soap operas, with his own distanced, ironic view. As May-Alice wakes up in a hospital bed, half-dazed by pain medications and sedatives, she watches her own performance on television, where she plays Scarlet, a character whose ailments go from abortion to amnesia in an increasingly twisted series of turns. This is what May-Alice hears from Scarlet's mouth, as her character discusses a dream with a psychiatrist inside the soap-opera story world:

Scarlet: All I remember was that I wasn't happy, was I?

Doctor: Scarlet.

Scarlet: You keep calling me that. It sounds like some other person.

Doctor: Isn't there anything else that you can remember?

Well, there is something. It's more like a dream than anything that really happened. I'm walking down a hallway. It's dark, and it's so quiet I can hear my footsteps echoing. The hallway is very long; it seems never to end. All the time I'm walking I have this feeling that when I reach the end of the hall I'll find something. It's very frightening at first, but if I can stand up to it, face it, it could be something wonderful...

There is, first, the insistence on the sounds of the footsteps. The ideas of "standing up" to your fears, and walking along a dark hallway, are all metaphors -noticeably ableist ones, at that, of the ability to empower yourself and pick up after a tragic event. The setting itself, a dark house, prefigures the old rural mansion where most of the story takes place. And then, there is the hope of something unexpectedly wonderful, at the end of a process that seemed to offer only fear. This is what happens to May-Alice, who emerges from the story with the beginnings of a new, more meaningful life, after what at first had seemed complete devastation.

As soon as the preceding dialog plays, the sound from the television set fades into the background. May-Alice only complains to herself bitterly: "He gave her my close-up. He gave her my fucking close-up." Right then, a nurse arrives. To May-Alice's frantic questions and accusations ("You gave me a shot; my legs went to sleep!"), she only offers a monotonous refrain: "I'm going to call Dr. Miles; he'll give you something to calm you down."

Though first-time viewers of the film are unlikely to pay attention to the words coming from the TV set in May-Alice's room in that opening scene, much less remember them, they are a clear expression of Sayle's logic of juxtaposing the world of the soap opera -replete with incongruous happenings and over-the-top acting style-- with a more sedate, subtle pacing of change in May-Alice's life.

With the help of her business manager, an unseen presence who takes care of the logistics from an office somewhere, she is soon back within the old, dark, wood-panel-covered walls of her childhood home, surrounded by lush meadows and swamps, devoting her days and nights to watching television and drinking wine. She is all alone,

save for the succession of hired care-takers. For the first twenty minutes of the film, Sayles establishes a comic tone through the dialog and the absurdly excessive situations he sketches through a few scenes, and a montage sequence. May-Alice, sitting on her couch, shabbily dressed in T-shirts and sweatpants most of the time, continues to throw snappy remarks at her companions, when she is not simply flinging food to the walls. So, at first, the film is all centered on her depressive state, as she progressively encloses herself away from the world in the old house, until, "the only light, in that room, in that montage where all the caretakers come, is the TV set..." (Sayles & Smith 201)

When the film establishes May-Alice's complete isolation, not only through the confining of the mise-en-scene to the house's living room, but by the progressive encroaching of obscurity around her, it is time to introduce the second protagonist of the story, Chantelle (Alfre Woodard), a black woman in her thirties, and like May-Alice a city person exiled to the Bayou for reasons beyond her choice. She is a recovering drug user in search of a second chance, something she at first does not reveal to her new employer.

The relationship between May-Alice and Chantelle, is a complex one and Sayles takes care to develop it step by step. The initial impulse for making Passion Fish, Sayles once said, came after watching Bergman's Persona, which he saw as a story about the relationship between "a nurse and a patient." However, he wanted to make it an American version from a comedic point of view (Johnston 165). He also was drawing on his own experiences working at a hospital, as well as on the stories his nurse friends used to tell him while he was there.

I got fascinated by the relationships between people who spend eight, 10, 20 hours at a time together, and yet don't necessarily have anything in common. They're stuck together; one needs the job, and the other needs the care. (Ebert, 162)

That mutual need between the protagonists sets up the twin themes of the film, the power relationship between the person with a disability and her caretaker, and the concept of "limits," in Sayles' words, which refers to the realization in people's lives that things have to be accepted. You have to commit to a situation outside of your own will, and cope with it, since the world will not simply adapt to your wishes. It is the pursuit of this second theme which motivates Sayles'

systematic contrast between the plight of his characters and the melodramatic conventions of the soap opera, a world, as he sees it, where:

When you don't like a story you can change it. So the actresses say: 'next week I am going to be a bad girl instead of a good girl. And when the producer comes back to ask May-Alice to return to the show, she's not just going to be in a wheelchair, she's going to be blind too. You can just do that with a snap of your fingers. (Sayles & Smith 203-204)

Sayles drives this theme home throughout the rest of the film, as he portrays the subtle changes in the lives of May-Alice and Chantelle brought on by their contact with the bayou and its people, as he contrasts their new world with that of the occasional outside visitors.

Limits and Possibilities

When Chantelle first appears, she has just stepped down from the bus near May-Alice's house. The camera slowly pans, revealing a placid, green landscape of grassland, a few trees, and a single, dust covered road that seems to continue forever into the distance without interruption: A truly desolate place, or so it seems to Chantelle, who at this point in her life only wants to settle down and recover the daughter whose custody she lost during her time of drug use. But the story develops

as Chantelle and May-Alice discover new, unexpected possibilities in their interdependence.

Soon after she settles into her relationship with May-Alice, a duel of wills whose give and take provides most of the conflict for the rest of the story, Chantelle gets to know the local color, in the form of Sugar LeDoux (Vondie Curtis-Hall). Sugar is a Cajun man who gives her a lift when May-Alice's old car runs out of gas on the road to town.

Sayles also introduces a "blast from the past" for May Alice, in the person of Rennie (David Strathairn), her childhood classmate who is now a local handyman. Chantelle hires Rennie to build a ramp so that May-Alice can go out of the house. This creates a chance for her to reacquaint herself with the man for whom she had a crush as a girl.

In the rest of the story, a series of visits from several people in May-Alice's life to the house add detail to the audience's knowledge of the character's psychology: Viewers find out about May-Alice's uncle and two of her childhood classmates; Chantelle's struggles to rebuild a relationship with her 8 year old daughter, and with her father who takes care of the child; Rennie's

unhappy family life with a zealously religious wife and a large number of children.

Chantelle and May Alice, and with them the audience, get to savor the Zydeco music of rural Louisiana, and to hear the story of the Passion Fish, which you have to squeeze tightly in your hand in order that your wishes come true. In the meantime, May-Alice opens up to the world and finds out the possibilities that her new life offers. She literally takes up a new point of view, when she starts taking pictures with an old camera that her uncle had left behind in the house.

Critical and Focus Group Responses

As intimated above, the logic of contrasting "life" versus "melodrama", works as an organizing principle of the whole project of Passion Fish. But it is one that for some critics of popular newspapers and magazines, was not successful. Perhaps David Denby is representative, when he writes of a later Sayles Film, Silver City (2004), that "As always, Sayles takes his time, meanders, never quite works up a full head of steam ... He not only disdains melodrama. He disdains drama." (Denby) A similar opinion of Sayles' style comes from Alyssa Quart, from Cineaste, for whom Passion Fish,

As plodding as it is plotted, is a flatfooted psychodrama that deprives us of any character dimension. Without a social nexus to provide a binding center, as it does in both City of Hope and Matewan, this film struggles admirably to establish place and character believability but gets lost in its own 'naturalistic' episodes. (Quart, 104)

Other critics, such as Andrew Sarris, were enthusiastic in their praise. For Sarris, who laments not having had a chance to include the film in his "Top Ten List" of the year 1992,

Life in a John Sayles movie proceeds at its own pace with no dramatic or melodramatic foreshortening, no bursts of orgasmic violence, no easy appeal to emotion, no stark contrasts between virtue and villainy, no maudlin self-pity, no devious lechery, no campy condescension. (Sarris, 3)

As for the focus group participants, their responses to Passion Fish varied in the course of the meeting. At first, some expressed similar feelings as those of Alyssa Quart, complaining about the film seeming 'slow,' and for one of them, it seemed that the film was still "a soap opera." (FG5, 10) In RI's view, the main problem with the film's story was that it centered on "a person of privilege," not someone who had to contend with the same financial problems, limitations of health care etc, that many people with disabilities have to live with. This

fact, of making May-Alice to be a successful and well-paid TV actress, limited the educational appeal of the film by making it unrepresentative.

She's not an average person with a disability in the sense that she was a professional actress that was probably very wealthy and, like you said, she hadn't driven for...

RA: Twenty years.

BO: Twenty years. Because she could afford cabs and, you know, again...

RI: Yeah, and that was one thing that was stark... stark that it quite... very much a person of privilege[...] versus, you know, somebody that, you know, lives across the street ... and you know really has a PA that comes in for three hours a day, very, very different that what you'd be seeing in here, I think. (FG 5 10)

"Drama vs. Realism": Comparing Movies to Life

A question that generated a certain amount of debate in the focus group about Passion Fish was the apparently unrealistic portrayal of some of the technical details of what a person with May-Alice's lesion could do or not do.

In one of the participant's view, the difficulty she was having in performing a transfer from her wheelchair was not credible for someone with a T-10 lesion of the spinal cord (FG5 8). Similarly, he expressed concern over the possibility that viewers might take May-Alice's

alcohol consumption and depression as typical reactions to impairment.

Bo: Not everybody becomes an alcoholic and isolates themselves from the rest of the world and dwells on what they can't do for years at a time. That's my only concern because that's a tendency in movies to over dramatize just for the sake of keeping your attention, and for the sake of drama and emotional, uh, hooks. So I don't know. I guess I would ask people about disabilities whether it gives them that impression or whether they really realize that it's just this person's story. But I don't know, I guess most people probably see that because they know being a famous actress or actor is not the experience of, you know, most ordinary people. (FG5 23)

In BO's reaction we have an expression of the wariness with which many people with disabilities respond to the possibility of damaging stereotypes. Here, May-Alice's initial tendency to hide from the world and her apparent alcohol problem suggest a familiar stereotype of the "bitter cripple" that is present in cultural products from radio shows to movies. Compare it for example to Ross' example of the "bitter and twisted" stereotype that her radio listeners complain about. (Ross, 425) Echoes of this are found in other authors, such as Longmore and Norden.

Interestingly, another group participant questioned BO's concern with over dramatization:

I'm assuming that there's probably been, I don't know a dozen probably pretty good [films], Coming Home, some of these, all had their own little twists on it and I think over time ... there's probably not necessarily reason to believe that those are over dramatized more than any other situation. Somebody loses a kid, that's a story about that. Well, is that over dramatization? I don't know, it's hard to say.

Bo: Yeah, that's very true.

RA: Or some of the addiction situations. Is that over dramatized, um...

BO: Uh-huh, yeah I know, I guess I'm totally sensitive about it... (FG5 25)

While BO's concern has to do with the unfair extension of an individual problem to a whole class of people (people with disabilities), a phenomenon running in the opposite direction, from the general to the particular, has been identified by Paul Longmore in his seminal essay "Screening Stereotypes": By relying on images of psychological conflict, films often "make [disability] an individual rather than a social problem." (Longmore, 9) This is a shortcoming that Passion Fish clearly suffers from, in spite of its considerable merits as a sensitive portrayal of disability²⁶. This criticism

²⁶ Regarding Longmore's observation, it seems to me that the focus on individuals is a shared trait of most of the

is also implicit in the responses of my focus group participants, when they point out that May-Alice's experience is too distant from that of the average person with a disability, who often does not have the financial means or the glamorous career with which May-Alice is endowed in the picture.

At the same time as participants criticized these details in the film, they responded with praise towards the film's character construction:

RI: Strong characters in there and the characters that were brought into the...into the scene were all very strong...strong characters from the child to the doctor, the blacksmith, the...the former actresses that came through, her childhood friends, I mean those were all very strong characters. (FG5 14)

RA: "It was a little sluggish I thought. But the characters were great. I thought that was fairly believable. Was rehab fairly believable?"

BO: Well it was such a short segment of that but yeah, in terms of them trying to motivate you and, uh, being realistic about what you needed to learn that's...*that was realistic and I was in rehab with that guy that was really angry.* (FG5 1, my italics)

output of the American film industry and its critique therefore has more to do with the general ideology of American society's individualistic values than with the specific depiction of disabilities.

Here it is also important to notice the comparison of the film's storyline and its depiction of disability issues to the viewer's own life experiences. This routine practice of contrasting the way things are in actuality, according to the viewer's perception of his or her own life and what the film is portraying forms a central theme in the participant's responses. This point, which I have called (in Chapter 3) the "drama vs. realism" criterion of interpretation, is central to the disability movement's critique of film portrayals of people with disabilities.

In addition to constantly evaluating the film against the background of their own life experiences, participants routinely contrasted it with the others we had watched during the study. Passion Fish emerged triumphant from the test, particularly because the film's story transcends May-Alice's paralysis and its conflict deals with something that can be relevant to people with and without disabilities:

RI: Well what I like about this movie was that [disability] became the driver of the movie but then the movie ...just kind of goes by the wayside. Her life continues just like you were saying, the characters come through and they're developed and the story goes on and just one of the... just one of the things that was

interesting about the character is that she is in a wheelchair. She is the main character of the story and the chair isn't the big issue. (FG5 26)

RA: I guess that the sort of disability stuff did recede into the background a little bit and you were looking more at that people than you were at the fact that she was a para in a chair...whatever...and I, you know, after the comments we had last week and other weeks, I think to some extent that's a...that's congratulatory about this. That it wasn't so... it wasn't done in a cumbersome fashion where it kept sticking the wheelchair in your face, you know. Because eventually you just kind of saw, you know... She's trying, she had other problems that are as difficult to deal with as being a para, drinking and whatever else. (FG5 13)

Participants appreciated Sayles' subtlety in dealing with the problems of disability, particularly in comparison with the treatment in Prelude to Happiness:

RA: The one we saw last week was, you know, this sort of here's my stump and I'll show you...you know, it was a little bit...whatever that film, whatever they spent on that, they must have spent twenty times as much on this one. Because it was, well everything about it was better. Scenery, the cinematography, you know, the actors. (FG5 6)

Sayles' film certainly cost more than Prelude to Happiness. The actors, most of them veterans of Sayles productions, are celebrated figures in the industry, like Mary McDonnell, nominated to an Academy Award for her

performance in Dances with Wolves, or Alfre Woodard, twice an Emmy winner performer (Summner, 158). Even though it is still a modest budget for the mainstream industry standards, the \$3.1 million dollars spent on Passion Fish (Summner, 158) meant that the film, while still an American Independent production, is in a different league in terms of quality, from Prelude to Happiness (made for a little over \$7,500).

What participants praised the most in Passion Fish was perhaps its ability to portray the problems posed by May-Alice's impairment as not the center of the story but just one among other situations in a spectrum of life events. They enjoyed as well the subtle depiction of Cajun culture, with its distinct features, and the way race relations are represented in the film.

BO: I think it made it really interesting. Just, you don't see that many movies that have Cajun, the Cajun South, you know, culture and I liked the fact that it had Caucasian and African American and Cajun people all mixed together and getting along and living together and there was, there was no real issue of race made, no commentary, and I liked that[....]

RI: That really is the bayou.

BO: Yeah, is that right?

RI: That really is. (FG5 20)

Here it is important to notice that the participant's view of the need for film to be realistic may seem naïve to film scholars steeped in post-modern theory, but it is nevertheless a central preoccupation of viewers in my study.

What I would like to underline in this reaction to the depiction of Cajun Life in Passion Fish is not how authentic Sayles' view may be, but the fact that the viewers in my group valued the inclusion of May-Alice's physical impairment as simply one element in a wide spectrum of circumstances, including the local color of the Bayou and its inhabitants. Therefore, the de-centering of disability as the main focus of the film allowed for the aesthetic response from the focus group participants to be expressed.

Finally, participants applauded May-Alice's decision to withdraw from the world of soap operas and instead embrace her new found closeness to the bayou and its people.

RI: The ending I thought it was kind of interesting that there where she decides that, you know, there's a much more fuller life where she's going to be at than perhaps maybe playing the role of the gimp in the movies. [She has a] new, more rewarding life even with disability.

Bo: Yeah, I was glad she didn't agree to play a stereotype that was really negative". (FG5 3)

This chapter has demonstrated the perils as well as the potentialities of portraying disability in films through melodramatic generic conventions. Prelude to Happiness, characterized by a naïve look at disability in its portrayal of love relationships, elicited a camp reading from participants in our focus groups. This implies both an enjoyment of the film that is wrested from it through a forcible mis-reading of its conventions, and it represents an affirmation of the resistant power of viewers over a film's ideological content. However, it also entails a loss of respect for the efforts of the filmmakers, and a form of distancing from the emotional content of the story and its characters.

In the participant's responses to Prelude to Happiness I find a willingness to rescue a few nuggets from what otherwise they would consider an unsuccessful film. Such is the charisma and personality of the actress, Rose Petra, whose life in person, as well as in her character, captivated the attention of participants.

On the other hand, the participant's responses to Passion Fish show an appreciation for the writing quality of John Sayles, in his ability to blend the disability theme in a rich spectrum of thematic concerns, as well as his ironic commentary on the conventional, illusionistic solutions to life's problems portrayed in melodrama, as expressed in TV soap operas. Participants were particularly complimentary of Sayles' strong characterization of even the small parts in the film, as well as his evocative use of the Louisiana setting, in a film where disability becomes one of the ingredients, but not necessarily the main one.

In the response of participants to Prelude to Happiness in particular I find a tendency for my respondents, who were all male, to distance themselves from the narrative through the adoption of a camp reading. At the same time, through their animated engagement with the text, when they root for Susan's success in her competition with Tiffany for Steve Hartman's love, they are diminishing that distance. The film that seems to provide the more visceral and joyful type of engagement is also the one which elicits the most critical distance from viewers. This is what I mean by

"ambivalence" in the reaction from participants. The root of it as I see it lies in three factors:

1. The male gender of my respondents, and their need to assert their masculinity by not showing much of an overt identification with the romantic aspects of the story.

2. Surface changes brought on by the passage of time since the production of the film, such as different fashions, for example, which act like signs to encourage a camp reading.

3. The historical changes in the integration of people with disabilities to social life, which render some of the attitudes and comments made in the film effectively outdated by comparison to today's realities: On the one hand, the passage of the *Americans with Disabilities Act* (1990) has meant a much greater degree of activity and visibility for people with disabilities in society, than what was current in 1974. On the other hand, and perhaps more clearly relevant for the discussion of this film, the progress in medical research and development of newer and better prosthetic devices means that the few limitations to Susan's life that Doctor Detweiler mentions in the film are no longer a

factor for today's amputee, provided that he or she has access to the latest prosthetic technology.

What in my view is most relevant in the response to Passion Fish, is the participant's insistence on the portrayal of a spectrum of events and character traits that include the character's disability but are not exhausted by it. In other words, their insistence on the blending of disability/impairment into a context of story events where other problems take center stage and the portrayal of disability is de-emphasized.

In the next chapter, I continue examining the melodramatic treatment of physical disability in movies, this time by focusing our attention to a specific genre: the film based on a "real story." To do this, I examined two recent films, The Brooke Ellison Story (2004) and The Sea Inside (2004), both of which deal with opposite responses to quadriplegia.

Credits:

Prelude to Happiness²⁷: Director: Gidney Talley Jr.; production company: Robert Pinkerton; presented by Cinema World Corporation; producer: Robert Pinkerton; assistant director: Susan Heyer; continuity: Laura Debolt; written by: Robert Pinkerton; camera: Richard Kooris; assistant

²⁷ BFI Film & TV Database. Prelude to Happiness.
<http://ftvdb.bfi.org.uk/sift/title/578886?view=credit>

camera: James Bogard; editor: Kim Bunch; sound recording:
Courtney Goodin; boom operator: Tom Herod.

Cast: Rose Petra (Sue Imes), Gary Davis (Dr Steve
Hartman), Carol Sowa (Tiffany), Susan Mulhollan
(Marilyn), Allen Ross (Larry), Dan Kamin (Joe), Bob
Jutson (Doctor Detweiler), Josephine Linton (head nurse),
Charles South (Mr. Bowles), Bob McGinnis (thug 1), Rocky
Guzman (thug 2), Paul McLain (Dick Burrus), Terri Ross
(Diane Burrus)

Passion Fish²⁸: Director: John Sayles; production company:
Atchafalaya Films; executive producer: John Sloss;
producers: Sarah Green, Maggie Renzi; Script: John
Sayles; photography: Roger Deakins; editor: John Sayles;
music: Mason Daring.

Cast: Mary McDonnell (May-Alice Culhane), Alfre Woodard
(Chantelle), Lenore Banks (Nurse Quick), Nora Dunn (Ti-
Marie), Leo Burmester (Reeves), Vondie Curtis Hall (Sugar
LeDoux), David Strathairn (Rennie), Will Mahoney (Max),
Nelle Stokes (Therapist #1), Brett Ardoin (Therapist #2),
Michael Mantell (Dr. Kline), Mary Portser (Precious),
Angela Bassett (Dawn/Rhonda), Daniel Dupont (Therapist
#3), Chuck Cain Attendant).

²⁸ BFI Film & TV Database. Passion Fish.
<http://ftvdb.bfi.org.uk/sift/title/474861>

Chapter 5

The Sea Inside and The Brooke Ellison Story: Truth, Lies and the "Based on a True Story" Disability (Melo)Drama.

In this chapter we turn our attention to the Spanish production Mar Adentro, also known in English as The Sea Inside (2004) an international film which received the 2004 Academy Award for Best Foreign Language film. Director Alejandro Amenábar and star Javier Bardem fictionalize the last years in the life of Ramón Sampedro, a real-life quadriplegic from the Spanish region of Galicia. Sampedro fought a long battle in the courts to gain the right to die. Facing repeated denials of his petitions, he took his own life through the help of a small number of friends, in a complex maneuver designed to avoid legal prosecution.

The second film under consideration is the television production The Brooke Ellison Story (2004), the last film directed by Christopher Reeve. Both films are studied as representatives of a particular genre of films based on real life characters²⁹, and in the context

²⁹ "Based on a true story," the contemporary label for this type of films, seems to have been introduced only in the 1990s, with the films Awakenings (1990) and

of the reception that the participants in my focus groups gave them.

On the evening of Wednesday, Feb. 25, 1998, television viewers in Spain's Antena 3 channel were witnesses to a scene that caused immediate controversy. It was the home-video of the death by cyanide of Ramón Sampedro, a 55 year-old Galician man, who for seven years had fought a fruitless legal battle to gain permission to end his life from the courts in his country, and in the European Union.

News of Sampedro's death had already shocked the country in January, when the success of his enterprise was first reported in Boiro, a seaside town on the cold, windy shores of his native Galicia. But the sudden appearance of a video lasting almost an hour, where he talked directly to the camera as the poison made its effect, was too much for some viewers, in spite of the television managers' making sure that the death itself

Goodfellas (1990) as the originators of the latest formula for a tried and true concept. See, Leitch, Thomas, Film Adaptation and its Discontents, The Johns Hopkins University Press, 2007. 280-303.

was not shown, and that only a few minutes of the video were broadcast.³⁰

Ramón Sampederro was a young sailor in the merchant marine who, on 28 August, 1968 snapped his neck at the C-7 level, while bathing in the sea, close to his parent's house. Twenty-eight years later, after spending half his life bedridden, unable to feel or move any part of his body below his neck, he published an account of his accident and of his thoughts, along with letters and poems, as part of a campaign to prove to the courts and the public opinion that he was sane and had good reasons for wanting to die. His book, entitled Cartas desde el infierno (Letters from Hell, 1996) contains a polemic in favor of active euthanasia as a personal right.

(Sampederro, 2004 13)

News of Sampederro's death caused a national commotion which was soon exacerbated by the surprising appearance of a video of his death, where he calmly explained that he was the only person responsible for the act. Spanish television then aired a number of documentaries about Sampederro. At the same time, a debate over "the right to

³⁰ The New York Times, Mar. 9, 1998. p. A.9

die" grew in the country, against the opposition of the Catholic Church and conservative groups which saw this as yet another example of the "culture of death" that Pope John Paul II repeatedly denounced.

Among those watching one of the television documentaries³¹ was film director Alejandro Amenábar (Open your Eyes, 1997; The Others, 1999), who took an interest in Sampedro's story. The first thing Amenábar did, he would later tell reporters, was to read Cartas, a book which struck him especially for the unusual finding in Sampedro of an erudite voice hidden away in rural Galicia³². But he did not find a story in the book, so he arranged to meet Sampedro's family, who told him details of their late relative's life, his trips as a young sailor, his role at the center of his extended family, and of the women who had loved him. Far from the bitter, frustrated individual one might imagine in such a dedicated seeker of his own death, Ramón Sampedro's relatives remembered him as "always smiling, a constant joker, a born charmer," writes Amenábar. (Sampedro, 8)

³¹ The Hollywood Reporter, Dec.13, 2004.

³² DVD Commentary, The Sea Inside.

The stories about Ramón Sampedro and the contradiction they implied fascinated the director and started him, his writing partner, Mateo Gil, and producer Fernando Bovaira, on the way to making Mar Adentro/The Sea Inside.

The film focuses only on the last years of its protagonist's life. As an example of the "based on a true story" subgenre of melodrama, it illustrates perfectly some of the paradoxes and attractions that such a story offers its viewers. For this reason, together with its opportune release close to the time when this project started, I decided to use it for my study of responses that a group of people with physical disabilities give to the representation of disability in contemporary cinema.

Truth and Lies in Adaptation

Among the problems that Amenábar and his team faced when adapting Ramón Sampedro's story to the screen was the need to simplify the number of characters, and to accommodate the real features of Sampedro's life to the demands of a fictional dramatic structure. The changes thus introduced in the story are significant. Amenábar and Gil's film:

1. Reduced the length of Sampedro's legal campaign from seven years to a little over two.

2. Reduced the existence of several friends and lovers of Sampedro's to a single character, named Rosa, who meets Ramón after watching an interview with him on television. The character is mostly based on Ramona Maneiro³³, a local woman who confessed to her participation in Ramón Sampedro's carefully contrived plan only after the legal limits for possible criminal charges had prescribed.

3. Fused several people in charge of Sampedro's legal battles into a single, fictional character, named Julia, a lawyer from Barcelona, in the Spanish autonomous region of Catalonia, who travels to Galicia to meet him at the star of the movie. Julia is a fellow person with a disability, and this fact plays an important role in his accepting her help. She lives with a rare illness called CADASIL, a neurodegenerative disease, similar to Multiple Sclerosis, which causes repeated, unexpected strokes whose effects may or may not be reversed.

³³ "After Mr. Sampedro's death, the police arrested Ramona Maneiro Castro, 37, who was a friend and bedside attendant of his. But she was released less than two days later and has not been charged." New York Times, March 9, 1998.

4. Simplified the number of relatives in Sampedro's family, so that his 3 nieces and 2 nephews were reduced to a single character, called Javi (short for Javier). Javi is a teenager, son to Sampedro's older brother, Jose, and his wife Manuela. The most senior member of the household is Javi's grandfather, Ramón and Jose's father. While Manuela is primarily responsible for Ramón's care, José tends to a small garden and a few farm animals, and Javi and the "abuelo" (grandfather) help Ramón by building machines that he designs.

In spite of these changes to numerous factual details in Sampedro's story, Amenábar feels that the resulting film passes the ethical test of announcing itself as based on a true story:

We decided that if this story needed to be seriously fictionalized, we would do it. But the facts were so strong, we didn't need to make things up, just put them in order and focus on which ones were important. ... We made sure we were being true to the soul of the characters and the soul of Ramon. (Hollywood Reporter, 13 December 2004)

He has elsewhere added the following rationale in support of his decision:

A movie that remains tied to reality would be a documentary, not a movie, so there has to be a dramatic intervention so that the facts are clearer to the viewer, so that we understand

better the meaning of what has happened to each character in this story. (Amenábar DVD Commentary)

At this point it may be useful to remember the comment of one of my focus group members, BO, who was particularly sensitive to issues of "realism vs. drama", or, in other words, to a presumed fidelity to life as lived outside the confines of a film. As the following excerpt shows, he is aware that when filmmakers use the expression "based on a true story," instead of a warrant it often should be taken as a disclaimer (Leitch, 282):

BO: And so I was wondering how much of it was actually what [the main character] did and how much of it was for the sake of movie and drama, you know, because I always got this in the back of my head when I see movies that at the end say it was based on a true story. That usually implies that a hundred percent of it is not the truth.

SH: Right.

CR: Hmmm.

BO: But the general story line is true and then there was the drama that was added for the sake of creativity or audience appeal or whatever.

SH: Right.

BO: Keeping the audience interested. (FG2 26)

To be precise, the credits of both The Sea Inside, and The Brooke Ellison Story (whose study occupies the second part of this chapter) only imply the claim for each film to be "based on a true story," rather than

present it emphatically in the text. Nevertheless, the link to identifiable characters from the headlines is still clear from the films' press coverage, advertising and extra features added to the video releases. In both cases, too, the real life counterparts to the film characters have offered their stories to the world through autobiographical books prior (or concurrently) to the films' production³⁴.

Thomas Leitch offers an insightful analysis of the "Based on a True Story" claim from the point of view of adaptation studies. He makes the case that when filmmakers resort to this approach to the selection of story material, what they are claiming, essentially, is that authority rests in their version of a story. He adds that with this claim reality itself seems to have been conveniently prepackaged as a story, "a master text that has all the authority of a precursor novel or play or

³⁴ In addition to Cartas desde el infierno, see: Ellison, Brooke and Jean Ellison. Miracles Happen: One Mother, One Daughter, One Journey. New York: Hyperion, 2001. 272p. The book, co-written by Brooke and her mother, served as source material for the film's screenwriter. (Interview with the Ellison family included in the DVD extra features for The Brooke Ellison Story.)

story with none of their drawbacks...its authority can never be discredited." (Leitch, 289).

In addition to this appeal to final authority, there are other, more immediate benefits of claiming this status for the film's authors, as Leitch's examples show. Behind each claim to tell the truth about a subject, there is a distinct promise of entertainment for the audience. Thus, Penny Marshall, in Awakenings (Dir. Penny Marshall, 1990), is really saying: "Isn't this sad,?" when the character played by Robert DeNiro and his fellow patients revert to their non-responsive state after a brief period of recovery from a long lasting neurological illness. Or in The Insider, (Dir. Michael Mann, 1999), about the Brown and Williamson tobacco scandal, the film says to audiences: "now it can be told." (286-287) Films based on true stories use these, and similar claims in order to offer a distinctly entertaining experience, independently of the relationship of those claims to history or the facts, says Leitch. He specifies some of the strategic or instrumental claims made by several films in this genre: "Don't blame us" (we didn't make this up), Dog Day Afternoon (Dir. Sidney Lumet, 1975); "Isn't it heroic?/inspiring,?" (To Hell and Back (Dir.

Jesse Hibbs, 1955), My Left Foot (Dir. Jim Sheridan, 1989), Erin Brockovich (Dir. Steven Soderbergh 2000); "behind the headlines," Star 80 (Dir. Bob Fosse, 1983), Shattered Glass (Dir. Billy Ray, 2003). (Leitch, 286-288) Further, he gives examples of films which have used the claim to be based on a true story, when in reality they were not, such as The Coen Brothers' Fargo (1996).

Amenábar's The Sea Inside would seem, in this light, to use of the claim Leitch calls "behind the headlines," together with "Now it can be told." The director's own story of first listening about Ramón Sampedro's from a television documentary supports this conclusion. Beyond the documentary, though, lay Amenábar's claims to find a more human truth, the one extracted from the very stories of the Sampedro family members and close acquaintances of Sampedro's. He goes as far as saying that in the casting of the film, he insisted that the actors be capable of speaking with a sense of natural, unmediated expression, so that viewers would "not even think that they were before a great actor. I wanted there, whenever they were watching the actors, to be absolute truth." (Amenábar, DVD commentary). I have no reason to doubt the sincerity of Amenábar's desire to find truth (whatever the

difficulties of finding "absolute truth" may be), but it seems disingenuous of him to refer to those high ideals of truth and transparency in interpretation at the same time as he claims that he does not need to stick to reality because that would make "a documentary" out of his film.

Keeping in mind Leitch's argument about the rhetorical functions of the claim of basing a film on a true story is helpful in realizing why for some viewers, for example for the participant in my focus groups that I am calling BO, it is important to try to separate truth from "dramatic excess" in a portrayal of disability on film.

Another scholar of "real life" based films, Steven L. Lipkin, helps to illuminate the issue of the rhetorical appeal of "based on a true story" films. Lipkin asked a similar question to a number of people, and this is the answer he got:

They said it was easier to believe in a story if its people and actions had a basis in actuality. It was intriguing to get the "inside story" about how things had "really" happened. It was easier to "relate to" what other had "really done," implying that something could be learned from the experiences shown because they had occurred in actuality. (Lipkin, ix, x)

But Truth, as Elayne Rapping³⁵ reminds us, is not the main concern in works of history. Rather than simple factual fidelity, anxiety over the truthfulness of a filmed story often hinges on the question of whose version it presents, and of the seriousness of its moral, intellectual or political stance towards a problem that is widely acknowledged as pressing for a given society. As Rapping writes, "Shakespeare's "untruthful" versions of history are infinitely more valuable than the Waco docudrama, or the McGinniss book[The Last Brother, The Rise and Fall of Ted Kennedy], because they are serious, complex treatments of human experience." (Rapping, 2)

A Movie or a Film: Distinctions of Ethics & Taste

Perhaps echoing a sentiment like Rapping's, one of the participants in my focus group about Amenábar's The Sea Inside, RA, decided to start the conversation by pointing out a distinction between "a movie and a film."

RI: Well I don't agree with the premise of the movie but, I think, artistically it's a beautiful film. I think that it has a point of view that is driven home but it's to me a very incomplete story. But it's well done.

³⁵ Rapping is a professor of American Studies at the University of Buffalo, SUNY.

RA: Well I like your use of the word film. I mean, I thought, this was, I wouldn't call this a movie. I'd call it a film. I thought it was, I mean, it was photographically beautiful and it was artistic in the way that, you know, just to look at the way that scenes were juxtapose where he's lying in bed. There's another character in the next scene that's reclining. So whoever put that together is a genius as far as filmmaking, I think. It's really interesting that at this point in time, we've got the Million Dollar Baby movie winning and I say movie and I haven't seen it, so maybe it's a film too, okay. (FG3 1)

These viewers in my focus group discussion are clearly aware of the customary taking of "artistic licences" that directors and writers practice when they adapt a story from the newspaper headlines to the fiction film screen. Some, like BO, may be more or less skeptical and suspicious of the risks of over-dramatizing or sensationalizing the subject matter for the purposes of attracting viewers, as we have seen above, but they are also appreciative of the artistry and care that some filmmakers put in creating a dramatic version of the events in a given story. In other words, there is an aesthetic response to the films in this audience which is important to keep in mind because it means that their responses hinge on more than the superficial accuracy of detail in depicting disability.

As exemplified by RA's concern about the proper way to refer to The Sea Inside, whether to call it a "movie" (in his mind a devalued product) or rather, a "film," (a work of cinematic art), it is clear that he pays particular attention to finding aesthetic value, as well as an honest portrayal in the film he is viewing. The distinction is based on taste, on the perception of the placing of the film on a higher realm than that of mere "movies" made for entertainment only.

In RA's estimation, Clint Eastwood's Million Dollar Baby, which is not based on a true story, seems to immediately conjure the specter of a prejudicial and negative portrayal of disability, even before each of them has had a chance to watch it. Therefore, he calls it "a movie." As another participant puts it:

RI: It's propaganda.

RA: Yeah, it really is.

BO: It's not accurate, it's a narrow, negative...

AF: So your objection is to those fantasy sequences where he flies and things like that?

BO: No, no, no.

RA: No, to the other. To Million Dollar Baby. (FG3 16)

What I find particularly interesting in this exchange, and in the reaction to BO that I quote next, is how the claim to being based on a real story allows these

particular viewers the possibility of accepting a potentially "negative" view of disability put out by the filmmakers of The Sea Inside, and yet discounting its negative aspects by ascribing it to the real character of Ramón Sampedro. As BO remarks in the following excerpt, this is one particular individual's story, and in that context it is not problematic, as long as viewers do not attempt to generalize Ramón's decision to the totality of the population of people with quadriplegia³⁶. Here I find a much more nuanced and complex reading of this film than those of some of the writers in the literature review, where the only question asked tends to be about "positive vs. negative" images.

In the following excerpt, BO stresses again the link between reality and the story of The Sea Inside and then goes on to praise the film for the quality of its treatment of a complex and serious predicament:

Bo: This is someone's actual life and it appears that they've made an attempt to accurately portray it and even in his explanation, he's not saying, all people should

³⁶ Here I would like to notice that some other viewers still found the film's stance towards euthanasia somewhat troubling. One of them was RI, who criticized it in terms of an "unbalance" between the pro-euthanasia stance of Ramón's and other possible reactions to disability among other quadriplegics who choose to live.

think like I do...And he's not advocating that other people should ... he's not judging other people. I didn't hear him judge other people with disabilities as being like why are you out there doing what you do, but the other one is fantasy and implication, that's what I really don't like, is using fiction to depict people with disabilities in a way that reinforces negative stereotypical negative views that life is not worth living...(FG3 14)

By contrast, BO raises the question of the use of disability in a film as a way to imply that the lives of people with disabilities are expendable or have less value than the lives of non-disabled people. Soon after this exchange, the reference is clarified:

BO: This is at least based on the person's real life. It's not for me to judge somebody else's life and their decisions they make, that's fine. I mean, I'm not going to say what he should have thought, I mean, that's just a reflection of the way his mind works and the choices he made. So, I'm not going to judge.

RA: But it's nuanced and complex, not a caricature like, and again, we should give, we should look at the other film, the movie.

BO: Right.

RA: I'm anticipating movie, okay. But it wins, it wins best picture and you go: why does it win best picture? Is it because the acting is great and the film is beautiful? Or is it because [of] the anticipation that someone who was a boxer and [a] gorgeous woman [...] winds up a quad and the next thing you know, she wants to be killed and that resonates with people because that's what they think: "Oh, if that happened to me, that's what I would want."? (Fg3 17)

In judging a film like The Sea Inside, participants are conflating the aesthetic judgment with the perceived intention of the filmmakers. In Million Dollar Baby they suspect a prejudicial portrayal of people with disabilities, which is then further rationalized by RA in his sentence "I'm anticipating movie," whereby he takes away the artistic merit of that production.

For both BO and RA a film which has "great acting," "beautiful photography," professional lighting and sound quality, and so on, would still fall short of their expectations (in RA's view, it would be a *movie* and not a *film*), if it seems to sensationalize the difficulties of life with a disability or if it can appear to promote a prejudicial solution to the predicament of life with a severe disability. A film of the second kind could be a perfectly acceptable film from a technical standpoint, and yet it would be found wanting on ethical/ideological grounds.

A Balanced Depiction or an Honest Depiction

What participants want to stress is the protagonist's individual decision to end his life. They respect the freedom of choice implied in this story, and see it generally as a balanced attempt to represent a

difficult dilemma. However, there is also a minority view:

RI: My only complaint with this movie was that there's a whole, you know, "book" that was not included as a counter weight to it [...] there are glimpses of it throughout but it doesn't stand the dramatic test, I don't think [....] There wasn't that other side of the argument of, you know, he who was chosen to be isolated, who has chosen to commit suicide, who has chosen to call it, fine he makes his case dramatically or otherwise. My point is there are other reasons why he could have been happy, he could have been much more involved, he could have been all of those things, but that isn't always included. (FG3 47)

Here the discussion moves to a different question around fairness or balance in the depiction of different attitudes towards disability and towards the subject of euthanasia that are central to the story of The Sea Inside. While some critics have also chastised the film for its perceived championing of the idea of euthanasia³⁷,

³⁷ For example, see this review from Sight and Sound's Vicky Wilson:

The Sea Inside puts forward the arguments around voluntary euthanasia with reasoned intelligence. First the bed-ridden Ramón must justify his case to his lawyers, who grill him about his feelings in the way they themselves expect to be interrogated by the judges. We hear from his elder brother José, who argues that everyone has to live within constraints

the dominant view in the focus group was that Amenábar had presented the other side of the issue in some way and especially that he had not presented Ramón Sampedro's decision as the only path available to someone with a severe disability. Does The Sea Inside show all sides of the story? It presents a different response to the dilemma of whether to live or die with a chronic severe

and expresses his resentment that he had to change his own life to support Ramón. We listen to Rosa, the naive factory worker who is in love with Ramón and believes he should stay alive because of the joy he brings to others. We even see a quadriplegic priest who delivers arguments about the love of God. But Ramón counters this opposition with patience and humour, insisting that "life is a right not an obligation" and that "life in this condition has no dignity". By the end of two hours we can be pretty sure all the boxes have been ticked.

Yet The Sea Inside delivers only one side of the story. For instance, the pro-life priest is an object of ridicule and shown to be lacking in human understanding in comparison with Ramón's sister-in-law Manuela, an archetypal wise peasant woman who supports his decision. The uneducated José with his "altar-boy conscience" is easily quashed and eventually even Rosa is converted. Julia, the lawyer suffering from a degenerative condition who offers to kill Ramón and then herself but reneges on her promise, is revealed in a told-you-so coda to be now so demented she no longer remembers who he is.

and progressive impairment. This opposite response is embodied mostly in the fictional character of Julia.

Almodóvar and Gil introduce Julia (Belén Rueda) towards the beginning of the film. She is first seen looking into the distance as she waits by the sea shore for Gené (Clara Segura) a representative from the Spanish organization *Derecho a morir con dignidad* (Right to Die with Dignity), who will drive her to see Ramón³⁸. In that introductory scene, she is shown walking with a crutch, and later in the film she suffers a stroke while Ramón listens impotently, unable to render any assistance from his bed. She uses a wheelchair thereafter, and makes a suicide pact with Ramón that she will help him die at her return from Barcelona to hand Ramón the first exemplar of his book from the printers. Julia, however, has a change of heart and does not come through with her plan, instead choosing to live on despite her debilitating disease. At the end of the film, she is unable to remember Ramón or to recognize Gené when she goes to visit Julia and her husband in their house by the sea.

³⁸ Gené Gordó, an actual person who was very close to Ramón in his last years, was one of the main sources for Amenábar, besides Sampedro's family. (DVD Commentary).

Participants in the focus group readily recognized the implied contrast between the characters of Ramón and Julia.

RA: ...there was another person who admitted to being as fearful of death or sort of attracted to death as him because they were deteriorating and, you know, degenerative disease, yet she decides not to, and of course, it may have been she decides not to kill herself, but she may have also decided not to help him kill himself. (FG3 20)

RA: I would assume [that] her attraction to coming and being his lawyer had something to do with him having a disability. There really is, while, you know, people talk about community or culture or things like that, disability community, disability culture, which is not like some people living in a certain area of the city or whatever, but they're very frequently are pretty interesting and intense relationships of people with disabilities and sympathy or empathy or attraction to each other because of their perception. (FG3 33-34)

In this comment by RA we find an important allusion to the idea of a disability community with its own culture, way of speaking, its own understanding of others who are in similar situations. The existence of a common awareness among people with disabilities and their willingness to reach out to others in a condition of disability surfaced several times in the course of the different focus groups.

The film itself gestures towards that same sense of community when Gené informs Julia that the fact of Julia's disability was important for Ramón in choosing her as his lawyer.

The film makes a second gesture towards showing a wider context of people with disabilities, in the form of a person who, living with a similar disability, makes a radically different decision from Ramon's. This character, Father Francisco, is a Jesuit priest, also quadriplegic, who decides to pay a visit to Ramón in order to convince him to abandon the project to kill himself. Participants had this to say about the priest's presence in The Sea Inside:

RI: I didn't really quite get all the particulars of the [...] debate that was raging but it was definitely, you know, just [...] he was going to go out there and maybe do an exorcism. I mean that's what it kind of reminded me of when he came in there [...] the old movies of the exorcist when the priest comes in and there's that staircase scene following in and he's going to go in and fight the demons that are going to be out there. (FG3 21)

RA: ...it was interesting that when he came, they were unable to, they were on two different floors [...] and it was, to me, [...] a depiction of the reality of this guy's life and sort of the other level of sort of religious, your life is not your own [...] It's God's will that your alive [...] it's a sin to commit

suicide, all those kinds of things. But it was interesting that they couldn't actually see eye to eye physically, so they were separated and then they're sending this messenger boy back and forth, who's trying to do his best to interpret what they're saying to each other. And then, eventually, they wind up sort of yelling at each other on two different levels. And I think it really was showing, you know, people, religious dogma or religious belief or whatever and the reality of someone's life can be so different that one can't really understand the other. Or maybe it's no longer relevant to this guy what the church thought. (FG3 22)

Both RI and RA agree that the scene is effective in conveying Ramón Sampedro's utter disregard for the Catholic Church doctrine on euthanasia. However, one viewer (RI) sees in the mise-en-scene of this episode a generic allusion to old Hollywood films, The Exorcist (Dir. William Friedkin, 1973) for example, while the other does an ideological reading of the scene. In this, RA's view, the placement of the characters in two different levels of the house -as the priest's wheelchair gets stuck in the narrow staircase of Ramón's old farm house- signifies at the same time the ideological abyss separating them. For another of the participants, BO, the scene served as a reminder of the individual freedom of

choice that every person with a disability should have regarding any issue:

BO: It's interesting because two people in the same circumstance who have a totally different perception and different ways of dealing with it [...] And it shows [...] so it reflected people who made different choices, one to stay relatively isolated and not participate and another who chose to participate and had a lot of responsibility and contributed and interacted with lots of people [...] So that was a positive thing because it showed how two people with similar circumstance made different choices, had different perceptions on themselves and life. (Fg3 23-24)

The Euthanasia Dilemma and "Dramatic Intervention"

As cited above, Alejandro Amenábar is emphatic in his intention to provide a version of Ramón Sampedro's story that could be as close as possible to an "absolute truth." This claim seems either tremendously naïve or perhaps extraordinarily disingenuous, even when considering his utmost honesty as an artist and a filmmaker. Because the simple act of transforming the life-story of Sampedro into a melodramatic structure, complete with a majestic mise-en-scene that includes aerial views of his character in flight and operatic arias in the background, already introduces that "dramatic intervention" he professes to have wished to avoid.

The Sea Inside offered a moving portrayal of a singular life-experience, and it gave the members of our focus group the chance to discuss important issues relative to the representation of people with disabilities, particularly of such a controversial topic as euthanasia. But even the most enthusiastic members of the group saw the complexity involved in this representation. For example, RA, who expressed great admiration for the film, explicitly marking it off as such against a mere "movie," nevertheless had a critical view of the way that the fictionalization of the story, its turning into a melodrama, affected the audiences' perceptions of the issues involved. In particular, he pointed out the fact of how casting a young, handsome actor such as Javier Bardem could tilt audience's perceptions immediately in favor of the option taken by his character in the story:

RA: ...the sailing and the diving and [...]the pictures of this robust young man, was about a physical, I mean, a physical [appeal]. This guy was not, you know, a mathematician. This isn't Stephen Hawking, okay... This guy is a much more attractive leading man, if you will, than Stephen Hawking in a wheelchair talking through a speech device. (FG3 12)

RA: "Just to get back to the physical attractiveness dimension though, compare and

contrast the priest with this handsome author guy lying in bed [...] Which one is the movie star person, okay?" (FG3 24)

Other members of the group also pointed out the existence of a predisposition in society to receive this type of story and turn it into a stereotype. BO talked about the fear for someone without a disability who, when faced with the prospect of a life without movement would readily accept death instead:

BO: Losing the ability to move your body, I mean, of course, it's going to get a reaction in people that have never experienced it or can't imagine how you could deal with it. (FG3 14)

And RA points out the main argument of disability advocates and activists regarding portrayals of such situations in the media:

RA: The debate in this country, at least as I've heard it, is that people who [...] think they want to take their lives, like in Million Dollar Baby, [decide this] real soon after [they become disabled][...] They haven't had a chance to see or really experience life with other people loving them and their love for them. Well this guy had [...] people [...] dropping in all the time, a family that took good care of him, pretty nice surroundings; he wasn't in a nursing home, all those kinds of things [...] Still wanting to die after all those things, it does get down to the point of going, well, if the guy could do it himself, he would have already done it. (FG3 4-5)

One thing I find particularly interesting in these quote from RA is that for him, the standard argument of the disability community against euthanasia does not apply really in the particular situation of Ramón Sampedro, since Ramón had enough time to think his decision over (more than 26 years, at least), and he clearly was surrounded by loving friends and family. Therefore, RA can respect Ramón's autonomous decision to end his life.

The other thing that this discussion brought to the surface was the fact that these particular members of the disability community are not uncritical of the orientations of the advocacy groups, even though they often echo positions that are standard within that community. For instance, on the same issue of euthanasia, RA adds:

RA: There is a certain amount though of lip service paid to choice[...] And if you'll grant that there's as wide a distribution of whatever behavioral characteristics or whatever in the able bodied population as there is with people with disabilities[...]then when you look at the spectrum of people that maybe have had all of the exposure to people with disabilities and they still say, I really want to off myself; there's a lack of acceptance, it seems to me, at least [in] what's published in the disability community [...] [that] still would not accept that even the one out of a hundred

or one out of a thousand [could decide to die]. Oh, but they're wrong, okay. And so there is a judgmental point of view from people with disabilities, I think, particularly their advocates, the *Not Dead Yet* movement. (FG3 37)

The issue is certainly complex and all participants, even those who would be willing to respect Ramón Sampedro's action (both in real life and as portrayed in Amenábar's film) are also ready to denounce any appearance of an ideological promotion of assisted suicide as the only logical choice for someone in Ramón's situation. This readiness to denounce the promotion of death in the context of a fictional film is illustrated in the strong disapproval of Million Dollar Baby, a film which does not have in its favor the roots in reality that The Sea Inside has by reason of being based on the life of Ramón Sampedro. As BO says,

BO: ...the stereotype is either tragedy, ultimate suffering like Million Dollar Baby or well, this is a person's life so I can't, I'm not going to judge another person's life, but you know, choosing to show that story rather than the other parts of the spectrum, there are many other parts of the spectrum, that's just what you're saying,

RA: Jerri Jewel for example who was a stand-up comic[...]who [...] did fairly well. She was hilarious. (FG3 45-46)

This fragment illustrates as well an important procedure of interpretation of this film that I observed again and again in the focus group discussions: the comparison between the story in the film and the background experiences from each participant's life, or from the public discourse circulating in society through the news organizations and the disability movement's own publications and organizations. The Sea Inside, as well as The Brooke Ellison Story brought up in particular a number of topics from the wider culture of the U.S. political and entertainment spectrum in recent years: the figures of Christopher Reeve, maker of The Brooke Ellison Story, of Terry Schiavo, whose drama played in the news for months prior to our focus group meeting, and of Jack Kevorkian, the well known "Dr. Death," notorious for his legal troubles stemming from his campaign to legalize medical assisted suicide in the U.S. We will expand on Christopher Reeve in connection with his production of The Brooke Ellison story, but at the moment, I would like to call attention to the participant's discussion of Kevorkian.

RA: "...the complaint about Kevorkian is that Kevorkian was attracted to or at least found himself in the circle of people who were viewed

as being pitiful. They're just, you know, they don't know, this woman with MS or this person with this, if they just knew these other people with disabilities and they had some kind of sense of community, they wouldn't be dealing with this quack. Okay. And yet you'd have to stand back and go, well somebody surely could have actually thought this thing through and said that's my outlet, that's my option right there. And Kevorkian was this woman that became this guys friend except he was sort of, you know, he was a dark character, you know." (FG3 37-38)

RI was probably the most critical participant in his reception of The Sea Inside, drawing attention to the apparent absence of other positions in the film relative to assisted suicide. He is emphatic, however, in stating the importance of having the free choice to die or not. This is an aspect where the participants coincided: the need to respect the individual's choice, even if they all know multiple cases of other similarly impaired individuals who have made different choices and lived happy, fulfilling lives.

In the course of discussing The Sea Inside, participants brought up the comparison between this film and Christopher Reeve's last production, a made-for-TV movie entitled The Brooke Ellison Story. This film had been shown and discussed in our previous focus group. I

move now to a discussion of that production, which has in common with The Sea Inside the fact of being a type of "docudrama," since both films are based on the stories of actual characters.

The Brooke Ellison Story

There is a paradigmatic scene near the beginning of Amenábar's The Sea Inside, when Ramón Sampedro tries to explain to his new lawyer, Julia, why he rejects the use of a wheelchair, which he sees as "crumbs of what used to be my freedom." He adds, referring to the space then separating him from Julia:

You are sitting there, right? A little less than five feet away. Well, what's five feet? An insignificant journey for any human being. Well, those five feet necessary to reach you, let alone even touch you is an impossible journey for me.

As he says this, the camera shows a close-up of their hands resting on the white sheets covering Ramón's bed, less than a foot from each other. Ramón concludes:

It's a false hope, a dream. That's why I want to die.

The camera then closes in on Julia, as she looks with a pensive expression on her face. Let us compare this scene from one in Christopher Reeve's last film, The

Brooke Ellison Story, a made-for-television movie which aired on the A&E cable channel on October 25, 2004. In this scene, Brooke, played by Lacey Chabert, is attending Harvard University, where she was admitted with a full scholarship thanks to her academic prowess. The scene is a short, transitional segment, just before a montage that will illustrate the four years that Brooke, with her mother by her side, spent at Harvard. It starts with a medium shot of a graphic representation of a cell, projected on the classroom screen. The camera starts to slowly tilt down, as we hear a male professor, lecturing his class:

Professor: The central nervous system is comprised of unique cells called neurons.

The camera has moved diagonally, placing the professor in the background, with Brooke's face, in profile, listening intently in the foreground.

Professor: Although neurons conduct impulses throughout the brain and body, they never actually contact one another.

The camera is slowly zooming out, to reveal Jean, Brooke's mother, sleeping by her side. Brooke's wheelchair is parked in the hallway between two rows of seats, extending into the distance, in a typical large

college classroom. Her classmates are visible, as they take notes or attend to the lecture as well. She is now seen in a medium shot, in frontal view, as the teacher continues:

Professor: Neurons are separated from one another by an infinitesimal distance called

The camera cuts, accentuating the professor's emphasis, as he gestures with his hands close together, but not touching, in a medium frontal shot:

Professor: A synapse.

There is then a cut to the montage sequence about Brooke and her mother's life at Harvard.

These two scenes effectively condense, using the metaphor of space, both the suffering implicit in the inability to move independently, and the two starkly contrasting attitudes that both protagonists take to their paralysis. Brooke Ellison, the real life protagonist of the Reeve film, is also a quadriplegic, paralyzed at the level C-2, when her neck was broken in a car accident at the age of 11. The film recounts her life and her family's from that fateful day when she late in returning from school and her parents found out that she was hurt on a street in her town New York.

Unlike Ramón Sampedro, however, Both Brooke and Christopher Reeve chose to live and to engage with society. The film they made gives us a chance to examine that other direction that RI was referring to, as he criticized Amenábar's film. My intention here is not to pass judgment on either character since, like Ramón, I would consider grave temerity to decide for someone else what is good for them. My interest resides in the different paths that artists like Amenábar and Reeve took to the depiction of the lives of people in this situation, and the stark difference in the responses that our focus group participants manifested to each film.

When I first watched The Brooke Ellison Story one night on television, I finished the film in a highly emotional state. The story seemed to me such a perfect example of the integration of a person with a severe disability as an active member of society, particularly in light of Brooke's final speech as her graduating class valedictorian. She speaks of her many years of close connection with her mother, and how she owes so much to Mrs. Ellison's constant attention and help, as well as to all the others, teachers, friends, family members who have supported her through the years. But as she talks,

Ellison's speech becomes a testimony of the connectedness of human beings, irrespective of their physical capabilities, a recognition that nobody achieves success in a vacuum, and that every legitimate accomplishment of an individual is also possible thanks to those who have accompanied her in this journey. Even without Brooke's hands touching anyone, she had touched many people in the course of her trip. The film appeared to me then as a celebration of the completion of that seemingly impossible journey that eluded Sampedro.

The Brooke Ellison Story was the initiative of Christopher Reeve, an American actor who first rose to international fame in 1978, with his star performance in that year's Superman, and who made himself synonymous with the role through three sequels (1980, 1983 and 1987). Along the way, he extended his acting career with memorable roles such as the one in the Merchant-Ivory productions of The Bostonians (1984) and The Remains of the Day (1983), and numerous television roles.

Reeve's international acting career suffered a traumatic impasse with the equestrian accident which left him quadriplegic in 1995. Since then, his fame grew as an indefatigable promoter of the search of a cure for

paralysis. Like Brooke Ellison, he too was classified as a C-2, having broken the second cervical vertebrae of his neck. Although he had a severe injury he made a notable recovery in the first two years after the accident (Orensky, 1750) As the director of the Kennedy-Krieger spinal cord injury center, in Baltimore (MD) said, Reeve "shattered [the] myth," that someone with an injury like his could not "recover more than one grade two years after injury." (Ibid) His regaining of the ability to move first his thumb, and then eventually most of his hand joints gave immense hope to the actor. By the year 2000 Reeves had started not only to publicly raise awareness of paralysis through his celebrity status³⁹, but also to use his industry experience in producing film projects related to disability⁴⁰.

³⁹ For an example of Reeve's early advocacy for a cure to paralysis, see the piece in Time magazine, entitled: "New Hopes, New Dreams" (08/26/96), by Roger Rosenblatt and Alice Park.

⁴⁰ Reeve's return to a leading role in a disability oriented film started with a re-make of Hitchcock's Rear Window, in 1998. Directed by Jeff Bleckner, the new version featured Reeve as the new protagonist, architect Jason Kemp, whose house is equipped with the latest assistive technology. In addition to starring in the picture, Reeve acted as executive producer. Just a year after his accident, in 1996, he had a small role in the independent film A Step Toward Tomorrow (Dir. Deborah Reinisch, 1996).

The Superbowl of that year marked a controversial appearance of Christopher Reeve on television. He figured prominently in one of the customary spectacular commercials that American audiences have learned to associate with that event. The spot, produced for Nuveen Investment Corporation, was a futuristic scene set sometime in 2006, where a presenter was addressing a crowd in an auditorium. He informed them of the amazing advancements that medical sciences had achieved in the preceding few years. He talked of great strides against AIDS, and cancer, and finally he presented Reeves, as one among several people cured from paralysis. To a swelling fanfare, Reeves was suddenly seen to rise up and walk towards a group of people.⁴¹

The spot for Nuveen created a controversial response widely covered in the media. (McRuer, 227) Television commentators and journalists followed it, as it showed a split between the mainstream understanding of Reeve as the paradigmatic Superman, now fighting the 'heroic fight' against paralysis, and groups of disability

⁴¹ See McRuer, 2002, p. 226-227

activists who were deeply critical of Reeve for his commitment to the idea of a cure⁴².

The controversies awakened by Christopher Reeve's much publicized campaign for the cure to paralysis and his subsequent promotion of stem cell research form the background of the reception of The Brooke Ellison Story among my focus group participants. Even before selecting this production for study, the topic of Christopher Reeve and his celebrity had come up in the general discussion of disability representation in film that constituted our first focus group interview.

Three people participated in focus group # 2, about The Brooke Ellison Story. These were BO, male, 53 years old, paraplegic and wheelchair user; SH, female, 43 years old, also a power wheelchair user who lives with Muscular dystrophy, and another younger male, CR, 36, paraplegic who uses a manual wheelchair. Some other participants, like RA and RI, watched the film but were not present for

⁴² A clear statement of the disability activists rejection of Reeve's advocacy is found in Peace, William J. "Wishing for Kryptonite: A response to Christopher Reeve's pursuit of cure." *The Disability Rag/Ragged Edge Reader*. V. 25, number 1. 46-48. 2004.

the particular focus group devoted to its discussion. The topic would reoccur in several of the other focus groups.

The following quote from focus group # 1 illustrates the general feeling towards Reeve that participants expressed:

CR: It was hard to watch ... when you know something about disability and where it's at, just, the whole hoopla: (imitates voice): "oh, he's so great, and he's gonna, you know, he took a step in a pool today" or something, you know what I mean, and it's just like, but knowing about disabilities and stuff and looking at him, and going, oh, man, you know, I mean, you know, I'm glad that he did what he did, but, you look at him and you go: He's gonna be dead. Pretty soon. You know. He's going down hill... (CR laughs nervously). (FG1 25)

CR's comment typifies the attitude of numerous people with disabilities who saw in Reeve's position a foolish retreat from reality. They specifically faulted him for putting all that emphasis on a cure that many see as a chimera, while in the "here and now" there are people with disabilities needing help with health care, jobs, campaigns for greater accessibility in public places and other urgent initiatives. This critical attitude colors all their perceptions of his work, even though some of the participants tried to give him some credit for the work he did towards the end of his life.

In CR's view, the particular situation of Reeve as a high level quadriplegic could explain his emphasis on a medical solution:

CR: And that could have a lot to do with his level of injury too.

SH: Uh-huh.

CR: You know, I mean, if he would have been a paraplegic, you know, and being able to race and ride bikes and water ski and everything, you know, maybe he'd be like, heck, you know, daily living is what it's all about.

In this opposition between Christopher Reeve's position against that of other people with disabilities, particularly disability activists⁴³ we see a personalized version of the wider ideological conflict between two radically different ways of understanding disability, the Medical Model and the Social Model, already discussed in chapter one.

In this respect, William J. Peace's reaction is indicative of the blunt tone of many activists' judgment of Reeve's: "Disability rights activists cringe when he

⁴³ Although widespread, the disability community criticism of Reeve's is not unanimous. For a counter-argument to the activists' position on Reeves from a well known disability author, see Kriegel, 2006.

is quoted and I am convinced his activities have not only hindered but harmed disability rights.”(47)

Participants in my focus groups shared this view, at least to some extent. Even when they tried to praise certain aspects of the film, this background resistance to Reeve and his celebrity status manifested itself in many statements:

ZA: Just off the subject, how did Christopher Reeve portray it?

BO: Well, you know, he tried to show the rehab process. She went back to school, she's a magna cum laude; she did really well in school.

RA: “Super Crip.”

RI: “Super Crip,” you know, super achievement.

RI: Yeah, that's kind of what...

RA: But it wasn't all the, I'm going to walk again stuff. (FG4 28)

And again,

BO: I think is one of the things that Christopher Reeve has been criticized for by other people in the disability community or but since he has such high level media exposure and opportunities to educate the general public, at the same time he's raising money for research to find a more effective treatment of spinal cord injury than any other kind of degenerative central nervous system condition that at the same time, he could be effecting positive social changes. You know, like more integrated services in the community.

SH: Right.

BO: Educational employment opportunities. How to live as participating active members of the

community while you have a disability⁴⁴. (FG2 15-16)

With this background discussion of the social and political context of the reception of The Brooke Ellison Story, we can now move on to discussing in more detail the film and some of the participant's reactions to it.

The Brooke Ellison Story and the Movie of the Week Genre

The film covers the ten years lapse between the day of Brooke's accident and her undergraduate graduation from Harvard University. It was filmed in the summer of 2004 in New Orleans. The project took four years to be completed, from the time in 2000 when Christopher Reeve first heard of the book that Brooke was writing together with her mom, Miracles Happen. As Brooke and her family

⁴⁴ Here I would like to add that most of my participants have had experiences with the disability community other than as users of services: BO works with an Independent Living organization that promotes the autonomous integration of people with disabilities into the community. Other participants have had ties to this type of organization and have had experience as activists or members of the disability movement. CR, currently a photographer, used to work for the Social Security Administration, where he had to process applications for SSI (Supplemental Security Income). RI, a psychologist, worked until a few years ago with the same institution that employs BO. RA, also with a degree in psychology, is active as disability representative in State organisms. And LO, one of the female participants in the study, who suggested The Brooke Ellison Story, is a disability sensitivity educator.

have recounted, it was a cathartic experience for them to remember those years and write them down in the book, which was completed "in tandem" with the film. They speak of the difficulty of putting their most personal memories in public view, of trying to be as honest as possible and leaving out only "very personal things." The Ellisons, says Brooke's father, Ed, "are just average people that live pretty average lives, at least in our estimation certainly, and to have somebody acting it out and making it seem so important was strange, very strange."⁴⁵ Jayne Ellison, Brooke's mother, emphasizes how important was for the late Christopher Reeve to make a film that would "portray the problems that people with disabilities face in general," so that the film would not be "just about Brooke." (Documentary in DVD Commentary)

These statements by the Ellison family fit well within the general description of the genre of docudrama known as the "Movie Of the Week," or MOV, for short, as described by Lipkin. (55-98) This type of film is characterized by an attempt to bring to personal terms a social problem or a situation of general significance.

⁴⁵ DVD extra features, The Brooke Ellison Story.

Its strategy of personalizing it, centering it on a family and an individual, in this case Brooke, is a staple in the type of programming that cable networks such as A&E specialized in through the 1980s and 1990s. These programs work because their audiences recognize them as "topical and current" (Lipkin, 55). The three main criteria that television producers seek in MOV programming are the characteristics they designate as "rootability," "relatability," and "promotability." The first of these refers to the possibility of connecting the story to the life of an actual person, and in the circumstances of real life, as seen in the news (Brooke Ellison had been making headlines through the newspaper USA Today since she was a member of the newspaper's ALL USA Academic Team, while a junior in High School, in 1996) The second characteristic is ensured mainly by casting and it consists of making the protagonists "average" by selecting mostly white, middle class, suburban families, irrespective of how the real-life characters look. In this case it is illustrative that the actress playing Jayne Ellison is Mary Elizabeth Mastrantonio, who is a few shades whiter than the real Ms. Ellison. In any case, the Ellison family broadly fits

the requirements of television stations as to "relatability" to their target audiences. The third main criterion, promotability, is met by the fact that the protagonist is already known to at least part of the potential audience through news stories and it is made easier also by the flexibility that the single film format allows television programmers in placing the spots anywhere in their schedule, in comparison to the time limits imposed by the series format. (Lipkin, 59)

The Brooke Ellison Story presents a chronology of the vicissitudes that the family had to go through after Brooke's accident. It is divided in five broad segments, chronicling their collective adjustment to Brooke's disablement:

1. Before the accident. This segment presents the Ellisons as an average, happy family, with the couple of Ed and Jayne, their older daughter Keyston, middle daughter Brooke, and young brother Reed. The setting is their suburban middle class home in Stony Brook, New York, and the school where Jayne is just about to start working as a teacher, and her children attend as students. Brooke is a vivacious, popular, 11 year old girl. The first shot in the movie shows Keysten calling

her sister to get out of bed -an ironic foreshadowing of what is to come. The segment follows the family's regular activities and ends with the accident that will leave Brooke paralyzed from the neck down.

2. At the Emergency Hospital. The initial shock of the family to Brooke's accident, the ensuing surgeries necessary to save her life and her initial treatment.

3. Family separation. Following Brooke's release from the emergency hospital, she has to travel out of town to a distant specialized care facility, where she goes with her mother, while Ed Ellison stays at home taking care of their other two children. This segment illustrates not only the emotional drama of being away from their loved ones, but the difficulties that each parent faces in confronting the consequences of Brooke's accident. While she remains the focus of the family's life, the film throws light on the efforts of her father to negotiate bureaucratic hurdles to health care, while his wife learns the ropes of Brooke's nursing care. A short scene set in the hospital dramatizes also a conversation between Jayne Ellison and a fellow mother, who mentions that the place is full of single mothers, whose husbands have abandoned them following the

accidents that sent their children there. This segment tries to give some more context to the problems of independent living that many people with disabilities face through the scenes where Ed Ellison, a worker at the Social Security Administration is seen having telephone conversations with different state and private organizations to try and get financial help for bringing his daughter home. The fact that there is help for people with disabilities to be housed in hospitals, but not to provide attendant care at home is highlighted in several of these scenes.

While this is happening, the film delineates Brooke's siblings' adjustments to their sister's catastrophic accident. Young brother Reed is always positive, making jokes and trying to cheer up Brooke, while the brunt of the pain seems to be on older sister Keyston. This is underscored in a scene where Jayne and Brooke watch a home video of a group of friends and family reunion in Brooke's honor, in order to help Ed adapt their home for her. While the young brother tells a joke in the foreground of the image, his sister is seen glumly staring down in the background, in a pattern of

reactions that will be continued through the rest of the film.

4. Coming Home. The inner conflict felt by Brooke's older sister is further dramatized in a scene when she sits alone in Brooke's wheelchair and stares at a ticking clock for several minutes while her family is busy surrounding Brooke in her new bedroom. This poignant scene, handled through close-ups and a shot-reverse shot editing pattern clearly indicates the effort on Keysten's part to understand what her sister is feeling, and therefore it seems designed to further a sense of viewer identification with Brooke and Keysten.

In relation to social context, this segment highlights the contributions of friends, co-workers and neighbors to Brooke's return home, as well as the hurdles represented here in the head of the school board, who initially refuses Jayne's request to allow her daughter to go back to school. Only when she presents the official with a letter certifying her as a caregiver is she able to take her daughter to class. The passage of time is visualized in this segment by a slowly circling camera around Brooke's head, as young Vanessa Marano, who had played Brooke as a child is seamlessly replaced by Lacey

Chabert, in her role as an adult Brooke. The scene's setting in a mathematics class underscores the theme of academic achievement that is paramount in the story. The segment ends when Brooke receives an offer from Harvard University.

5. Life at Harvard. In this last segment of the film, the story develops the theme of academic achievement in Brooke's life, making clear her close relationship with her mother, who attends every class with her and is her primary care giver. It also dramatizes the social and romantic difficulties attendant to Brooke's life in a wheelchair, paralyzed from the neck down. The segment shows her repeatedly dreaming with dancing, free of her chair, and it tells the story of her infatuation with a fellow student who then becomes engaged to another woman. It ends triumphantly with her successful completion of an honors thesis and her graduation, *summa cum laude*, from Harvard. The last scene shows a slowly spinning Brooke dancing in her chair to the tune of a romantic song. In the background, a singer repeats the refrain: "It's gonna be O.K., It's gonna be all right. Tomorrow is a new day. Try to keep your head

up. Don't you ever give up, even if your heart breaks.
It's gonna be O.K...."

Emergent Themes in the Group Responses to T.B.E.S.

The optimistic tone of the film, its message of resilience in the face of adversity, fit well with the rhetorical message found by Leitch in other docudrama adaptations. In The Brooke Ellison Story, the underlying claim may be: "isn't this sad?," but more than that, "isn't this heroic?" This rhetorical appeal, united to the overall suspicion of its creator on the part of an important segment of the disability community, cited in Chapter 3 ("*I think a lot of us didn't trust Christopher Reeve for a long time.*") explain the generally cold reception that most of my focus group participants gave to The Brooke Ellison Story. In addition to this, however, I suspect the presence of a gender bias in the response, as the male participants were more likely to criticize the film on the grounds of presenting a "super crip" stereotype, while female viewers seemed to relate to the story much more and to give it a more positive evaluation.

For instance, quoting a female participant from focus group # 1, it is clear that she was positively impressed by Christopher Reeve's production:

LO: Uh, I actually just recently saw, The Brooke Ellison Story, Which was the last thing Christopher Reeve directed just before he died,

RI: Oh

LO: And I was *totally* impressed.

RA: Really, why?

LO: *with the realism* of how this woman with a very high spinal cord injury and her family life was portrayed.

This positive response to the film is aligned with the generally positive report from another female participant, SH, who attended the second focus group, devoted specifically to the Reeve film, while LO unfortunately could not attend. In that focus group, #2, the following themes were prominent: 1. Celebrity and Disability. 2. Drama vs. Realism. 3. Social Integration vs. Segregation of people with disabilities. 4. The importance of the family setting and of the Mother as a caregiver.

The first theme emerged in the context of the opposition from an organized sector of the disability community to Christopher Reeve's prominence as an advocate for the cure to paralysis, as we have seen. Participants seemed to echo the arguments voiced by

Reeve's critics, who saw in his stance a continuation of the "medical model of disability," with its emphasis on viewing it as a tragic event that must be overcome through medical and scientific interventions. This theme was not only alluded to in focus group # 2 but it formed a constant through the rest of the focus groups and it is, to my eyes, what primarily explains most participants' dismissal of The Brooke Ellison Story as a "super cripp" portrayal. In the eyes mostly of my male participants, the film reinforced the attitudes of placing more emphasis on the individual tragedy of the family and in the medical aspects of the story than on the social and legal context, which are charges often leveled at the director's activities as a whole.

The second theme, drama vs. realism was mentioned especially when participants claimed that the film did not seem to show all the difficult activities involved in the day to day care of a person who is paralyzed from the neck down. -This is something they mentioned as well regarding The Sea Inside- A quote from one of the participants, CR summarizes this theme:

"Movies do not show all the hassle."
Participants explained this by linking this

absence to the dramatization involved in creating a picture for an audience. For them, the reality of disability is downplayed for the consumption of non-disabled audiences, as it could be frightening or "not marketable" (FG2 3). They were also aware of the fictionalization that occurs when a person's life story is adapted for the screen -a process described in the beginning of the chapter in relation to Ramón Sampredo's story. Therefore, they would ask: "-How much is based in real life?" When Brooke decided to introduce herself to her Harvard classmates with an explanation of why she is in a wheelchair, one participant asked: "How much of that was for the sake of the film or did she do that? Did she do it once? Did she do it in every class that she went to?" (BO FG2 25)

The third theme, concerning the existence of barriers to the social integration of people with disabilities was the dominant topic of conversation throughout the focus group interview. It often was invoked by a participant wishing to relate the film's story to his or her own life experiences. Together with this a fourth theme, around the importance of family relationships and the care-giving role of a mother (Mrs. Ellison, in the film) also became prominent.

A female participant, SH, tended to systematically compare the film to her own life and her vicissitudes as both a person with a disability and a care giver to other

disabled family members. Her interventions often extended away from the film itself into her own life stories.

SH: When she had to go to that rehab institute and then a woman said, "oh they'll be here forever." [...] And when my brother had an ulcer on his leg and he had to go to the hospital [...] he had to stay in the hospital for quite some time and he couldn't get up [...] He tried walking [while supported on parallel bars.] They would get him up and he would try, but he couldn't do it and so he then at that point had to get his wheelchair and they had to start and that was in the 90s and none of those people ever told him about any programs that were available to help him live somewhere besides there. He actually lived in a nursing center for four years.

A male participant, CR, also related the film's story to his own experiences of acceptance or prejudice on the part of non-disabled people. They both mentioned that older people seemed to have a harder time accepting the integration of people with disabilities as active participants in public life. They cited the children's favorable response to Brooke, when she comes back to classes in her wheelchair.

This discussion prompted some participants to relate stories about their ways to negotiate non-disabled people's questions about their disability. In different focus group situations, both SH and RA mentioned the possibility that an acquired disability might be more

acceptable to non-disabled people than a congenital one. Likewise, a mild disability seemed to be more accepted than a severe one.

Participants discussed the fact that some people with disabilities prefer to disclose the causes and circumstances of their impairment immediately after meeting a new acquaintance, in order to get past that curiosity factor, like Brooke does in the film. But BO, as we have seen, wondered if that could not be simply a result of the movie's fictionalization.

Bo expressed his wish that the film had dealt more extensively with the existence of institutional barriers to integration, as seen in behavior of the school board in the film: he mentioned a possible inconsistency with the law (since the Individuals with Disabilities Education Act, IDEA, of 1975⁴⁶ would have mandated Brooke's right to go back without interference).

⁴⁶ Originally named the *Education for All Handicapped Children Act*, it guaranteed the right of children with disabilities to attend public schools for the first time in U.S. history. See Longmore and Umansky, 10, Scotch, 383-384. "Under IDEA, local districts could no longer deny disabled children access to public school programs or relegate them to generic, essentially custodial programs." (384)

Regarding the fourth theme, CR and SH highlighted the importance of Brooke's mother as her primary caregiver. They exalted the film's portrayal of motherhood and especially of Brooke's mother's sacrifice in contrast with cases of institutional neglect or abuse of people with disabilities in nursing home environments. The safety and reliability of having Brooke's mother as her caregiver was an important factor in the participant's assessment of the film. CR and SH underscored the imminent danger of death for a person with a ventilator if it malfunctions, which in the film is the main reason that Mrs. Ellison offers for her constant presence by Brooke's side. CR: "I don't know if they really, I don't know if they got across how lucky she was to have the mom be that big of a support, you know." (FG2 10)

This aspect of the film's story motivated their discussion of caregiver abuse of people with disabilities which is still a problem at health care institutions. Participants also agreed that there is an institutionalized bias against home care, seen in the movie, when the state and the insurance companies refuse

to pay for Brooke's home care, but would do it if she stayed in a medical facility.

Summing up, participants in both focus groups emphatically rejecting stereotypical images of disability on the screen. As BO pointed out above (FG3 45-46), there is a wide spectrum of possible lives for someone with a disability, and he was especially ready to voice suspicion when only some particular types within that spectrum are selected for dramatization on film and television. In the same vein, we have RA's reflection:

RA: You know, if you're all this sort of dark [mood and have] this dramatic story to tell[,] for the other ninety-nine people out of a hundred that go through this and don't get this depressed "I'm going to kill myself thing", they just kind of get up, go through getting dressed, make sure the van's been gassed up and they get out and they get in and they transfer, you know, their chairs[...] all that kind of stuff, there's really nothing, there's not such much to tell about. They're just ordinary people. (FG3 41)

Expressions such as these are very consonant with the overall theme that emerges from the discussions as a whole, that as people with disabilities, what participants overwhelmingly want from the media and entertainment industries is to be treated like ordinary people, and not only that, but they want to be respected

in their individuality, beyond labels and stereotypes. This, in itself, does not sound too surprising, and yet, it was a valuable discovery, if you will, in the sense that my initial expectation was that they would be searching for representation on the screen as a minority group, fighting for recognition as a separate community.

Initially, I would have thought that they wanted more people with disabilities to appear as the center of the films. And what they kept telling me was that they preferred a more discreet, yet "realistic" type of appearance. Just to be seen in the background, in such inconspicuous roles as the protagonist's office mate or next door neighbor, for example, or the person in the elevator.

To the question of what would constitute for them the proverbial "positive portrayal" in a movie (or film, I am not here making the distinction so dear to RA), both RI and RA encapsulated this feeling in the following quote, from the focus group on The Sea Inside:

RI: You think of the very best movie that you've seen, and then envision somebody like BO as that character, that lead. And then what would you do? All you'd do is make the modification and stuff [an actor with a disability] would [need], to be able to have that great movie part. And that's it. Yes,

it's possible but it depends on script, depends on talent, depends on...

Ra: You know, but the thing of it is, I think, when you start focusing on the disability... people with disabilities are saying, it isn't that bad. It's different, it's inconvenient, but it isn't that bad that it needs to be focused [on]...in and of itself, it's not necessarily something that you would want to have, movie after movie after movie about. So, you see, the McDonald's ad that has a guy in a chair rolling in, okay, and you see him in the background. The question is, why don't you see, exactly what RI said, why don't you see people with disabilities get to be actors? and the answer is, because there's no parts for them, other than the *gimp* parts. (FG3 41)

This type of representation of disability in films and television would constitute the ideal 'positive' image. Here the word "positive" may be misleading, however, inasmuch as they are only asking to be shown as any other group or individual in society, with an approximation to the diverse dimensions that constitute a complex person and that would be traditionally associated with a realist portrayal.

In conclusion, this chapter presented me with a contrasting response on the part of participants to two stories based on real life. In The Sea Inside, participants responded critically to the depiction of a severely disabled man who decides to take his own life, but they did not automatically reject the film on the

basis of a defense of life at all costs, or as partisans in a battle against euthanasia on the part of disability groups. On the contrary, they showed themselves to be open to the possibility of accepting euthanasia as a free, individual choice, and made emphasis on Ramón Sampedro's freedom of choice. Regarding the film's treatment of the subject, they unanimously considered it respectful and deserving of praise as a work of art, even when at least one of them was critical of the perceived bias in favor of Ramón's decision. Participants showed themselves to be highly influenced by contextual factors such as the discussion of the Terry Schiavo case and the publicity given to Clint Eastwood, and especially Christopher Reeve in the mainstream media and in the disability community publications such as The Ragged Edge, for example (see also Chapter 3 for their discussion of disability and celebrity).

The distinctly negative response to Christopher Reeve on important segments of the disability community seemed to color the participant's reactions to The Brooke Ellison Story. It is unclear whether this negative response was combined with gender. However, those more likely to dismiss the film as an instance of the "Super

Crip" stereotype were male viewers. The strength of the public controversy among disability activists against Eastwood's Million Dollar Baby was useful for comparison to the participant's reception of both The Sea Inside and The Brooke Ellison Story, since they had already judged Eastwood's film, even without seeing it, on the basis of a negative campaign conducted by disability activists. This indicates to me the importance of contextual factors beyond the film's text to create its meaning for viewers located in particular social and historical circumstances.

Chapter 6

Conclusions

When I started this dissertation, I was asking several questions about the responses of viewers with disabilities to narrative films that place disability at the center of their story and thematic concerns. The responses that the group of participants in my five focus groups provided showed me a range of coincidences, but also departures from the picture of disability representation offered by the literature on the subject within the film studies field, as well as from disability advocates and scholars in the disability studies field.

Specifically, I was asking whether my respondents would coincide with the literature (Klobas, Norden, Longmore) about the presumed harmful effects of disability stereotypes from these films on their audiences. What I discovered, which perhaps should not have surprised me, but it was somewhat shocking nonetheless, was that the viewers who responded to my inquiries did not place a particularly strong importance on films about disability. It took them usually a long time to remember a few titles, and one of them (CR) simply said ““I don’t watch those kinds of movies.” When

asked about the reason for his avoidance of these films he said that they reminded him too much of the traumatic experiences of his past, of hospital beds and other unpleasant memories that he preferred not to remember too often.

My first research question inquired whether the participants in my study would show any evidence of a strategies of rejection, negotiation or subversion of these images in their interpretation of the movies. In this connection I did not find the more extreme type of "subversive" reading that other writers posit for audiences of lesbians watching romantic films, for example (Ellsworth, 86), with the possible exception of the camp reading of Prelude to Happiness. Participants in my study were not perhaps invested enough in the resistance to these particular film representations to rely on specific strategies of "reading against the grain" or other modalities of interpretation within oppressed minorities. However, they did show signs of resistance, particularly in their constant awareness, and emphatic rejection of the possibility of stereotypical representations, and in their critical stance towards

disabled celebrities like Christopher Reeve (Chapters 3 and 5).

The most important finding in this connection is that the participant's responses to the films ran the gamut from preferred readings to negotiation to resistance, even within a single film. Some even rejected the films altogether, as in the case of CR, who simply refuses to watch these films, and who abandoned the study after focus group # 2.

An important procedure participants used when interpreting the films under study was that of comparing the storyline to their personal experiences and to their prior knowledge of similar cases in their working life. This factor played a large role in the participant's evaluations of The Brooke Ellison Story, where the discussion went towards the social and institutional context of life with a disability. It would frequently come up also when they were trying to adjudicate how "realistic" or "dramatic" a particular story line or performance was. Sentences such as "I knew somebody just like that in rehab," or "My brother lived something similar to this...," signaled that procedure at work.

Finally, a notable conclusion is that participants, contrary to the dire projections of some of the literature on disability representation, did not show a homogeneous or unified response to all of the films and their representation of disability. Even when they would use the language or rely on the arguments of the disability movement's criticisms of Christopher Reeve' or the "Super Crip" stereotype, for example, they would also manifest differences of opinion regarding the disability movement's discourse, as exemplified by the discussion on euthanasia around Amenábar's film The Sea Inside (Chapter 5). This fact, and the differences in evaluation of The Brooke Ellison Story, for example, showed me the importance of taking into account the social context of interpretations, and the role of "interpretive communities" such as the one we were studying here, instead of positing a blanket, direct (and mostly harmful) effect of films over their viewers, as the earlier literature from Klobas, Longmore, Norden et. al has done.

Regarding my second research question, on whether they would consider these representations of disability present in the movies we studied as harmful or positive

to the advancement of their interests in society, and what specific types of representations participants would prefer to see in television and film, they were unanimous in their preference for representations of disability that would "normalize" it. They were not particularly interested in stories that centered on disability, and especially not on those that put emphasis on the traumatic onset of many disabilities, with its potential for images of tragedy and pathos. Instead, they valued those representations of disability that could fall within what Rosemarie Garland-Thomson calls "the rhetoric of the realistic," (Thomson, 2001 344-345). This is a type of rhetoric where the representation does not call attention to the physical difference but rather emphasizes the commonalities between people with and without disabilities. Participants cited examples from television shows and commercials where a person with a disability is seen in the background, as one more extra in a scene, or when this person performs a role not defined by disability, such as the next-door neighbor, the office-mate, etc. These images of integration are exemplified by their positive responses to Passion Fish and Prelude to Happiness (Chapter 4), with their strong

themes of re-integration into society through work and social/romantic relationships.

In contrast with the preceding result, however, stands the participants' complaint that movies fail to show "all the hassle" of living with a disability. The portrayals are, as Ross, in her study of BBC radio listeners, "made palatable" or "sanitized" for the consumption of non-disabled audiences who might be put off by the sight of a transfer from a wheelchair or by the details of the use of a catheter (Ross 426). Participants seemed to wish more "realism" in the accurate depiction of such details, yet they also saw the problems in the "acceptability" of these images for a wide audience. Related to this issue of a wider audience's acceptability is a very interesting commonality between the different films we studied: the appearance in all of them of visual representations of the inner fantasies of the characters, often in the form of "healing scenes." In these, the impaired characters suddenly could walk, as in a romantic scene in Passion Fish, where a sensually dressed May-Alice approaches Rennie on the dock by her house; or in more extreme ones they achieve super-human feats, such as the scenes where

Ramón Sampedro flies over the green pastures and streams of Galicia to encounter his beloved Julia by the sea shore, and the one in Prelude to Happiness, when Susan is shown to have suddenly grown a new leg. Not only are these fantasies expressions of "miraculous healing" but they are systematically presented in the context of romantic situations. A similar example not examined in our selection is Jennifer Chambers Lynch's Boxing Helena (USA, 1993), where the title character undergoes a similar healing right at the moment of sexual intimacy with her captor/lover.

These fantasy sequences, as recurrent as they are, seem to me to be gestures towards a non-disabled audience, designed to allay the majority's fear or awkwardness in the face of the sexual desirability of people with physical differences. And yet the presence of these fantasies seemed entirely non-interesting in most cases to the focus group participants. They found them transparent, and unproblematic, with one exception which I will mention next. Before going on to it, however, it is interesting to notice that participants in the group interpreted these fantasy sequences in aesthetic terms, as pleasurable visual representations, like in The Sea

Inside, or as commonplace daydreams, such as those fleeting ones that any person can experience multiple times through a single day sometimes.

The one instance where the fantasy images were not transparent to the focus group participants was the visual representation of Brooke Ellison's ballet memories in the Christopher Reeve film. The recurrence of the images of a dancing Brooke as a signifier of success, both interpersonal and academic, seemed to them a possible manipulation of the viewer's sensibility. The image is present at significant points in the film, from the title sequence, to the final scene, where Brooke joyfully spins around in her power chair as she contemplates the successful end of her studies at Harvard. As SH remarked, "She was even having that in her head when she was trying to come out of the coma..." This insistence on the ability or inability to move gracefully, to dance, seemed somewhat problematic to the group.

BO: I'm sure there were times, you know, all of us who have had, you know, full physical capacity, at least I do, I reflect back to things I use to do every now and then, but it happened so often during the film, that I just wondered were they taking that from their conversations with Brooke and what she was

communicating to them. I mean, did she think about that every time she achieved something. Because wasn't it at the end of the film when she graduated with honors or something? (FG 2 23)

CR also recalled that "They did a dance scene together," between Brooke and the male classmate who ends up not corresponding her romantic feelings. The implicit link between being able to physically dance and success in other areas of life seemed bothersome to the group, to the extent that it could foster a dichotomy of representation of a person with a disability as either a tragic or a super human figure.

Other than this probable use of dancing as a metaphor in The Brooke Ellison Story, the other fantasy sequences were viewed as fairly commonplace. When asked about them, BO in particular was emphatic in clarifying that everyone dreams or daydreams with whatever experiences he or she has had in life, and therefore for someone who uses a wheelchair as a consequence of an accident, for example, it is not rare to dream of running, as it is part of the life experience stored in his or her brain. Others, such as RA, whose impairment started in very early childhood, do not describe this

kind of fantasy experience, but they do not attach a particular importance to it either.

Thirdly, I asked whether they would identify any exceptionally satisfactory representations in the hypothetical case that they were as dissatisfied with the dominant images presented in the media as the literature suggested. In terms of the degree of satisfaction or dissatisfaction with current representations, participants showed a mixture of praise and criticism. They were alert to stereotypical representations, but also open to honest or fair ones. Their responses, as evidenced in the preceding chapters were far from unified or simplistic. As for the participant's ideal vision of how characters with disability should be presented in films made for the cinema and television (research question # 3), one reply is especially telling:

RI: You think of the very best movie that you've seen, and then envision somebody like BO [a wheelchair user] as that character, that lead. And then what would you do? All you'd do is make the modification and stuff [an actor with a disability] would [need] to be able to have that great movie part. And that's it. (FG3 44)

An additional insight related to this process also came from RI. It is the injunction to "look at what's

going on with the minor characters," (see above, pages 88 and 93-94) when trying to establish what advances are being made in terms of the inclusion of people with disabilities in media representation.

In terms of the relations between the participants' views and the literature on disability representation, they did demonstrate knowledge of the general lines of criticism of films coming from the disability studies scholars. They were alert to the appearance of stereotypes, like the "tragic disabled" or the "Super Crip," and the debates within the disability community and its publications over disabled celebrities like Christopher Reeve colored their interpretation of several of the films we discussed, particularly Reeve's production of The Brooke Ellison Story. Here there is another interesting difference regarding the gender of participants: Female viewers were generally positively inclined towards the film, while male participants tended to dismiss its version of Brooke Ellison as a "Super Crip" figure. This difference might indicate that the issue of stereotypical figures can be more complicated and relative than it might appear at first glance.

Related to the idea of avoiding stereotypes, whose appearance participants linked to a desire for drama and the creation of pathos in an appeal to non-disabled audiences, they frequently insisted on the need for accuracy in the depiction of details of the daily life of people with disabilities. The issue of realism loomed large in their interpretation and evaluation of the films under study. Here it may be objected that the participant's wish for films to show disability in a normalized fashion, as just another instance of social variation is not realistic at all, but an idealized expectation. However, when I refer to realism in this context, what I mean is that they advocate for an image that is realistic by contrast to the older visual rhetorics of the exotic, the wondrous etc, as explained by Garland Thomson, which are always 'lurking in the background' as it were, calling for people with disabilities to be looked at as far above or below the level of the rest of their peers in society. So, in this case, a call for 'realism' means a call for a more restrained aesthetic and rhetorical position on the part of film producers, which will help turn attention away from bodily difference and on to traits most people

share. It is important here to notice that the very notion of normality, which my study participants wish to extend, has come under radical scrutiny from several authors in the disability studies field. Thus, Garland Thomson coined the category of the "normate," and Paul Darke writes that "by aligning issues of disability with normality, one both degrades impairment as a lived experience and participates in the further segregation of those with extreme or multiple impairments that cannot be brought under any definition of normality, no matter how wide." (Darke, Introduction, 5)

Problems and future avenues for research

As noted in the introductory chapter, some limitations to my study were imposed by the reduced size of the sample of participants and by the fact that I had to conduct the study without the benefit of a group of collaborators, which in the case of other empirical studies helps accelerate the advance of the research. Further, under the restrictions of the University's "informed consent" agreement, I could not count on the participants' commitment to a set number of interviews, but they were completely free to leave the study at any time, as some of them did. This was a limitation for me,

although I accept it as an established part of the research protocols. A similar study which could count with a larger set of participants, possibly with some sort of financial incentive for them, and with the help of collaborators to complete the time-consuming tasks of transcribing and coding would probably be a more productive experience for everyone concerned. That said, I still consider that my study and its results are valuable in that they point towards interesting directions of further study. These are:

1. The possible differences in interpretations related to the gender of the viewers concerned (as suggested particularly by the participant's reactions to Prelude to Happiness and The Brooke Ellison Story).

2. The comparison between the responses of a group of viewers with disabilities and a comparable group of non-disabled viewers watching the same films.

3. A study of the incidence of minor characters with disabilities represented in film and television productions as an index of the integration of people with disabilities in a given culture.

4. A cross-cultural study of the responses of similar groups of people with disabilities in countries

different from the U.S., where the legal and social context of integration or isolation of people with disabilities is different than that of this society.

5. Similar audience studies focused on disability related productions created by producers with disabilities, and how these differ from or are similar to mainstream productions with comparable thematic and story lines.

A Personal Conclusion

Finally, as a personal conclusion, this project proved extremely challenging not only from an academic point of view, but from a more intimate, personal dimension. It mobilized my intellectual interests but also my emotional connections to people with disabilities in my past and present. On a less pleasant note, it also revealed some wrong assumptions I had made initially about the possible results of my project, and it showed me the extents of my fears and my tendency to emotional paralysis when immersed in a state of confusion. Finally, it showed me the virtues of gradual work, of resiliency and of forging ahead even when the outcome of the process is much less than clear. Completing this dissertation required not only all of my strength, faith and hard

work, but also the friendship, concern and care of many of my mentors, colleagues, friends and family members. I am grateful to all of them, first of all to those who responded to my invitation and generously participated in my focus groups.

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