

What are you looking at?:

Representations of disability in
documentary films.

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Declaration

I declare that I have composed this thesis by myself and that it embodies the results of my own research. Where appropriate, I have acknowledged the nature and extent of work carried out in collaboration with others included in the thesis.

Maria Tsakiri

Dedication

*To my best friends Δώρα & Σταύρος,
for supporting me to stay strong and positive,
and to my wonderful family
for reminding that Spartans never surrender!*

*«Το παιδί μας «μοσχοβολάει» σχολείο, μωρέ!»
Παππούς Πολυχρόνης-Ο δάσκαλος, ο Τσακίρης.*

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ABSTRACT

This study sets out to explore the representations of disability in documentary films. Its starting point is that when such representations of disability films are under examination, one needs to take into consideration a level of complexities that come with disability, the construction and functionalities of representations, and more particularly the impact of documentary films on understanding disability. In order to address this issue, I draw upon disability theory and disability aesthetics, crip theory and crip willfulness, as well as practices of good looking, synthesising in this way a theoretical framework that responds to matters of intersectionality and criticality in relation to the analysis of representations of disability. To this end, I employ a mixed method design, which is based on participant observation, the methods of the written festival and a critical disability studies (crip) analysis for examining selected documentary films alongside a thematic analysis of semi-structured interviews that were conducted with disabled viewers who attended the *Emotion Pictures – Documentary and Disability Film Festival in Athens, Greece*. Its findings indicate that representations of documentary films familiarise viewers with disability. This familiarisation and the development of political engagement by depicting crip killjoys are the key elements that create representations of a different context and meaning in comparison to those produced by media and fiction films. My analysis reveals that depictions of crip killjoys who are conscious of their political identity, speak out and take action are depictions that ask for political engagement. As such, they can produce good staring. Visibility and social dialogue are two of the benefits of disability film festivals that are highlighted by disabled viewers.

Table of contents

<i>Copyright & Declaration of Authenticity</i>	3
<i>Dedication</i>	5
<i>Acknowledgements</i>	7
<i>Abstract</i>	9
<i>Table of contents</i>	11
<i>List of tables</i>	13
CHAPTER 1: INTRODUCTION	15
1.1 TURNING THE IDEA INTO A QUESTION	17
1.2 SETTING THE CONTEXT FOR THE STUDY	18
1.3 STRUCTURE AND ORGANISATION OF THE THESIS	20
CHAPTER 2: REPRESENTATIONS OF DISABILITY	21
2.1 RESEARCHER'S MOTIVATION.....	22
2.2 REPRESENTATIONS OF DISABILITY IN FILMS.....	23
2.2.1 <i>Disability In Cinema of Isolation – A Historical Overview Of American Industry</i>	31
2.2.2 <i>Types Of Disability In Fiction Films</i>	35
2.2.2.1 <i>Blindness & Visual Impairments</i>	35
2.2.2.2 <i>Deafness & Hearing Impairment</i>	37
2.2.2.3 <i>Physical Disabilities</i>	38
2.2.2.4 <i>Mental Illness</i>	38
2.2.3 <i>Disabled Actors</i>	39
2.2.4 <i>Disability And Documentaries</i>	40
2.3 DISABILITY AND MASS MEDIA.....	47
2.4 REPRESENTATIONS OF DISABILITY IN LITERATURE	57
2.5 DISABILITY IN CULTURE AND THE ASTHETICS OF DISQUALIFICATION	62
2.6 THE DISABILITY AESTHETICS AND DISABILITY CULTURE.....	69
CHAPTER 3: MANAGING THEORETICAL COMPLEXITIES	75
3.1 RESPONDING TO DIFFERENT LEVELS OF COMPLEXITY	75
3.2 THINKING DISABILITY	79
3.2.1 <i>The Social Model</i>	79
3.2.2 <i>The Affirmation Model</i>	86
3.2.3 <i>Disability Theory</i>	88

3.2.4	<i>Intersectionality</i>	91
3.2.5	<i>Crip Theory And Crip Killjoys</i>	97
3.3	THINKING DOCUMENTARY	103
3.3.1	<i>Practices Of Staring And Looking</i>	106
3.4	THINKING CRITICALITY.....	109
CHAPTER 4:	METHODOLOGY.....	113
4.1	CRIP ANALYSIS.....	113
4.2	WRITTEN FESTIVAL: A PARTICIPANT'S OBSERVATION	115
4.3	DATA COLLECTION	119
4.3.1	<i>Documentary Films</i>	119
4.3.2	<i>Interviews With Filmmakers</i>	121
4.3.3	<i>Interviews With Disabled Viewers</i>	123
4.4	MY POSITION WITHIN THE RESEARCH.....	126
4.4.1	<i>My Role As Professional</i>	127
4.4.2	<i>My Role As Viewer</i>	128
4.4.3	<i>My Role As Researcher</i>	130
CHAPTER 5:	DISABILITY FILM FESTIVALS.....	135
5.1	EMOTION PICTURES - DOCUMENTARY & DISABILITY FESTIVAL & OTHER INTERNATIONAL DISABILITY FILM FESTIVALS.....	135
5.2	THEMATIC PREOCCUPATIONS IN DISABILITY DOCUMENTARY FILMS.....	141
5.3	LANGUAGE IN THE SYNOPSES OF SELECTED DOCUMENTARY FILMS	143
5.4	DISABLED VIEWERS ON EMOTION PICTURES - DOCUMENTARY & DISABILITY INTERNATIONAL FESTIVAL.....	144
5.5	CONCLUSIONS	158
CHAPTER 6:	FILM ANALYSIS	165
6.1	INTRODUCTION.....	165
6.2	FLUCTUATION OF "OTHERNESS" IN A DANCE PROJECT THAT PROVOKES TABOOS	166
6.3	GROWING TOGETHER: A FATHER'S CONFESSION LETTER.....	176
6.4	DISABILITY AS CASUALTY: A BODY OF WAR TAKES PAIN TO ACTIVISM	183
6.5	EXTRAORDINARY BODIES IN CONTROL OF MAKING: AN EXAMPLE OF TRAINING AND SUPPORTED EMPLOYMENT	187
6.6	EDUCATION ON THE FRAME: MATTERS OF INCLUSION AND TRANSITION .	193
6.7	CRIPPING REPRESENTATION: KILLJOYS IN ACTION!	199

6.8 EVALUATION OF REPRESENTATIONS	207
CHAPTER 7: CONCLUSIONS	211
7.1 IMPLICATIONS & IDEAS FOR FURTHER RESEARCH.....	218
7.2 FINAL WORDS.....	220
REFERENCES.....	223
<u>APPENDIX A</u> : RELEASE FORM	237
<u>APPENDIX B</u> : RELEASE FORM TRANSLATED IN GREEK	239
<u>APPENDIX C</u> : INTERVIEW QUESTIONS FOR VIEWERS	241
<u>APPENDIX D</u> : INTERVIEW QUESTIONS FOR VIEWERS (GREEK VERSION).....	243
<u>APPENDIX E</u> : INTERVIEW QUESTIONS FOR FILMMAKERS	245
<u>APPENDIX F</u> : SYNOPSES OF FILMS FROM THE PROGRAMMES OF EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM FESTIVAL AND OFFICIAL WEBSITES OF FILMS.....	247
<u>APPENDIX G</u> : EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM FESTIVAL POSTERS 2007 & 2009.....	253
<u>APPENDIX H</u> : THE OTHER FILM FESTIVAL POSTERS.....	255
<u>APPENDIX I</u> : PHOTOS & LINKS FOR TRAILERS OF EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM FESTIVAL.....	257

List of tables

<i>Table 1. <u>Evaluation of representations</u></i>	209
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CHAPTER 1: INTRODUCTION

“How far can you see?” Imagine this question being addressed to a student with visual impairment by a learning support assessor. Is this really the question for evaluating the student’s needs for educational support? Should this question be addressed to the student who is partially sighted? How about addressing this question to all professionals: policy makers, teachers, educational support assistants, academics, social workers, support workers, as well as sex workers, doctors, nurses, physiotherapists, speech therapists, occupational therapists, psychologists, architects, engineers, or even all individuals involved with disabled people: family members, friends, classmates, maybe also random passers-by: How far can we see, literally and metaphorically. What do we see when it comes to disability? And I use “we” here intentionally, including myself into the list of professionals, because the very moment we get involved with disability matters, we actually participate in disability discourse. Is it possible to see beyond disability? And perhaps more provocatively: Do we have the required knowledge to see *beyond* disability? This question seeks the level of in-depth and critical understanding of disability and its many complexities. It generally ignites a conversation about the nature of disability, its constructions, the stereotypical positionings of disability within the politics of ableism, the problematic of ‘seeing’ and of ‘the look’, and most importantly, the varied and often problematic ways in which it assumptively positions disabled people in the broader social domain within the frames of ‘representation’. Disabled people that are scrutinised daily through questions that serve the medical model of disability and gazes that are clinical or simply curious, often talk back by asking: *“What are you looking at?”*. In cases where visual activism takes place, disabled artists and activists invite their non-disabled audience to look at them as a provocative encouragement to become engaged, and to insight discomfort in order to resist stereotyping and become familiar with them.

Disability film festivals encourage this engagement and they contribute to the development of familiarity with disability, as they are the spaces where the audience is exposed to various representations of disability. Becoming aware of the proliferation of disability film festivals, that mostly include documentaries in their screening, I became

interested in the socially-constructed manifestations of disability and its filmic representations. My initial thought was that documentaries will depict a counter-image of disability to the one constructed within fictional films, particularly the Hollywood productions. After attending the first event of the *Emotion Pictures – Documentary and Disability International Film Festival* in 2007, in Athens, I became more intrigued to investigate this topic as my initial expectation was neither confirmed nor disproved after the screening. My research in literature showed that there was a paucity of relevant literature in the exploration of disability depictions in documentaries within the field of disability studies (Pointon, 1997, Snyder & Mitchell, 2006, Koppers, 2007, Quinlan, Smith & Hayward, 2009, Schwartz et al., 2010), and that the space of disability film festivals has even less coverage (Mitchell & Snyder, 2008). Following my investigation into this area, there appears to be no complete and comprehensive review on representations of disability in documentary films, neither have disability film festivals been thoroughly explored. Consequently, research in this area through a critical disability studies perspective is of significant importance as it makes a critical contribution to unravelling the many ways in which documentary depictions of disability can be transformative in relations to the ways disability is understood.

Even though this thesis will not provide a comprehensive and exhaustive historical overview of representations of disability in documentary films, as it explores only a selection of documentary films screened at disability film festivals, it will describe and analyse the context of the *Emotion Pictures – Documentary and a Disability International Film Festival* as exemplary manifestation of such festivals. The *Emotion Pictures – Documentary and a Disability Film Festival* was the first disability film festival organised in Greece. I examine this event as an exemplary manifestation of this category of special themed film festivals due to its size – a three day event – and the extent of involvement – the Greek cinema community collaborated with the disability community to organise an international festival with a cross-disability and cross-cultural context receiving funding and support from governmental and private agencies. One more element that contributed in the unique form of this event was its organisation based on accessibility. The choice of venue, audio descriptions, print in Braille, and interpreters for Greek Sign Language suggested an accessible and inclusive festival/cinema. The aim was the development of a constructive social dialogue in Greece focusing on disability matters through arts and more particularly the documentary films. This initiative was

pioneering and ground-breaking considering the Greek political and socio-cultural approaches to disability, so unquestionably the *Emotion Pictures – Documentary and Disability International Film Festival* was the most intriguing setting for undertaking fieldwork.

Through the theoretical frame that combines strands of disability theory, crip theory and killjoy feminism, I examine the different assumptions, significations and projections that documentaries reveal, such as depictions of disability within the context of disability film festivals. In this way, the thesis contributes to the body of literature on depictions of disability in documentary film, and therefore to the fields of disability and media studies more broadly. The research also opens opportunities for the development of materials and programmes for educational purposes that address critical awareness of representational dilemmas within disability contexts in the social domain. It can be used as an introductory module for professionals of education, social work and social sciences offering a critical view to disability matters, representations, aesthetics and activism through a critical disability studies perspective. The issue of voice is also a critical contribution here, as there are limited opportunities in research where the voices and perspectives of disabled people might be heard in respect of their reflections and ideas on depictions of disability in documentaries, or of their interpretive processes of viewing such documentaries with a critical eye on the nature and social functions of disability representation.

1.1 TURNING THE IDEA INTO A QUESTION

Since there is extant research on representations of disability in films, for the purposes of this research, I decided to focus on depictions of documentaries starting with the overarching research question addressed by this research: *How is disability constructed through representations of current documentary films?*

The question “how” has been answered in several works mentioned in my literature review but there is a paucity of research on documentary films. In order to answer this question I examine the context of documentary films that were screened and selected from the *Emotion Pictures – Documentary and Disability International Film Festival* and I also present the thoughts of disabled viewers who attended the festival. I

consider the involvement of disabled viewers vital as I did not wish this thesis to be one more on the list that disregards disabled people's political call: nothing for us without us. The functionalities of disability film festivals and the experience of attending such an event, also dictate a look at the feedback from disabled viewers. Furthermore, I thought that it would be valid to add to my perspective the context of documentary films and disabled viewers' reflections on films and film-festivals, aiming to capture multiple voices. This would, on the one hand, give a holistic sense of the content of my research, while, on the other, trying to minimise the distracting heteroglossia - in the Bakhtinian sense - wherever possible. In order to achieve this, my research seeks to answer the following sub-questions:

1. What difference do disability theory, crip theory and killjoy feminism make in the construction of disability through current documentary films, and what do they reveal?
2. How do disability film festivals function towards disability culture and inclusion?
3. What are the themes of documentary films that negotiate disability and what are the representations they shape?
4. How do these representations differ from existing media and cinematic models and how do they contribute in filling the gap between representation and disabled people's actual experiences (as much as this can be ascertained)?
5. What are some of the ways in which disabled people respond to the representations of disability in documentary films?
6. What might disabled people's views be about disability film festivals?
7. What are the limitations in the representations of disability in documentary films and what alternative representations do disabled people envisage?

1.2 SETTING THE CONTEXT FOR THE STUDY

I do not harbour any illusions about whether people are fond of documentaries. Unfortunately, documentary as genre often tends to have been stigmatised as boring to watch, too educative, "what else is there to watch – change the channel!" However, I find all these misrepresentations produced by the commercial 'easy for consumption' fiction

films, unhelpful. I recognise that both fiction and documentary genres offer rich material that could be used as educational tools for discussing matters about disability and teaching about human rights, prejudice, stereotypes and inclusion. After spending the first years of my studies looking at fiction films, I was intrigued to find out what actual disabled people's counter-narratives might be. I came across disabled academics, artists and activists' criticisms but I was also interested in finding out if and how they participate in the making of their own stories, their representations of self. Moved from an optimistic desire that there should be a valid constructed argument against the tradition of misrepresentations screened by fiction films, I became interested in documentary films produced from the beginning of 2000 onwards. Searching for documentaries, I discovered that disability film festivals were proliferating in this period, which was a fortunate coincidence for this research choice. I was informed by friends that there was a disability and documentary film festival running in Athens in 2007, and this was a newly organised and pioneering event. I decided to attend the *Emotion Pictures – Documentary and Disability International Film Festival* in 2007, under my own initiative, as I had not started my doctorate at that time. I was there as a researcher, for the next two events in 2008 and 2009, collecting data for my doctoral research.

As the field of documentary films and disability film festivals offers rich material for research, because they combine different voices, practices and functions, I had to make decisions in order to narrow down the options of using this material in a way that would contribute to the development of my doctoral research project, according to the expected criteria. My thesis examines the image of disability depicted by documentary films through a critical disability studies perspective and the functionalities of disability film festivals by combining my initial idea that documentaries have the potential to offer counter-images to the stereotypes produced in fiction films, through the unfolding of counter-narratives given by actual disabled people, and the undiscovered field of disability film festivals. Since there is a sense of innovation – even though there have been seven years since the first disability film festival in Athens, the field remains relatively undiscovered. As for the lack of a solid theory for examining representations of disability in documentary films, I sought the most recent developments in critical disability studies that could contextualise and support the particular and complex aspects of my research. The combination of disability, crip and feminist theory is the most suitable for examining and analysing the image of disability in documentary films and

the functions of disability film festivals, as they touch on matters related to culture, aesthetics, socio-cultural locations, disability politics and activism.

1.3 STRUCTURE AND ORGANISATION OF THE THESIS

This thesis is divided into seven chapters. This first introductory chapter presents the rationale of the study by outlining the matter of representations of disability in documentary films and the contribution of disability films festivals in shaping representations. An overview of the aim and research questions of the study is also stated. In the second chapter, I comprehensively review the literature on approaches that come under the discipline of what we currently call disability studies and examine representations in fiction films and media and patterns of narratives in literature. In the third chapter, I discuss the theorising representations of disability in documentary films taking into account the complexities that come with a) disability, b) the construction and functionalities of representations through systems of communication, and more particularly c) the impact of documentary films on the functionalities of social representations. In chapter four I describe the methodology of my study discussing the critical disability studies analysis, ethical considerations, the data collection and my position within the research. The fifth chapter is set as a contextual foyer where I attempt to present the context and the social climate of disability film festivals. I present the thematic preoccupations in disability documentary films, the summaries of the selected documentary films, a brief comment on linguistic choices in relation to disability, and the disabled viewers' thoughts on the festival by focusing mostly on the *Emotion Pictures-Documentary & Disability International Festival* where I undertook my fieldwork. In chapter six, I analyse the selected documentary films and I evaluate the representations of disability in them. The final chapter concludes by re-visiting the sub-questions of the research and elaborates on the implications and limitations of the study pointing to future research recommendations for researchers interested in expanding the importance of political building of documentary films that negotiate disability matters and their engagement with representations of crip killjoys.



CHAPTER 2: REPRESENTATIONS OF DISABILITY

What are you looking at? This is the main question that expands in all aspects of my thesis. I had to address it throughout the process of conducting this research. What are we looking at when we watch a film about disability or when we look at an image of a disabled child or the nude of adults affected by thalidomide? What directs our critical response to these images and what are the socio-cultural and historical factors that shape the prisms that we apply when we look at representations of disability? This is one main question that can be answered in various ways but it can also be followed by a few other sub-questions. It is also a question that talks back to those who stare at disabled people. The intrusive quick look that scrutinises abilities or inabilities, reflects curiosity or fear. This encounter of staring usually bears the question: “what happened to you?”, and is based on the assumption that something must have happened that disturbed the socially and culturally accepted rules of normativity. In this non-verbal but intense interaction disabled people talk back and ask “what are you looking at?”. However, this is not always the case as through disability culture and particularly documentary films, disabled artists and activists invite the audience to look at them thus bringing different dynamics in this encounter and allowing the development of an interaction that will give birth to a deeper understanding of disability and the disabled body.

In this chapter, I will present the background against which my thesis will be developed. To this effect, I will start off by briefly mentioning my own questions, which prompted me to pursue this study in the way that I have. Then, I turn to discuss the ways in which disability is depicted in films, focusing in turn on the American industry, the types of disability represented in fiction films, the issue of presence and absence of disabled actors in fiction films and the representation of disability in documentaries. Following this, I examine the representation of disability in mass media, paying particular attention to the stereotypical representations often used in them, before turning to its depiction in literature. In the next section, I look at the perceptions of the presence of disability in culture from the perspective of critical disability studies and Siebers’s analysis of the aesthetics of disqualification. Closing the chapter, I discuss the

counterargument that Siebers calls disability aesthetics and the significance of disability culture.

2.1 RESEARCHER'S MOTIVATION

When I asked myself several times what I am looking at, I decided that first I had to answer what I had learned to look at. In order to find that particular answer, I went through researches and academic work where disability was a central matter and specifically aimed to examine the representations of disability in films, media and literature. As the research on representations of disability in documentary films is very limited and documentary is an unexplored field in relation to depicting disabled people, I decided to look at work that represents approaches that come under the political umbrella of what we currently call disability studies and examine representations in fiction films and media and patterns of narratives in literature. Since representations of disability in documentary films remains a genre that requires further development, the examination of depictions in fiction films, media and literature is really important as there are deep connections and influences between these fields. In this respect, analyses that focus on literature works offer effective methodological approaches that can also be used for the examination of representations of disability in films, considering that literature influences filmic narratives or the creation of characters.

Research on representations of disabilities in fiction films and media was initially mostly descriptive, aiming at the creation of various categorisations, focusing first on listing films depicting characters with disabilities, and later on films depicting specific types of disability with a 'fixation' on categorising stereotypes. Later work was influenced by the popularity of the social model of disability and examined mainly the "negative imagery" of disability. I therefore felt that a further review of the presence of disability in culture and the notion of the aesthetics of disqualification was required. This review offers a better understanding of how disability operates in western culture and how figures of "otherness" are constructed. The closing section of the literature review covers the perspective of disability aesthetics and the functionalities of disability culture as a counterargument to the misleading discrepancies, stereotypes and exclusion that were products of the aesthetics of disqualification. The purpose of my research leads to the

examination of this particular area since I aim to examine the representations of disability in documentary films, most of which were independent productions that were screened at disability film festivals, spaces where disability culture takes action and develops. With this in mind, I will now turn to discuss the representation of disability in fictional films.

2.2 REPRESENTATIONS OF DISABILITY IN FILMS

I have been interested in the subject of representations since the beginning of my postgraduate studies and it was then that I realised that the literature on the specific subject was quite limited. Since I was studying in a Greek University, I first looked for Greek literature and, with no surprise, I discovered that there was no work on depictions of disability. The echo of this gap was so profound that even my MA supervisor tried to encourage me to change the subject of my thesis. Considering that there are so many fiction films, particularly Hollywood productions, with disabled characters I kept on believing that there must be some work by the British and Northern American academic community. Thus, dealing with a limited literature, I decided to collect findings that would answer the question of what we currently know about the representations of disability in films. In order to collate a review of what we know, I started searching what work has been developed so far, focusing mainly on research and essays that were published even before the official formation of disabilities studies, but could still be included in this academic discipline. The early works focused on quantitative findings, offering some valuable reports of the number of films that depict disabled characters, or the frequency of particular types of disability that were screened. As first attempts to examine representations, these early examinations are important because they shaped initial listings of films and types of disability presented in films. However, these attempts followed a descriptive approach and as such they lack a more in-depth analysis of representations. Later work influenced by the idea that disability is socially constructed demonstrates the shaping of filmic stereotypes and narrative patterns. These developments start setting the political frame for the discussion of filmic stereotyping and its impact on disabled people. As these studies created the methodological approach of negative or disabling imagery that became very popular and influenced that core of the essays in the '90s, I consider them as an important section of the literature review.

Starting from the early attempts to examine the portrayals of disability in cinema, Byrd and Pipes's (1981) quantitative research sought to determine the nature of disability depiction in feature films. This research also reported the frequency in which specific types of disability were depicted, as well as mapped film critics' evaluations. Longmore's (1985) essay reveals some of the stereotypes repeated in films and television that reinforce the cultural prejudice against disability. Longmore points out that the repeated depiction of disability as an isolated and personal matter distracts the attention from the social context of disability. Klobas's (1988) collection of Hollywood disability drama films and American television series or episodes was one of the first attempts to list films that depict disability and explore the representations. Klobas's listing was developed in categories based on types of disability: blindness, wheelchair – users, deafness, amputation, developmental disability, small-stature, "other disabilities". Klobas's work offers a long list which covers approximately 55 years of disability drama. However, it is limited to the description of plot and stereotypes found attached to the disabled characters.

Martin Norden's (1994) study has a clear historical content that follows a general, "*reveal and resist*" approach which actually tells the story that is hidden behind the cameras, explaining the development of particular stereotypes and unravelling misconceptions ascribed to physical and sensory disabilities. This work focuses on the American commercial (Hollywood) cinema and on a number of international films that were popular in the U.S.A., covering almost a century of depictions of physical disability. Norden discusses films that reflect the trends of the cinema industry during that time. Further, the impact of the political background of each era is made clear in relation to the examined films. A range of stereotypes unfolds in Norden's work. Most of them distort the image of disability but socio-political circumstances that marked the periods examined by Norden established these distorted images as the principal patterns for filmic representations. A detailed review of the development of these stereotypical images will be presented under the section "Disability in Cinema of Isolation – A Historical Overview of American Industry". Norden (1994) and Safran (1998) shape the first comprehensive collections of cinematic stereotypes. They distinguish particular stereotypes ascribed to specific types of disability, which indicates the different approaches to different impairments, thereby proving that film-makers and producers do not perceive disability as a unified case. This suggests that film-makers or producers do not always recognise the complexity and fluidity of disability identity but rather the audience's different

responses to different types of disability, in particular the political and historical periods. In this context, these examples also highlight the socio-political and cultural background that supplied these stereotypical images.

Longmore (1985, p. 32) in his analysis on disabled people's imagery in horror films, mentions three main stereotypes that the film narrative follows:

- a) Disability is depicted as a punishment that follows a sin or an unethical action;
- b) Disabled people are presented as having grief status for their unfortunate “fate”;
- c) Disabled people envy non-disabled people and wish to destroy them.

Finally, Longmore observes that for monstrous and disabled characters who are criminals, the final narrative solution is death. He asserts:

[...] these dramas present death as the only logical and humane solution. But instead of eliminating the disabled person who is a violent threat, it relieves both the individual viewer and society of the impossible emotional, moral, and financial burden of severe disability. (Longmore, 1985, p.33)

For the depiction that death was related to suicide, Longmore notes:

The disabled characters choose death themselves, beg for it as release from their insupportable existence. The non-disabled characters resist this decision, but then reluctantly bow to it as necessary and merciful. Once again, the non-disabled audience is allowed to avoid confronting its own fears and prejudices. (Longmore, 1985, p. 33)

Mitchell and Snyder (2000) interpret that which Longmore described as a “kill or cure” pattern in literary work, as a “quick fix” that erases disability and removes the audience's need for dealing with the anxiety that disability is affixed to. The “quick fix” is recognised as a textual prosthesis that is used for this specific purpose; to “alleviate discomfort by removing the unsightly from view” (Mitchell & Snyder, 2000, p. 8).

According to Longmore (1985) disability for both fictional and non-fictional stories is a matter of coping and personal acceptance and its management depends on the individual's choices and emotional strength. This perspective shifts focus and responsibility from society to the individual, since issues of social stigma and discrimination are hushed up. Zola (1985) adds that film-makers are not interested in screening a realistic depiction of disability and, in that case, disabled people are presented as a threat against society, as victims or as “children” who never grow up. This empowers the construction of negative imagery. Shakespeare (1999, p. 164) also utilises negative imagery, focusing on three popular stereotypes:

- a) *The tragic but brave* disabled character who puts at risk his own life to save a non-disabled person;
- b) *The sinister cripple*, who is actually the paranoid evil;
- c) *The “supercrip”*, who is a character that manages superhuman achievements by overcoming the limitations set by his/her impairment. This particular depiction is ascribed to the disabled person who triumphs through his/her personal tragedy.

Safran (1998) suggests that an alternative to the established negative portrayals is the “sociology of acceptance” wherein people with disabilities are depicted as equal members of their families and communities with close interpersonal relationships. Lopez-Levers (2001) follows the guidelines set by the Institute for Information Studies (1979), and suggests that positive depictions should present disabled people interacting as equals, having insight into societal barriers, having complex personalities, being part of the mainstream, and having loving relationships.

Longmore (1985) concludes his report on images of disabled people by highlighting that the roots of cinematic stereotypes were shaped by socio-cultural factors related to approaches to disability. He suggests two inseparable tasks of analysis:

The scholarly task is to uncover the hidden history of disabled people and to raise awareness of the unconscious attitudes and values embedded in media images. The political task is to liberate disabled people from the paternalistic prejudice expressed in those images and to forge a new social identity. (Longmore, 1985, p. 37)

In a parallel vein to the discussion of “positive” portraits, Shakespeare (1999) underlines the danger that critiques of the negative imagery are “extended into simplistic and over-censorious readings of almost every film including impairment” (p.165) for the sake of “disability correctness”. In similar lines as political correctness, disability correctness criticises film narrative and acting on grounds of misrepresentation, inaccuracies and stereotypes. Shakespeare (1999) criticises setting fast rules of representations on film and simplistically characterising portraits as negative and suggests a more complex thinking on films and authorial intentions. Shakespeare argues that films should be seen as an art form and judged on artistic elements. He comments that if a portrayal is not good (in the context of Shakespeare’s analysis the use of the word “good” does not necessarily replace the term “positive”), it is because the film is not “good” in general. At the end of his analysis, Shakespeare very briefly mentions the audience’s

involvement and the work that in some cases is required by the audience and critics on approaching a film about disability.

Darke's (1999) doctoral thesis examined representations of physical disabilities in films and tried to reveal the social constructions that are adopted and re-enforced by cinematic depictions. This research was focused on the use of stereotypes, the representation of family in relation to physical disability, and the use of the abnormal body to pathologise impairment. It is a first attempt to analyse the content of six films *archetypally* and *stereotypically*. Darke uses Dyer's (1993) definition of archetypes and divides them from stereotypes but he puts both under the perspective of the Social Model:

There are two specific ways in which the stereotypical differ from the archetypal: the first is the process of self-labelling, or self-definition, in the interests of defining the parameters of that specific society's limits on self-identity and in giving it a legitimacy that it would not otherwise possess. Secondly, stereotypes assist in the creation of an in-group and an out-group that is defined within the text itself (not by a morality extrinsic to the film's own sense of reality) in order to create the basis of inter-group relations. (Darke, 1999)

Under this framework Darke's investigation leads to the following concluding observations: firstly, that the stereotype of disability in films is more complex. Secondly, that "the ideologies and hegemony of disability are multi-functional and thirdly the body is the key in any examination of the ideologies of disability and the cultural construction of both the disabled as abject and impairment as disability" (Darke, 1999). Undoubtedly Darke's work has its own value in disability imagery because it scrutinises depictions of physical disability through the Social Model and the notion of "Otherness", which was a popular academic matter during that decade. Since then, disability studies have moved from the binary social – medical model, since disability and its depictions require a wider analysis, and the Social Model has received criticism for its limitations even by its supporters (Shakespeare 2006, Oliver, 2013).

In a later work, Snyder and Mitchell (2006) start with a critical review, particularly of fiction films and Hollywood mechanisms for attracting viewers' responses. Here they argue that disabled bodies marked by disciplinary practices were "offered for consumption as objects of necessary scrutiny or even just curiosity" (Snyder & Mitchell, 2006, p. 157). Disability in Hollywood is used to allow able-bodied viewers to look at bodily differences, minimising the fear that an inter-personal interaction would involve. The Hollywood representation also creates the belief that viewers witness a phenomenon

that was previously hidden or secret. Analysing *Excessive Film Bodies*, the authors follow Linda William's feminist perspective, focusing on her diagram titled, "An Anatomy of Film Bodies," which categorises genders' responses to bodily sensations. According to William's analysis, melodrama attracts girls and women, horror appeals to adolescent boys and pornography to men. Each genre is associated with a prototypical effect: pornography with sadism, horror with sadomasochism and melodrama with masochism. Snyder and Mitchell (2006), after coming to the conclusion that "disabled bodies have been constructed cinematically and socially to function as delivery vehicles in the transfer of extreme sensation to audience" (p. 162) adapted William's analytical structure to *An Anatomy of Disabled Bodies in Film*, aiming to provide a better understanding of the system and structure of body genres. Keeping two of the original genres of film narrative, horror and melodrama, and swapping pornography with comedy, they created a table of psychic structures found in Hollywood films depicting disability. In this respect, Snyder and Mitchell indicated that every genre depends on specific types of disability:

Like film plots, the disabled body, itself can be said to solidify a form of visual shorthand. Its appearance prompts a finite set of interpretive possibilities now readily recognizable to audiences weaned on the grammar of visual media. (Snyder & Mitchell, 2006, p. 164)

In Snyder and Mitchell's analysis, depictions in comedy, horror and melodrama are scrutinized according to bodily display, emotional appeal, presumed audience, disability source, originary fantasy, resolution, motivation, body distortion and genre cycles. For example, in a comedy depiction, the bodily display is a faked impairment, the emotional appeal would be superiority, presumed audience would be men, disability source is performed, the originary fantasy relates to sadism, resolution reflects on humiliation, motivation is duplicity, and body distortion reflects on malleability. The analysis of body genres in this Hollywood depiction shows that "disabled people are constantly negotiating a self-image with respect to a normative formula" (Snyder & Mitchell, 2006, p. 169). Snyder and Mitchell's critical review gives a more sophisticated insight, by focusing on the disciplinary practices applied on the disabled body, into the creation of stereotypes in Hollywood films.

Snyder and Mitchell's analysis is also included in a collection of essays, edited by Sally Chivers and Nicole Markotić (2010), which offers new frameworks and modes of analysis to representations of disability in films. This collection invests on disability

theory, providing a framework that focuses more on the ways that narrative and mise en scene create the problem body. Chivers and Markotić have selected essays that explore critical notions of “projection” and filmic constructions of “problem bodies”. Projection is addressed taking under consideration narratives that project identities, intersectionality and spectatorship. Engaging in a post-Mulvey perspective, Chivers and Markotić (2010) redirect strands of film theory in relation to spectatorship and gaze involving disability studies and intersectionality. They expand the matters of gaze by bringing forward the mis-assumed relationships between looking and knowing and the importance of getting an audience to stare at disabled bodies without censure. The call for staring at disabled bodies as an engagement that can lead to a political action is based on Garland-Thomson’s work on staring (2002 & 2009) that actually offers a groundbreaking perspective through a critical disability studies lens, and to which I will return in the third chapter where I will examine practices of staring and looking (3.3.1). The other aspect that this collection invests on is disability studies as a field that can provide a rich methodology for complicated film narratives that cover a wide range from film noir and classic Hollywood to Korean and European cinema. All in all, Chivers and Markotić (2010) argue that disability theory can strengthen film analyses when it comes to representations of disability, something that this thesis also values and defends.

Another collection of essays that aims to respond to the paucity of scholarship on disability in film and television offering analyses from a disability studies perspective is edited by Marja Evelyn Mogk. The nineteen essays of the edition offer a highly international content as the selection of authors is spread across United States, Canada, the United Kingdom, Australia and India, and the films it touches on are productions from France, China, South Korea and Thailand. This collection is organized in two sections: a) disability on screen and b) disability in production and reception. The first section includes essays that examine a variety of dynamics in relation to disability and film, looking at genre, community, commodification, modernity, and globalization. It also covers matters of representation of disability on TV examining narrative function, curing, satire, and competitive reality shows. The second section is composed of essays that examine more the involvement of disabled people on the levels of partnership, authorship and spectatorship. Mogk (2013) also tries to contribute to the introduction of disability studies in the film studies field. It is interesting that the introduction of this edition is a comprehensive tutorial on the basic but important aspects of disability studies: the social

and the medical model of disability, disability studies, the invention of normal and the instability of disability. Under the introduction of disability studies there is a brief description of the five methodological approaches for examining stereotypes ascribed to disability in literature and film introduced by Mitchell and Snyder (2000) in *Narrative Prosthesis: Disability and the Dependencies of Discourse*, and which I will return to discuss in section 2.4 below.

Both editions (Chivers and Markotić, 2010, Mogk, 2013) are dedicated to combine disability studies analyses with film studies, refer to Mitchell and Snyder's work as a significant and pioneering step that offered a perspective that led to shifting the focus to a more disability studies approach in examining representations of disability in films. Benjamin Fraser (2016) contributes to the field of critical disability studies and cinema with a third collection. The aim of Benjamin's edition is to expand the content of disability studies into a more global one beyond the Global North. Fraser (2016) argues that disability studies do have a significant contribution in thinking about disability but the context of all produced developments seems to be preoccupied with and are limited to Anglophone publications dealing with Anglophone contexts. The ambition of this collection is thus to shift the focus of disability studies to a non-Anglophone context, particularly in relation to representations of disability in films. Contributors from Australia, Austria, Canada, the United Kingdom, Germany, Ireland, Italy, Malawi, the Netherlands and the United States look at films from Belgium, France, Germany, India, Italy, Iran, Japan, Korea, Mexico, Netherlands, Russia, Senegal, and Spain. Fraser also acknowledges the work developed by Siebers, Mitchell and Snyder, which is essentially link with critical disability studies, but he does not address them as such. Even though he acknowledges Mogk's (2013) collection, Fraser makes a strong argument about the lack of investigation of representations of disabilities in films in non-Anglophone contexts. Therefore, credit can be given to Fraser's (2016) edition on the basis that it is the only recent work exclusively dedicated to non-Anglophone contexts and that it makes a call for the need of more cross-cultural representations and perspectives on disability.

These last three collections come to fill the gap between disability and film studies focusing on various aspects in relation to disability and cinema. All the editors support the argument that when it comes to looking at disability in films, disability studies can enrich its analysis. The dialogue for involving disability studies, and moreover critical disability studies, even though no one names their context as such, with film studies has

started. Clearly, there is a call for further contribution in order to address all the different levels of complexity of representations of disability in films. Before developing the argument of critical disability studies can offer the context for examining the complexity of disability matters, however, it is important to understand the production of stereotypes that are frequently used in fiction film and have haunted disabled characters and people in general for many decades.

2.2.1 Disability In Cinema of Isolation – A Historical Overview Of American Industry

Norden's (1994) historical overview of physical and sensory disabilities in American cinema can offer a better and overall understanding of the production of stereotypes in fiction films of the American industry in the 20th century. Even though there is not much in-depth analysis, and this discrepancy is covered by Snyder and Mitchell's work, Norden's overview is a valid documentation of the development of filmic stereotypes historically demonstrating the socio-political factors that influenced the formation of specific imagery in particular periods. In this context valid knowledge is gained by going through this historical summary because the majority of the stereotypes described by Norden are still reproduced even beyond the boundaries of film industry and the geographical boundaries of the U.S.A. as they were and still are spread in the media and film industries worldwide. Also, by understanding the socio-political factors that impacted on the creation of particular disabled characters, for example the disabled war veteran after periods of war, a critical view can be applied on their modernised reappearance on screen (eg. the main character of film *Avatar*). One more aspect that is detectable is the shifting in themes, particularly when social policies change or there is a popular demand by the disability community. For example, in the last decade there were films that negotiate matters of emancipation, and independent or supported living, (eg. *Inside I am dancing* -2004, *Yo tambien* -2009, *The Intouchable* -2011).

The first storytelling film depicting disability was Thomas Edison's *Fake Beggar*; a fifty second long film, where disability is faked by beggars and this way becomes a source of humour. Norden (1994), who recorded the history of representations of physical disabilities in films notes that the fakery became a theme that many other films adopted, producing a number of comic scenes. The audience was allowed to laugh at people with

physical disabilities with the alibi that the characters were not really disabled. The victimisation of people with disabilities became a popular pattern not only for comic films but also for dramatic films. The illustration of the “tragic victim” was popular until 1908, and during this period characters with blindness also appeared in these films. People with visual impairment are depicted as poor and socially cast out. Often the solution in their story comes with their death. The depiction of the “tragic victim” derived from the real economic circumstances at that time. Industrial accidents happened in high frequency and disabled workers were by-products of the industrial age. In many cases disabled workers became impoverished and they had to beg to make their living. The “films of despair” (Norden, 1994, p. 27) reflected the matter, focusing more on people with blindness. In order to increase the volume of audience’s weepy reactions, film-makers usually chose the tragic victim's death as the unavoidable end of despair. As law started introducing compensation for workers that became disabled by industrial accidents, the depiction shifted, to that of the impoverished disabled character that was salvaged by big-hearted non-disabled characters.

In 1908, with the introduction of the film d' art movement, where films were the extension of theatrical plays or novels, the depiction of people with disabilities changed again. There were two popular depictions that of the “disabled-villain,” and the “Sweet Innocent,” a dichotomy attached to the gender of character: the villainisation for male characters and the infantilisation of female characters. Based on the popular belief that disabled people depend on others, specifically on kind and generous non-disabled persons, film-makers created the “Sweet Innocent” disabled character, usually a child or a woman. This particular character included all the personality elements that make someone *exceptionally pitiable* (Norden, 1994) with a reactive rather than proactive approach towards other people and life. A character that reflected society's paternalistic attitude and its need, “to create and then “service” a charity-worthy underclass to enhance its sense of superiority” (Norden, 1994, p. 36) became evident. The audience started showing their preference to dramatic films that chose as narrative resolution, a miracle cure instead of death for the “nice” characters. The addition of biblical subjects to cinematic themes helped the development of the divine intervention and miracle cure resolution that was presented as a fair reward for the disabled people's kind and pure heart.

A few years later, the stereotype of the “Obsessive Avenger” makes its appearance in films. This was the representation of an adult male who was looking for revenge against

those who were responsible for his disability or against his moral values. In the 1920s, cure was the trend of narrative structure. An indication of more than 90 disability films out of 200 produced during that decade, followed the narrative solution of cure. The most curable type of disabilities were blindness and paralysis as they became quite popular matter during wartime. Interestingly, what Norden highlights is that most of the cured characters presented, returned to their “normal” pro-disability self, totally unaffected by their experience of becoming disabled, an experience that gets rapidly erased, without leaving any traces on the character's identity. Cure, either by divine intervention or corrective operations, and death, for those who were dangerous deviants. These narrative solutions reflected the attitudes of mainstream society towards physically disabled people.

During the 1930s, the stereotype of the “Obsessive Avenger” and the depiction of disabled villains became popular in horror films. The competition between film industries and the success of horror films expanded the interest on “Obsessive Avengers”, characters and scenarios that in many cases were based on the cultural construction of Freakshows. After the World War II, the focus shifts again on to war veterans, rehabilitation and post rehabilitation matters as these were “hot box-office material”, (Norden, 1994, p.160). The interest in veterans' stories increased the sensitivity to matters of physical disabilities as film-makers often created films based on actual experiences of real disabled veterans. This effort though, did not prove to be powerful enough to change the motives that film industries followed for the construction of disabled people's images.

The period that starts in the late 1940s and early 1950s is when the Hollywood blacklisting era was born (Norden, 1994). Political and economic pressures imposed on producers and filmmakers led to the creation of “Civilian Superstar” stereotype that reflected the expectations of a conservative society and the political shift towards ‘responsibilism’. Films depicted determined civilians that had trust in their own abilities and/or in support from family and friends to overcome difficulties and cover their own expenses in contrast to disabled veterans that relied on assistance from the government. In the decades from the 1950s to the 1960s, the types of “Sweet Innocent” in many cases as a receiver of divine cures, and the disabled villain attached more to amputee characters this time had also returned to the screen. As politics shifted and disabled people became more active claiming rights and bringing the Independent Living Movement on the activist scene, Hollywood production started changing the depictions of disabled people

and their lives. The rehabilitation of Vietnam veterans was a matter that put some extra pressure on changing not only the legislation but also the cinematic portrayals. There were films that tried to create a sympathetic image but many other created the stereotype of drug or alcohol addict, psychotic or sadistic killer (*Apocalypse Now*, 1979), (Norden 1994, Safran 1998).

In the late 1970s and 1980s, depictions follow a mainstream trend, trying to create balance between more realistic portrayals and characters that will shake the audience's emotions, thus troubling the construction of the image of disabled people. In the 1980s comedies used disability as a condition to cause comical incidents that made audience laugh at people with disabilities, whereas, horror and sci-fi films represented disabled people as “Techno Marvel” (Norden 1994), a stereotype that consists of the disabled characters that use high technology prosthetics and bionic aids that reduce the human element, turning them more into a high-tech machine. The image of the technology expert was also attached to male wheelchair-users of high intelligence who operated the technological equipment that served a non-disabled superior. These representations were characterised by a dehumanising quality as wheelchair-users appeared to be experts on “operating the high-tech equipment because, by virtue of their wheelchair usage, they appear to be part machine themselves”, (Norden, 1994, p. 299).

An interesting development has been the representation of people with disabilities as sexually active and in many cases being more in control of their lives in terms of personal choices, employment, support, parenting, and advocacy. Hollywood has been making efforts for more realistic depictions when it comes to biographical films but disabilities such as autism or mental illness are still used as narrative prosthesis to create an intense atmosphere. As American society deals with one more generation of veterans from the wars in Iraq and Afghanistan, cyborgs and transitional or alternative types of embodiment (*Avatar*, 2009) become the current trend in film production, as post-humanism gains focus.

Even though the changes in the socio-political circumstances and policies had an impact on the film industry, the stereotypes and narrative motives that were developed, especially by Hollywood industry, have been well established, resulting in a significant influence on the audience's preference and perception. In this context, it is interesting to review how specific types of disability have been depicted in fiction films as it shows how the filmic imagery adopts the differentiations amongst socio-culturally formed

perceptions and misunderstandings ascribed to different types of disability. By adopting and presenting these socio-cultural misconceptions on screen, the mechanisms of stereotyping are reinforced and, as a result, particular misbeliefs and inaccuracies haunt specific types of disability.

2.2.2 Types Of Disability In Fiction Films

2.2.2.1 Blindness & Visual Impairments

Byrd and Elliot's early research on representation of people with blindness suggests that blindness affects 13% of disabled characters in films (Byrd & Elliot, 1988), a percentage that over-represents the actual rate in the general population. There were specific reasons that made blindness so popular in film production. Firstly, it was a disability that could bring the element of dramatisation in films. Secondly, it was also feared by many individuals who would typically avoid contact with blind people (Safran, 1998). It was easier for the audience to satisfy their ignorance or their curiosity by watching a film with blind characters than by interacting with a real blind person. Klobas (1988) added one more reason: Helen Keller's story, which fascinated the audience and made blindness a box office success. Writers also believed that visual impairments were always translated into total darkness whereas partially sighted characters were not considered as profitable by Hollywood industry.

There have been several inaccuracies and myths attached to blindness, one of the most common ones' being the existence of a "sixth sense" or "second sight" that allowed blind characters to sense objects or situations. The "sixth sense", which is traced back to 1909 (Norden, 1994), was usually coupled with supernormal hearing, and as a result a supernatural skill was ascribed to blind people, constituting a myth that haunted them. "Face feeling" was one more inaccuracy that became popular through the depiction of Helen Keller and film-makers used it as blind characters' way to initiate interpersonal relationships. "Wooden stare" was used as an indication for making this particular disability more visible to the audience, a misconception that also became popular and a challenge for acting, as the actors had to keep their head in a fixed position without moving their eyes (Klobas, 1988, Safran 1998).

Stereotypes differentiate according to the gender of the character. The ratio was

two male to one female character, and usually the “Sweet Innocent” stereotype is ascribed to young women or girls as they are depicted as pure, kind and good-hearted. Films that represent this illustration, also follow the narrative solution of magic or divine cure. A great example is Charlie Chaplin's *City Lights* (1931) (Norden, 1994). Blind female characters were also depicted as quite vulnerable, easy targets for kidnappers, drug dealers or murderers (Safran, 1998). Norden (1994) describes male characters as “saintly sage” because they were presented as wise older men who would express the required reasoning to put a chaotic world in order. In conclusion, blindness meant victimisation for women but wisdom for men. The “saintly sage” representation could possibly be a cultural relic of ancient Greek tragedies where loss of sight was balanced by an internal profound awareness and knowledge that in many cases would transfer the gods' will.

Darke (1997), pinpoints three types of blind men's representation:

- a) The blind beggar or villain who uses his impairment to exploit non-disabled people;
- b) Supercrims -usually detectives that dealt with and fought criminals in equal terms by overcoming their loss of sight;
- c) Musical types who prove that the flaw of their blindness can be substituted by their great talent and the incredible function of the rest of their senses. There were female characters depicted as musical types but the most common depiction was the *tragic terrorised victims* or *tragic but inspirational* that made viewers feel good about themselves (Darke, 1997).

Looking at other social groups, Darke (1997) notes that Black or Asian blind characters appear rarely in Western cinema, mainly in films about poverty in developing countries where visual impairments and blindness is presented as a result of food shortage and lack of medical provision. Gay characters with visual impairments in mainstream films are also hard to find. In terms of narrative pattern, films with characters with visual impairments cannot escape the general negative stereotypical pattern of films that screen disability, which translates to despair, dependency on non-disabled people, loneliness, and vulnerability. All the limitations that the characters have to deal with seem to derive mainly from the impairment, rather than the barriers that society imposes upon them. In this context blindness and visual impairments are presented as characters' personal tragedy.

2.2.2.2 Deafness & Hearing Impairment

The portrayal of deafness and hearing impairment is limited in comparison to other types of disability. The limited number of films that depict deaf characters is partly a result of the deaf community boycotting Hollywood for not employing actors with hearing impairments to perform in roles of characters with hearing impairment. Exaggeration, inaccuracies and misleading representations also apply on this type of disability, constructing an image that fails to present deaf people as healthy, active and independent. The most common depiction was that of characters being dependent on hearing people, downgrading people with hearing impairment to objects of pity (Safran, 1998). Experts in lip-reading and fast learners of sign language, which in some cases appears as a natural skill, are the most popular inaccuracies. Cinematic portrayals fail to show the complexity of non-verbal, manual communication and the societal barriers that make world inaccessible for deaf people and their community (Klobas 1988, Schuchman 1988, Norden 1994, Safran 1998).

According to Schuchman (1988), films wanted characters with hearing impairment to get cured with the use of a medicine on trial, a surgical operation or psychotherapeutic intervention. There were also narratives that presented the miraculous acquisition of speech and verbal communication without any therapeutic intervention. Hollywood production would avoid including more than one deaf character or a deaf family in its films. The reason was that the Deaf community was perceived as a linguistic minority, so the dialogues between characters had to be in a different type of language and this created technical complexities. The most obvious solution to this was the use of subtitles but the industry stopped using them with the development of “talkies”. On one hand, producers and film-makers dealt with subtitling as an extra technical process. On the other, viewers were not familiar with reading subtitles while watching a film, and showed low preference to those that used them. These reasons prevented the establishment of subtitling and the increase of communication based on sign language. A simplistic and basic form of sign language was developed instead and presented for cinematic purposes. This misleading construction was developed in order for films to illustrate a non-verbal communication easy for hearing viewers to understand.

Even though the Deaf community has a rich history of political action, films never touched any matters related to this dimension of deafness and hearing impairment. The

fact that deafness exists in a world that takes the ability of hearing and speaking for granted was never a theme for fiction films. Hollywood focused on and exaggerated the tragic consequences of being deaf in a hearing society, like accidents, failures and misunderstandings that the character had to experience due to the loss of hearing. Deaf characters were attractive for narrative structures for two reasons: they were “easy” victims- as their disability was invisible, and viewers did not find their appearance appalling (Schuchman, 1988).

2.2.2.3 Physical Disabilities

Under the category of physical disabilities, war veterans, the “tragic victims” and the “paranoid sinister” are included. Most characters had acquired disabilities, usually after an accident, or because of orthopaedic and skeletal deformities. Scenarios wanted characters with physical disabilities to be rejected when they were trying to develop personal and sexual relationships. Mental health problems, dependency on non-disabled persons and miraculous cures were the basic characteristics of film narration. As it was mentioned in Norden's (1994) analysis, the “paranoid sinister” or “Obsessive Avenger” would try to put obstacles into non-disabled people's lives and make it difficult as an expression of revenge for all the rejections and frustration caused by becoming disabled.

Morris (1991), in her analysis on disability in Western culture notes:

The makers of these films are not actually portraying the lives of disabled individuals; rather the disability is a vehicle for exploring the pain of dependency and vulnerability for men. A man in a wheelchair is an easily recognisable metaphor for a lack of autonomy, because this is how the general culture perceives disabled people. [...] The films do not challenge the stereotype; they use it and in so doing exploit us. (Morris, 1991, pp. 95-96)

2.2.2.4 Mental Illness

Hylar (1988) analysed specific clinical categories in depth and stated that portrayals he examined were reasonably accurate and could help for professionals' training purposes. Hylar et al. (1991) identified six cinematic stereotypes: the “rebellious free spirit” who are characters that try to escape from psychiatric institutions, (McMurphy in *One Flew Over the Cuckoo's Nest*, 1975), the “homicidal maniac” who is a threat for the society and kills innocent citizens (Hannibal Lecter in *The Silence of the Lambs*,

1991), the “female patient as seductress” who tries to attract, usually a male, psychiatrist. The fourth stereotype is the “enlightened member of society”, characters that actually refuse to follow a compatible to norm life style, rejecting any established system and they present a different way of living. The “narcissistic parasite” is the fifth filmic stereotype of people with mental illness. Woody Allen's characters are the best example of this portrayal: “a self-centred, attention-seeking person who cares little about the needs of others”, (Safran, 1998, p. 473). The “zoo specimen” depicts patients as dehumanised laboratory species used for scientific experiments. Lopez-Levers (2001), in her ethnographic content analysis of Hollywood films, added the stereotype of “artistic/creative genius”.

2.2.3 Disabled Actors

Before examining the literature of representations of disability in documentary films which is a factual genre, it is valid to mention the issue of presence and absence of disabled actors in fiction films since performing disability has also added on to the formation of stereotypes. The film industry preferred and still does prefer non-disabled actors performing as disabled characters. Film-makers used the bodies of disabled actors when they wanted to create an effect of shock for their viewers. This particular treatment of the disabled body is considered as a case of exploitation. Disabled actors were aware of non-disabled viewers’ curiosity about the disabled body and they fully participated in this game of exploitation by exposing their “extraordinary” body for financial reasons. During the period where the “miraculous cure” of disabled characters was the most popular theme, disabled actors were given some of the roles but they had to hide their impairment after the “cure” scene as the narrative dictated (Norden, 1994).

Many non-disabled actors are keen on disabled characters because acting disabled is considered a big performing challenge which in cases has been rewarded with an Oscar award (eg. Daniel Day Lewis for his performance in “*My Left Foot*”, Tom Hanks in “*Forrest Gump*”, Sean Penn in “*I Am Sam*”). However, the matter in this case is that disabled actors and actresses are not employed for the roles of disabled characters, something that causes a justifiable reaction: disabled actors claim that their right of being employed by film and theatre productions is being marginalised. A very significant

activist initiative was the boycott of Hollywood productions in the 1980s by the deaf community.

Barnes (1992) supported the claim that disabled characters should be played by disabled actors, arguing that non-disabled actors should not play disabled characters, much like it is unacceptable for white actors to be cast as black people and men to be cast in female roles. In this context, Barnes also makes a call for producers, film-makers and performing arts schools to create space and offer training for disabled actors. Disabled actors taking over the role of disabled characters could be considered as an act of empowerment because people that experience disability in their lives combine this experience with their talent, and with their performance deconstruct misunderstandings or elements of exaggeration. Furthermore, the employment of disabled actors breaks down one more barrier, that of super handsome or beautiful, white, fit actors and actresses that the film industry has promoted for many years.

2.2.4 Disability And Documentaries

The above works describe the representation of disability in fiction and mostly Hollywood films. Disability Film Festivals brought more genres on the scene and some of them focused on documentary films emphasizing on non-fictional representations.

Pointon (1997) examined documentaries in British television and suggested that there is a lack of critical analysis in presenting disability issues. Pointon describes four basic themes of these factual programmes: transformation, tragedy, normalisation and spectacle, arguing in each case, the failure to meet the aims of disability culture and to challenge aspects of cultural oppression:

The effect on “disability”, around which there exists so little widespread cultural challenge, is that prejudice, stereotypes and other preconceptions are played to rather than changed. (Pointon, 1997, p.87)

In Pointon’s critique, it is also mentioned that factual programmes are usually characterised as “moving”, which shows that documentaries, like fiction films, target viewers’ emotions too.

In their joint work, David Mitchell and Sharon Snyder have made a great contribution in critical disability studies with their work (Mitchell & Snyder 1998, 2000, 2016; Snyder & Mitchell 2006, 2008) which is foundational in many respects. During

the years they have offered important critical input in the discussion on representations of disability in films and literature as well as in disability film festivals. In their reflective work on making their video documentary *Vital Signs: Crip Culture Talks Back*, a ground-breaking work, representative of disability studies context, that was awarded the Grand Prize at the 1996 World Congress of Rehabilitation International. Mitchell and Snyder made *Vital Signs* with footage from the University of Michigan's 1995 conference on disability and the performing arts, *This/Ability*. Their initial aim was to make a film about the evolution of disability studies and its connection with disability politics but as their footage included the performances of different artists/academics/activists, their film turned to be a documentary on disability culture, still constituting ground-breaking work with political value. Their reflections on making the film also has a great value as it could be used as an introductory guide for all those who wish to make a film about disability while taking into consideration the complexity of the subject and the politics of disability. Mitchell and Snyder (1998) came to film-making with a planned strategy: a) they made their own subjects larger-than-life on screen, in order to achieve visibility and familiarity, b) they gave the freedom to all disabled participants to determine the way and the degree to which they wanted to speak about their disabilities. The second part of their strategy was intentionally decided because they wanted to provide the space to their participants to control the presentation of their bodies in their performances and scholarship. The interviews with the participants brought up a wide range of disability matters with a strong political context, such as visibility and invisibility, passing and coming out, accessibility and silence, mainstreaming and isolation, civil rights and public neglect, independence and institutionalisation. Mitchell and Snyder (1998) also explain their decisions about following particular techniques of film-making, eg. shooting the interviews from a low angle, one-take, cinema verité approach. The ways they adopted for filming were intentionally chosen with the aim of breaking down all the clichés used in representations of disabled people; they wanted to articulate a “disability perspective” that was led by a politicised definition of disability. The disabled participants in *Vital Signs* therefore talk about the disability experience through an interpretative methodology that refuses to present the disability experience as a static notion. Mitchell and Snyder’s work is pioneering for two reasons: firstly, they produced their film and their reflections on it in late ‘90s within a disability community promoting, disability culture and indicating the strong connections of disability culture with disability politics. This is an action with

historical importance for the growth of disability culture and disability studies in the U.S.A. Secondly, their strategies in film-making and their reflection on them opened to road to making a documentary about disability that responds to the politics of disability.

In a later work, Snyder and Mitchell (2006) initiated the discussion on “New Disability Documentary Cinema”, that they describe it as the genre where “one encounters the privileging of disabled people's voices and also the explicit foregrounding of a cultural perspective informed by, and within, the phenomenology of bodily difference” (p.170). A shift in the representation of disability is noted in documentary films, which are related to subcultural communities influenced by the action of disability rights movements and the context of disability studies. Snyder and Mitchell examine specific documentary films that they consider significant examples of film history in the U.S.A. during the eugenics era and later years. The film content had to support the eugenics propaganda and film techniques were applied accordingly to cause effective sensations to the viewers. The effect that these documentary films had is described as similar to that of horror films: a horror justified by medical textbooks. The shift in disability issues brought changes in depictions. The basic and important element that documentary films offer, the intimacy with disabled characters stays as a principal rule, but the perspective is different:

While the proselytizers of the eugenics period denoted the disabled body as the objectionable object within a sea of normalcy, new documentary cinema designates degrading social contexts which need to be rehabilitated. (Snyder & Mitchell, 2006, p.173)

In this context, new documentary cinema is described as the effort of re-introducing disabled people to the audience, supporting the depictions of an ordinary life with disability and by doing so, breaking down the Hollywood tradition of disability imagery:

One could argue that the primary convention of this new documentary genre is the effort to turn disability into a chorus of perspectives that deepen and multiply narrow cultural labels that often imprison disabled people within taxonomic medical categories. (Snyder & Mitchell, 2006, p.175)

The disconnection from medical categories does not mean that disability documentary films deny or try to erase the biological side of disability, but they reject labels imposed by the medical model which limit disabled people's lives. The new disability documentary cinema shifts the focus from the disabled body, to the social context and questions the systems and bureaucracies that have an impact on disabled

people's lives.

Kuppers (2007) makes a brief reference to *Murderball* – a documentary about wheelchair-using rugby athletes. She examines *Murderball* (2005) in her analysis on the performance of disability by disabled people, particularly wheelchair users, and she comments that in this documentary film the rugby players are presented as “people to whom the chair is not just a narrative, but a tool, a lived experience, an aesthetic statement, and a form of self-identification” (Kuppers, 2007, p. 81). Kuppers uses this particular documentary to tease out the complex ways in which the rhetorical use of the wheelchair can be read and interpreted. *Murderball* does not present the wheelchair through a narrow lens that only focuses on the technical support that implies the lack of ability for mobility, on the contrary, the documentary “focuses on a wheelchair as material artifact, tool, and a sign of freedom, sexiness, and regained masculinity-machismo” (Kuppers, 2007, p. 81). Robert McRuer (2010) also examines *Murderball* and he argues that the disabled characters of the documentary are presented with a “proper sexuality” in order to reaffirm stability within a politically and economically unstable world. By taking responsibility for their own bodies, the disabled characters of *Murderball* promote the responsibility toward the “common good”, reaffirming values held within western neoliberal societies.

In support of the argument that documentaries approach representations of disability in ways that elevate the complexity and fluidity of disabled characters' identity, Quinlan, Smith and Hayward (2009) put their perspective on *Plan F*, a documentary about Ed Marko's life. Ed Marko is a car mechanic who lost his sight from a degenerative disease. After working as rehabilitation councillor he opened his own car care shop. For Quinlan, Smith and Hayward (2009), Ed's story told through this documentary redefines “what it means to be blind when one can be employed and doing what he or she loves” (p. 61). They also highlight that in contrast to the stereotypes reproduced by fiction films, the documentary unfolds the complexity of Ed's character and also his business skills.

Schwartz et al. (2010) record the results of their effort of dispelling stereotypes during the film festival that was organised at Hofstra University. The aim of the festival was to provide authentic representations of people with disabilities. The film selection was based on documentaries that cover the themes of: Special Education, Counselling, Creative Arts Therapy, Rehabilitation Counselling and Gerontology, the actual disciplines of the Department of Counselling, Research, Special Education and Rehabilitation. The

results of this brief research project showed that films which desensationalise disability and include portrayals of real people, were seen as a way of dispelling stereotypes and also as a potent learning tool.

Samuels (2013) examines the two televised documentaries that conjoined twins Abigail and Brittany Hensel made as adolescents about their lives, *Joined for Life* (2001) and *Joined for Life: Abby and Brittany Turn Sixteen* (2006). Samuels questions matters of self-representation and agency in the analysis of these two documentaries. She makes references to historical representations of conjoined twins and she continues with the decisions made and practices adopted by the family of the twins to pass them as normal. An interesting point of the analysis is that Abigail and Brittany's parents perceive disability as an invalid challenging existence that would exclude their daughters from social life. This approach to disability is embraced by both films, and Samuel addresses issues of "extraordinarily normal". She continues with discussing the shifts of managing representation teasing out matters of agency and authorship. The decision making about when and what the camera records fluctuates among Abigail and Brittany, their parents and film-makers. The multiple layers of representationality and agency raise questions about control of exposure and privacy in relation to the sisters' private life. Taking into consideration scenes that are multi-layered and meta-representational, Samuels discusses whether these film-making is reflexive or reflective. Continuing with the challenges of agency and control, Samuels addresses the disruption of knowledge-effect due to practices of distribution and reception of these documentaries. The majority of the extended distribution in digital media for these two films was based on fragmented representations that have proven to be quite problematic as they separate the content of the films from their creators' control and intentions.

The film-making process is also discussed by Veronica Wein (2013) who reflects on her own experience as a film-maker and mother of a disabled child. Wein (2013) reflects on the making of her documentary film: *18q-: A Different Kind of Normal*, which features the film-maker, her family and members involved with the Chromosome 18 or 18q community. In order to produce a film that would serve the aims of parental advocacy and the 18q community's expectations, she draws on the four step evaluation suggested by Larry Gross, John Stuart Katz and Jay Ruby (1988) adding a fifth step herself. The main aspect of this essay is the decision making and the ethical responsibility of a film-maker in the process of parental advocacy film-making. It is a really compelling writing

as it puts through the perspective of a creator who has three different roles: she is a mother, a film-maker and an advocate. Wein's ethical framework and its application in critical phases of decision making is a great contribution, as it delineates the ethical aspects and the challenges it brings in the parental advocacy film-making. These issues need to be addressed and become well understood, given the proliferation of documentary films made by film-makers who are parents of disabled children. My thesis examines two documentary films by parents/film-makers; one of them falls under the category of parental advocacy film-making.

Mitchell and Snyder (2016) discuss a few documentary films addressing matters of overarching modes and methods operational in international in(ter)dependent disability films. They initially discuss the Russian documentary *O Lubvi* (About love) as an example of documentary films about disability that focus on easing the audience into their material by downplaying the urgency of the social and political issues they pass as background. They continue their analysis with the category of documentary films that they name: 'Introduction to My Disability', which usually try to get the audience to understand disability conditions through a diagnostic and quite medicalised context. However, they refer to the documentary film *Goodnight, liberation* (2003) by the African American filmmaker Oriana Bolden, as an 'Introduction to My Disability' documentary that shifts the focus from the medical context to a political one. Through the diagnostic motif that most of these films adopt, Bolden exposes the lack of systemic access to public healthcare in United States. Mitchell and Snyder (2016) introduce one more thematic of disability films, which they call "disability in motion", they refer to films that depict disability dance. Christian von Tippelskirch's *Invitation to Dance* (2014), a documentary about the life of Simi Linton, a disability scholar, activist and dance advocate is also discussed by Mitchell and Snyder in the context of disability dance and disabled bodies claiming their position in public spaces. The writers argue that "we need to understand disability as a baseline model of interdependency rather than a tangential or exceptional situation" (p.27). According to Mitchell and Snyder (2016), the understanding of interdependency allows "audiences to discover alternative ethical maps" (p. 28), as they get to recognize the value of non-normative embodiment and they disentangle their lives from normative habitudes. The writers conclude with developing their initial argument that, when contextualized and screened in a meaningful way within international

disability film festivals, independent disability films contribute to alternative ways of understanding disability.

This is an interesting and valid find for the purposes of my research but it also made me think that depicting stories of or about real disabled people is not a privilege that only documentary films have. Literature referring to essays or research on representations of disability in mass media should have also discussed similar findings. Considering that the literature about documentary films and disability is limited, I thought that research that examines media portrayals would be really valid for my research purposes as their representations refer also to real disabled people and issues of everyday life. Reviewing early and later reports and research in American and British media, I came across literature that is mostly orientated on the negative imagery, since Biklen and Bogdan's (1977) listing became the paradigm on which Barnes (1992) based his report about representations of disabled people in media for the British Council Organisations of Disabled People. Barnes presents eleven recurring media stereotypes, adding one more to the initial list of Biklen and Bogdan, but he also proposes principles for avoiding the creation of negative imagery. Markova and Farr's (1995) edited selection of articles also negotiates the matter of representations of health, illness and disability through different theoretical and methodological approaches. Particularly, Eyrs et al (1995) research on representations of learning disability in charity campaigns highlights people's responses to charity posters and their intentions of donating. Charity campaigns rely on a particular imagery that can manipulate the audience's emotion and their drive to donate. Since charity refers to being in need, it draws a particular conceptual line for imagery which by definition is not meant to be empowering. Thus, by examining the mechanisms of charity campaigns we actually exemplify the politics of media portrayals. Riley's (2005) comprehensive analysis of misrepresentations of disabled people and the politics of media in the U.S.A. reveals a number of arguments that actually eliminate my bewilderment caused by the realisation that the findings about the impact of media portrayal are not the same as the one of documentary films.

2.3 Disability And Mass Media

In an early study on American media portrayals of disabled people, Biklen and Bogdan (1977) identified ten stereotypical representations of people with disabilities:

1. The person with a disability as "pitiable and pathetic," an object to be pitied.
2. The person with a disability as an "object of violence".
3. The person with a disability as "sinister and/or evil".
4. The person with a disability as "atmosphere".
5. "The person with a disability as "Super Crip".
6. The person with a disability as "laughable".
7. The person with a disability as "his/her own worst-and only-enemy".
8. The person with a disability as a "burden".
9. The person with a disability as "non-sexual".
10. The person with a disability "as incapable of fully participating in everyday life".

In his report about representations of disabled people in media and principles for eliminating negative imagery that he wrote in full cooperation with the British Council of Organisations of Disabled People (BCODP), Barnes (1992) presents his analysis based on Biklen and Bogdan's (1977) list of ten commonly recurring media stereotypes but he adds one more: *The Disabled Person as Normal* (Barnes, 1992).

This list of eleven recurring media has been the first comprehensive collection that puts representations of disabled people under scrutiny. More specifically the *person with a disability as pitiable and pathetic, an object to be pitied* is the character that shakes non-disabled people's emotions like compassion and kindness mixed with pity. In this cinematic depiction, non-disabled people are those who protect the disabled characters, who as weak and passive are incapable of being independent. Charity shows and telethons construct and invest on this particular stereotype, as their purpose is to present disabled people, preferably disabled children in need, as second class citizens since they address non-disabled viewers as those who have the power to soothe the attached to disability "frustration". Hill (in Morris, 1991) commenting on Telethons deliberates: "the more pathetic, the more crippled we are, the better television we make", (p.111). The story of John Merrick, *The Elephant Man* and Tiny Tim, in *Christmas Carol* are two examples that fall under this category.

The person with a disability as an object of violence is a representation that derives from cases of neglect and abuse by non-disabled people that are frequently reflected in the media. Prejudice and beliefs, related to cultural, religious and historical background - for example, that disability was translated as evil, witchcraft, or as a threat to humanity causing racial degeneration - became the legitimacy for violence and systematic murder of disabled people. Barnes (1992) notes:

Besides reinforcing the notion that disabled people are helpless, pitiable and unable to function without protection, these stories reinforce, albeit implicitly, the Eugenic conviction that the “natural” solution to the problems associated with impairment is a violent one. (Barnes, 1992, p.11)

The person with a disability as sinister and/or evil is one of the most popular stereotype. It is a common reference, that of the “bad” guy, usually with a visible impairment or deformity. A twisted body is equivalent to twisted mind, wooden legs, hooks replacing hands, eye patches, missing fingers and limbs, hunched backs, deformed and covered faces are some of the common characteristics of a sinister person in films, signifiers of wickedness and villainy. In contrast, the characters that represent goodness are well built, handsome, fit, healthy and virtuous. As the sinister disabled person is one of film-makers' favourite choices, the list of films which depict this is long: *Dr. Jekyll and Mr. Hyde*, *Dr. Strangelove*, *The Sting*, *The James Bond films* (Barnes, 1992).

One more depiction that empowers the belief that appearance is linked to a person's morality and value is that of *the person with a disability as atmosphere or curio*. Disabled people are reduced to and used as objects of mystery and curiosity. Filmmakers include disabled people in the narrative to create a certain atmosphere, especially when their films require the sense of mystery, menace or the exotic. This stereotype has its roots in freak shows as disabled people were put on display to attract the viewers' curiosity and play with their fear of the unknown exotic other. As Barnes concludes, “such exhibitions represent little more than disability voyeurism because they encourage lewd fascinations with impairment” (Barnes, 1992). This particular depiction is frequently found in horror and science fiction films.

The *Super Crip* (Cripple) portrayal wants disabled people to have super qualities or skills that, not only compensate for the deficit that their impairment creates but they also make non-disabled people recognise the value of their existence. By presenting disabled people's superhuman “almost abilities” rather than their “disabilities”, non-

disabled viewers admire characters with disabilities. The argument though is that this creates a respect on a false basis, that of the myth of a little “extra” or a little “super”. Barnes (1992) comments that this stereotype is similar to portrayals of black people as having “super” abilities – for example, a sense of rhythm, music talents, being great dancers or athletes - in order to gain white people's respect. Popular examples are the “sixth sense” and the musical talent of blind people and the extraordinary memory of people with Apserger's syndrome or autism. The *super cripp* portrayal is also constructed on the reductionist habit of praising excessively for ordinary achievements, an attitude that actually expresses non-disabled people's low expectations for disabled people's abilities. Morris (1991) includes the *super cripp* stereotype in the *overcoming all odds* type of cultural representation: “a brilliant mind in a crippled body” like Christy Brown in *My Left Foot*. These stories have a significant element of “a striving competitiveness but also the important role of lessening the fear that disability holds for non-disabled people”, (Morris, 1991, p. 101). As Morris notes, this striving competitiveness confirms and preserves the construction of the “norm” and “normal”. Disabled people are presented as making an admirable effort to live a life as “normal” as possible without questioning what is set and perceived as “normal”.

The more energy and time we spend on over-achieving and compensatory activity that imitates as closely as possible “normal” standards, the more people are reassured that “normal” equals right. If we succumb to their temptations they will reward us with their admiration and praise. (Morris, 1991, p. 101)

Morris explains that adjusting to society's standards of normalcy is introduced as the only positive role that is open to disabled people. This kind of adjustment seems quite superficial. Asking disabled people to ignore disability suggests that they are asked to deny a fundamental element of their identity and experience. Pretentious adjustment does leave space for diversity and this limitation of space means oppression and declination of rights.

A less complex interpretation is depicted in *the person with a disability as laughable/ object of ridicule*. Barnes (1992) states that laughing at disability has been a common reaction of non-disabled people for centuries. Jokes about different types of impairments, women and foreigners are a big chapter of “popular” humour. A form of entertainment for non-disabled people was the display of “idiots” and the visits to “mental” institutions (Barnes, 1992). Comedy, in many cases, was built on this tradition

of mockery and comedians performed acts of disablist humour. Disablist humour favourably prefers physical, sensory, speech and learning disabilities, implying that it is allowed to laugh at them. There are serious negative implications for disabled people in this type of imagery as it is a type of abuse. It undermines their status as humans who should also be respected by a non-disabled society. The impact of mockery, especially on the confidence and self-esteem of disabled children, is also negative. Barnes (1992) argues that “being mocked publicly is only acceptable if the negative images which ensue can be offset against positive ones, or if those being ridiculed are able to defend themselves should they choose to”. For many years there was a lack of positive images of disabled people and legal framework that could be used to fight this discrimination. Disabled stand-up comedians provoke disablist humour in their performances but the impact is not as large as the damage caused by cinematic depictions. An interesting point for discussion is the use of, both, cynicism and comedy. On one hand, disabled artists seem to prefer this form of cynicism in their work, on the other, comedy has been exhaustively based on pejorative representations or comments of disabled people. Allan (2005), in examining the use of cynicism in disability arts, as a way that disabled artist fight discrimination and stereotypes, notes that disabled artists’ practices “appear to represent a form of cynicism, which is embodied, raunchy, and ‘in your face’ ” (Allan, 2005, p. 5).

This “in your face” performing practice should not be interpreted just as cynicism but also as an action that derives from the approach of transgressive reappropriation that was introduced by Mitchell and Snyder (2000), and is further described in the following section of the literature review.

In their former work, Stronach and Allan (1999) tried to examine the shifting of the comic and tragic elements in disability discourse, analysing the use of jokes as practice of transcendence and the existence of the comic in the tragic and vice versa. Albrecht (1999), Corker (1999), Robillard (1999) and Shakespeare (1999) take Stronach and Allan’s prompt, and discuss the subject of comedy / tragedy and joking further. Clark (2003) takes into account the disabling comedy and the effects on the public’s perception and the disabled writers’ or performers’ work. Reid, Stoughton and Smith (2006) analyse the humorous construction of disability focusing on the case of stand-up comedy in United States. Interesting points related to:

- a) the distinction of disability humour (Albrecht 1999, Reid et al. 2006), from the disabling humour;
- b) the power of humour and jokes to provoke taboos (Shakespeare 1999) and political correctness;
- c) the internal codes of joking deriving from disability culture, have been put forward by the above writers.

However, the majority of their references come from literature, theatre, stand-up comedy performances and some TV series. There are very few and random references to films, either exploring the disabling comedy (Barnes 1992, Norden 1994) or the disability comedy.

The person with a disability as his/her own worst-and only-enemy is ascribed to disabled characters that feel sorry for themselves. Grief, denial, self-pity and self-harming are the main elements of their psychological situation as disability is presented as the source of psychological trauma. Anti-war films follow this particular narrative reproducing this stereotype, for example, *Coming Home* and *Born on the Fourth of July*, where war veterans struggle to come to terms with their disabled body and their new identity. Usually, a female non-disabled character serves the role of the catalyst, whose unconditional love supports them to make a new positive start. The majority of these films fail to discuss the major issues related to disabled war veterans, such as support from state, rehabilitation, employment, housing, environmental and societal barriers. Under this category, media depictions of people with HIV also fail. Scenarios tend to present people's stories as personal tragedies without questioning the part of society in terms of political and economic factors. Barnes (1992) claims that such depictions derive from the medical model of disability, since disabled people's behaviour is interpreted as individual pathology, and he notes:

It allows able-bodied society to reinterpret disabled people's legitimate anger over disablism as self-destructive bitterness arising out of their inability to accept the "limitations" of impairment. It helps them to avoid addressing the true cause of that anger; i.e. the attitudes and policies of an overtly disablist society. Indeed, in the same way that lesbians, gay men, black people and women are blamed for homophobia, racism and sexism, so too disabled people are blamed for disablism. (Barnes, 1992)

The stereotype of *the disabled person as burden* derives from the view that disabled people are unable to control their lives so they rely on non-disabled people's care, a view that dismisses the disabled people's ability of independence. It also shifts the focus from the matter of support, accessibility and facilities that allow equal opportunities for autonomy. Disabled people's needs are misguidedly presented to be different from those of the non-disabled, requiring a high amount of society's resources. This seems to create a "discrepancy" for society's economy that justifies the notion of "burden". The "burden" stereotype is also justified on screen by depictions where family, or a specific family member, dedicates his/her life to the disabled character's daily care. Oppression, grief, anger, guilt and misery are the common emotions that are expressed by both disabled and non-disabled characters, reinforcing the belief that family life would be better off without the disabled member.

Disability and sexuality are the themes that cause anxiety. Popular representations are those where the disabled person is asexual or *sexually abnormal* (Barnes, 1992). The type of representation varies depending on the character's gender: usually disabled women are presented as asexual or with reduced sexual desire. Barnes (1992) notes that "such depictions can only lower the status of disabled women; a status which is already disproportionately undervalued due to the widespread misconception that they are unable to fulfil women's traditional roles of wife and mother". Disabled male characters are more sexually active and attractive. Their sexual desire is clearly claimed but in some cases it becomes sexual starvation as a result of rejection. Sexual perversion is commonly connected to mental illness in films, reinforcing constructed misconceptions about people with mental illness.

The last stereotype on Biklen and Bogdan's (1977) list is *the disabled person as incapable of participating fully in community life*. According to Barnes' (1992) report, on rare occasions, disabled people are presented as active and productive members of society. Usually they are unemployed, dependent on non-disabled family members, partners or carers, unable to participate actively in community life. These depictions are obviously of lower status in comparison to those of non-disabled people and *feed the notion that disabled people are inferior human beings who should be segregated* (Barnes, 1992).

Barnes (1992) added to Biklen and Bogdan's (1977) list the depiction of *disabled person as normal*. This depiction is more focused on the actions of a character who *just happen to have impairments*. Morris (1991) and Barnes (1992) see these portrayals as a positive improvement on representations of people with disabilities but they also pinpoint the risk of the “normalisation” of disability.

Like all media portrayals of disabled people they do not fit neatly into able-bodied perceptions of normality. Also the emphasis on normality tends to obscure the need for change. Logic dictates that if disabled people are perceived as “normal” then there is little need for policies to bring about a society free from disablism. (Barnes, 1992)

Omission of disabled people's identity does not challenge the barriers set by a disabling society, and weakens the importance of rights and inclusion.

Marková and Farr (1995) edited a selection of articles that negotiate matters of representation in the mass media of communication and their impact on the delivery of health care, quality of life and human agency. The main subjects seem to be mental illness, AIDS/HIV, learning disabilities and diabetes, and they are examined through different perspectives, such as a social representations approach, attribution theory, socio-anthropological, sociological and constructivist approaches. Eayrs et al (1995) examine the *Representations of Learning Disability in the Literature of Charity Campaigns* in this edition, by combining the attitudes towards people with learning disabilities, the role of charities and images in advertising. The article presents the results of an experimental study where the object was the interaction between media material, charity posters and the people viewing them. This empirical study was based on two objectives: the impact of posters on viewers' perception of people with learning disabilities and their intentions of donating as a result of their perception. The posters were experimentally designed and divided into positive and negative, where the positive posters promoted employment training, the right and skills for independence, while negative posters focused on dependency, need and lack of choices in life. Eayrs et al. came to the conclusion that “the twin objectives of raising funds and positively influencing public attitudes may be incompatible” (Eayrs et al., 1995, p. 84), and suggested that the challenge was to find new images and slogans that would draw the public's attention by developing a positive representation of people with learning disabilities based on dignity and respect. They also highlighted that the commercial model for managing advertising “leaves disabled people

out in the cold” (Eayrs et al. 1995, p. 87), and in that case, the involvement of disabled people in the running of charity organisations was regarded as an improvement in that area.

Charles Riley (2005) examines the misrepresentation of people with disabilities in a variety of media: magazines, newspapers, television, films and on the web. Having the experience of being a journalist and co-founder of *WeMedia*, the first multimedia company devoted to people with disabilities in the U.S.A., Riley also gives an insight on certain factors that influence publishers' and media producers' decisions. Profit, fame, shock and entertainment, are some of the reasons that the media industry accordingly bends, the representation of people with disabilities. Examining how the media transform the image of disability, Riley describes the political background of representation in the U.S.A. The medical model and the introduction of the social model of disability through the text of the Americans with Disabilities Act, had their impact, with the medical model, of course, leading the way in media but Riley also describes a third model: the consumer model – a model which is more of use to advertisers as it is based on demographic figures that target and classify the audience with disabilities:

Coverage, advertising, casting, budgets, technology (such as closed captioning), and other business variables pondered by media executives depend in large part on the raw numbers assigned to various types of disability. (Riley, 2005, p. 16)

Riley presents the *raw numbers* based on the Harris Poll, Number 59 of October 2000, which showed that the media statistically depict wheelchair users as *the token person with disability*. This reflects that people with mobility impairments are the bigger population of Americans with disabilities. Deaf and hard of hearing follow. However, this is a group that makes things more complicated for the media because of the use of sign language and the debate over their linguistic autonomy. The blind and visually impaired add more challenges, especially for media based on print. At the bottom of the list there is the “forgotten group”, as Riley describes it, which includes people with mental and learning disabilities, people with AIDS and those in rehabilitation from drug and alcohol use. Riley, going a bit deeper than a journalistic approach to the subject, adds some theoretical strings, trying to present why representation of people with disabilities becomes so complicated. Examining the matter from the perspective of the disability community, the complexities of identity and coming out as disabled are still current issues. Riley refers to Erving Goffman's (1963) *Stigma* to analyse the question of

“passing” and managing stigma:

Managing stigma is largely a question of what happens in public. Mass media vehicles such as magazines and television are a paradigmatic example of how this plays out. The popularity of disability comes at a price. (Riley, 2005, p. 20)

“Resident aliens” memoirs, that involve techniques of “passing”, turned out to be an important genre because it offers an in-depth examination. Riley finds it essential for journalists to link disabilities studies with African-American, post-colonial, women's studies and queer theory, to understand the concept of dual identity and the aspects of the disability community's complexity. It turns out that the literature related to the disability movement derives from advocacy journalism, memoirs, and academic studies. Prosthesis is described as the key theme by the author, and in this context, “the narrative or the medium performs a useful function for some, while for others it connotes replacement” (Riley, 2005, p. 20). Riley refers to Henri-Jacques Stiker in the description of the function of replacement but also the risks of it. Assimilation and the development of a homogeneous culture could be the main risks, and because disability is denied as a condition, it becomes eliminated and adjusted to able-bodied standards. Riley notes that assimilation has caused frustration to writers and readers with disabilities, something that he himself also realised through his experience; “not everybody likes you to speak for him or her”. One matter is, who speaks for whom, and in addition, who facilitates communication:

Here we have journalists with little experience of disability in charge of writing or producing the story, or writers with disabilities doing their best to impress editors and book buyers who are non-disabled with narratives that are dramatic enough to be worth publishing, and readers who have limited capacity to care or comprehend trying to take it all in”. (Riley, 2005, p. 23)

With respect to this point, Riley suggests that communication will improve when the authentic voices of disability are heard clearly with no intermediaries. In the chapter, “I'd Like to Thank the Academy”, he focuses on films and television, exposing again the variables of the offensive treatment of disability. Disability, as a Hollywood production, usually is a challenge for actors that is awarded with Oscars and increases their blockbuster ability. Even though disabled characters have brought many Oscars for performing actors and productions, disability is depicted according to very specific motifs:

Producers, directors, and writers package disability in such a way as to safely ensure that the audience feel nobly uplifted, even ethically superior, for “supporting” what is in effect a blatantly over-sweetened version of life with disability as concocted by a community that cannot countenance physical imperfection except in certain sanctioned and saccharine forms. (Riley, 2005, p. 71)

Hollywood deals with disability through a system well built on profits and vanity, where imperfection becomes the reason for actors to prove their talent, since they perform “awkward” behaviours and adopt physical characteristics that deform their “perfect” picture. By empowering the feeling of superiority to non-disabled viewers and presenting life-based stories, donations to American charities have increased dramatically. But this focus on charity organisations changes according to the type of “blockbuster hit” disability or illness that plays on screen. In some cases, the real people with disabilities, whose story became a film, receive publicity and profits through publishing their biography, going to talk-shows, giving talks and performing. Riley warns that this well performed media promotion creates a very specific perception of disability. It brings disability on the scene as long as the lights are up and tickets are sold. All this noise targets very specific profits but very few for the disability community, as it is linked to charity and a number of misconceptions.

Hollywood made adjustments to include difference in terms of race, gender and age. Riley argues that one reason seemed to be the “steady erosions of segregationist prohibitions” (Riley, 2005, p. 74), but in reality financial goals indicate interest in minority audiences. Despite the efforts of studios and television to develop minority programming, minority communities still feel segregated. Riley pinpoints that there have not been similar efforts for viewers with disabilities. The paradox is that Hollywood industry invests a significant amount of money on films with disabled characters, targeting a non-disabled audience whose money will keep the production of these particular films alive.

Riley gives a brief insight into comedy, documentaries, television and talk-shows. Documentaries are considered as better portrayals of disabilities. The key is to avoid depicting the “cripple of the week” and focus more on cause than effect, on valid studies and real people with disabilities rather than popular actors. His analysis on documentaries is very brief and based on a couple of examples. Riley concludes his analysis on media in the USA by suggesting that there is still space for improvement and pinpoints the need

of developing a media that will go over the tight focus of specific disability organisations, advocates and publishers. These suggestions and Riley's analysis of the politics of media when presenting disability themes are valid points that contribute to the understanding of media mechanisms and their failure to address to disabled people and represent their stories in ways that will go beyond the reproduction of stereotypes and imagery that is discriminative and disempowering for the disability community. Even though the essays on media representations unfold the politics of decision making when it comes to the shaping of disability imagery, they were still lacking a more sophisticated theoretical approach that could lead to a more in-depth analysis of the matter of problematic representations. Thus far, the examined works have offered listings of films depicting disabilities, information about the frequency of appearance of a disabled character, listings of popular and recurring stereotypes and narrative patterns, empirical researches and inside investigation with a touch of disability and media politics. I still feel, however, that my question about what we are looking at has not been answered as the matter of representations unfolds as quite problematic and perplexing. The approach of negative imagery served the purpose of early developments when the discussion of representations of disability in films and media was still at its infancy. It also complied well with the perspective of the social model of disability that was the most influential theoretical tool in disability studies during the 1990s. However, the matter of representations, particularly when it combines films and disability, involves a complexity that cannot be fully examined and understood under the structuralist approach of negative imagery.

2.4 REPRESENTATIONS OF DISABILITY IN LITERATURE

Mitchell and Snyder (2000) also address these concerns while they examine representations of disability in literature through the perspective of narrative theory. They examine other essays on disability in literature and films in order to show the discontents of representation, suggesting that representation is complex and that the act of characterization encourages readers and viewers to search for a larger concept, experience, or population (p.40). They suggest that the "problem" of representation relies on two factors: overheated symbolic imagery and disability as pervasive tool of artistic characterization (p.16). They analyse five groups of methodological approaches that

humanity scholars follow: negative imagery, social realism, new historicism, biographical criticism, and transgressive re-appropriation.

Negative imagery is the first and most popular category that Mitchell and Snyder (2000) analyse. In this category, they include Longmore's (1985) and Norden's (1994) work. *Barnes'* (1992) report could also be included in the negative imagery, since it lists ten stereotypical depictions of disability that –as it was examined at the beginning of this section, are actually based on constructed misconceptions and distort the experience of disabled people. Interestingly, Mitchell and Snyder do not refer to this work. Scholars that focused on negative imagery insisted on the repetition of representations that were based on two poles of characterisation: threat and pity. It was suggested that these limiting depictions had strong links with humiliating cultural attitudes towards disabled people. Disability is depicted as an isolated case and as an individual's problem, with no reference to the limits deriving from the social context. In plots where negative imagery is used, the disabled characters will earn or lose their value by their ability to adjust and overcome their difficulties. The analysis of negative imagery was based on a structuralist perspective and it became quite popular, as quite a few scholars, Biklen and Bogdan, Longmore, Barnes, Safran, Norden, Lopez-Levers, used it in introductory works on classification and examination of representational modes. Mitchell and Snyder (2000) argue that despite its popularity, the negative imagery methodology could easily lead all representations “into a sterile model of false consciousness” (p.20). As Pointon and Davies (1997) pinpoint: "It is too simplistic to talk about 'negative' compared with 'positive' images because although disabled people are in general fairly clear about what might constitute the former, the identification of 'positive' is fraught with difficulty", (Pointon & Davies, 1997, p. 1). Mitchell and Snyder (2000) agree that negative imagery methodology contributed to the support of the argument that disability is socially produced.

Social realism is the methodological approach that highlights the necessity of realistic representations. “The social realists' primary criterion centres upon whether literary depictions serve as correctives to social misapprehensions about the specifics of experiences of disability.[...] Realism promotes a more direct depiction of the reality of disabled characters—from architecture to attitudes” (Mitchell & Snyder, 2000, p. 21). Realistic depictions aim to decrease the alienation ascribed to disability, offering familiarity within more accurate images. In the context of accurate representation, social

realism brought to the surface autobiography as a counter narrative to fiction and other artistic metaphors. It is important to note that under the definition of inaccurate images the characterisation “positive” - as opposed to “negative”- is not central:

In identifying examples of inaccurate characterization, social realism does not call for "positive images" that would celebrate the lives of people with disabilities in a romanticized light. Rather, scholars approach even self-styled "positive" portraits with scepticism and save some of their most severe critiques for notions of disabled "heroism". (Mitchell & Snyder, 2000, p. 23)

Mitchell and Snyder choose to include Darke's (1994) Foucaultian analysis of David Lynch's *The Elephant Man*, to prove their argument. Darke tries to reveal the hidden agenda of the film, highlighting some of the inaccurate elements that were used for creating a “positive” portrait and coming to the conclusion that “often the positive image of disability is really very negative” (Darke, 1994, p. 341). The analysis of *The Elephant Man* is an example of what is considered as the problem of inadequate representation, within the social realist perspective. The majority of depictions of real disabled people also seems to be problematic as two poles of images are created: the “pathos” of a disabled person, or the portrait as “superhuman” of an overcompensating disabled person. According to social realists there are two basic issues: “the complete paucity of “positive” examples in narrative traditions or the undertheorized nature of what constitutes a negative image” (Mitchell & Snyder, 2000, p. 23).

The important impact of social realism, was the supply of a politicized image of disability promoting advocacy and political action for deconstructing misunderstandings and barriers set by society. The representations that social realism supplies emphasise the necessity of a social model. According to Hevey (1992), "the reformation of oppressive imagery is only important (or, at least, more than superficially) if it is linked to wider social issues, such as access" (Hevey, 1992, p. 102).

Critiques of social realism followed four principles:

- 1) Social realism assumed that disability tended to be concealed rather than pervasive in literary and film traditions;
- 2) the practitioners created a largely ahistorical paradigm that overlooked the specificity of disability representation as an ideological effect of particular periods;
- 3) social realism presumed that no disability perspective informed "inaccurate" images that pervaded the social realist's critique; and
- 4) social realism projected its own contemporary desires onto the images it sought to rehabilitate. (Mitchell & Snyder, 2000, p. 25)

Social realism added the political context in disability representations but it did not avoid

some of the established methodological patterns. Falling in the trap of the ahistorical paradigm was the result of a focus that is shifted on the perspective that wants disability as hidden, or with limited presence in literature and films. One more factor that led to this trap was the disconnection of representations from socio-political and cultural frames of the periods that literature works and films were created or refer to. It seems that social realism also enclosed risks of supplying distorted images of disability through the frame of “acceptable images” that was developed as a counter frame to that - full of misunderstandings and confusion - “positive image”. According to social realism, acceptable images promote representational advocacy and signify political action against societal barriers and misconceptions. Undoubtedly, it is a frame that promotes disability politics and suggests an alternative image to the negative imagery, but still there is the risk of a troubling image, as this particular depiction might turn to be monothematic and, in addition, there are still groups of disabled people who claim to be underrepresented within disability movements.

As Mitchell and Snyder (2000) note the classification of representations of disability based on the static structuralist methodologies of negative imagery and social realism, brings up the risk of an ahistorical interpretation that skips the cultural and historical factors that influence the construction of these representations. New historicism adds an anthropological perspective to the examination of representations of disability. The historical analysis shows the key role that narratives took in explaining biological, psychological and environmental factors or causes of disability. Disability is seen as a product of specific cultural ideologies. In this context, there is a more dynamic interaction between author, culture, story and audience, where the disabled body is shaped and re-shaped as a product of complex cultural beliefs. New historicism did not bring changes to the representations of disability but it changed the methodological approach: “Scholars applying this approach deflect attention away from disability representation and toward a critique of social institutions that authored disability as ‘Other’” (Mitchell & Snyder, 2000, p. 28).

The important outcome from academic essays, which were based on this methodology, was that the “normal” - as this was set in different cultures - became the core factor of pathology. Furthermore, historical revisionists proved that disability had a strong presence in human communities refuting the argument that disability was isolated as an exception.

New historicism also supported the development of biographical criticism as there was a focus on disabled artists and authors.

Within biographical criticism's approach to the contexts of authorship three tendencies have predominated: 1) analyses of critical readings of disability by able-bodied and disabled scholars alike; 2) the analysis of the relationship between literature and medicine; and (3) interpretations by disabled writers of other disability characterizations in history. (Mitchell & Snyder, 2000, p. 30)

The benefits of biographical criticism were that scholars realised that: a) depictions of disability were created not only by able-bodied authors but also by disabled, and b) the examination of the influence of disability on non-disabled authors' lives was important for the interpretation of their works.

The last methodological approach described by Mitchell and Snyder (2000) is that of transgressive re-appropriation. Scholars examine the subversive effect of hyperbolic meanings ascribed to disabled characters. It seems that disability is restricted from finding a cultural meaning within the space of identity politics, while the hyperbolic meanings ascribed to disabled figures cause and, at the same time, invest on extreme emotions such as fascination or repulsion. The reason behind this restriction is that disability is an “undesirable state of being that no political triage can repair” (Mitchell & Snyder, 2000, p. 35). As an action of claiming identity, and reaction to restrictions, the disability community embraces derogative labels, re-signifies them and empowers the transgression attached to disability. Advocates for disability rights, activists, artists and scholars alter the pejorative force of labels such as cripple, gimp and freak, into an ironic context against the societal barriers, the constructed and enforced “normalcy”, and the imposed oppression on disabled people. As Mitchell and Snyder state:

The power of transgression always originates at the moment when the derided object embraces its deviance as value. [...] The embrace of denigrating terminology forces the dominant culture to face its own violence head-on because the authority of devaluation has been claimed openly and ironically. Thus, the minority culture deflects the stigmatizing definition back on to the offenders by openly advertising them in public discourse. (Mitchell & Snyder, 2000, p. 35)

The result of transgressive re-appropriation is that it humiliates dominant culture by pushing it to face its own dehumanizing and discriminatory standards that get openly exposed. Transgressive re-appropriation seems to function as a political boomerang, since what was perceived as a devalued identity establishes its existence by gaining power from

patronising and derogative labels. Questioning the meaning of disability in the context of popular beliefs and values of different periods and cultures is the most important impact of this methodological approach.

At this stage, it is necessary to explore the cultural positioning of disability within the context of western culture. Disability seems to be chosen to serve narratives and aesthetical motives that produce misrepresentations and stereotypes and support the practices of disqualification of disabled people.

2.5 DISABILITY IN CULTURE AND THE ASTHETICS OF DISQUALIFICATION

Morris (1991), in her feminist analysis on disability in western culture, recognises a primary reasoning based on psychological reactions towards disability. According to this primary reasoning, disability is perceived as a signifier of vulnerability and mortality of human experience, so fear, denial and avoidance are the reactions to this realisation. Avoidance is also the defence mechanism that leads to the construction of misrepresentations of disability in western culture. Misleading representations and the denial of the disability experience feed the oppression and isolation of disabled people. Morris (1991) notes that ignoring or misrepresenting disability, is a practice decided by and for non-disabled people. The management of disability in culture reflects non-disabled people's feelings and their understanding of disability, which is also part of disabled people's oppression:

We all experience oppression as a result of the denial of our reality. If our reality is not reflected in the general culture, how can we assert our rights? If non-disabled people would rather not recognise disability, or only recognise specific forms, how can they recognise our experience of our bodies? If we do not “appear” as real people, with the need for love, affection, friendship, and the right to a good quality of life, how can non-disabled people give any meaning to our lives? (Morris, 1991, p. 91)

Morris (1991) determines that if disabled people's experiences get told or presented, freed from non-disabled people's filters, then they will contribute to the diversity of human experience. Non-disabled people's feelings or interpretations, usually related to fear and abhorrence, create difficulties and barriers to disabled people's effort of taking a place within culture. Morris claims that non-disabled people's denial for their

feelings towards disability distorts representations of disabled people in the general culture. The absence of disability is set as a criterion of confirmation of non-disabled people's stereotypes for beauty, health, femininity or masculinity. The absence of impairment, chronic illness, disfiguration or deformity is the criterion that ascribes eligibility to an individual for the registration with the community of the norm. The interesting point that Morris makes is that this approach is more representative of non-disabled people's attitudes towards disability than disabled people's experience:

Disability is used as a metaphor, as a code, for the message that the non-disabled writer wishes to get across, in the same way that "beauty" is used. In doing this, the writer draws on the prejudice, ignorance and fear that generally exist towards disabled people, knowing that to portray a character with a humped back, with a missing leg, with facial scars, will evoke certain feelings in the reader or audience. The more disability is used as a metaphor for evil, or just to induce a sense of unease, the more the cultural stereotype is confirmed. (Morris, 1991, p. 93)

Rosemarie Garland-Thomson (1997) investigates how disability operates in culture and how figures of otherness are constructed by discourses of disability, race, gender and sexuality. Her aim is to challenge the established perception that the opposite of "able-bodied-ness" is "disability". In a parallel line to Morris' description of primary reasoning, Garland-Thomson notes that the physically disabled body signifies the embodiment of corporeal insufficiency and deviance. As such, it attracts social anxieties caused by the troubled management of vulnerability, control and identity. Garland-Thomson approaches disability as a "reading of bodily particularities in the context of social power relations" (Garland-Thomson, 1997, p. 6):

Disability is a representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then is the attribution of corporeal deviance – not so much a property of bodies as a product of cultural rules about what bodies should be or do. (Garland-Thomson, 1997, p. 6)

Garland-Thomson highlights that the socio-political meanings of expectations about human behaviour are culturally determined. Beauty, fitness, independence, competence and normalcy are standards that are culturally constructed that also get perceived through socio-cultural and political filters. The interesting impact is that these culturally generated standards exclude and validate human bodies as disabled or able, extraordinary or ordinary, imposing cultural and corporeal inferiority on those categorised

as disabled or extraordinary. Cultural dichotomies function as tools of evaluation where bodies marked as inferior become spectacles of otherness:

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 status. Thus, the cultural other- and the cultural self - operate together as opposing twin figures that legitimize a system of social, economic, and political empowerment justified by physiological differences. (Garland-Thomson, 1997, p. 8)

In this context, representation in cultural products reinforces an embodied type of normative identity, and develops a narrative of corporeal difference, that marginalises bodies or behaviours that do not comply with the culturally generated standards. Garland-Thomson examines the construction of the disabled figure, analysing examples of American literature and she also challenges the normate.

The term “normate” usefully designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them. (Garland-Thomson, 1997, p.8)

The figure of normate is a conceptual strategy that takes the analysis beyond dichotomies based on binary identity differences; male/female, able-bodied/disabled, white/black or straight/gay, highlighting the interrelations among social identities. Garland-Thomson explains that the normate subject position appears only when discourses and social processes that involve physical and cultural otherness are examined. Power relations mark figures of otherness, especially in cases of marginalisation, and the cultural visibility of these figures as “others” legitimates and galvanises the normate.

The disabled figure, on the other hand, is a discursive construct developed more by people's perception of disability, than actual experience or interaction with disabled people. As such, construction circulates in culture and gets reproduced, with the use of conventional codes of literary representation. Garland-Thomson notes that “disabled literary characters usually remain on the margins of fiction as uncomplicated figures or exotic aliens whose bodily configurations operate as spectacles, eliciting responses from other characters or reproducing rhetorical effects that depend on disability's cultural resonance” (Garland-Thomson, 1997, p. 9).

The construction of the disabled figure based on non-disabled people's

assumptions and interpretations confirms once again that the figure of otherness is built on positions, perceptions and meanings upon bodies. Representation produces and reinforces cultural identities and categories that function as paradigms for organising and giving meaning to raw and unknown presences such as the presence of disabled people. As Snyder and Mitchell (2000) note, “to represent disability is to engage oneself in an encounter with that which is believed to be off the map of "recognizable" human experiences” (Mitchell & Snyder, 2000, p. 5). In this particular case, the narratives and the use of metaphors misrepresents the experience of real disabled people. Apparently, there is a gap between disabled people and their representation in literature and as Garland-Thomson explains:

The rhetorical effect of representing disability derives from social relations between people who assume the normate position and those who are assigned the disabled position. [...] Textual descriptions are over determined: they invest the traits, qualities, and behaviours of their characters with much rhetorical influence simply by omitting -and therefore erasing- other factors or traits that might mitigate the delineations. A disability functions only as visual difference that signals meanings. Consequently, literary texts necessarily make disabled characters into freaks, stripped of normalizing contexts and engulfed by a single stigmatic trait. (Garland-Thomson, 1997, p. 10)

The conventional codes that are used to express non-disabled people's interpretation and their misunderstanding of disability are also used to create cultural assumptions when there is lack of information. Stereotypical portrayals and caricatures derive from these cultural assumptions that fill the gap between representation and the actual experience of disability. Stereotypes and caricatures are perceptual categories, products of interpretive schemata that people construct in order to make an understanding of their worlds. Garland-Thomson notes that disability has a rhetorical effectiveness in literature, which relies on the interpretation and the responses of readers that characterise themselves “normates”.

The more the literary portrayal conforms to the social stereotype, the more economical and intense is the effect; representation thus exaggerates an already highlighted physical difference. Moreover, Western tradition posits the visible world as the index of a coherent and just invisible world, encouraging us to read the material body as a sign with transcendent meaning. In interpreting the material world, literature tends to imbue any visual differences with significance that obscures the complexity of their bearers. (Garland-Thomson, 1997, p. 10)

Stereotypical portrayals that focus on body features as the disabled figure's most significant and influencing characteristic lead the normate reader to a confrontation with the disabled figure. This confrontation is predetermined as cultural notions about disabilities will be projected and it is a result of the static encounters that literary representation creates between disabled figures and normate readers. In contradiction, as Garland-Thomson (1997) states, real social relations are always dynamic and allow space for the complexity of disabled people's identity and experience. Literary representation intentionally does not allow the development of dynamic relations because the disabled figure is created to serve the conventions of spectacle. In order to complete this mission, the disabled figure will remain 'other' for readers supporting this way, the rhetorical potency of stigma.

So, like "tableaux vivants", beauty pageants, and freak shows – all related forms of representation grounded in the conventions of spectacle- literary narratives of disability usually depend on the objectification of the spectacle that representation has created. (Garland-Thomson, 1997, p. 12)

Mitchell and Snyder (2000) state that disability is presented as transgressive in literary texts and for this reason the disabled body remains as a troubled body, which also occupies a troubling position within culture. This is a troubling position that should not be interpreted simply as cultural reference, since it has strong links with the social position of real disabled people, with a tremendous impact on their lives.

[...] While literature often relies on disability's transgressive potential, disabled people have been sequestered, excluded, exploited, and obliterated on the very basis of which their literary representation so often rests. Literature serves up disability as a repressed deviation from cultural imperatives of normativity, while disabled populations suffer the consequences of representational association with deviance and recalcitrant corporeal difference. (Mitchell & Snyder, 2000, p. 8)

Narrative prosthesis is introduced by Mitchell and Snyder (2000), as a technique that serves the discussion about disability within literature - and also film- managing the paradox of artistic and historical presence of disability. This paradox is developed since literature, or art in general, cannot be censured for linking disability and aberrancy. At the same time disability distinguishes for its nonconformity to social standards of normativity and valid lives. There are many relations between the artistic and the historical, which can also take various interpretations, so narrative prosthesis facilitates the discussion about disability in literature representations, taking into account the social context.

First, narrative prosthesis refers to the pervasiveness of disability as a device of characterization in narrative art. Second, it enables a contrast between the prosthetic leanings of mainstream discourses, that would disguise or obliterate the evidence of physical and cognitive differences, and the literary efforts that expose prosthesis as an artificial, and thus, resignifiable relation. Third, it refers to the problematic nature of the literary's transgressive ideal in relation to social violence that often issues from the repetition of a representational formula (or antiformula). This third approach draws out the often discomfiting "fit" between literary disability and the "real" of disabled peoples' historical experiences. Finally, it acknowledges that literary representation bears on the production and realization of disabled subjectivities. (Mitchell & Snyder, 2000, p. 9)

Mitchell and Snyder (2000) reveal the presence of disability in western culture and more specifically in literature and film. They bring to the surface examples where disability is presented as “a social and lived phenomenon” (p.13). Disability turns out to be both a destabilising characteristic of cultural prescriptions of the body, and the main status that defines the figure constructed as disabled. Representations of disability prove to be more complex for simplistic analyses that rely on dichotomies: able-bodied/disabled, white/black, straight/gay, middle/working class and on limiting methodologies such as the negative imagery. Mitchell and Snyder's (2000) analysis gave prominence to the shifts of literary representations of disability and their interpretations. However, they admit that there is a lack of a coherent methodology for analysing disability narrative. What they suggest to scholars is to localise, historically and culturally, the politics of disability narrative, and also to examine the disability counter narratives that contrast the storytelling - adopted and produced in majority in Hollywood- that re-enforces traditionally stereotypical images and plots.

The argument about the paradox of significant presence of disability in arts and culture is also supported by Tobin Siebers (2006), who analyses the function of aesthetics in human disqualification (2010), and the perspective of disability aesthetics. Starting with the definition of disqualification Siebers notes: “Disqualification as a symbolic process removes individuals from the ranks of quality human beings, putting them at risk of unequal treatment, bodily harm, and death. (p. 23) [...] Disqualification is produced by naturalizing inferiority as the justification for unequal treatment, violence, and oppression” (Siebers, 2010, p. 24).

Disability has been set as the marker that indicates inferiority and through this process disqualification. It is the marker of ‘otherness’ that characterises disabled people's

existence as less valued and more as dangerous deviation. Disability also functions as a disqualifier when it intersects with race, gender, class and nationality. Siebers determines that “before disability can be used as a disqualifier, disability, too, has to be disqualified. Beneath the troping of blackness as inbuilt inferiority, for example, lies the troping of disability as inferior. Beneath the troping of femininity as biological deficiency lies the troping of disability as deficiency” (Siebers, 2010, p. 24).

Disqualification relies on the appearance of bodies and particularly on the way that bodies are presented according to aesthetic principles. Basically, disqualification is justified by aesthetic principles. According to Siebers' definition, “aesthetics studies the way that some bodies make other bodies feel” (Siebers, 2010, p. 25). In the term “bodies” he includes not just human bodies but also a range of artefacts, animals and objects in the natural world. Within this range of bodies, the sensation of otherness finds its space and unfolds as “powerful, strange and frightening”. The power of aesthetics relies on the fact that its influence occurs almost involuntarily. Apparently, bodies presented to other bodies cause feelings that denote an unconscious communication between these bodies. As Siebers states, “aesthetics is the human science most concerned with invitations to think and feel otherwise about our own influence, interests, and imagination” (Siebers, 2010, p. 25).

Siebers claims that the aesthetics of disqualification is not just a matter of artistic expression and critique sheltered in museums but it should be approached as a political process, since the oppression of minorities derives from their disqualification determined also by aesthetic principles. An understanding of aesthetics is crucial because it reveals the operative principles of disqualification used in minority oppression.

Oppression is the systematic victimization of one group by another. It is a form of intergroup violence. That oppression involves “groups,” and not “individuals,” means that it concerns identities, and this means, furthermore, that oppression always focuses on how the body appears, both on how it appears as a public and physical presence and on its specific and various appearances. (Siebers, 2010, p. 26)

The understanding of aesthetics is important because oppression uses aesthetic elements to justify its actions and also because operations of oppression are visible in art works, which open the discussion about the aesthetic criteria used for the creation and appreciation of bodies.

2.6 THE DISABILITY AESTHETICS AND DISABILITY CULTURE

The aesthetics of disqualification are dealt with the counterargument that Siebers calls “disability aesthetics”; a critical concept which shakes down the conception of otherness and exoticism applied in representations of disability as the notion of aesthetics expands to different criteria and values. Disability aesthetics introduce a critical framework that could also be the reference for examining and creating aesthetic productions; documentary films included. Specifically, Siebers (2006) states:

A critical concept that seeks to emphasize the presence of disability in the tradition of aesthetic representation. Disability aesthetics refuses to recognize the representation of the healthy body—and its definition of harmony, integrity, and beauty—as the sole determination of the aesthetic. (Siebers, 2006, p. 64)

Siebers introduces the concept of disability aesthetics, not for examining the exclusion of disability from art but for bringing the impact of disability on arts to the surface of academic interest. He sets his aim on two forms: “1) to establish disability as a critical framework that questions the presupposition underlying definitions of aesthetic production and appreciation; 2) to establish disability as a significant value in itself worthy of future development” (Siebers, 2006, p. 64).

With his critical analysis on disability aesthetics, Siebers claims that disability has a rich but hidden role in art and by accepting its presence, materialistic notions of aesthetics become richer and more complicated. In contrast, if the influence of disability is rejected then the definition of artistic ideas and works is set as limited. The presence of disability in art requires us to question and revise traditional conceptions of aesthetic production and appreciation:

Disability aesthetics prizes physical and mental difference as a significant value in itself. It does not embrace an aesthetic taste that defines harmony, bodily integrity, and health as standards of beauty. Nor does it support the aversion to disability required by traditional conceptions of human or social perfection. [...]The idea of disability aesthetics affirms that disability operates both as a critical framework for questioning aesthetic presuppositions in the history of art and as a value in its own right important to future conceptions of what art is. (Siebers, 2006, pp.71-72)

Disability aesthetics seem to find expression and application through modern and avant-garde art. Most importantly in terms of meaning-making and adding to the shaping of disability identity, disability aesthetics find ground and flourish within disability culture.

The existence of disability culture and the need for disability arts seem to be questioned by many disabled people (Morrison & Finkelstein, 1992). There are questions about the context and the organised collective voice in the disability culture. There is also the potential risk of not everybody being represented and disability culture being a matter just for the elite of the disability community (Morrison & Finkelstein, 1992). It is quite obvious that these concerns reflect the impact of the difficulties to establish and claim commonality in the disability community.

However, it is clearly claimed that disability arts and disability politics are intimately connected (Sutherland 1997, Barnes 2003, Vasey 1992). Organising arts and the formation of Disability Arts Forum in the U.K. was an initiative taken by a group of disabled activists, so politics and arts came together, influencing one the other. Disability culture was firstly based on the shared oppression that disabled people experience but this was seen as a risk for enforcing the “personal tragedy” approach of disability. Further, the “celebrating disability” statement was another misconception related to disability arts, causing confusion about what exactly there is to celebrate. Vasey, Morrison and Finkelstein (1992) tried to make clear the use of the shared oppression and Humphrey (1997) explains that Disability Arts celebrates humanity and difference. The important issue about disability culture is the shaping and expression of disabled people’s identities. Galvin (2003) argues against the “shared oppression” base of disability culture, criticising this approach as paradox, which does not celebrate but disables the enhancement of positive identities. Peters (2000) responds to the challenge: “Is there a disability culture?” From a post-modern perspective, Peters suggests three possible worldviews of disability culture: culture as Historical/Linguistic, culture as Socio/Political, and culture as Personal/Aesthetic.

Despite the fact that there are writers that support the existence of a disability culture and recognise the aims and the value of disability arts, many disabled people object. There should be further discussion about the reasons that these people raise in their arguments. The political part of disability arts has been an important issue starting from Vasey (1992), who asks for disabled artists with strong beliefs in disability politics, and Morrison and Finkelstein (1992) support the strong connection between politics and arts. However, there are disabled artists that have no interest in involving disability politics in their work, or deny creating anything just for the purposes of the disability community and its rights.

Another quite contradictory issue, related to disability arts, is the objection to educate the non-disabled public. Vasey (1990) rejected the education of non-disabled public as a function or responsibility of the London's Disability Art Forum, although in a later discussion, admitted that since the world of arts is conquered by non-disabled people, they have to be educated:

[...] non-disabled people have to be worked with, have to be educated, even if it's just to get the resources out of them so that we can do our stuff, which is educate each other about what we're about. (Vasey, 1992)

Morrison and Finkelstein (1992) strongly support that it is about communicating with and educating non-disabled people. If the aim of disability arts is communication, then most would claim that is about education too. Oppression is considered as practice that comes from non-disabled people's fears and prejudice, as a result of inadequate knowledge. Arts could be a powerful tool for challenging stereotypes, pejorative and discriminatory attitudes. Disability arts could be provocative, using the same material that established widely accepted stereotypes to reverse roles and messages.

Barnes (2003) gives a definition focused on the social model of disability, arguing that disability culture is linked with the International Disabled People's Movement in the 1970s. The social model is the significant tool of that period where there is a strong focus on disability politics:

Disability culture, (on the other hand,) is therefore a minority, sub, or subordinate culture. It emerged from within, and is associated with, the international disabled people's movement, and reflects the norms and values of disabled activists, their supporters and allies. Key elements of disability culture are the redefinition of disability by disabled people and their organisations, and the radical socio/political interpretation of disability commonly referred to as 'the social model of disability'. (Barnes, 2003, p. 4)

In this context, it was unavoidable for disability politics and culture not to be linked. Disability culture gave space for disabled people to meet internationally, interact and create their own artwork, without having to face the conformist barriers set by mainstream norms. Besides this, one more approach that differentiates disability culture from mainstream is "the acceptance of impairment as a symbol of difference rather than shame, and recognition of the significance and value of a disabled lifestyle" (Barnes, 2003, p. 6). Barnes considers the analyses made by Vasey (1992), and Morrison and Finkelstein (1992), and he combines their views claiming that disability arts are all about

communication with an empowering role in the shaping of identity, exposing disabling imagery and the processes of society. In this vein, he states that:

[...] disability art is potentially educative, transformative, expressive, emotionally exploratory, participative, and involving. It is a conception of cultural action that owes much to playwrights such as Berthold Brecht and educationalists like Paolo Freire because it is radical, challenging and progressive at an individual and social level. (Barnes, 2003, p. 9)

This view is responsive to the critiques about the educational role of disability arts, the “celebrating disability” or “disability pride” perspective and the risk of being exclusionary for non-disabled allies. Barnes rightly recognises the educative role of disability arts, as by definition, they include change and aim to change. Education, also by definition, encapsulates change through the process of learning. Consequently, disabled and non-disabled audiences get involved in a process of learning with their involvement or interaction with disability arts. In relation to the criticisms on the non-shared “disability pride” and the risk of the disability culture being exclusionary, Barnes first insists on referencing the distinction between disability and impairment, as people with degenerative conditions or painful impairments question the approach of “celebrating” and “pride”. Secondly, he explains that:

[...] disability culture and arts are the outcome of a ‘minority group’ consciousness. As a consequence, their potential for initiating meaningful and radical political and social change may be limited. Moreover, the disability arts movement has yet to make a significant impact on other sub-cultural groupings. (Barnes, 2003, p. 17)

Surely, there are limitations that a minority or subordinate culture encloses but also has to deal with, undoubtedly though, and I agree with Barnes, disability culture challenges conventional assumptions and representations of disability.

Since disability culture, as every other current culture, is in action and interaction, the dialogue continues. Roman Leslie, Geoff McMurchy, artistic director for the KickstART Festival, and Catherine Frazee, co-director of the Ryerson University Disabilities Studies Program, ran The Unruly Salon, a disability arts, culture and scholarship series, at Green College, of the University of British Columbia, from January to March 2008, aiming to open the discussion on substantive citizenship and cultural politics. Artists, activists and scholars put their thoughts and work together to present the power of disability arts and culture and their influence in shaping “new and transformative

forms of social citizenship by, with, and for disabled people to create generative and innovative public discourses about disability as difference”, (Roman, 2009, p. 1). The series focused on self and collective representations of disabled people, highlighting that disability arts always had a role in the disability advocacy movement as ‘innovative’ and ‘public’:

Because on an individual level, the urge to express oneself artistically has always run through people with disabilities as much as anyone else. What’s key, and provides interesting opportunities for innovation and public engagement, is the combination of this urge to express with a sense of social justice. (McMurchy, Roman, and Frazee, 2009, p. 11)

Disability advocacy, independent living and self-help movements supported one another and also prepared the ground for disability arts giving space to disabled people in order to take the challenge for making their voices and claims public. As Frazee very accurately notes referring to the series of The Unruly Salon:

This Unruly Salon both celebrates and generates the confident claiming of place, space and culture by a people who will no longer be colonized, sidelined or silenced. At the same time, this Unruly Salon ordains and inducts each of us to pay attention, to make connections, to respond- in short to contribute to the opening and unfolding of this cultural space. (Frazee, 2008, p. 2)

This is something which also applies to all functionalities of disability culture. Clearly the discussion has gone beyond the question about the existence of disability culture, which seemed well established and supported by advocates of disability rights, activists, artists and scholars. The focus is on the actions developed within the space of disability culture and their contribution to inclusion, participation and accessibility. One of the essential, but very important, benefits that disability culture offers is a range of artistic means for unfolding and understanding disabled people’s experience and the complexity of their identity. I consider disability film festivals as one of the disability culture spaces, open to these particular practices of unfolding, understanding, communication and participation.



CHAPTER 3: MANAGING THEORETICAL COMPLEXITIES

While trying to answer the question posed in the title of my thesis (“What are you looking at?”), I examined representations of disability in cinema, media and literature through academic insights that were developed from the early years of disability studies to the most recent emergence of critical disability studies. Questioning what we are looking at in relation to representations of disability in documentary films, we are actually invited to deal with a number of complexities as we need to take into account the complexities that come with a) disability, b) the construction and functionalities of representations through systems of communication, and more particularly c) the impact of documentary films on the functionalities of social representations. To this effect, I will start off by positioning critical disability studies in the academic plateau. I will then go on to discuss some prominent approaches to disability, before turning to examine the ways in which social representations are constructed and the ethical considerations involved in documentary films. In this way, I will complement my discussion of the literature on representations of disability in the previous chapter, situating the present study in a more precise theoretical background.

3.1 RESPONDING TO DIFFERENT LEVELS OF COMPLEXITY

Disability studies emerged as a growing academic discipline that influenced research and professional education across the Western world from the 1970s continuing to the beginning of 21st century, making an impact on various other fields such as social studies and humanities, but also applied sciences, like architecture and engineering (Meekosha & Shuttleworth, 2009). According to Goodley (2013), disability studies, particularly in Britain, was introduced as the modernist project that challenged the oppression and practices of exclusion resulting from capitalist practices. In this context, Marxism had a large contribution to make in theorising disability. The materialist social model of disability, which was the leading theoretical tool for almost four decades, was developed by Mike Oliver, Vic Finkelstein and Colin Barnes who drew on neo-Marxist and Gramscian analyses of material barriers to education, community and employment,

experienced by disabled people. The social model politicised disability by shifting the focus on societal barriers that led to exclusion and raised the demand for increased socio-political participation of disabled people in decision making.

Undoubtedly, disability studies made a great contribution in unravelling disability matters and took the discussion further involving interdisciplinary and multidisciplinary perspectives. Also, the social model of disability brought radical changes to the way we think and approach disability from socio-political angle. However, at the beginning of 21st century there was a level of criticism that called for the re-evaluation of disability studies and the development of critical disability studies. According to Meekosha and Shuttleworth (2009) there were three main factors that led to this: firstly, the social model of disability was based on the binary way of thinking, starting from the conceptual distinction between impairment and disability, and then expanding to other binary understandings such as the social and medical model of disability or British and American disability studies. Secondly, developments occurring from humanities and cultural studies gained ground in the discussion about disability-social justice-diversity, suggesting that perspectives on these matters should not be only social, economic and political, but also cultural, psychological, carnal and discursive. The third factor was the co-option of the language of disability studies by traditional human service professions (e.g. institutions of rehabilitation and special education), in the sense that their practices and guidelines were still regulatory and controlling. Critical disability studies claim a distance from those who adopt the language of disability studies for suggesting practices of normalisation. The fourth and last factor is the contribution of critical race theory, critical legal theory, critical queer studies in theoretical, conceptual and methodological grounds (Meekosha & Shuttleworth, 2009). Critical disability studies follow these, some of them recent, developments as there is a level of identification in the examined issues: discrimination, politics, law, race, compulsory heterosexuality, elimination of oppression.

Meekosha and Shuttleworth (2009) also note that critical disabilities studies partly emerged “as an outcome of the tensions that surfaced as a reaction to the more authoritarian Marxism and economic determinism associated with the social model”, (p.50). While I completely embrace the value of the social model of disability and its contribution in thinking disability, I have to also recognise its discrepancies and limitations, especially when my aim is to examine disability through documentary films which as a genre of art carries its own complexities. In order to address the levels of

complexity involved in my research, applying a theoretical perspective drawn on intersectionality was thus imperative. Complexity here, derives from three main factors:

- a) the complexity of understanding disability;
- b) the complexity of analysing representations in documentary films, and
- c) the broad cross-cultural and cross-disability content of selected documentary films.

Starting from thinking disability, I believe that the social model still has a strong validity as disability is also a political matter, and in many cases the lack of the sense of political identity leads to passivity and indifference, putting human rights at stake. Being aware of the limitations of the social model, due to a rigid materialist perspective that on one hand left some social divisions out of discussion and on the other examined some aspects through a narrow framework, like the negative imagery for representations of disability in films, I value post-social model theoretical works that try to expand the discussion on disability matters, responding to the call for intersectionality. The affirmation model was a suggestion by Swain and French (2000) supported also by Cameron (2010) as a complementary positivist insight to disability identity adopting a disability culture perspective. Even though the affirmation model examined representations of disability in films and media (Cameron, 2010), it did not become very popular probably because the materialist impact regarded most positivist approaches as suspicious or naïve in terms of fading the importance of political matters through claims for celebrating difference, since the disabled Marxist felt that there was not much for celebration. To my mind, the affirmation model is not a naïve proposal as it added the element of pride within disability identity and highlighted some of the functionalities of disability culture. Continuing with more critical developments that go beyond the binary understanding for which the social model was criticised, Siebers (2008), in his *Disability Theory*, unfolds a critical realist conception of the body. Siebers openly brings to the centre of attention the matter of impairment and pain without the fear of being accused of being less political. He erases the guilt ascribed to pain experienced by disabled people by breaking the silence imposed by approaches influenced by social constructionism. These approaches had allocated pain as one of the characteristics of the personal tragedy model that see disability as the disabled person's unfortunate condition for which he or she needs to take responsibility. Siebers combines critical and cultural theory in his work contributing to a more critical understanding of the disabled body. Since disabled bodies

are marked by various social divisions, intersectionality should be part of theoretical accounts that examine the factors that lead to multiple oppression.

From a critical race theory perspective, Kimberlé Crenshaw (1989) introduces the term “intersectionality” stressing the necessity of emphasising social divisions when examining matters related to black women. When social divisions are overlooked, we fail to address issues of multiple oppression, and this was one of the weaknesses of the social model of disability. Garland-Thomson (2005) and McRuer (2006) discuss intersectional accounts in their work by merging feminist with critical disability and queer with disability studies respectively. Johnson and McRuer (2014) add a feminist insight in McRuer’s (2006) crip theory in their introduction of cripistemologies. Following Ahmed’s (2010) analysis on feminist killjoy and willfullness they create the theoretical concept of crip killjoy and crip willfullness, which describe the disabled people’s political decision and action of resisting imposed positioning and expectations by a normative society. Even though it is still in its infancy, I find this concept very powerful, because through an intersectional and critical approach offers a political content of being or not being.

Against this backdrop, considering that most of documentary films depict factual stories containing levels of political building, I will be seeking for crip killjoys and crip willfullness in the analysis of selected documentary films. This takes us to the matter of theoretically managing the complexity of analysing representations in documentary films. To this end, I explore the conceptual and ethical issues that are central to documentary making, as these aspects are also central when examining representations of disabled people in documentary films. Since disability is subject to being scrutinised by different types of gaze, theorising practices of staring and looking is also mandatory, as it will contribute to answering the question “what are you looking at?”.

Unavoidably, the theoretical management of the complexities of the issues under examination leads to an interdisciplinary critical approach that could be identified as a critical disability studies approach. However, I was never pro labelling, not only in relation to social groups but also in relation to drawing distinctive lines for shaping narrow theoretical frameworks. Taking into consideration the criticism that critical disability studies received on the grounds of being “in danger of becoming a new uncritical orthodoxy – one distanced from empirical evidence and often only internally critiqued” (Goodley, 2013, p. 641), I proceed with “thinking criticality” combining Giroux’s (2004) and Freire’s (2005) insights. In this respect, I consider criticality in terms

of understanding the mechanisms of oppression, discrimination and injustice in our neoliberal times and how this understanding could bring changes through situated learning which, in this case, takes place in disability film festivals. According to Goodley (2013) the antidote to the danger that critical disabilities studies face is “spaces for the development of praxis: the inter-twining of activism and theory” (p.641). All in all, criticality and interdisciplinary perspectives are not only a valid means for dealing with the complex nature of disability, but also a way of approaching the three levels of thinking involved in my research:

- a) thinking disability
- b) thinking documentary film, and
- c) thinking criticality.

3.2 THINKING DISABILITY

3.2.1 The Social Model

The social model, which was for many years established in disability studies as the “big idea” (Hasler, 1993), was introduced in 1976 by UPIAS, (Union of the Physically Impaired Against Segregation and the Disability Alliance). It signalled the beginning of a new era in disability movement and Disability Studies. The definition of the British social model comes in the document, *Fundamental Principles of Disability*, and states:

Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (UPIAS, 1976, p.15)

Finkelstein’s *Attitudes and Disabled People: issues for discussion* (1980), and Oliver’s *Social Work with Disabled People* (1983), followed UPIAS’ *Fundamental Principles of Disability*, establishing the idea of the social model of disability and extending the definition of this specific model. Since then, the social model opened new routes for disabled people, from the perspective of disability movement actions, and for academics, through Disability Studies.

This social model analysis has had many positive outcomes, not least in challenging disabled people's own internalised oppression by enabling them to make sense of their experience in a way which explains that it is not, after all, 'their own fault' that they face discrimination and social exclusion. (Tregaskis, 2002, p.457)

For the first time, through the social model, there was a statement which officially claimed that the oppression experienced by disabled people derives from the society and the barriers that it sets, marking a shift from the medical and personal framework of disability to the social. There is also space for political challenges of established socio-economic systems, bringing in an understanding that the ways in which disability is framed within society has ideological influence:

An analysis of oppression within capitalist societies, has shown how the previously taken-for granted, naturalistic category 'disability' is in reality an artificial and exclusionary social construction that penalises those people with impairments who do not conform to mainstream expectations of appearance, behaviour and/or economic performance. (Finkelstein, 1980; Oliver, 1990, p. 11; Thomas, 1999, p.131; UPIAS, 1976, pp. 3–4 in Tregaskis 2002, p.457)

How could disabled people be included in the capitalist societies, when these need "healthy" people who can be productive and competitive up to the maximum level, so they can achieve the aim of high levels of production and big profits? If people's worth is based on their ability to be productive in capitalist terms, or on how much they can produce, the category "disability" could easily be fixed, set and established.

Since its original conception almost four decades ago, the social model has received many criticisms and the need for revising it has often been expressed. In this setting, the most impressive reaction was that of Tom Shakespeare, who defended the social model with his work in 1997, but nine years later strongly claimed that this model is wrong (Shakespeare, 2006, p.53), causing a stir in the world of disability studies.

One of the basic criticisms is that the social model relies on modernist dichotomies: impairment - disability, the biological – the social, the body – society, medicine – politics, therapy – emancipation, pain – oppression, the medical model – the social model, disabled people - non-disabled people. From the perspective of post-structuralism and phenomenology, Hughes and Paterson (1997) ask for "an embodied, rather than a disembodied, notion of disability", (Hughes & Paterson, 1997, p. 326). They also suggest that the social model should consider an internal critique related to the dualisms impairment – disability, body – society, in order to give a holistic definition to the impaired body, including the perspective of culture and history. There are further

arguments against the concept of impairment as a medical issue; “[impairment] is both an experience and a discursive construction. It has phenomenological parameters, and it can be analysed as an effect of discourse and language” (Arney & Bergen, 1983, in Hughes & Paterson, 1997, p. 328). An early effort of attaching a social context to the term “impairment” has been also made by Abberley (1987):

Claims about the social origin of impairment, however, are directed at the explication of the social origin of what are material and biological phenomena, and should be understood not as dissolving these material elements into attitudes or ideas, but rather as pointing to the inextricable and essential social elements in what constitutes a material base for ideological phenomena. (Abberley, 1987, p.12)

Jill Humphrey (2000), describing her experience of a researcher shifting from a non-disabled identity to a disabled and then back to a non-disabled one, suggests that: “the social model in practice is grounded upon a dubious premise - namely the antinomy between ‘disabled’ and ‘non-disabled’”, (Humphrey, 2000, p.81). According to Humphrey, this creates inadequacy and separatism, since people who cross over between disabled and non-disabled identity are not considered by the social model. This argument highlights the question: who is considered as disabled? Is this a case of the social model not including shifted identities, or is it a badly made application of the social model? Another issue in disability studies raised by the disabled academics and activists is about non-disabled researchers undertaking research in the field of disability. The main arguments are the disabling approaches and the lack of the experience of being disabled and oppressed. As a non-disabled, or more succinctly put, a temporarily able bodied researcher¹, I find this argument quite contradictory. It seems quite an oxymoron, considering, especially, that it comes from disabled people who fight against limitation, barriers and oppression.

Another criticism of the social model comes from the debates about some specific groups of disabled people being less privileged, considering their presence in committees, published academic work and advocacy. Goodley (2004), criticises the social model for holding the potential for the inclusion of all disabled people and disabled activists. It is also observed that people with mental health problems or learning difficulties have not gained an adequate place in academic work. Goodley (2004), comments that, “failings”

¹ a term used to stress that in relation to several factors, such as age, health and societal barriers, everyone could potentially become disabled.

of the social model are the reasons for this. Humphrey (2000), also found that “the actual absence of people with learning and mental health difficulties meant that in these cases there was representation, rather than presence, and advocacy rather than self- advocacy” (Humphrey, 2000, p.74).

Morris (1991), a disabled feminist writer, refers to a “white-dominated disability movement” and admits that there are links between discrimination against disabled people and racism. Criticising non-disabled academics’ analysis around women / race / sexuality and disability, Morris (1991) argues that:

the experience of Black and ethnic minority disabled people, disabled women and disabled gay men and lesbians are integral to the experience of being disabled....Sexism, racism and heterosexism affect us all and the struggle against them must be an integral part of any disability politics. (Morris, 1991, pp.179-180)

Further, Hill (1992), an activist writer and journalist, whose criticism was about the movement becoming too elitist, admits that, despite the efforts made by black disabled people and those who represent the disability movement, “they have not yet become an integral and important part of the disability movement as it moves ever progressively forward”, (Hill, 1992, p.184). Black people experience double oppression and exclusion. This can be explained in terms of racism and ableism. They are excluded from the white-dominated disability movement and society as black people and they are marginalised in black communities as disabled people.

Stuart (1992), on the contrary, after analysing the oppression and exclusion of black disabled people, disagrees with the term “double oppression” and he notes that it “is rather empty.” Alternatively, he suggests, “that racism within disability is part of a process of simultaneous oppression which black people experience daily in Western society. It is also an experience that divides disabled people from their black able-bodied peers” (Stuart, 1992, p.179). He then continues his argument pinpointing that, despite the fact that white disabled people experience oppression, they are accepted members of their society and they are considered as part of the norm, in terms of race. Even though Stuart argues against the phrase, “double oppression”, suggesting the term “simultaneous” for the oppression that black disabled people suffer, he finds the idea of constructing a separate and distinct identity for black disabled people, a very dangerous option.

Focusing on disability politics and the gay pride movement with a view to applying the social model to the experiences of gay and lesbian and disabled people, Corbett (1994)

analyses the area of dual oppression in the permutations of experiences of being identified as black and disabled, female and disabled, gay or lesbian and disabled and mentions that the complexity that these identities present is the element that is challenging. “There are too many variables which may conflict and create unease” (Corbett, 1994, p.350). She underlines that the complexity of disabled people’s identities, instead of being a positive factor, functioning as a useful key for opening doors to inclusion, turns into a problem for different groups or communities. It seems like communities are organised according to one single element, characteristic or variable.

Dual, double or simultaneous, oppression comes from many fronts expanding the marginalisation of disabled people with complex identities. In this case, the application of the social model and its inclusiveness are problematic. There is no more comprehensive description of the failing of different communities to deal with complexity and multiple identities, than Renteria’s poem “Rejection” (1993):

*SOCIETY REJECTS ME for being Deaf.
The Deaf community reject me for being a Lesbian.
The Lesbian community reject me for not being able to hear them.
The Deaf-Lesbian community rejects me for being into S&M.
The S&M community reject me for being Deaf.
Society rejects me for being Chicana.
The Hispanic community reject me for being a Lesbian.
The Gay Hispanic community rejects me for being Deaf.
Patriarchal society rejects me for being a woman.
I am rejected and oppressed,
Even by those who cry out readily
Against rejection, oppression, and discrimination.
When will it end?*

Complex identities and different types of disabilities seem to be one of the failures of the social model and disability movement, making some writers wonder who is to be considered as disabled. Humphrey (2000) emphasises the efforts of disability community in recognising its own heterogeneity and multiple identities but she also underlines a boundary problem. She notes that “from the ‘inside’ there are deaf people who are

classified as disabled in legislation and by society, but who repudiate the disabled identity on the grounds that they constitute a distinct linguistic and cultural minority” (p.65). She continues her criticism of the social model by describing the difficulty of some organisations to reach out to people with different disabilities who identify themselves as disabled or not. Humphrey (2000), finds that more efforts have been made by these organisations to include black and gay disabled people than to include people with different disabilities. Having a personal experience of being and not being included, she defines it as the *Achilles heel* of the disability politics, underlining how hard it is to find an accurate and satisfactory answer to the question: *who is to “count” as a member of the disability community?*

Despite the calls of some writers and academics for applying the social model widely, covering and including whoever experiences any kind of disabling practices and wants to combat discrimination, the social model has been criticised for failings and pitfalls. Different groups of disabled people still feel excluded and misrepresented. This suggests that, even though the social model brought a number of changes for disabled people’s lives, with a huge impact on social policies, education and political movements, taking multiple identities under consideration still seems problematic within the disability community.

Tregaskis (2002) and Thomas (2004) reviewed the development of the social model, underlining the achievements so far but also make suggestions for further theoretical work. Tregaskis (2002) analyses different accounts related to the social model, such as the social model as academic paradigm, the materialist social model accounts, the cultural creation of disability, attitudes in the social model, sociology of impairment, feminist and psychoanalytic accounts and connections with other oppressions. These accounts derive from a variety of theoretical approaches such as Marxist materialism, cultural politics, feminism, psychoanalysis, gay and ethnicity politics, showing the multi-faceted issues that the social model has to deal with. Tregaskis asked for the development of a social model theory, combining the words “model” and “theory”, whereas the only term that the social model theorists (Oliver & Finkelstein) accept is the term “model”. However, it seems that there is enough space for development but there are concerns for resistance from social model theorists. The urge for a more flexible social model seems to be directly connected with the practical use of the model, aiming for the reduction of the splits between the disability theory and practice by activists.

From a feminist materialist perspective, where capitalism and patriarchy are central in understanding women's oppression, Thomas (2004) suggests the development of the social relational in the social model, identifying four basic themes for the theoretical agenda: "the political economy of disability, the psycho-emotional dimensions of disability, theorising difference and theorising impairment and impairment effects", and arguing that "disability involves a nexus of social relationships" (Thomas, 2004, p.43) between disabled and non-disabled people, which actually promote "normal" people's regime. These relationships should not be ignored, but should be examined in order to find what shapes and establishes them.

Shakespeare (2006) criticises the social model in his book, *Disability Rights and Wrongs*, focusing on: the political dangers of the model, his view that the model has been unchanging and needs to be updated, the ongoing impairment/disability distinction supporting the importance of impairment and the barrier-free utopia. Shakespeare's writings caused reactions in the academic world and his arguments have been questioned. Reviewing Shakespeare's *Disability Rights and Wrongs*, Peter Beresford (2007) wonders if it is about a progressive or reactionary challenge. Mike Oliver's (2007) review is much sharper and defensive, writing from the position of the retired academic; Oliver does not hesitate to make his criticism against Shakespeare's theoretical approach more personal. He describes Shakespeare's book as a "mish mash of contradictory perspectives" (Oliver, 2007, p.230), and indicates confusion and distortion of his and other scholars' works.

Barnes (2007) makes an effort to bring the focus to the initial roots of barriers that derive from the capitalist structure of economy. He argues that there has been a de-radicalisation of social sciences and some approaches of disability studies "shift attention away from the primacy of economic forces in the creation of disablement toward a politically benign focus on culture, language and discourse" (Barnes, 2007, p.18), and concludes that the social model was a major catalyst for the shift in perceptions of disability, which also changed the focus of policies and legislation. Undoubtedly, the impact of the social model was big internationally, but marginalisation, poverty and disablism is still what people with disabilities experience daily. Barnes notes that policies proved unsuccessful and current economic, environmental and demographic challenges will not make the situation easier. In that case, he claims that the social model should be a tool for deconstructing the reasons behind the barriers in order to contribute to change, and not - as he puts it, with some sarcasm - obscure theorising useful only in lecture theatres and seminar rooms.

3.2.2 The Affirmation Model

Swain and French (2000), introduced a model that aimed to promote a positive identity for people with disabilities but never became as popular as the previous two. This new model emerged within disability culture in opposition to the personal tragedy model based on the social model:

It is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being impaired and disabled. (Swain & French, 2000, p. 569)

Swain and French adopt a disability culture perspective and they add the view of positive individual and collective identity, this way filling some gaps that the social model did not cover in relation to this aspect. Barnes probably would reject the disability culture perspective as de-radicalised and obscure theorising. However, Swain and French argue that the social model was accepted by non-disabled people at a basic conceptual level, almost superficially. Specifically they suggest:

Non-disabled people can generally accept that a wheelchair-user cannot enter a building because of steps (i.e. the person is disabled by barriers in an environment built for non-disabled people). Non-disabled people are much more threatened and challenged by the notion that a wheelchair-user could be pleased and proud to be the person he or she is. (Swain & French, 2000, p. 570)

Possibly, the superficial acceptance of the social model by the non-disabled and the quick digestion on a conceptual level, could be one of the reasons of the failure of policies, since it was a change of focus and not a fundamental change of perception and mentality. The social model challenges the societal barriers but it also leaves the factor of impairment out of the scene and this makes it subject to leaving space for enclosing elements of personal tragedy. Firstly, because disabled people are identified as member of an oppressed group within society, and this on basic conceptual level is easily associated with and interpreted as personal tragedy. Secondly, the disassociation of impairment from disability allows the development of a superficial interpretation. This interpretation is constructed on the binary understanding of impairment and disability, where impairment is perceived as personal tragedy whereas disability is seen as a social product of the imposed societal barriers.

It, thus, leaves the possibility that even in an ideal world of full civil rights and participative citizenship for disabled people, an impairment could be seen to be a personal tragedy. (Swain & French, 2000, p. 571)

The affirmation model was born upon writings and narratives that represent impairment and disability as positive experiences with benefits. People with disabilities that support the idea of positive individual and collective identity tend to claim that they gained access to sufficient resources due to their disabilities that improved their lives. They also escaped other barriers and risks that they would have to deal with due to their culture, class, gender and age. Others described their disability as an epiphany that changed their approach to their lives to a more fulfilling one.

The affirmation model does not deny the content of the social model, the impairment or the frustration and anger that discrimination causes to disabled people, it adds to all the above, suggesting how they can construct a positive identity:

Through group identity it is recognised that just because there are benefits from being excluded from non-disabled society (which is capitalist, paternalistic and alienating) does not mean that disabled people should be excluded. From this way of thinking, disabled people enjoy the benefits of being ‘outsiders’, but should not be pushed out, i.e. should have the right to be ‘insiders’ if they so wish. (Swain & French, 2000, p. 578)

This model was introduced by disability culture and disability arts. In Swain and French's first attempt to describe the affirmation model, there is a focus on the “Proud, angry and strong” content but it is not just that. The disability arts perspective brings the matters of inclusion and rights on a level more approachable for non-disabled people, which could have a constructive impact on the way they think about disability. Disability arts combine aesthetics, politics, narratives, humour and daily social references, so in this case, the societal barriers are not overlooked but they are addressed in a different way, still empowering for disabled people. As arts build conceptual and social bridges in the unique way they do, disability arts function towards this direction, giving space to disabled artists to create, expose and communicate. Challenging stereotypes and discrimination through various prisms, disability can be understood as it is experienced by disabled people in a disablist world:

Affirmation is about being different and thinking differently about being different. The affirmative model is about disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on disabled people's terms, of human embodiment, lifestyles, quality of life and identity. (Swain & French, 2008, p. 185)

In this context, the affirmative model does not suggest that disabled people are meant to celebrate difference and come to terms with disability and impairment as a

simplistic positive attitude to the marginalisation they experience. The affirmative model does not try to idealize exclusion by suggesting “benefits of living and being marginalized and segregated within a disablist society” (Swain & French, 2008, p. 185). Even though the affirmative model was introduced as complimentary to the social model, it did not become popular. The reason, stated by its supporters, was that “there are no clearly defined formulas for change here. There is no comfortable remit. The affirmative model itself does not provide a different set of presumptions to replace those that characterise individual models, particularly the tragedy model” (Swain & French, 2008, p. 186).

Cameron (2010) made an effort to create a clear definition of the affirmation model as he felt that it was leaving space for misconceptions and confusing assumptions. So according to Cameron's affirmative model definitions, *impairment* is defined as “physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society, and disability as the loss or limitation of opportunities to take part in community life on an equal level with others due to physical and social barriers” (Cameron, 2008, p. 24).

The above definitions are proposed variations of Disabled People's International social model definition (Barnes, 1994, p. 2), where Cameron replaced, “normal life” with, “community life” as the term normal is problematic and can have various interpretations. He also noted that the definition of impairment was the core difference between the social and the affirmative model. “Heavily loaded terms used in the definitions of *UPIAS (1976)* and *DPI (1981)*”, such as “functional loss”, “individual limitation”, “lack” or “defect”, were not included in the definition suggested by the affirmative model (Cameron, 2010, p. 37). Even though words and definitions are important for reflecting a specific content and proposing ideological paths, redefining the affirmation model clarified the purposes but it did not make it as popular as the social model. Its promotion as one more tool stayed on an initial introductory level.

3.2.3 Disability Theory

The criticism that the social model received seems to be a call for an intersectional approach to disability matters. Siebers, in his work *Disability Theory* (Siebers, 2008), tries to give a refreshing perspective in critical and cultural theory for disability studies' benefit. The “refreshing” element in Siebers' work consists of connection points between critical and cultural theory and disability studies and also of issues that disability studies

bring in “adjacent fields of cultural studies, literary theory, queer theory, gender studies, and critical race studies” (Siebers, 2008, p. 1). Siebers covers a wide range of debates giving a more holistic perspective to disability matters, taking them many steps forward from the dyadic medical/social model. The agenda includes discussion about identity, ideology, politics, social injustice, status of representation and the disabled body. Disability identity is one of the core issues and Siebers finds an intersectional approach as the most appropriate to understand a complex embodiment that combines social and corporeal factors.

Having an insight into body theory, related to disabled body, Siebers examines the dominant theory of social constructionism. Gender studies had a big impact on theorising the body and this theoretical development offered an alternative perspective to the medical model of disability:

The medical model situates disability exclusively in individual bodies and strives to cure them by particular treatment, isolating the patient as diseased or defective, while social constructionism makes it possible to see disability as the effect of an environment hostile to some bodies and not to others, requiring advances in social justice rather than medicine. (Siebers, 2008, p. 54)

Social constructionism established that the body is socially constructed, offering a “more flexible definition of human beings”. Siebers argues that this theory has a weak side because it proposes that the perception of bodies is influenced by a society’s dominant ideas, attitudes, and customs. Social constructionism seems to invest more on a common sense approach to how people victimise individuals unlike them. Siebers (2008) argues that:

[...] this common sense approach is so very common, as many persons with a disability will explain at great length: people easily perceive when someone is different from them but rarely acknowledge the violence of their perceptions. (Siebers, 2008, p. 55)

In a society that is ignorant of the complex nature of disability, apparently temporarily able people do not realise that their perceptions might have an impact on discrimination and exclusion. According to this argument, the use of ‘*common sense*’ that social constructionism claims, is not obvious to everybody. Siebers pinpoints to this grey area of social constructionism caused by non-disabled people's perceptions - rather misunderstanding due to lack of knowledge - of disability. However, society's influence stays a strong statement of social constructionism, quite valid for inclusion discourses.

Siebers suggests the application of a linguistic model that highlights representation as an important ideological force.

Strong constructionism posits that the body does not determine its own representation in any way because the sign precedes the body in the hierarchy of signification. In fact, political ideologies and cultural mores exert the greatest power, social constructionists claim, when they anchor their authority in natural objects such as the body. [...] Bodies are linguistic effects driven, first, by the order of representation itself and, second, by the entire array of social ideologies dependent on this order. (Siebers, 2008, p. 55)

Criticism by disability authors on constructionism highlights suppression of disabled people's physical realities. It seems that performativity takes over corporeality, focusing on “intellectual achievement, bodily adaptability, and active political participation.” Siebers notes that disability proved to be difficult to theorise for social constructionism and continues his analysis of body theory with the examination of pain and its impact on the identity of people with disabilities. Pain is perceived as a subjective and individual matter, which actually puts more pressure on disability identity discussion. The individuality that pain brings as an effect is an element that people with disabilities have to fight for the sake of civil and community rights. Siebers argues that this individuality should be established and intersecting identities should be stretched but this might cause an imbalance in disability studies:

[...] the greatest stake in disability studies at the present moment is to find ways to represent pain and to resist models of the body that blunt the political effectiveness of these representations. I stress the importance of pain not because pain and disability are synonymous but to offer a challenge to current body theory and to expose to what extent its dependence on social constructionism collaborates with the misrepresentation of the disabled body in the political sphere. (Siebers, 2008, p. 61)

Pain is not completely ignored by theorists. Siebers identifies some references. The most dominant one presents pain as, “regulatory or resistant,” and in this individualised form, is not seen as a characteristic for a group identity. In other cases, pain is described as, “a repressive effect that marks out the individual as a site of resistance to social regulation” (Siebers, 2008, p. 61). In body theory, pain is rarely physical. Usually it is more related to guilt or social suppression and this is quite widespread. Siebers notes that even in the rare occasions where theorists examine the physical side of it, they still follow the conventional model where suffering and disability are presented either as new possibilities of pleasure, or a different way for arranging the physical resources of the

body. According to Siebers, “pain is most often soothed by the joy of conceiving the body differently from the norm” (Siebers, 2008, p. 62).

Cyborgs come in body theory as a creation based on extending disability to an advantage, and presenting people with disabilities with new powers that replace the stereotype of “subhuman” with that of an existence that has abilities more than a human. This particular representation probably has some benefits for non-disabled people's imagination, disabled people's narratives gaining space in literature and arts, however, Siebers strongly claims that cyborg representation offers nothing but a mythologised image of disability with no real political power for body theory:

Theories that encourage these interpretations are not only unrealistic about pain; they contribute to the ideology of ability, marginalizing people with disabilities and making their stories of suffering and victimization both politically impotent and difficult to believe. (Siebers, 2008, p. 64)

3.2.4 Intersectionality

The criticism that the social model could not respond to complex inequalities (Morris 1991, Hill 1992, Stuart 1992, Renteria 1993, Oliver 2013) and also leaves space for the creation of a disability type hierarchy within the disability community (Humphrey 2000), creates the need for an intersectional approach. The Feminist movement was called to respond to the complex experiences of women. The challenge of that call was to expand its structure beyond the interests of the most privileged, white, able-bodied, heterosexual, middle class women. Black, queer and sex radical feminists (Hooks, 2000, Collins 2000) respond to this challenge with the theory of interesectionality. The term, “intersectionality,” was established by Kimberlé Crenshaw (1989) when she examined black women's employment experience in U.S.A. and it posits that women’s “social locations in terms of race, class, gender, sexuality, nation of origin, ability, age, etc. are not easily parsed out one from the other” (Shannon & Rogue, 2009, p.6).

The term “intersectionality” became very popular and it was also mentioned in United Nation and Non-Governmental Organisations' forums (eg. Resolution E/CN.4/2002/L.59). It occurred from the debates on “triple oppression” which was a claim that black women suffer three different discriminations: a) as black, b) as women and c) as working class members. Anthias and Yuval-Davis (1983, 1992), argued against the notion of “triple oppression” stating that it cannot be claimed since:

Each social division has a different ontological basis, which is irreducible to other social divisions. However, this does not make it less important to acknowledge that, in concrete experiences of oppression, being oppressed, for example, as ‘a Black person’ is always constructed and intermeshed in other social divisions (for example, gender, social class, disability status, sexuality, age, nationality, immigration status, geography, etc.). (Yuval-Davis, 2006, p.195)

Crenshaw (1991), in her analysis about identity politics and violence against women of colour, states that identity politics ignore the differences within the discriminated groups and this is problematic as in its essentialisms it creates tension and reproduces efforts to politicize the issues that are based on single social divisions:

Although racism and sexism readily intersect in the lives of real people, they seldom do in feminist and antiracist practices. And so, when the practices expound identity as woman or person of colour as an either/or proposition, they relegate the identity of women of colour to a location that resists telling. (Crenshaw, 1991, p.1242)

Crenshaw (1991) clarified that she did not intend to introduce intersectionality as, “a new totalizing identity theory”. Her aim was to suggest a methodology that will disrupt the tendencies to see each category (eg. race, gender) as exclusive or separable. She organised her analysis under three categories of intersectionality: a) structural, b) political and c) representational. Under structural intersectionality, Crenshaw discusses, “the ways in which the location of women of colour at the intersection of race and gender makes experience of domestic violence, rape and remedial reform qualitatively different from that of white women” (Crenshaw, 1991, p.1245). Political intersectionality focuses on the ways in which both feminist and antiracist politics contributed to exclude issues related to violence against women of colour. Crenshaw's third category, the representational intersectionality analyses the cultural construction of women of colour, more specifically, “how controversies over the representations of women of colour in popular culture, can also elide the particular location of women of colour and thus become yet another source of intersectional disempowerment” (Crenshaw, 1991, p.1245). Crenshaw examined cases of rap artists that represent black women in a misogynistic objectified way by talking about violence against them in their lyrics. There were claims that rap artists challenge racist stereotypes in this way, in part, in many cases of the approach of racist humour, which aims to tease out the ridiculousness of racism. Crenshaw pinpoints that nothing can justify an anti-racist action that relies on sexist content:

Though racial humour may sometimes be intended to ridicule racism, the close relationship between the stereotypes and the prevailing images of marginalised people complicates this strategy. [...] Humour in which women are objectified as packages of bodily parts to serve whatever male-bonding /male competition needs men please subordinates women in much the same way that racist humour subordinates African Americans. (Crenshaw, 1991, p.1293)

Crenshaw (1989) had also argued in previous work that an analysis focused on the privileged groups and the particular inequalities they experience is a distorted analysis because it excludes those that are discriminated against in more complex and multiple ways. Such an analysis is based on experiences that come from a “subset of a much more complex phenomenon” Crenshaw (1989) examining the judicial treatment of intersectionality in relation to black women's cases, states that:

The refusal to allow a multiply-disadvantaged class to represent others who may be singularly – disadvantaged, defeats efforts to restructure the distribution of opportunity and limits remedial relief to minor adjustments within an established hierarchy. (Crenshaw, 1989, p.145)

Shannon and Rogue (2009), argue that it is problematic to refer to women's experience as a universal case, since womanhood is experienced in many different ways, depending on factors such as race, age, class, sexuality etc. The same argument applies for disabled people as a number of factors influence how disability is experienced. All the elements of identity mentioned by Shannon and Rogue (2009) apply to disability but particularly ability, that could be translated as a type of disability, has an impact on hierarchy within the disability community and as a result of this, in representation and participation. Specifically they note:

Our various social locations and the hierarchies they inform, intersect in complex ways and are not easily separable. People don't exist as “women”, “men”, “white”, “working class”, etc. in a vacuum devoid of other patterned social relationships. Further, these systems of exploitation and oppression function in unique ways. [...] These structured inequalities and hierarchies inform and support one another. (Shannon & Rogue, 2009, p.7)

Shannon and Rogue's argument is that the construction of classification of social struggles according to categories such as primary, secondary or peripheral is unnecessary. It has been proved historically that this method of ranking causes trouble when it comes to solidarity because it is divisive.

Mike Oliver (2013), in his article, “*The Social Model of Disability: Thirty Years On,*” recognises, as one area of the criticisms suggests that “the social model fails to take account of difference and presents disabled people as one unitary group, whereas in

reality race, gender, sexuality and age mean that disabled people's needs and lives are much more complex than that", (Oliver, 2013, p.1025). Examining disability should not be based only on the marginalisation of white heterosexual male wheelchair-user. Accounts coming from female, queer, black or mixed race disabled people should be considered at the same level of importance. In addition, different disabilities, especially those to whom it presents a challenge to be represented, and those that are known as "hidden" or recurrent. I would also add experiences beyond the Western world, where in some cases, people with disabilities, mainly females, had the opportunity to get an education due to their disabilities, as they were sent to special schools, whereas for able-bodied girls, the chances for schooling were quite low.

One of the particular purposes of intersectional analysis is to "give voice" to groups that are invisible within the marginalised groups. Black feminists claimed that race, gender or class were factors that brought qualitative differences in their experience of oppression. Similar claims were made by disabled people, with the most distinguished being the one addressed by Renteria (1993). In the case of disability, access to health care, support, education, adaptable equipment and other provisions is differentiated according to class and race, especially in countries where financial benefits, disability allowances or other provisions are very limited. Choo and Ferree (2010) state that the qualitative differences (eg. race, gender, class etc.) "made achieving "voice" a significant political as well as intellectual demand" (p.132) because the political matters that emerge from the groups' experiences can be addressed by movements that work towards their inclusion. The political and intellectual demand for giving voice, and therefore inclusion shifts multiply-disadvantaged groups from the margin to the centre.

Intersectionality as a human rights policy methodology suggests the examination of the ways that inequalities affect and emerge from multiple identities. Charlotte Bunch at the World Conference Against Racism stated that "if the human rights of any are left unprotected – if we are willing to sacrifice the rights of any group, the human rights of all are undermined" (Center for Women's Global Leadership, 2001, p. 111). The above statement emphasizes the importance of a holistic approach in order to tackle inequalities. However Yuval - Davis (2011) finds this theoretically and politically problematic because it overlooks "the differential positionings of power in which different identity groups can be located in specific historical contexts," and "the dynamics of power relations within these groups" (Yuval - Davis, 2011, p.204). Such an essentialist analysis addresses, as

Yuval- Davis describes it, a fragmented, additive model of oppression, whereas an intersectional analysis:

should carefully separate, and examine separately, the different levels in which social divisions operate in the communities where they work and which were discussed earlier, i.e. institutionally, intersubjectively, representationally as well as in the subjective constructions of identities. Only when such a contextual analysis is carried out can there be an intersectional review of policy initiatives and systems of implementation. (Yuval- Davis, 2011, p. 205)

In her analysis on disability feminist studies, Garland-Thomson (2005) states that disability is a critical category because it “is probing identity, theorizing intersectionality and is investigating embodiment” (p. 1559). Feminist analyses focus on the ways that gender interlinks with race, sexuality, class, age and ethnicity, highlighting the relations between body and identity. Disability is the category that challenges the perceptions about embodied identity and promotes the discussion on complexity. Disability feminist studies examine the social construction of identities and they approach disability as part of this construction.

Feminist disability studies defines disability as a vector of socially constructed identity and a form of embodiment that interacts with both the material and the social environments. [...] Feminist disability studies questions the dominant premises that cast disability as a bodily problem to be addressed by normalization procedures rather than as a socially constructed identity and a representational system similar to gender. (Garland- Thomson, 2005, p. 1559)

Thinking about disability brings forward matters that are of parallel concern for feminist studies such as politics of appearance or representation, procedures that concern, affect and shape bodies, for example, selective abortion, medical and genetic testing, normalisation through surgeries or adaptive technologies, the position of disability or gender towards the promotion of specific models of health and fitness and the ideology of normalcy. Other matters also related to reproductive rights and the ability or inability for taking over the parenting responsibilities, are dealing with stigma and claiming access and inclusion.

The above are all matters that are approached by documentary films across various international productions. An additional benefit of a feminist disability analysis, that is also applicable for examining disability documentary films, is offered by the two critical practices that Garland-Thomson (2005), characterises as “counterintuitive”. The first practice focuses on communities of people that share disability experience instead of looking at groups based on diagnostic and medical labelling. It examines the patterns of

developing meanings projected onto bodies that are perceived as defective and are marginalised in our societies. As Garland-Thomson (2005) notes:

Social categories parallel to “disabled”, such as “people of color” or “queer”, also embrace a wide range of varying physical characteristics, identities, and subjective experiences, even while they risk flattening significant differences. Such social - rather than biological - labels accurately capture the single, reductive, exclusionary social category that conflates and stigmatizes a range of differences according to a subordinating discourse. (Garland-Thomson, 2005, p. 1558)

The second practice of feminist disability studies is related to the use of precise language that could be considered as complex when it refers to disability. The purpose of examining the use of language is the avoidance of essentialist definitions of disability that describe inferior embodiment. According to Garland-Thomson (2005), “this language calls attention to the hidden norm that lurks behind our understanding of disability, one that makes some bodies seem naturally deficient or excessive and others seem superior” (Garland-Thomson, 2005, p. 1559).

Examining the reflections on the language of disability, Zola (1993) states that the matter of naming is not just personal but also a political issue:

[...] Language was one of the mechanisms by which dominant groups kept others 'in place'. Thus, as minority groups sought to gain more control over their lives, the issue of naming - what they are called - was one of the first battlegrounds. (Zola, 1993, p. 167)

According to Zola, labelling is a mechanism that is used to control minority groups since labels can be confirmed with scientific justification, - medical science especially- has contributed to this process-, and also “justified” labels that encompass specific characteristics and expected behaviours, create particular expectations about positions and actions that minority groups could take in society. Zola mentions two implications of naming with practical and political impact: the first is connotational and associational, and the second is function that aims to pervasiveness and generalization. Looking into the process of recontextualizing names, Zola notes that the reality of disabled people's conditions should not be denied while the connotations and the pervasiveness of labels change, and he argues that thus “biology may not determine our destiny; but, as with women, our physical, mental and biological differences are certainly part of that destiny” (Zola, 1993, p. 170).

Garland-Thomson (2005), also adds that the language used for representation or “narratives” can challenge negative meanings of disability and set ideas about, “what

constitutes happiness, attractiveness, suffering, dignity, or a livable existence” (p. 1559). In this context, the choice of language in documentary films beginning from the title, the films synopsis, and continuing with the use of specific terms in the narration, has an important role in the representation of disabled people.

3.2.5 Crip Theory And Crip Killjoys

Robert McRuer (2006), introduced Crip theory combining disability studies and queer theory to address concerns in relation to bodies and identities and their representations either as “normal” or as abject. Crip theory questions cultural locations and socio-political constructions that reproduce compulsory heterosexuality and compulsory able-bodiedness. As McRuer (2006) states:

[...] crip theory (in productive conversations with a range of disabled/queer movements) can continuously invoke, in order to further the crisis, the inadequate resolutions that compulsory heterosexuality and compulsory able-bodiedness offer us. And in contrast to an able-bodied culture that holds out the promise of a substantive (but paradoxically always elusive) ideal, crip theory would resist delimiting the kinds of bodies and abilities that are acceptable or that will bring about change. (McRuer, 2006, p.31)

The establishment of heterosexuality and able-bodiedness as norms, created an authority that influences depictions of what shifts away from these norms. However, McRuer claims that the systems of heterosexuality and able-bodiedness that reproduce this authority are at risk of collapse because “these systems depend on a queer/disabled existence that can never quite be contained” (McRuer, 2006, p.31).

Queer theory could be seen as the institutional transformation of lesbian and gay studies. The term was introduced by the theorist Teresa de Lauretis in 1991, in an issue of *Differences: A Journal of Feminist Cultural Studies* covering academic studies examining the construction of sexuality and sexual marginalisation. De Lauretis distanced herself from the term three years later explaining:

As for 'queer theory', my insistent specification *lesbian* may well be taken as a taking of distance from what, since I proposed it as a working hypothesis for lesbian and gay studies in this very journal (*differences*, 3.2), has very quickly become a conceptually vacuous creature of the publishing industry. (de Lauretis, 1994)

The term “queer” however, was established taking space in academic studies, shifting away from slang and pejorative connotations. As Jagose (1996), explains,

institutionally the term “queer” refers to lesbian and gay subjects but its analytic framework also includes matters such as cross-dressing, hermaphroditism, gender ambiguity and gender-corrective surgery.

Broadly speaking, queer describes those gestures or analytical models which dramatise incoherencies in the allegedly stable relations between chromosomal sex, gender and sexual desire. Resisting that model of stability--which claims heterosexuality as its origin, when it is more properly its effect--queer focuses on mismatches between sex, gender and desire. [...] Whether as transvestite performance or academic deconstruction, queer locates and exploits the incoherencies in those three terms which stabilise heterosexuality. (Jagose, 1996)

Queer theory came to question the “norms” constructed according to the authority of heterosexuality and describe identities and bodies through different perspectives, shaking the normative frames. By using the term “queer”, the idea of identity becomes broader, since the compulsion about categories is abolished and nothing is fixed:

Queer is more often embraced to point to fluidity in identity, recognising identity as a historically-contingent and socially-constructed fiction that prescribes and proscribes against certain feelings and actions.[...] Queer thus denotes a resistance to identity categories or easy categorisation, marking a disidentification from the rigidity with which identity categories continue to be enforced and from beliefs that such categories are immovable. (Giffney, 2009, p.2)

Recognising the heterogeneity within identity groups, queer theory questions the essentialist approach of fixed identity categories. It promotes the fluidity and the constant formation which is also seen in groups of people with disabilities. Sherry (2010) pinpointed that queer theory draws a parallel with the argument of Oliver and Barnes (1998), who had stated the number of people with disabilities changes according to the presence or absence of disabling environments. Societal barriers and disabling environments are the main factors that turn an impairment to disability, and this also adds on the fluidity in the identity of people with disabilities.

The term “cripple” or in short “crip”, like “queer”, embraces fluidity and transforms internalised oppression to pride. As offensive labels reflect hostile attitudes against people with disabilities, who used it to claim their own crip culture, crip jokes and humour as counter-argument, counter-hegemonic and an act of resistance to this hostile world. Clare (1999), specifically notes that “cripple makes me flinch; it too often accompanied the sticks and stones on my grade school playground, but I love crip humour, the audacity of turning cripple into a word of pride” (Clare, 1999, p. 69) .

“Crip”, like queer, is used to shock and provoke either the derogatory use of it, or any superficial political correctness, a word to claim pride of disability identity and resistance to discriminatory practices, contributing this way to the shaping of politics. Similarly, to a “homeotherapeutic” approach: hate, discrimination and exclusion, which was reflected through the derogatory and offensive use of the terms, get challenged by taking pride and ownership of these same terms. This tactic is called “flaunting” (Clare, 1999 & Sherry, 2010) and proved to be a popular form of transgressive politics. Commenting on the use of *ugly words*, Clare states:

To transform self-hatred into pride is a fundamental act of resistance. In many communities, language becomes one of the arenas for this transformation. Sometimes the words of hatred and violence can be neutralized or even turned into the words of pride. To stare down the bully calling cripple, the basher swinging the word queer like a baseball bat, to say “Yeh, you're right. I'm queer, I'm a crip. So what?” undercuts the power of those who want us dead. (Clare, 1999, p. 92)

However, Clare (1999) also clarifies that this approach is not easy for everyone to follow as the *ugly words*, words of hate, are still used with a sense of their original meaning. The balance between subjection and subjectification is still unsteady, so flaunting might not always work the way is described. It takes a conscious acceptance of identity and a deep understanding of identity politics. Fluidity in identity, resistance to categories of identity and socially-constructed fiction can also be found in the disability studies agenda. The process of becoming, cannot be rigid as it is a process of making one's self, and as such, fluidity is unavoidable. Socially-constructed limits set categories, which can easily become labels that unify people under groups attached with specific characteristics and expected behaviours. Groups who are identified under queerness or disability are diverse in terms of race, class, age, gender, sexuality, religion, and political positions but historically, had to face similar cases of discrimination in public or private lives. Queerness and disability were both pathologised and subjected to various practices of cure, translated to a sin by religions, under-represented by law and policies, in terms of rights in health, education, employment, housing, partnership and parenting, stereotyped by cinema and media, victimised and discriminated against. Sandahl (2003) states that, “as academic corollaries of minority civil rights movements, queer theory and disability studies both have origins in and ongoing commitments to activism” (p.26). The main similarity among these disciplines is their positions towards perceptions of

normalcy, as they all argue against the compulsion to construct and serve different types of norms, (corporeal, mental, sexual, social, cultural, subcultural, etc.).

Framing people is a result of interpreting and seeing through fixed and narrow conceptual prisms, which on one hand supports the authority of “normal”, on the other, leaves people in the closet. The coming out process has the same significance for queer and disabled people as it stands as, “a declaration of identity outside the norm, or against the stream” (Swain & Cameron, 1999, p.68). Coming out is not just about breaking the silence or confirming what was assumed or ascribed, it is an action against oppression, an action of taking ownership of an identity where society favours its invisibility. This declaration changes what was set as known and challenges the fixed conceptual filters. Taking ownership and pride of an identity, that did not fit the boxes of what was set as normalcy, changes the discourse. Swain and Cameron (1999) note that the most important impact of coming out is the change of the meaning of disability. They describe two significant changes: firstly from impairment to disability, which actually translates as the shift from the medical model to the social model of disability, and secondly from being non-disabled to being disabled. The second change refers to the embrace of the disabled identity and the rejection of the dominant discourse that relates disability with abnormality and dependency.

Coming out does not only change the discourse but it also shifts validity for two reasons: firstly because invisible disabilities become visible, rejecting strategies of “passing” (passing as non-disabled) and secondly and most important, disabled people perform their coming out stories in their own voices, instead of being talked about by others. McRuer (2006) states five principles of what crip theory, coming out crip, or cripin' could involve. Firstly, “claiming disability and a disability identity politics while nonetheless nurturing a necessary contestatory relationship to that identity politics” (p.71). Secondly, “claiming the queer history of coming out, “out of the closets, into the streets”, while simultaneously talking back to the parent culture (or for that matter, any parent culture, including disability studies or the disability rights movement)” (McRuer, 2006, p. 71). The third principle refers to an accessible word constructed in opposition to neoliberalism. McRuer pinpoints that access should be understood “both very specifically and very broadly, locally and globally”. The fourth principle insists “that the disabled world is possible” as a counter-argument to left movements tied to “liberationist models that need disability as the raw material against which the imagined future world is formed” (McRuer, 2006, p. 71). Neoliberalism brought changes in the role of welfare

state and government intervention (Owen & Harris, 2012). The priority for neoliberal approaches is the development of the free market and economy, not social rights and this had an impact on policies for the provision of benefits, by reassessing the criteria for eligibility and also by introducing employability plans for disabled people. There was a wave of welfare reform based on the motto, “no rights without responsibilities” (Owen & Harris, 2012), which came along with re-entrenchment of social rights affecting disabled people. As Owen and Harris (2012) state:

The impacts of the neoliberalism can be summarized by considering that neoliberalism embodies the recommodification of labor; that is, market participation is required for an individual to meet their needs and be considered a citizen. While governments have adopted this approach to varying degrees, individual needs are now the responsibility of the individual and they receive minimal government assistance. (Owen & Harris, 2012)

Flexibility was introduced as a motivation for disabled people going into employment, and employers, according to equality and diversity policies, should make reasonable adjustments to accommodate equal opportunities. This offer of flexibility, though, proved problematic and disabled people's rights were retrenched as a result of neoliberal practices on Human Rights.

The last principle is a call for examining, “how private or privatized versus public cultures of ability and disability are conceived, materialized, spatialized, and populated” (McRuer, 2006, p. 71). This principle refers to cultural geographies that, “are mapped onto bodies marked by differences of race, class, gender, and ability” (McRuer, 2006, p. 72).

Sherry (2010) summarised the similarities between queer theory and disability studies in two aspects: a) in the experience of queer and disabled people and b) as intellectual disciplines. The similarities that queer and disabled people experience are familial isolation, high rates of violence, stereotypes and discrimination, and the difficulties associated with passing and coming out. Sherry (2010) notes that “rejecting pathologization and politicizing access, as well as using humor and parody as political tools have been important for both movements” (p. 781). Both queer theory and disability studies are opposed to hegemonic normalcy and deconstruct the essentialist explanation of identity by insisting on fluidity, they are deeply influenced by feminism. Feminism introduced the claim that the personal is political, the distinction between sex and gender and the notion of “Other” in relation to disabled women (Wendell, 1996). These analytical

tools developed by feminism were embraced and used by both queer theory and disability studies.

A latest development that combines feminist and crip theory strands, is the notion of crip killjoy. Johnson and McRuer (2014) draw upon Ahmed's (2010) work on feminist killjoy and willfulness to create the idea of crip killjoy and crip wilfulness as a basis of their introduction to cripistemologies. Ahmed (2010) examines happiness and socio-cultural instructions for acting happy in an oppressive context, where individuals' (particularly female) positioning is fixed, ordered and imposed according to society's perceptions of different social divisions. She specifically notes that:

The figure of the feminist killjoy makes sense if we place her in the context of feminist critiques of happiness, of how happiness is used to justify social norms as social goods (a social good is what causes happiness, given happiness is understood as what is good). [...]Not to agree to stay in the place of this wish might be to refuse the happiness that is wished for. To be involved in political activism is thus to be involved in a struggle against happiness. (Ahmed, 2010, p.2)

Crip killjoys also refuse to fake satisfaction and happiness to justify social norms that actually are oppressive for disabled people. According to Johnson and McRuer's cripistemologies, disabled people are called to deal daily with the inter-implications of capacity and debility, which, as in the authors' cases, led them to crip wilfulness:

... a refusal to insist - a refusal to act in accordance with the system of compulsory able-bodiedness -that requires individuals to mask, suppress, and disregard discomfort in the process of determining what is possible, of what we are capable. (Johnson & McRuer, 2014, p.136)

Social norms create particular social expectations that inherit discrepancies to individuals, since there is a gap between how they feel and how they should feel. Ahmed explains that:

Willfulness as a judgment tends to fall on those who are not compelled by the reasoning of others. Willfulness might be what we do when we are judged as being not, as not meeting the criteria for being human, for instance. (Ahmed, 204, Kindle Locations 445)

The importance of willfulness is the transformation of being when not being (not being white, not being male, not being straight, not being able-bodied), is coming up against being. When crip killjoys act and become willful against the oppressive -imposed by compulsory normalcy- comfort and happiness, it is a conscious political decision, "to be

unstable, incapable, unwilling, disabled,” and this decision, “opens up a world of possibility” (Johnson & McRuer, 2014, p.137).

3.3 THINKING DOCUMENTARY

Disabled people are one of the social groups that are affected by stereotyping and exclusion. As I already discussed in the Literature Review chapter, the film industry has contributed greatly towards the construction and distribution of specific stereotypical images of disability. Fiction films in particular developed a culture of stereotyping, following the socio-cultural demands of each historical period. Little emphasis has been given to documentary films that are a particular genre which depicts social representations. According to Nichols (2001):

Documentaries of social representation offer us new views of our common world to explore and understand. [...] Belief receives a premium in documentaries since these films often are intended to have an impact on the historical world itself and to do so must persuade or convince us that one point of view or approach is preferable to others. [...] This is what aligns documentary with the rhetorical tradition, in which eloquence serves a social as well as aesthetic purpose. We take not only pleasure from documentary but direction as well. (Nichols, 2001, p.2)

Documentary represents and engages with the world in three ways: a) by offering a recognizable familiarity of the real world, b) by standing for or representing the interests of others and c) by making a case or an argument. According to Nichols’ definition:

Documentary is not a reproduction of reality, it is a representation of the world we occupy. It stands for a particular view of the world, one we may never have encountered before even if the aspects of the world that is represented are familiar to us. (Nichols, 2001, p. 20)

The definition of documentary has proved to be quite problematic for theorists and filmmakers. There is the constant discussion of the matter of representing reality and the identification of non-fictional films as documentary films. According to Ward (2005), “a nonfiction film or programme is one in which the people and events depicted are known to have (or are asserted to have) a real-world existence”, (Kindle location 175-176). Documentary films are non-fictional but not all non-fictional films can be defined as documentary films. It becomes more complicated when documentary films adopt techniques that are associated with fictional filmmaking or, even, when reality TV or

advertising use techniques ascribed to documentary film-making. Ward (2005) suggests that “the key distinction is never one of form or style, but rather of purpose and context”, (Kindle location 181-182). Renov (1993) warns that the label of “nonfiction” is a valid categorisation but should lead to disregard the fictive elements in a documentary film. He notes that “documentary shares the status of all discursive forms with regard to its tropic or figurative character and it employs many of the methods and devices of its fictional counterpart”, (p.3). Following a Derridean approach to the theoretical problem of truth and fiction in documentary films, Renov argues:

No discourse is ever able to say precisely what it wishes to say insofar as the very saying is dependent on language forms which are necessarily figurative and connotatively enmeshed. And furthermore, the “very saying” of what is to be said is itself premised on another “saying” which is left unsaid. Language is ultimately a regress which cannot be followed to its end. (Renov, 1993, p.10)

Discussing the poetics of documentary, Renov (1993) suggested four fundamental tendencies or –as he notes- rhetorical/aesthetic functions in relation to documentary practice: 1) preservation, 2) persuasion 3) analysis and 4) expressivity. These tendencies are not exclusive or rigid. The combination of them contributes to the development of various non-fictional forms in the visual arts. In the genealogy of documentary film, Nichols (2001) has offered the most influential insights by identifying six modes: Poetic, Expository, Observational, Participatory (the renamed ‘Interactive mode’), Reflexive and Performative. This taxonomy suggested the different types of documentary film on the basis of displaying different characteristics. The identification of six modes had an impact in introductory work on documentary film. However, scholars like Bruzzi (2006) found Nichols’ ‘family tree’ as quite problematic and criticises this taxonomy arguing that “the result – whether conscious or not – of having imposed this ‘family tree’ on documentary history is the creation of a central canon of films that is exclusive and conservative”, (p.4). She finds that the organisation of this classification does not recognise loans or interconnections between different modes and as a result of this, documentary films that are characterised by heterogeneity co-exist within one mode. Another criticism is that there an implication that the development of Nichols’ ‘family tree’ serves documentary film-makers’ pursuit efficient and authentic ways to represent reality. For Bruzzi, this causes a fallacious expectation in terms of imagining documentary as the genre that will dissolve the difference between reality and representation. Her proposal on theorising the

matter of documentary- reality and the documentary spectator is influenced by Judith Butler's work on critical theory and suggests that:

it is perhaps more generous and worthwhile to simply accept that a documentary can never be the real world, that the camera can never capture life as it would have unravelled had it not interfered, and the results of this collision between apparatus and subject are what constitutes a documentary – not the utopian vision of what might have transpired if only the camera had not been there. (Bruzzi, 2006, p.10)

Bruzzi thus approaches documentary films as performative acts that consist of fluidity and build upon elements of performance or performativity. Within this definition of documentary, “truth comes into being only at the moment of filming”, (p.10). In this context, authenticity is also redefined on the basis of a performative exchange between subjects, filmmakers/apparatus and viewers.

Representing others is central in documentary making, which unavoidably raises some ethical concerns. These considerations arise from the condition that real people, rather than professional actors performing fictional characters, are the social actors whose lives are represented as if the camera was not present. Filmmakers usually film people or groups of people that they do not know and ethical considerations attempt to reduce possible risks in the interaction between filmmakers and social actors, bringing a balance in their relationships. Social rights and personal dignity should be respected and not sacrificed to the benefit of making a spectacular documentary.

Apart from the above essential principle, a central question that influences but also represents ethical considerations and the dynamics between filmmakers and social actors is “how should we treat the people we film?” (Nichols, 2001, p. 13). As Nichols notes, the most common formation is “I speak about them to you”, where each pronoun is significant of a particular position or separation. “I” refers to the filmmaker who speaks directly or through a surrogate, which technically is the narrator. From this position, a subjective view of things is expressed, that of the filmmaker's personal perspective, and it is expressed either as persuasion or just as an expression. “Speak about” refers to the filmmaker's action of representing others. According to Nichols (2001), “the sense of speaking about a topic or issue, a people or individual lends an air of civic importance to the effort” (p.14). “Them” signifies the separation between the filmmaker and social actors, the speaker and the subject. The speaker separates his/her position as non-identical from those whom he/she speaks of. Within this condition, social actors or subjects are presented to the viewers for examination. “You” refers to those that listen, the audience

and signifies one more separation, as those who listen occupy a different position from the “I” that speaks.

Documentary, in this sense, belongs to an institutional discourse or framework. [...] As an audience we are typically separated from both the act of representation and the subject of representation. We occupy a different social time and space from either; we have a role and identity of our own as viewers and audience members that is itself a distinct aspect of our own social persona: we attend the film as viewers, audience members, even though part of our reason for doing so may be that the film will speak about people and issues whose actual life experience compares or contrasts with our own. (Nichols, 2001, p.15)

This might be the most common structure of the three-way relationship among filmmaker, subject and audience, but it is not the only one. There are also variations: a) “it speaks about them or it to us” and b) “I or we speak about us to you.” The first variation tries to claim lack of individuality as the filmmaker fades out his/her personal perspective through an institutional discourse. The second variation characterises anthropological filmmaking and it is suitable for auto-ethnography. The use of “us” suggests that the filmmaker is closely involved with social actors, so it actually indicates a position of commonality instead of a position of separation. Another important position in documentary making is the story making from, “below, as lived and experienced by ordinary but articulate people rather than [...] from above, based on the deeds of leaders and the knowledge of experts” (Nichols, 2001, p.33).

The above positions suggest specific ethical matters that should be taken under consideration when representations of disability (or indeed any representations) in documentary films are examined. Who speaks for whom, from below or above, as an insider or an outside observer has a particular impact on the construction of representation and images of disability, thus defining the relations of power. Considering also the statement “nothing about us without us” that reflects and demands acknowledgement of disabled people’s full participation in actions that refer to them, we need to approach documentary depictions within a theoretical and analytical frame that takes into account the different formulations of three-way relationship and the chosen positioning.

3.3.1 Practices Of Staring And Looking

The Other Film Festival that takes place in Melbourne had the profound question; “What are you looking at?” added to its official name. A question that clearly is a

reference to disabled people's positioning of talking back. For me, it also questions what we look at when we watch films that focus on disability. Disabled people are regularly subjected to and exposed to different gazes and practices of being stared at or looked at. The medical gaze initially was the one that came with the power to regulate, "lives worth - or not - living", classifying them in labelled categories and objectifying disabled people to case studies and medical experiments. Disabled people were exposed to this medical gaze from the moment they were born, dealing with normalising practices that contributed to the construction of "other" in oppressive and painful ways (Clare, 1999, Lapper, 2005, Galloway, 2009). Foucault (1979) called it the *clinical gaze* and as Garland-Thomson (2009), comments, it "is one form of person-to-person staring that is highly impersonal, scripted, and asymmetrical" (p.28) as it is practiced for an invasive visual scrutiny that focuses on isolated elements that indicate pathology. In historical cases, the clinical gaze engaged a particular hostile stare at people considered degenerated, Garland-Thomson (2009), calls this stare, "the eugenic stare": "a perverse form of recognizing human particularity in order to extirpate it" (p. 177).

Another regulatory and oppressive gaze is the controlling gaze of applied panopticism in asylums, clinics, institutions and segregated schooling. As Foucault (1979), describes at this settings of surveillance, "the gaze is alert everywhere" (p.195), in order to reassure that obedience is retained through the discipline mechanisms and punishment is applied to tackle transgressive actions. Within the settings where panopticism is applied, each individual is, "the object of information, never a subject in communication" (Foucault, 1979, p.197), because the dissociation of the see/being seen dyad is secured. Disabled people were given the position at the peripheral ring of the Panopticon; where "one is seen without ever seeing" whereas in the central tower, those that exercise power on disabled people's lives, "see everything without ever being seen" (Foucault, 1979, p.197).

Garland-Thomson (2009) notes that the gaze is different from the stare, as the first one is defined as, "an oppressive act of disciplinary looking that subordinates its victim" (p. 9). Staring on the other hand is, "an ocular response to what we don't expect to see. [...] More than just looking, staring is an urgent eye jerk of intense interest" (p. 3). Staring comes with questions that demand the story of people whose appearance or activity challenge our set expectations and this way it makes meaning. According to Garland-Thomson (2009), "staring offers an occasion to rethink the status quo. Who we are can shift into focus by staring at who we think we are not" (p.6). Staring is a face-to-face

encounter between the starrer and the staree where a visual confrontation takes place, bringing various reactions such as engagement, avoidance, mutuality or a combination of these. The reactions derive from socio-cultural and psychological filters, and also the residuals of gaze traditions that are involved in learning how to look, or how to look away. Curiosity is the genuine response when we encounter novelty but limits of indulging our curiosity are set by socio-cultural and moral rules. Not knowing how to look is the result of the limitations imposed by those socio-cultural and moral rules that regulate not only curiosity but disability too. The face-to-face encounter between the starrer and the staree is a “living communication filled with complex and dynamic interrelations” (Garland-Thomson, 2009, p.86). As such it brings valuable knowledge that could cease personal and social anxieties, firstly by teaching us how to look, and secondly by offering the opportunity to interact and think about expanded aesthetics. Garland-Thomson suggests that “accomplished starees can help starrers maintain face by relieving them of anxiety, understanding their motivations, working with them to overcome their limited understanding of human variation, and indulging their social awkwardness” (pp.86-87). In this context, starees stare back and they even make open calls for being looked at.

The management of staring requires the application of interpersonal techniques and communication skills that allow the shifting of the power within looking. Visual and performing arts are powerful mediators that allow this shifting. Social groups that are stared at and have experienced the oppression of clinical, controlling, or colonising gaze, invite viewers to have a good look at them either in performances, photography exhibitions, film screenings or narrative accounts, where they choose how to present themselves and how they wish viewers to look at them. Thus, starees take the lead in directing the staring encounters. This is also translated as an act of emancipation. Garland-Thomson (2009) notes that the “scenes of staring can help us understand our impulse to look hard and our responses to being looked at hard” (p.94). As scenes of staring, she defines “sites from which interactions arise” (p.95), and this could be “stareable aspects of human anatomy” (p.95) such as faces, hands, breasts, bodies.

Documentaries that focus on disability and disability film festivals offer a rich material of such scenes that invite audiences to have a good stare, challenging them to reflect on the way they look at disability. Viewers are engaged in a mediated but also in some cases a direct encounter with starees and this brings a new knowledge that has the potential to alter or expand their understanding of disability.

3.4 THINKING CRITICALITY

Documentary is the film genre based on evidence in order to support social actors and social issues. In many cases documentary films have been used as the visual material, either to support human rights, participation and matters of democracy, but also as propaganda against all these. Criticality is required, either in terms of understanding but also in terms of making. In times of neoliberalism, that has a big impact on the organisation and focus of education but also on the positioning of disabled people, critical thinking is the essential safety mechanism for fighting for social provisions, democracy and social justice. Giroux (2004) notes that:

Educators and other cultural workers need a new political and pedagogical language for addressing the changing contexts and issues facing a world in which capital draws upon an unprecedented convergence of resources -cultural, political, economic, scientific, military, and technological- to exercise powerful and diverse forms of hegemony. (Giroux, 2004, p. 32)

Giroux suggest the development of a critical pedagogy that draws upon various theoretical approaches such as feminism, critical theory, post-structuralism, neo-Marxism, and I would add disability, queer, and crip theory, aims to challenge the changes and the new “ethos” that neoliberalism dictates. Giroux also emphasises the importance of cultural politics as pedagogical sites on which identities are shaped. Cultural politics are also the pedagogical site where, “subject positions are made available, social agency enacted, and cultural forms both reflect and deploy power through their modes of ownership and modes of public pedagogy”, (Giroux, 2004, p. 32). If we think of disability film festivals as a public space that promotes the wider education for children and adults, then they definitely support the development of cultural politics. They are the public spaces where pedagogical practices take places with film as the main medium.

According to Giroux (2004), one of the threats that corporate power poses is the attempt to subject public life to the requirements of the market, “while simultaneously working to empty democracy itself of any vestige of ethical, political, and social considerations” (p. 39). This particular threat also applies to public education and the main concern is that the educators’ role gets reduced to that of “technicians” or “corporate pawns” that will support the preparation and production of generations of other “technicians and corporate pawns”. The antidote to neoliberal demands is the presence and the action of progressive educators who act and engage as public intellectuals, encouraging their students to develop their critical thinking. Giroux (2004) notes that:

“such a redefinition of purpose, meaning, and politics suggests that educators critically interrogate the fundamental links between knowledge and power, pedagogical practices and social consequences, and authority and civic responsibility” (p.40).

As Freire (2005) pinpoints, dehumanisation “marks not only those whose humanity has been stolen, but also (though in a different way) those who have stolen it, is a distortion of the vocation of becoming more fully human” (p.42). The neoliberal practices can lead to dehumanization through the undermining of democracy and the abolition of social justice. Human is not central where markets are, and that becomes more and more clear within the changes that neoliberalism brings to education, welfare, provisions and social policies. The struggle of the oppressed should aim for the restoration of their and their oppressors’ humanity. For Freire (2005), “the great humanistic and historical task of the oppressed is to liberate themselves and their oppressors as well” (p.42). Before the oppressed lead the praxis towards liberation, there should be an understanding of oppression and the model of “humanity” that oppressors serve and believe in. For example, disabled people’s institutionalisation was believed as a doctrine with many “benefits” for disabled and non-disabled people. For disabled people, safety, care, education and discipline were secured and for non-disabled also safety, care - in a different political context to that for disabled people - knowledge, new professions and the ethos of charity. For many years the model of institutionalisation was the model of “humanity” that people served and supported and still brings up debates for some cases of disability. Disabled people, as the oppressed in this case, are those to lead the struggle having the required understanding of their oppressors’ dehumanisation.

At this point, it is necessary to recognise what Freire (2005) describes as the duality that the oppressed suffer from: “they discover that without freedom they cannot exist authentically. Yet, although they desire authentic existence, they fear it” (p.46). So it is important to shape a pedagogy “with, not for, the oppressed”, which will be “an instrument for their critical discovery that both they and their oppressors are manifestations of dehumanization” (Freire, 2005, p.46). The oppressed need to discover and realise that their oppression is not a cul-de-sac but a limiting situation that can change and achieve freedom. The oppressors, firstly, discover themselves as such but after this stage they need to come in solidarity with the oppressed, entering into their situation. This is a praxis that defines a radical posture for those that used to be the oppressors.

Both Freire and Giroux support the development of critical pedagogy as the important instrument that promotes democracy and social justice and supports social

changes towards a human society for all. Documentaries and disability film festivals can work towards and encourage social changes for creating democratic societies for all. Disability festivals, in many cases, are not only the public spaces where situated learning can take place but are also defined as spaces for visual activism. Disability film festivals involve disability culture and politics, planting the seed for an understanding, which is required for social changes towards inclusion and disability rights. Viewers encounter “the unexpected first hand and in the flesh” (Ott, 2010, Kindle Location 6546) as they are exposed to a number of different cross-cultural and cross-disability narratives, and also in many cases with the praxis or the presence of passionate activists. When these encounters are particular experiences with crip killjoys, then viewers are called to process the provocative positions that are revealed to them. Through this interaction, critical thinking for disability rights, politics, culture and studies can definitely flourish, using documentaries as the medium and the disability film festivals as the space for public and situated learning.

Having laid out the background against which my own study took place, I will now turn to report on this study, by first presenting the methodology I used in it, before describing the scene where I conducted my fieldwork and of course presenting and discussing my findings.



CHAPTER 4: METHODOLOGY

This chapter provides an overview of the methodological approach taken in this study to analyse disability documentary films. I present the methods applied for the data collection which involved the selection of documentary films and interviews with filmmakers and disabled viewers. Finally, I elaborate on my position within the research in relation to my roles as a) professional in the field of education and social care, b) viewer and c) researcher.

4.1 CRIP ANALYSIS

As I demonstrated in the previous chapter, when it comes to responding to the complexity of examining disability and documentary films about disability, my theoretical approach derives from the field of critical disability studies. As Goodley (2011) notes “critical disability studies attend to the relational components of dis/ablism”, (p.159). A critical disability studies perspective examines questions in relation to individual that is valued by society and how culture reflects the fears of non-disabled society. Identity is also central looking at transgression, performativity, affirmation and possibility. In this setting, transgression describes the identities that challenge the dis/ability distinction. Performativity is the heart of crip/disability culture; the regulated disability identity calls for embodied alternatives. Affirmation, as I delineate in the section on the affirmation model, approaches disability as a positive identity. Goodley (2011) comments that affirmation relates to queer: “subversive, unruly and enabling aspects of being non-normative”, (p.161). Possibility is a neologism introduced by McKenzie (2009) to describe the ways that disabled children challenge educational systems to become more imaginative and inclusive. Critical disability studies offer the theoretical framework to examine dis/ablism and impairment through the ways in which they are materialised in different institutions: education, health care, social care, family and community. The discursive construction of disability and ability within these institutions gets under examination in order to question the factors that contribute to this construction and consequently the oppression and exclusion they allow to take place.

Critical disability studies also contribute to academic research in relation to cultural politics. Goodley states that, through performing arts, film, music and poetry, disabled people challenge misconceptions and stereotypes about disability. Performing the action of talking back is a common practice for disabled artists/activists, as they challenge sociocultural notions that have been imposed on their identity. In a similar line of talking back, writing back has been developed by disabled poets, writers and academics, giving voice to their views and experience. As Goodley discusses:

There are clear overlaps between the writing back of postcolonial thinkers, the development of feminist stand/ sitpoint theory, the queering of heteronormative research production and the emergence of participatory/emancipatory approaches to disability. Writing back invites subjugated voices to re-enter cultural and political critique: deconstructing taken-for-granted imaginary and symbolic elements of everyday life. (Goodley, 2011, p.163)

I consider talking back and writing back as crip killjoys' actions where they perform crip willfulness by being when classified as not being. The participation of crip killjoys in cultural politics also supports the promotion of disability aesthetics (Siebers, 2006) and the politics of atypicality (Mitchell and Snyder, 2008), demanding in this way the visibility of disability and recognition of its variety and complexity.

Intersectionality and inequalities of globalisation are also central in critical disability studies. Disability, at all levels of its complexity, is affected by the developments in the Global North and the ways that these are imposed onto the rest of the world, and also by the ways that funds, policies and other provisions are controlled and distributed by more powerful nations and organisations such as the United Nations, the World Bank and the International Monetary Fund. In cases where some of these organisations or more powerful nations police less powerful nations or nations in crisis, the status of inequalities increases; on the one hand, due to austerity measures, lack of provisions for welfare and education, and, on the other, due to the creation of fertile ground for the growth of racism, fascism and other schisms that violate human rights, social justice and democracy. These inequalities are also depicted in documentary films that are produced or filmed in nations beyond the Global North. Disability film festivals are spaces to discover such documentary films. In the context of resistance to inequalities and writing/talking back, critical disability studies also contribute to the discussion of disability activism; a part of disability politics that again requires the crip killjoys' involvement. Activism can take place in disability film festivals either in the form of visual activism through the medium of films and particularly documentary films, or in the

form of calls for collective action against oppressive practices/policies and lack of provisions for disabled people. The field of critical disability studies is in dialogue with other disciplines such as gender studies, queer studies, philosophy, sociology, architecture and cultural studies. As Chiver and Markotić (2010) and Mogk (2013) suggest, critical disability studies can enrich film studies and film theory, and I would like to add that the dialogue should expand to film festival studies too. A crip analysis or a critical disability analysis can respond to the different levels of complexity in understanding disability and analysing representations in documentary films while taking under consideration the broad cross-cultural and cross-disability content of selected documentary films. What is secured through a critical disability studies perspective is that disability is analysed within a framework that can track contexts of stereotyping, sensationalising or placing disability as narrative prosthesis. A crip analysis of documentary films can tease out matters of disability aesthetics and culture, disability identity, disability politics and crip killjoys' activism, as well as educational and social inclusion matters, through an intertwined and interdisciplinary frame that demands the understanding of the political context and meaning of all these aspects. In this respect, a critical disability approach is applied to the analysis of selected documentary films as a response to the complexity of depicting disability on films, but also as a suggestion for an alternative methodological way to look at disability in documentary films and disability film festivals.

4.2 WRITTEN FESTIVAL: A PARTICIPANT'S OBSERVATION

I attended the *Emotion Pictures – Documentary and Disability Film Festival* from the first year of the event (June 2007) and for two consecutive annual events –June 2008 and 2009. I was very interested in the organisation and the context of the festival as it was the first one dedicated to disability to be organised in Greece. It was few months before the beginning of my PhD studies and I had already an offer to start my research on representations of disability in films, so the *Emotion Pictures Festival* gave me a great opportunity to explore a potential fieldwork, which actually turned to be the fieldwork of my research in 2009. Every June, I was present during all the days of the festival watching films, attending Q&A panels and talking to organisers, film-makers, disabled and non-disabled viewers, members of different disability associations, journalists and photographers, while collecting films and other written materials and conducting

interviews. As Bernard (2006) described it, participant observation positions the researcher where the action is and allows him/her to collect data. In this case, data were collected by participating and observing through recording and analysis. According to DeWalt and DeWalt:

participant observation is a method in which a researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one of the means of learning the explicit and tacit aspects of their life routines and their culture. Within this formal definition, "explicit" culture is a part of what people are able to articulate about themselves. (DeWalt and DeWalt, 2011, p.13)

Participant observation is usually applied in ethnographic fieldwork by “ethnographers who observe and/or take part in the common and uncommon activities of the people being studied” (p.14). The method of participant observation requires recording in field notes that can be informed by participation in the activities of the community but can also underlie other techniques of ethnographic fieldwork such as sampling, open-ended interviewing, creation of interview guides and questionnaires. The advantages that participant observation provides to a research are:

First, it enhances the quality of the data obtained during fieldwork. Second, it enhances the quality of the interpretation of data, whether those data are collected through participant observation or by other methods. Participant observation is thus both a data collection and an analytic tool. Third, it encourages the formulation of new research questions and hypotheses grounded in on-the-scene observation. (DeWalt and DeWalt, 2011, p 22).

An additional advantage is also what is considered as community within the participant observation. The nature of “community” where the social research takes place has become more expanded to new subjects and forms in comparison to its initial descriptions in the fields of cultural anthropology and ethnographic research. Participant observation can be used for short-term research that aims to contribute in planning, implementation and evaluation involving communities that might also be formed for a short-term period or might even be virtual. I consider the community of the *Emotion Pictures – Documentary and Disability Film Festival* as one of those that occur under the new forms of communities that participant observation can be used. It was a community that was coming into solid but renewable shape every June for three days for three consecutive years at the same space. Stringer (2013) recognises that festivals create festival communities, since a “principal reason to hold a film festival is to interact with and celebrate the very public who gathers together at such an event” (no page number). For Stringer, the examination of festival communities is as important as the analysis of

screened films, because the festival communities experience the entertainment, the educational opportunities and the forms of public display that come with attending a film festival.

Against this background, I participated and observed the actions and the function of this community in order to collect the data of my research. My participation in this community can be more closely identified to what is described as moderate participation because I was present at the scene of the action and identifiable as a researcher. I did not actively participate to the level of contribution to organisation and promotion of the festival but I participated as a viewer. Still, I find that the interaction between myself as a researcher and other people of the community was more frequent than what DeWalt and DeWalt (2011) define as occasional when describing moderate participation. However, I recognise the condition that interaction took place to the occasion of the *Emotion Pictures – Documentary and Disability Film Festival*. Stringer (2013) describes this position as “a festival outsider, one who gazes upon the phenomenon from a distance”, (no page number). The festival outsider is not institutionally affiliated with any specific film festival, does not write about the festival for publications and has no involvement in the cultural policies of the event. In short, the festival outsider is a researcher that is an interested but detached observer.

From this position, I kept field notes in the form of sketch diary that combined 9 hrs of recording with a camcorder moments of the festival, such as the opening and closing event, Q&A panels, the space where the festival was organised, written notes after attending screenings or Q&A panels, reminders for contacting film-makers in order to discuss their films, scheduling and keeping notes from the interviews with disabled viewers, and keeping notes while attending the International Annual Conference: “*People with Disabilities and Mass Media*” that was organised in connection to the *Emotion Pictures Festival*. In his analysis of the social construction of a film festival, Daniel Dayan (2013) notes that he approached the existence of Sundance festival as a collective performance as there is a variety of stories: “the story of film-makers, the story of films, the story of audience, the story of journalists and the story of festival itself. Each of the stories proposes a temporal continuity, a plot, and a specific form of suspense”, (p.48).

Some of these stories are told in print and, as Dayan (2013) suggests, this creates a double festival: the visual festival of films and ‘the written festival’. The ‘written festival’ cannot be ignored, since no matter how much observation and interviews contribute to the collection of data, the researcher has to read the print produced by people of diverse

convictions.e Stringer (2013) thus also values the festival brochures and other print as key sources of information. In this vein, I decided to keep all the printed material that was either produced by the *Emotion Pictures Festival* and the International Annual Conference: “*People with Disabilities and Mass Media*” or was distributed at the receptions of the two events. This included: brochures and screening programmes for each year’s event, informative booklets and handouts for types of disability and day centres, magazines published by the disability community about and for disabled people, guidelines for media representation and disability, guidelines for language and media representation of disability, collections of presentations from the International Annual Conference: “*People with Disabilities and Mass Media*”, and film magazines with articles dedicated to the festival. I also created a mini archive of newspaper articles reporting on the festival; few of them spotted in newspapers I had bought during the days of fieldwork and the rest of them searched online and saved on my computer in a folder named: “disability festival”. A very important source of my written festival was of course, the official website of the *Emotion Pictures – Documentary and Disability Film Festival* where there was also a detailed archive of each year’s event with information about the programme of screenings, lists of award winning films, reviews of the festival and links to newspaper articles. Some of the copies of the documentary films I received, included booklets with information about the filmmaking procedure, cart postals with stills from the films, and promotional flyers for other productions or educational projects. As Dayan (2013) comments: “the written festival turned out to be made of different versions, relaying different voices, relying on different sources of legitimacy. But it also provided its own common threads” (p.57). Aiming to develop a contextual foyer in order to communicate the general organisation and atmosphere of the festival, I relied and invested methodologically on the written festival as this would secure a contextualisation reflecting the different stories of the different groups that participated and attended the collective performance, that is, the film festival.

4.3 DATA COLLECTION

4.3.1 Documentary Films

To recap, I attended the *Emotion Pictures – Documentary and Disability Film Festival* for three consecutive annual events – June 2007, 2008 and 2009. I watched most of the documentary films screened, highlighting in my notes those that I considered as either presenting a political context or challenging notions of disability. During the three annual events of the festival, 120 films were screened but I will not claim to have seen them all; my records count 80 films. By attending the screenings, I had the chance to meet most of the filmmakers and had several informal conversations exchanging feedback and experiences. Many of the filmmakers, who were actually more independent in terms of production and distribution, had the habit of carrying copies of their films and were happy to provide them to other film-makers or people like myself who wanted to analyse their films.

In cases that they did not have a copy ready to give away, they had business cards with their contact details, and I can positively confirm that they responded to my e-mails. Films were therefore collected in two ways: a) personal contact with filmmakers at the events of *Emotion Pictures – Documentary and Disability Film Festival* and b) receiving the films through the post after online communication with film-makers or production/distribution co-ordinators. A number of free copies of the documentary *Please Listen To Me* were distributed during the 2008 event.

Initially, based on my field notes and on the responses of filmmakers, I collected 40 documentary films. I consider these films as a sample of what Buzzi (2006) described as new documentary and more specifically, what Snyder and Mitchell (2006) discuss as new disability documentary cinema. The documentary films negotiated various themes, focusing on different types of disability in different countries of the world. I need to highlight that the majority of these films were offered or sent to me with no charge. The only agreement I made with filmmakers was that I should seek their permission if I were to screen the films publicly and that I should inform them of the submission of the final draft of my thesis, as they expressed an interest in reading it.

A smaller selection of samples than the 40 films received and viewed were used for the critical disability (crip) analysis as I had to respond to the limitations of a PhD thesis. Criteria for this selection were set based on the triad that informs this research: festival –

audience – researcher. Keeping in my mind this triad, films were selected on the basis of their: a) awards -indicating the preferences of the jury of the *Emotion Pictures – Documentary and Disability Film Festival*, b) popularity with disabled viewers – indicating the interviewees’ preferences and c) my own preferences. I also had to add two more limitations in my selection, deciding that I would not include art videos, which were part of the screening schedule of the festival, and documentary films that negotiate issues related to mental illness. The reason for not including mental illness was that I consider it a matter of the emerging discipline of Mad studies. With the numerous complications and implications that this entails these documentaries might be more suitable as a subject for a distinct future research project. In addition, the fact that there are film festivals specifically dedicated to mental health/ illness brings a different perspective in the field that would require further examination. By setting these criteria, my intention was to secure a selection that would not necessarily represent a particular type of disability. I had hoped that the selected for analysis films would reflect the cross-disability and cross-cultural context of the festival while also giving space to matters of intersectionality. The set criteria led to the selection of 9 documentary films for analysis.

At this point, I need to mention that, in the end, I decided to include in my analysis two documentary films that were awarded in 2007, the first year that the festival took place even though I officially undertook my fieldwork the year after. There are two reasons for taking this decision: a) when I attended the 2007 event I had already received my offer for embarking on my PhD studies and b) the disabled viewers that participated in interviews sessions made reference to this very first event, so skipping the representations of this year would create a contextual and historical gap.

The range of types of disability that are depicted in the selected films fluctuate amongst physical disabilities (acquired and by birth), learning disabilities and learning difficulties, as well as sensory and developmental disabilities. The selected films are:

Emotion Pictures – Documentary and Disability Film Festival 2007:

Invitation to the Dance (Germany, 2006) – First Prize for Best Documentary Film
Masterpiece Part I (Greece, 2007) – Special Jury Prize

Emotion Pictures – Documentary and Disability Film Festival 2008:

Breadmakers (Scotland, 2007) – First Prize for Best Short Documentary

Please Listen to me (Greece, 2008) – Second Prize for Best Feature-length Documentary

Emotion Pictures – Documentary and Disability Film Festival 2009:

Body of War (U.S.A., 2008) – First Prize for Best Feature-length Documentary

Letter to Lou (Belgium, 2006) – Second Prize for Best Feature-length Documentary

Including Samuel (U.S.A., 2008) – Disabled viewers' preference

Researcher's own suggestion:

Shameless: The Art of Disability (Canada, 2006)

NoBody's perfect (Germany, 2008) – Human Rights Award – Special Mention at Buenos Aires International Festival of Independent Cinema 2009 – Film Award in Gold – Best documentary at German Film Awards 2009

These films' stories negotiate matters such as: intersectionality and inequalities of globalisation, disability aesthetics, accessibility to supported employment and vocational training, a father's confession to his disabled son, disability as war casualty, educational inclusion, disability arts and activism.

4.3.2 Interviews With Filmmakers

Since my knowledge and experience is related to disability studies, I utilised the interviews I conducted with filmmakers as an opportunity to expose myself to the filmmaking world. Having some previous experience analysing films that depict disability, I was very interested in finding out how each filmmaker orientated themselves toward making a documentary focusing on disability and what their starting point was in its conceptualisation. I wanted to be aware of their intentionalities in documentary filmmaking of this nature and how their knowledge and experience related to matters on disability. The reason for exploring all these had to do with achievement and communication. Achievement in terms of the ways in which they projected their ideas and intentionalities to viewers effectively, and by communication, I refer to recognition of filmmakers' ideas, polemic, social, political, or aesthetical claims as communicated to viewers.

The interviews with filmmakers served as the blueprint so I could gain a comprehensive understanding of how the idea of making a documentary was conceived and how this developed through the process of film-making. Interviews were conducted during the festival events in 2008 and 2009. In most cases, I met the filmmakers personally and the interviews took place during breaks between film screenings on days that the *Emotion Pictures – Documentary and Disability Film Festival* was running. Interviews were recorded with a digital camera, either with the camera function on or off, following film-makers' wish. When the camera was on, I also received technical advice from them, as I was not that experienced in many technical applications beyond the basic functions. Some interviews were conducted via e-mail, where I sent my questions and I received the answers in written format. It was not always possible to meet filmmakers in person as they had a busy schedule during the festival and they were also interested in watching the screened documentaries in their available time. The reasons for using online communication were purely practical but most importantly it reassured me that the filmmakers were interested in me using their work and their concept behind it for the present study. As the final selection of films for analysis was made after the festival I also looked up more interviews from the public domain.

The interviews were semi-structured with twelve questions, which aimed to elicit information on the filmmakers' interest or trigger for making a film about disability, the process of film-making, their knowledge/ideas about disability, the potential impact of their film and the differences between the representations of their documentary films and those of popular fiction films. A copy of the questions addressed to filmmakers are included in Appendix section.

Sixteen film-makers from Argentina, Belgium, Greece, Israel, Italy, Lebanon, the U.K., and the U.S.A responded to my call to be interviewed. Even though I maintained my focus on the filmmakers whose work is examined, I consider these collected data as valuable material for a couple of reasons: firstly, I achieved my aim of ascertaining a better understanding of making a documentary and the film-makers' relation with disability; secondly, it is an original material, not just in terms of context, but also in terms of time and space. *The Emotion Pictures – Documentary and Disability Film Festival* was one of the first victims of austerity in Greece. It stopped its functioning after the last event in 2009, and so any recorded material also has a historical value. Thirdly, one of the filmmakers, subsequently passed away. Her film still has a big impact in her country and

beyond, as screening and talks keep being organised. The documentary has also an entry in UNESCO's official multimedia archives e-services.

While interviews with filmmakers were conducted, they were not planned to occupy a specific part of my eventual analysis. The data collected at this stage were used to inform the part of my thesis that I name contextual foyer in the next chapter. For the films for which I did not conduct personal interviews with the filmmakers, I applied the written festival methods, collecting information from online resources – the filmmakers' websites, interview video clips, interview transcripts or printed books that accompanied the copies of documentary films and included interviews with the film-makers.

4.3.3 Interviews With Disabled Viewers

I consider disabled people's views on disability documentaries and film festivals very important as I fully support the claim, "nothing about us without us" ("Nihil de nobis, sine nobis"). I did not wish my research to be yet another focus on disability through a privileged gaze without having disabled people involved. Adopting this approach in all aspects, I was also very interested in finding out the thoughts that disabled viewers might have on disability film festivals like the *Emotion Pictures – Documentary and Disability Film Festival* and if they considered these events as organised by, with and for them. Their views on the representations of disability that were depicted by the documentary films screened during the festival were vital for my research. Participation and involvement are stepping stones for identity empowerment and it was important to examine if disabled viewers found that disability film festivals functioned to support their participation, inclusion and empowerment.

I proceeded with semi-structured interviews with disabled viewers during the last event of the *Emotion Pictures – Documentary and Disability Film Festival* in 2009 in Athens. Seventeen disabled participants were interviewed during the three days of the event. I had prepared a short introductory letter in Greek, where I introduced myself as a PhD student, the subject and aims of my research and the reasons for conducting interviews with disabled viewers. I described the type of the interviews and how they would be recorded. I also stated that I would follow all the required regulations that cover ethical considerations and protection of personal data set by Scottish Educational Research Association and the School of Education of the University of Stirling. In my letter I asked participants to give a written consent when they agreed to be interviewed

but they had the right to cancel their participation at any point, during or after the interview. It was also highlighted that anonymity will be kept in all cases. My contact details were provided if they wished to share any ideas or make any questions at any point. The choice of providing written information to the disabled participants was an outcome of taking under consideration the ethical requirement for informed consent and the stages of negotiating access when a researcher approaches individuals to participate in research. As Corti et al. (2000) note the researcher is responsible for explaining to participants what the research is about, how the data will be used and published and how confidentiality will be kept. Participants should also be informed about their right to refuse or withdraw from participation in the research and/or to re-negotiate consent. According to Lewis (2003), negotiating access is a crucial part of early stages of a research, as it can influence how successful the research will be. An effective engagement with research participants is achieved when the researcher (Lewis, 2003) a) is clear about the aims and objectives of the study, and the choice of the fieldwork, b) explains openly what the research involves, the ways of disseminating data and findings, the conditions of anonymity and confidentiality, c) is responsive to concerns or sensitive matters, and d) is flexible about adapting the research in response to the conditions of fieldwork and participants.

Negotiating access also involves seeking the approval of senior people that are perceived as the “gatekeepers” (Lewis, 2003) of the organisational structure of the research setting. In this vein, I informed the festival organisers in person about my research agenda. The event though was perceived as an open and public one, so no specific permission for access was required. The festival organisers were aware of my presence from the second event in 2008, and spoke positively and supportively about my research focus. Initially, I approached a few disabled viewers through proximal and easy access, but after the first day of interviews, the word spread. After this, participants started coming voluntarily, which was surprising to me contradicting my experience as a Greek within the same culture. In all, seven female and ten male participants covering an age spectrum from 20 to 50 years old, with different types of disabilities agreed to be interviewed.

All participants were Greek so questions and interview transcripts had to be translated from Greek into English and vice versa. In this procedure the translation of the phrase “Disability Films vs. Disabling Films” proved to be problematic as there are not equivalent Greek terms that could transfer the same meaning. In this case, I had to rephrase my question and change it into: “films about disability and films that

create/construct negative representations of disability,” which in Greek, the qualitative difference between the content of these two types of films was marked. Interviews were semi-structured based on eleven questions that aimed to elicit information on: a) motivation for attending the disability film festival, b) knowledge or interest on disability films, and c) documentary films about disability and their impact. These questions are listed in the Appendix. Anonymity and confidentiality were core principles and they have been fully respected. The ethical guidelines of the British Educational Research Association (BERA) were adhered to and approval through the School of Education procedures were sought. The participants were given the choice to be fully recorded on camera or to record just their voice. It was also up to the individual to reveal their full name and the type of their disability, as they were informed that anonymity was one of the principles followed for this research, and the type of disability was not considered as an important variable for my thesis. Their testimony that identified them as disabled was in itself a justified criterion.

The data collected are analysed through the process of thematic analysis, which I considered a suitable process for working with raw data. This was in order to identify and explore key ideas and themes. The benefits of thematic analysis are that it supports the organisation of data in a way that the researcher can: a) identify key themes b) compare these across cases c) develop categories of data d) highlight the relationships among these data and e) spot overarching themes (Matthews & Ross, 2010, pp. 384-385). For interview transcription, I followed a first step of coding which was applied in organising the order of interviews transcribed. All the mini discs used for recording the interviews were dated and each clip of recording was numbered by the set functions of the digital camera I used. Consequently, the interviews were coded using the date and the number of recording, for example: 22/07/2009, DW_C0025. At the first stage all interviews were transcribed in Greek language. At the second stage, I applied codes in order to keep anonymity and confidentiality for all participants, so the code FP was set for female participants and MP for male participants, followed by numbers from 1 to 17. Participants' answers were translated and organised collectively according to the order of the questions addressed during the interviews. Each question had a total of seventeen answers, which I examined, highlighting the key views or themes, which in some cases were common among interviewees. These key ideas/ themes and common answers were listed under each question in a first attempt of interpreting the collected data. Third stage diagrams were developed in order to map the key views/ideas on: 1) disability film festivals and 2)

documentary films that focus on disability matters. The findings from interviews with disabled viewers are presented in the following chapter where I examine the organisation and functions of disability film festivals.

4.4 My Position Within The Research

In undertaking this research, I needed to scrutinise my position in relation to my roles as professional in the field of social care and education, viewer and doctoral student. In addition, my experience as a Greek who lives in Scotland but undertakes research in a Greek context, put me in an unavoidable position of comparison between systems and circumstances, in terms of organisation, understanding and support, in relation to provisions for disabled people. In many cases, I had to remind myself of the current circumstances in Greece, and the sociocultural understanding of disability, as I was quite influenced by Scottish standards. These different roles brought with them knowledge of specific domains, theoretical perspectives, support settings for social and educational inclusion and the differences between the two countries I have shared my life in.

In several cases, especially after each event of the *Emotion Pictures – Documentary and Disability Film Festival* in Athens, I had to distance myself from such positively overwhelming experiences with such diverse but immense inputs, in order to think critically and work with collected data on a basis suited to my research and its theoretical background. One additional reason that I had to stay focused on my discipline was that the matters and aesthetics of filmmaking can be different from disability politics and disability aesthetics although these are analytical categories and work together in reality. However, it would be naïve to claim that I managed in this way to achieve complete objectivity, as I fully respect the argument that knowledge is socially constructed and culturally relative (Kuhn, 1961).

One matter that I feel should be mentioned, is my position as a non-disabled individual conducting research on disability. There has been strong criticism in this respect (Barnes & Mercer, 1997, Oliver, 1997, Barnes, 2003), especially in cases where non-disabled researchers have claimed that they did emancipatory research. The arguments based on power matters, for example, research from “outside” and “above” through a privileged gaze, are important and justifiable. I am not dismissing this position. Nevertheless, the reflexive discrediting of strong, valid research that should support

positive changes towards disabled people's rights simply because they were undertaken by non-disabled students or scholars is in itself exclusionary practice. While I believe it is necessary for scholars to reveal their personal positions and be upfront about their experiences and subjective relations with those with whom they research, it is nevertheless possible for to undertake critical, ethical research that can make a positive contribution to the lives of those marginalized in a non-patronising manner. As I will describe in the following section, my studies, career and personal experience justify a gained experience "in relation" (Price & Shildrick, 2002, Johnson & McRuer, 2014), that allows me to deepen my understanding of disability through my relationships with students, service users and family members. Working in the context of disability has been a significant part of my adult experience, and it is my hope that this research will help to contribute to understandings and perspectives that will positively influence those marginalised by disability discourses and popular constructs.

4.4.1 My Role As Professional

My professional experience started as a special education teacher for an inclusive class in public primary school in Greece. Through this experience, I witnessed all the projected barriers for educational inclusion in terms of organization, i.e. curriculum, provisions, facilities and buildings and teaching staff's awareness and mentality. There was a great amount of prejudice that I witnessed being directed toward disabled children daily, and in many cases, assigned to me personally as the "sensitive" teacher of "difficult and unpredictable"/ unwanted pupils.

After moving to Scotland, I started working for supported living and community outreach organisations for adults and young people with different types of disabilities. For the first three years, I supported people on a 24hr shift basis, doing sleepovers at their accommodation. Working with and for disabled people as a support worker and supported living coordinator, offered me a valuable knowledge and awareness, not only of policies, funding, practices and understanding of social inclusion, but also mainly of the experience of disability on a daily basis. After four years of experience in this sector, I moved to further education, supporting students with learning disabilities and mental illness. Further Education (FE) is the sector I practice professionally.

As I have moved from the role of students' educational support assistant, to one of learning development tutor, I have become familiar with FE courses, categorisation of

Scottish credits and framework, criteria for access, guidance criteria and provisions for students' support. Changes in funding procedures and in aims of vocational training brought new challenges in planning and partnerships, in order to adjust the courses to new requirements and find more resources for work placements and positive destinations for the group of disabled students I was supporting. Art courses were amongst the most popular and offered the longest duration as students could progress across three levels: - from Access 1 to 3, and some of them could continue up to BTEC 1. In order to support art students with placements and positive destinations, collaborations with local galleries were developed and a few of them offered apprenticeships so students could make art work for one year. Being a students' educational assistant offered me a great experience, rich with new knowledge that became available to me in many ways. Firstly, working on the side of art students, I could experience how they perceive art and how they express themselves and their understanding through it. Secondly, by working together on an educational and emotional level towards positive destinations, I was proud for them to see some of them making work for and connections with the Scottish art community.

In my new role of learning development tutor, I deliver tutorials to FE students, disabled and non-disabled, where in many cases, short films are used as educational material. Consequently, my working experience from FE allows me to come across different perspectives and understanding of the educational context of art and film. I feel that this range of experiences that relate to disability, intertwine in a constructive way, allowing an ongoing reflection where I am challenged to think critically about disability and inclusion, combining academic knowledge and action in practice.

4.4.2 My Role As Viewer

Cinema has been one of my favorite interests. I always enjoy watching a good film that will launch issues to reflect on, or stories to escape with. I am also interested in assessing the quality of different filmic genres and techniques. I became more interested in the documentary genre during my undergraduate studies, not so much for the educational form that is applied in many of them but mostly for the use of evidence and the methods of research. When I decided to combine cinema with disability studies, it was a great challenge, as one of my free-time interests will be brought under scrutiny through theoretical and academic filters. Another factor was that if I was to work with film, I had to learn about film and filmmaking, at least on a basic introductory level and

this was to be only the beginning of my big adventure. Studying the works on representations of disability, while collecting and watching fiction films with disabled characters for my Master's thesis, brought several changes in the way I would watch films. New filters, new criteria for reading, perceiving and interpreting were applied and in the very early stages I realised that this was irreversible and there was only space for further development. I admit that in some cases the indulgence of relaxing while watching a film was spoiled, but at the same time there were more benefits from this developmental growth and what could be a greater benefit than being offered the opportunity to develop your knowledge and critical thinking?

Following the *Emotion Pictures – Documentary and Disability Film Festival* in Athens, I was conscious that I could only watch the documentaries through my developed filters based on my experience and knowledge from the disability studies field, education and social care sector. I was concerned in case this was limiting in terms of distracting me from the filmmaking world and blurring some aspects that for other viewers could be more obvious or more open for interpretation. As I explained in a previous section, in order to widen my perception filters and develop a holistic understanding, I had to communicate with filmmakers and learn directly from them.

Being a viewer at the *Emotion Pictures – Documentary and Disability Film Festival* in Athens helped to soothe my initial concerns as there was space that supported the communication and discussion with filmmakers, either through organized Q&A sessions after film screenings, or by meeting filmmakers in person. This was very beneficial as I became more aware of my own thinking and assumed perspectives. It was clear that there was an automatic switch between my two roles: viewer and researcher. Once I accepted this as a workable position, the experience became easier and more enjoyable. Two realisations also contributed to this enjoyment and ease. Firstly, after watching numerous documentary films and communicating with filmmakers, I realised that there was distinct merit in each of them but for different reasons and in different ways: aesthetic, technical, background research, presentation of evidence, conditions of film-making, impact on viewers. Secondly, I had to allow time for processing. As the disability film festival was a big event running for three days, with a high number of scheduled screenings there were exciting discussions taking place constantly. It therefore was inevitable that time for processing was required. After all, a common viewers' response is reflecting on and talking about films months or even years after they have first watched them, depending on the impact they had on them at the time and also on viewers' particular circumstances.

4.4.3 My Role As Researcher

My main concern about being seen as a researcher by filmmakers, disabled viewers and festival organisers, was that they would perform differently, polishing their views in order to respond to an “expert’s” requirements. On a few occasions I felt that the use of camera or voice recorder brought different dynamics in my interaction with the above groups. As soon as the camera was switched off, the conversation would turn to a more relaxed and open style and usually the most important matters would be mentioned when recording had stopped. The majority of disabled viewers asked to read the final draft of my thesis, not so much to see their views written, but mostly they expressed a genuine interest in the outcome of my research, as they found the subject original and unusual. Some film-makers also expressed the same interest.

Being conscious about the several criticisms and the overall discussion about disability research and the role of non-disabled researcher (Oliver 1992, Stone and Priestley 1996, Barnes and Mercer 1997, Goodley and Moore 2000, Humphrey 2000, Kitchin 2000, Mercer 2004), I wanted to follow an approach that would minimise any power issues that would occur in my interaction with disabled interviewees. I am aware of the strong criticisms made by the social model writers against non-disabled researchers and their involvement in emancipatory or disability research (Oliver 1992), so I had to find a way to reduce the confusion ascribed to a non-disabled researcher’s profile, as this is addressed by Humphrey (2000): “the non-disabled researcher appears as a Janus-faced creature coming from one life-world and becoming part of another: Is s/he a partisan or parasite, partner or oppressor, participant or voyeur etc.?” (p.77). From the early years of my studies I had recognised the risks of forming an academic utopia, when research is undertaken from outside and above with the only benefit of researching for research and writing for the sake of publishing; and this is not just my own concern. Oliver (1992) has also criticised the research that has failed to be relevant to disabled people’s lives in terms of initiating policies that could improve their lives and/or challenge social oppression and marginalisation. More specifically, in relation to the social relations of research production, he noted that “research has been and still is, an activity carried out by those who have power upon those who do not”, (p.110). In a similar vein, Stone and Priestley (1996) suggested six core principles of the emancipatory research paradigm that actually minimise the power issues in disability research:

- the adoption of a social model of disablement as the epistemological basis for research production
- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers
- the evolution of control over research production to ensure full accountability to disabled people and their organizations
- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people. (Stone and Priestley, 1996, p.10)

My only amendment to the above principals would be the adoption of critical disability studies as the epistemological basis for disability research, as there are now further developments and additions to theorising disability. I consider the rest of the principals very important and essential for every disability research, and in every step I had to ensure that my research responds to and embraces the politics of disability working towards the understanding of the complexities involved. I think the type of questions I addressed to film-makers and disabled viewers, my availability to continue the discussion after the recording stopped and my approach to social and political matters brought up in our discussions, contributed in minimising the fear of talking to an “expert”. I believe that it became clear that there is a genuine interest from my side, to learn and exchange views on an equal basis, avoiding the use of academic terms which would be difficult to understand and would create boundaries between myself and the interviewees. My approach was quite similar to DeRoche and Lahman’s (2008) three “strategies to reduce the uneven power relationship: 1) maximizing participant control of the interview, (2) allowing the participant to control the tape recorder, and (3) using appropriate verbal and non-verbal language during the interview”, (DeRoche and Lahman, 2008, para.29). As Kitchin (2000) notes, in the inclusive approach for undertaking disability research, the disabled interviewees feel that they are involved more in a collaborative relationship with non-disabled researchers when they approach the research from a “disabled-friendly” position. Such a “disabled-friendly” position is evident when the researchers’ perspective is shaped by the understanding of disability matters, identity and politics, and their work challenges barriers and supports inclusion. From the disabled interviewees’ responses, I believe that my position was received as “disabled-friendly” and this also contributed in reducing the uneven power relationship between them and myself as the researcher.

Unavoidably, there were various and diverse discussions where matters, such as the use of language, political correctness and ways that we talk about disability, were raised. Another interesting part before or after conducting interviews with disabled viewers, was the exchange of experiences and information about the provided access and support in education, community and employment in Greece, the U.K. and other European countries.

I admit, nevertheless, that there were a couple of uncomfortable incidents where I had to use my professional and diplomatic skills to distance myself from discussions that were not of my interest. As with every big event that also involves competition for artists, an atmosphere of competitiveness among filmmakers and/or a jury panel was to be expected closer to the end of the festival, and disappointment triggered criticism which was not always constructive. In these cases, the interesting issue that was raised, and it turned out to be a challenge for the organisers, was the constitution of the jury and the criteria for deciding on the winning films. This matter caused several informal discussions at the close of the festival each year, revealing aspects of the internal politics of organising a disability film festival.

Politics proved to be an influential factor, something that I would have expected to be the case, since politics occupy a significant part of Greek history, culture and way of life. Members of the Greek parliament and other politicians attended the opening and closing ceremonies, giving speeches and promises for changes that would improve disabled people's lives. This presence became more frequent and intense in the events that took place a few months before elections in 2007 and 2009. Within this atmosphere, I was directly asked which party I would vote for. This question was addressed as an implication that my preference signified my perspective on disability politics and the approach I followed for my research. I admit that as a researcher that made me uncomfortable because it raised the question of "belonging" that would change the dynamics of communication with some organisers. At this point, I need to explain that it was not a matter of being open about my political views, because as a person and researcher, these are part of my beliefs and perspectives, the issue was that this question took me back a few decades when Greeks had to declare the political party they voted for before talking politics, a labelling that proved to be problematic because as the political history of my country shows, political parties do not always apply the ideology they represent. Another practical factor was that that I had distanced myself to some degree from Greek politics after having lived in Scotland for some time.

Undoubtedly, the planning of my research, the methodology and analysis are influenced by the knowledge and experience that all the above roles bring together. Personal views and beliefs also influence choice and decision-making, in the context, for example, of the following particular theoretical and methodological approaches. As I mentioned earlier, claiming objectivity would be a naïve position to take. I have tried through the different stages of my research to reflect on my roles and be conscious of the preoccupations and assumptions that my positions brought to bear on my analyses. After all, our self is always present no matter the role(s) within which we constitute ourselves.



CHAPTER 5: DISABILITY FILM FESTIVALS

This chapter is set as a contextual foyer where I attempt to present the context and the atmosphere of disability film festivals based on the sources collected through written festival methods and my sketch diary. Focusing mostly on the *Emotion Pictures- Documentary & Disability International Festival* where I undertook my fieldwork, I describe its organisation and the organisers' statements that reflect the concept and the aims of the festival. I outline the thematic preoccupations in disability documentary films, and I continue with the summaries of the selected documentary films as they were published in the festival's official website and programme for screenings. At this point, I think it is imperative to comment on linguistic choices made by the organisers in relation to disability. I proceed with a comparison with *The Other Film Festival*, one of the largest disability film festival in the world with important contribution in arts and disability community in Melbourne. After the description of the organisation of the *Emotion Pictures- Documentary & Disability International Festival* and the summaries of the selected documentary films, I present the views of the disabled viewers that attended the event and responded to my call for interviews. The structure of this chapter is based on the logic of preview, an attempt to transfer the set-up, the context, the atmosphere and some of disabled viewers' critique, as a foreword to the film analysis that follows in chapter six.

5.1 EMOTION PICTURES - DOCUMENTARY & DISABILITY FESTIVAL & OTHER INTERNATIONAL DISABILITY FILM FESTIVALS

In June 2007, I attended the *Emotion Pictures-Documentary & Disability International Festival*. Friends in Greece, familiar with my interest in films and disability, informed me about the event and I decided not to miss the chance. It was actually a great chance to explore potential fieldwork.

Emotion Pictures- Documentary & Disability International Festival was the first of this type of festival, part of a worldwide artistic movement focusing on disability. This festival in Athens became one more link to the disability film festivals network among

other popular festivals such as; *The Other Film Festival* in Melbourne, *Picture This...Film Festival* in Calgary, *Breaking Down Barriers-International Disability Film Festival* in Moscow, *The Way We Live-International Short Film Festival* in Munich, and London's *Disability Film Festival*. Some of the above festivals are still running, taking issues related to disability, art, access and inclusion forward, some of them though were victims of funding cuts and they are currently on a “pause” status.

As stated on the official website, the festival's aim of the event was:

[...] to bring to prominence, using the documentary as the medium, the concern of artists from all over the world on disability issues and to encourage the development of a fruitful social dialogue in Greece with art – the common language of us all – as the starting-point. (www.ameamedia.gr)

The organisers characterised the festival as: “a cultural event, a meeting place, and a celebration”. In trying to communicate a clear message to the audience, they adopted the slogan: “Diversity is the only truth that unites us all.” In contrast, the *Other Film Festival*, which is the biggest festival of this category, uses a more direct and simple line: “What are You Looking At? - New cinema by, with and about people with disability”, (<http://otherfilmfestival.com>). Further, the focus on the mission statement of the *Other Film Festival* is that of leadership and agency:

We have a simple definition of leadership. Change the environment in which you operate for the better. Everyone can take a leadership role. Everyone can make an impact. The *Other Film Festival* has a simple goal of changing how everyone thinks about disability. We do this through screening the best films from around the world, by making sure that everyone is included and by meeting everyone's access requirements. Most importantly, we want you to be entertained, enthused and energised. We hope you enjoy the festival in all its many parts. We ask you to have high expectations of your experience at the festival. (<http://otherfilmfestival.com/about/mission-statement/>)

In this mission statement, change and active participation is the aim: change of the environment and change in the way disability is seen. The element of leadership is raised as empowering for every individual – with and without disabilities – who is keen on making the necessary changes. The focus on leadership carries a note of call for all those that want to claim rights and access in order to improve their living environment.

Picture this...Film Festival has a slightly different profile. This festival attracts films by and/or about people with disabilities, aiming first to stimulate the voices of disability communities by creating a venue for people with disabilities to tell their stories, and secondly, to educate the broader community about the lives of people with disabilities

and the contributions of disabled citizens. In this statement, the element of educating the community about disability issues as well as the contribution of people with disabilities in the society is highlighted. This is in line with Vasey's argument (1990), according to which, a main responsibility of an art event is to educate a non-disabled audience. However, this aim is adopted by most of the disability film festivals, as the need to inform non-disabled people on disability issues and critically address entrenched stereotypes is evident.

In her welcoming message in the festival's programme, film director Maria Hatzimichali-Papaliou, who was the artistic director of the 2007 *Emotion Pictures-Documentary & Disability International*, pointed out that:

Disability is a form of diversity and the way in which societies deal with it is an indicator of their civilization. Every difference is entitled to its space, because it is an existing human condition.[...] The documentary is an ideal medium of self-expression for persons with disability, and it conceals an enormous political power. Through the films, persons with disability themselves present their picture to us, without mediations and far from social stereotypes. They also initiate a dialogue with society concerning the basic condition of their life. Today, we, as a society, face a challenge: to overturn the social stereotypes about disability, by overcoming our prejudices and our fear when confronted with pain, in order to reconcile ourselves with the images we have shut out of our life, but which are still right beside us. (Hatzimichali-Papaliou, 2007)

In this context, as Hatzimichali-Papaliou notes, giving space to disability is an indicator of civilization and documentary is an artistic form that brings the political power that is needed to establish the space for disability. She refers to pain that is attached to disability, and the fear effect that it has on a society. This pain becomes the challenge that films ask viewers to overcome. Undoubtedly, pain, whether physical or emotional, is a part of disability. Siebers brings this matter to the forefront in his *Disability Theory* (2008), arguing that the focus has shifted so much from societal barriers, that the issue of 'pain' has been silenced almost to the point of a pretentious denial. However, the immediate connection of disability with pain seems like quite a general assumption, addressed strongly to an audience which includes two groups: a) disability-ignorant viewers and b) disability-related viewers. In both cases, the perception and views on pain will be varying, depending on the experience. This statement hits at the reductionist perception of disabled people as sufferers while there is a range of disabilities for which pain is not an element. It is interesting to note that the artistic director of the festival highlighted pain and the fear of it as a feature on which to reflect with regard to disability. It may have closer reference

to temporarily able people's fear of becoming disabled and the pain that this fear causes them.

Rick Randall, film maker and director of the *Other Film Festival* had a different approach in his welcoming message in the programme of the event in 2010:

From its inception, The Other Film Festival has always had its gaze fixed firmly on the future. The festival dares to dream that one day everybody's story will be written boldly across the cinema screen and that universal access to the cinema will be the norm not the exception.[...] The festival works to ensure that the needs and aspirations of people with a disability inform all of our activities. This informs our support for the nation-wide campaign for increased cinema access throughout Australia. [...] So come and check out the future, because it's right here, right now. (Randall, 2010)

The Other Film Festival begins with a mission statement focused on leadership and change and its director continues with a proactive approach to think about the future: “a future where everyone's experience will be represented so this will become the norm and not the exception” (<http://otherfilmfestival.com/about/mission-statement/>). Randall mentions cinema access and by this he refers to access to all levels, from film making to screening and viewing. Clearly it is a message free from psycho-emotional references, derived from a mentality of inclusion and its practicalities. It can be argued that this message is more closely connected to the perspective of making cinema but Randall seems to have a clear idea of how access can be offered to everyone. The setup of the *Other Film Festival* includes, other than screening films, sessions dedicated to particular disability groups, workshops for filmmakers and actors, and forums on accessible cinema. Randall considered films as the “sexiest medium” that would attract people's interest in the connection of disability and art. This is how the idea of setting up the festival was conceived; to create a disability festival that was not a marginalised event, but “a fully-fledged film festival of stand-alone in its own right”, (Tracton, 2008, p.51).

The *Emotion Pictures- Documentary & Disability International Festival*, was organised by the Secretariat General of Communication- Secretariat General of Information, in collaboration with the Greek Film Centre. It was funded and promoted by various organisations & cultural foundations such as the John F. Costopoulos Foundation, the Institut Français d' Athènes, the British Council, the Goethe Institute, and the Beijing Film Academy.

All the events over these three summers had a good turnout. The festival was hosted at the new Benaki Museum building and entrance was free of charge. During daytime,

screenings took place at the amphitheatre of the museum, capable of seating three hundred people, whereas at night the courtyard, which covers a space of 850 m², was used, giving a sense of a summer cinema. Viewers had the chance to watch as many films as they wished. They could leave for a break and come back for the evening screenings or the next day.

The festival was widely advertised since it had the support of the media, with national and international broadcasts (eg. TV5 Monde, National Greek Broadcast). Additionally, eighty cinemas in Athens (eg. Apollon, Cinemax, ODEON, Village) participated and several print presses and book companies were the communication sponsors. Various commercial businesses also offered support, either for the promotion or execution of the event. The President of the Hellenic Republic, Karolos Papoulias, supported the *Emotion Pictures Festival* by attending the event personally and sending a videotaped message, screened during the opening ceremony each year. Internationally distinguished personalities also promoted this festival with their presence or via messages, actors such as Daniel Day Lewis and Richard Gere, Special Olympics athlete and actress Aimee Mullins, famous photographer Amy Lyne, popular Hollywood actress Eva Mendes, Oscar-winning director James Ivory, celebrated directors: Wim Wenders, Danny Boyle, and award-winning Patrice Leconte, the Nobel Peace Prize Laureate and chairwoman of international associations to promote the rights of children and women, Betty Williams and many others.

The programme included three-day screenings, followed by discussion panels with filmmakers, and people with disabilities who were the main characters of the documentaries and the festival organisers. Special screenings on the themes of “Disability & Environment”, “War and Disability” and “Autism” were organised with the support of the High Commission of the United Nations (UN), the World Wide Fund for Nature (WWF), Greenpeace, and Médecins sans Frontières (Doctors without Borders). Special events also took place during the opening and closing ceremonies of the festival with guests being directed to engaging in significant action in the international disability community. On the last day of the screenings, the International Annual Conference: “*People with Disabilities and Mass Media*” started in connection with the *Emotion Pictures Festival*, funded and organised by the Greek Secretariat General of Information - Secretariat General of Communication. The conference opened the discussion on issues of accessibility to media, mainly referring to the Greek TV, and print but also exchanging views with international speaker-journalists. The new developing environment of digital

media such as social web, blogs, wikis, and facebook was also a topic included in the programme. During the second year of the festival, the organisers hosted an animation film workshop in collaboration with the Chinh India Forum and two award-winning filmmakers, Meenakshi Rai and Vinay Rai, who have developed a method that provides the opportunity for children with disabilities to express their creativity. Thirty children from the Greek Cerebral Palsy Society participated in the workshop and made a film, which was screened at the closing ceremony of the festival. The Hellenic National Commission for UNESCO and the John. F. Costopoulos Foundation funded this particular workshop, and the film was distributed to all schools that were under the auspices of UNESCO.

It is important to mention that the *Emotion Pictures Festival* was distributed beyond the borders of the Greek capital. For 2010-2011, numerous municipalities and associations organised events hosting screenings of films from the festival. There were also collaborations with the University of Thessaly, the Technological Educational Institute of Crete, and the Aristotle University of Thessaloniki, where educational screenings took place. The Primary Education Department of the University of Crete included screenings and workshops from the *Emotion Pictures Festival* in an international symposium with participation of 200 scientists and teachers. Universities in the USA and Europe, such as the University of Pennsylvania, Bryn Mawr College, Swarthmore College and Brown University and the University of Aix en Provence - City of Marseille, were also added to the list of collaborators. Links with other film festivals around the world were developed through support and participation, aiming to develop activities that empower the voice of people with disabilities and promote social dialogue.

One of the major actions that the festival took, was the distribution of an educational package, with the award-winning films being circulated to 3000 schools in Greece and abroad, in collaboration with associations of expatriate Greeks (USA, Canada, and Australia). This project was sponsored by the Stavros Niarchos Foundation, with the support of UNESCO.

As previously mentioned, in order to run and accommodate their events, offer workshops and invite guests, these festivals need support from various sources. *The Other Film Festival* has the support of the Australian government and numerous other partners defined as: 'public' (eg. City of Melbourne, Screen Australia), 'principle' (eg. The Ian Potter Foundation, Perpetual), 'media' (eg. 774 ABC Radio Melbourne), 'venue' (eg. Arts House), and 'festival partners' (eg. Red Bee Media, Caramel Creative), and

supporters (eg. Australian Federation of Disability Organisations (AFDO), Australian Leadership Awards, and Fed Square (<http://otherfilmfestival.com/about/partners/>)). *Picture this...Film Festival* relies on a group of sponsors with similar profiles: the Government of Alberta, Canada Council for the Arts, Alberta Foundation for the Arts, Calgary Region Community Board- Person with Developmental Disabilities, Accessible Media Inc., CKUA-Radionetwork, and Glasswaters Foundation (for the full list see here: http://www.ptff.org/ptff_main/sponsors.html).

Taking into account the list of supporters of the *Emotion Pictures Festival* that were mentioned at the beginning of this chapter, it is obvious that local and national authorities, different organisations and foundations, cultural and arts centres and commercial businesses become involved, in order to support this initiative to reach the public. On one hand, there are great benefits for national governments to take the responsibility and put their name to funding for these events. On the other, in the case of the *Emotion Pictures Festival* this sealed its fate when the Greek economy experienced the first turbulence of its European Union-centred economic crisis. Maria Hatzimichali-Papaliou, the artistic director of the *Emotion Pictures- Documentary & Disability International Festival*, announced the tacit abolition of the festival by the Greek state at the *ENTR '2 MARCHES- International Festival of Short Films on the Theme of Disability in 2011* (www.ameamedia.gr). There were major difficulties in running the event in 2010, however, the organisers still managed to set screenings for one day only, in protest for the financial state of the festival. The artistic director stated that the authorities of the Greek state showed no interest in funding the festival. No official decision was announced by the ministries involved. They simply silently cut the funding, with organisers, filmmakers, the Greek disability community and the audience feeling let down. Maria Hatzimichali-Papaliou made a call for solidarity from the other international disability festivals and a petition was initiated. This, however, did not bring any positive effect.

5.2 THEMATIC PREOCCUPATIONS IN DISABILITY DOCUMENTARY FILMS

The *Emotion Pictures- Documentary & Disability International Festival* was organised for three consecutive years, from 2007 to 2009. Unfortunately, it was one of the first victims of the Greek economic crisis. Previously, it had been a large event that attracted a considerable amount of participation, in terms of films, filmmakers and

viewers. According to the records from the official website of the festival (www.ameamedia.gr), organisers counted one thousand film entries from all over the world. From these films, one hundred and twenty were screened in three years and the viewers' numbers came up to approximately fifteen thousand people. The films of the programme were divided in two sections: the Competition and the Informative Section, also including the special themed screenings: “Disability & Environment” in 2007, “War and Disability” in 2008 and “Autism” in 2009. There was an attempt to cover a wide range of disabilities in the selection of films, such as: learning disabilities, visual and hearing impairments, autism, mental illness, physical disabilities, disfiguration, dwarfism, amputation, cerebral palsy, and degenerative illnesses, such as: muscular dystrophy, neurological disorders, Tourette’s syndrome, people affected by Thalidomide, war and poverty victims, epilepsy, dementia. There were also a variety of themes that had a diverse approach to disability issues. The screenings included documentaries related to education, rehabilitation, independent living, supported employment, families of children with disabilities, disabled athletes and artists, activism, civil rights, sexual relationships, awareness against stereotypes, disability aesthetics, poetry, personal stories and personal achievements of living with disabilities.

As the majority of disability film festivals are international, since they include in their programme films that they receive from all over the world as a response to their open call, the themes of the films are not limited to a specific type of disability, and in this way the organisers provide a cross-cultural and cross-disability perspective. The agonistic character of the festivals emerges from the mission statements and the focus on specific aims such as leadership and change. This was achieved in the *Other Film Festival* with the artists concerns on disability matters, and the promotion of social dialogue, (<http://otherfilmfestival.com/about/mission-statement/>). For the *Emotion Pictures Festival*, this was achieved through empowerment of disabled people voices, and the education of broader community was attained through *Pictures this...Film Festival*, (www.ameamedia.gr). The themes of the films that negotiate cases of accessibility, bureaucratic barriers, social and educational inclusion, independent living, ageing, rehabilitation, employment, sex and relationships, expose the viewers to a list of matters that provide opportunities for critical and reflexive thinking as long as the film lasts, and perhaps offer spaces to discuss it with other viewers, friends, colleagues or students. This way, it can be argued that festivals contribute to the dialogue about rights and policies related to disability. Initially such discussion would probably be focused on the local

needs of the community that hosts the event, but the international element of the films and invited guests present, add a dimension of reactivity catalysing comparison. Either during the discussion panels or while relaxing between screenings, viewers, filmmakers, scholars, organisers and disability community representatives tend to exchange knowledge and experience from their respective country contexts. Comparisons about educational arrangements that support inclusion, amounts of financial benefits and eligibility criteria, medical cover, access to arts and sports, ramps and accessible city plans, and the setting of supported or independent living, were some of the popular topics discussed at the café of the Benaki Museum during the functions of the *Emotion Pictures Festival*. I had the opportunity to attend and record a part of this sharing of knowledge, either by attending and recording the Q&A panels after the screenings, or by participating in discussions at the café and keeping notes at the end of the day.

5.3 LANGUAGE IN THE SYNOPSES OF SELECTED DOCUMENTARY FILMS

In the third chapter, I addressed the criteria for selecting the documentary films which I analyse in my thesis. It is relevant to show how these films were described in the official programme of the *Emotion Pictures- Documentary & Disability International Festival* as this was a part of the written festival that I had to look at several times before and during the film analysis. I cite the synopses from the festival's programme at the appendices in the order in which I am following for the film analysis in the sixth chapter. These synopses were interesting to read in terms of what is perceived as the “catchy” part of the film that will draw audience’s attention and the choice of words to present this. Some of the linguistic choices in the text of the festival’s programme are indicative of discrepancies in terms of understanding disability politically, such as: “suffers from muscular atrophy” (*Invitation to the Dance – Body and taboo*), “mentally different” (*Letter to Lou/Lettre à Lou!*), “extraordinary and heroic young man” (*Body of War*). Also some of the punch lines that are chosen to attract the viewers’ interest highlight misleading messages such as individualism and the act of shifting the burden of responsibility onto disabled people, as for example at the synopsis of the film *Please Listen to Me* we read: “If I fall, I have the strength to get up. If they tease me, I will not cry. I want to make friends. Let me be responsible for myself”, (<http://www.ameamedia.gr/en/node/86>). I also consider some of these discrepancies as

inaccuracies that originate from problematic decision-making in language translation. By this, I mean that the organisers focused more on translating the text from Greek to English in a way that would attract the viewers by presenting the films in an inspiring context, rather than by focusing on authenticity in translation.

5.4 DISABLED VIEWERS ON EMOTION PICTURES - DOCUMENTARY & DISABILITY INTERNATIONAL FESTIVAL

As mentioned in my methodology chapter, conducting interviews with disabled viewers has been an important part of my data collection, as I considered disabled people's involvement vital. I conducted semi-structured interviews with disabled viewers during the last event of the *Emotion Pictures – Documentary and Disability Film Festival* in 2009 in Athens. Seventeen disabled participants were interviewed during the three days of the event. The questions were set to explore their views on disability film festivals and disability films. Particularly, in relation to disability festivals, the questions explored:

- a) The reasons for which the festival attracted their interest.
- b) Disabled viewers' interest or knowledge on disability films and disability culture related events.
- c) Representation of all types of disabilities in disability film festival.

The reasons for which disabled participants attended the festival were:

- Having an interest in disability films due to personal experience through having a type of disability
- Being interested in films/events related to disability.
- Being interested in films and art events in general.
- Previous positive experience of attending the festival and finding its content interesting:
- Taking part in the festival (eg. participating in selected films)
- Being curious about the ways that filmmakers choose to depict disability
- Word of mouth.

Seven of the interviewees cited their interest, particularly in disability films, to be due to their studies in media and/or interests in cinema in general but also to previous experience of participating in films about disability. The rest of them claimed that they

were not interested in watching films about disability until: a) they identified themselves as disabled and b) they got a first taste of the *Emotion Pictures- Documentary & Disability International Festival*²:

If I am to be honest I wasn't interested in disability films until I got my disability. I like cinema a lot but I wasn't looking for films depicting disabilities. (Emotion Picture Festival viewer FP5, 2009)

This is a complicated question because it has to do with my personal experience. I wasn't disabled from birth, so I wasn't bothered with disability before experiencing it personally. In the same way, I hadn't connected cinema or the arts in general with disability before. The trigger was my personal experience. So there wasn't any previous knowledge. (Emotion Picture Festival viewer FP15, 2009)

The content and the organisation of the festival, made disabled viewers return as viewers and in some cases as participants for the second and the third event in 2008 and 2009. Some of them noted that getting to know people from the Greek disability community, was an additional factor that attracted their interest:

I have attended this festival for the last 3 years. I got into it from the first year because I could see other views on disability, as I listened to stories narrated by actual persons with disability. This is what I really liked. (Emotion Picture Festival viewer FP5, 2009)

I've attended the previous two festivals and they were amazing. Power and humanity came out of them, not misery or grief. I've also got something of mine this time, a video. (Emotion Picture Festival viewer FP11, 2009)

I attended the previous two as a viewer. I've been always here, but this time I participate in a film. In general, I like attending events or festivals related to disability. (Emotion Picture Festival viewer MP12, 2009)

This is my second year here. Last year I met interesting people from the disability movement. I believe that the festival plays an important role in making the Greek society understand disability as a wider notion. (Emotion Picture Festival viewer MP1, 2009)

Disabled viewers attended the *Emotion Pictures- Documentary & Disability International Festival* for various reasons, but one of them was to find references in the films and make connections with other disabled people, either the characters in the films, the filmmakers or other viewers. It could be argued that for some this interaction, which can be indirect or direct, creates a sense of affirmation, belonging and solidarity:

² All translations from Greek are my own.

Disability is an integral piece of who I am. Usually this part is not expressed but it finds ways of expression through this effort here (the festival), ways that I couldn't even admit to myself in my daily life. (Emotion Picture Festival viewer FP4, 2009)

I am a disabled person and I wanted to see how disability is depicted or more specifically how filmmakers negotiate it in their work. I also believe that this is a new thing in Greece and I wanted to grab the opportunity to compare with what's happening abroad. (Emotion Picture Festival viewer FP15, 2009)

There aren't any depictions of disability in media, cinema or TV. There is the negative imagery of disability that contains misery and pain. I wanted to see if these films negotiate, not a virtual perfect reality but just the reality. I wanted to see if the main characters are actors or real people with their families, a parallel world to mine. Something familiar, but also something unknown. The international element of the festival attracted me more than anything. (Emotion Picture Festival viewer FP13, 2009)

The participation in the disability film festivals could be perceived as part of what Shakespeare (1996) had named disabled people's "coming out" process, which also was a resistance to the negative implications of the medical model:

This "coming out" is the process of positive self-identification, rejecting the categorisation of subjection, and affirming subjectivity and collective power. It is about developing new definitions and new political forms. [...] While this can be a private and individual development or personal awakening, it is more likely to take place in a collective context: self-organisation itself prompts the process of identification. (Shakespeare, 1996, pp. 99-100)

Rephrasing Shakespeare's (1996) comment on the disability movement, it can be claimed that disability film festivals offer the space where collective voices can work towards their political identification through processes that challenge the imposed compulsory normalcy profile that disempower disabled people. In this collective context, disabled people are well positioned to open up the social dialogue about disability, a dialogue that would foster the application of suitable approaches that take into consideration the required political and activist content.

In response to the question on full representation of all types of disabilities in the screenings of *Emotion Pictures- Documentary & Disability International Festival*, eight interviewees answered positively that there was full representation. Two of them said that they were not able to give an accurate answer, as they were not aware of all different types of disability. One claimed that learning disabilities were under-represented. The rest of the disabled viewers mentioned that there was not full representation, but that they

recognised the effort made by the festival organisers to include a wide range of disabilities in the film screenings.

Disability film festivals are a very particular space where challenges might arise emerging from the dynamics between disabled and non-disabled participants/organisers and/or among the diverse groups that constitute the disability community. Gamson (1996), examining the impact of the Lesbian and Gay Film Festivals, makes the point that although collective identities are not considered organisational inventions, their shaping is influenced by the filters and methods of reproduction applied by the organisational bodies.

While film festivals take actions on behalf of “communities”, they do so also as organisations largely autonomous from those populations. [...] The shape of collective identity -how internal instabilities and diversities are accommodated and the sorts of cultural resources that become publicly used- thus depends not only on the emergent characteristics of the “collective”, but also on the resolution of challenges particular to organisational fields. People make collective identities, but not in conditions of their own making. (Gamson, 1996, p. 235)

Mitchell and Snyder (2008), focusing specifically on the disability film festivals argue that corporation is not established and the “concept of disability collectivity is elusive”, (p.12). They feel that the organisational structures cannot support the disability collectivity and the main action is directed towards an anti-stigmatising effort but still, even in this way, disability film festivals bring the element of change. This change has an impact on different levels. Firstly, the planning of a public space accessible to all has to accommodate the viewers' needs:

Disability film festivals provide alternative “concepts of reception” & operate as active filters for forging new ways of “being disabled” in the twenty first century. Unlike other minority groups, and as a result of the film festivals they have spawned, disability movements have had to re-imagine public space in terms of its historical exclusion- including, theatres, presentation methods, projection techniques, and discussion formats. [...] [As such] Film festivals transform public arenas and help to revise cultural infrastructure of accessibility for all bodies. (Mitchell & Snyder, 2008, pp. 13 & 14)

Secondly, the multiple functions of the festival and the exposition of various representations tease out identity issues:

As one of the few public spaces to actively fashion alternative disability identities, film festivals challenge internal and external orthodoxies that tend to quickly sediment within politicized identity gatherings. They not only serve the important function of historical recovery, they also seek out a variety of perspectives on the meaning of disability from older and younger generations of

disabled people and non-disabled allies. Disability film festivals actively disrupt static boundaries of disability identity--even with respect to disabled peoples' concepts of their own collective make-up. (Mitchell & Snyder, 2008, p.14)

The interview analysis continued with disabled viewers' thoughts on disability films, specifically documentaries. The questions that were related to documentary films depicting disability matters or focusing on disabled people, teased out aspects such as:

- The impact of these films on viewers
- The ways that documentary films challenge or not, the misconceptions and stereotypes ascribed to disability
- Disabled viewers' understanding of differentiation between disability films and disabling films
- Disabled viewers' expectations of a documentary that depicts disability
- Disabled viewers' personal thematic choices for making their own film on disability.

Nine of the interviewees expressed doubts in relation to the impact of the films on viewers. Their strongest argument about this was that they felt that the audience was a very specific one as it could be divided in two groups: a) disabled viewers and b) viewers that have an interest in disability matters, either because they work with or for people with disabilities, or they are related to a person with disability. One of the interviewees added one more category to these groups; "the festivalists", people that enjoy attending festivals in general without necessarily having a genuine interest in disability:

I don't believe there is going to be any impact because there are not too many viewers. If you consider that we live in a city of 5 million people, statistically the attendance is not even 1 in 100.000. On the other hand, things are happening, so I don't want to undermine the whole event. (Emotion Picture Festival MP1 viewer, 2009)

To be honest I don't think there is going to be any impact. The majority of the viewers are people with disabilities, so they are aware of disability theme. The non-disabled that attend the festival usually have some kind of experience with disability. The cases of viewers with no disability experience or involvement are very few. However I consider the festival as a positive action. (Emotion Picture Festival MP2 viewer, 2009)

I'm afraid that people with no experience of disability, you know like having a friend or family member with disability, won't pay attention. They won't be interested. (Emotion Picture Festival FP3 viewer, 2009)

I'm not sure that people have realised what's going on here. I've seen the festival trailer on TV and cinema screens but I don't think viewers understand what this

is about. I can't say the festival is packed, ok, I've seen actors, politicians and those I call "festivalists" attending,- you know they go wherever there is a festival, it's the festival community-, but I don't think the majority has been attracted. People living outside of Athens do not have a clue about this event. (Emotion Picture Festival FP13 viewer, 2009)

Disabled viewers also noted that the audience's lack of experience in disability matters was a drawback because even if some matters were depicted in films, nevertheless non-disabled viewers were not able to understand disabled people's realities, and as a female interviewee said: "non-disabled viewers live in their own pink cloud" (Emotion Picture Festival FP11 viewer, 2009). Another reason for which the lack of experience is a drawback, is non-disabled viewers' psychological reaction: "viewers often get emotional or scared and see disability as something appalling" (Emotion Picture Festival FP15 viewer, 2009). Eight of the disabled viewers believed that documentary films had an impact on viewers because these films create an image of justification, and in many cases films transform the deficit into a privilege. Other reasons are that viewers become more familiar with disability, they get an initial idea of disabled people's reality, and through documentary films they realise disabled people's active part in society. Disabled viewers also noted that disability film festivals create a space for dialogue by screening numerous documentary films and promoting disability matters within the local communities:

First of all you won't find these films on Greek TV – for example, the Waves of Aegean has been on twice but after midnight and on digital TV – so not many people had the opportunity to watch it. As a theme, disability does not have a great representation on Greek TV, cinema or arts, so I think that this festival offers a lot. Those who attend the festival, even maybe just for one film, get the chance to talk about disability matters. There is no access to these particular films even for people like me who have this specific interest. This festival offers the opportunity to watch many films on this subject and also to bring the community in touch with disability. I'm referring to artists, film-makers and viewers. It is very important to have this dialogue. It is important to achieve this contact since it's not happening in our daily routine. (Emotion Picture Festival MP14 viewer, 2009)

I hope viewers realise that people with disability can have an active part in society. (Emotion Picture Festival MP16 viewer, 2009)

This festival tries to raise awareness and make people realise that everybody should care about disability, not just the state. We are all able to contribute and support people with disabilities. (Emotion Picture Festival MP17 viewer, 2009)

The opinions were also divided as whether documentary films in fact do challenge misconceptions and stereotypes ascribed to disabled people or not. Thus, the viewers who believed that documentary films do challenge stereotypes, stated that these films are effective when:

- They depict reality and focus on originality.
- They show disability as a social phenomenon.
- They screen children's stories.
- They shock the viewers.
- They familiarise viewers with disability.
- Screenings take place in the presence of the filmmakers:

What I find fascinating is that films are screened with the presence of filmmakers and some of them are parents of disabled children. We really need to think about it! I think by their films and their presence, they play a very significant role in breaking down stereotypes. They do it in a very balanced way – I believe it happens in a balanced way. (Emotion Picture Festival FP4 viewer, 2009)

I believe that films break down stereotypes. Especially films that focus on young children – and I really like this – who overcome their disabilities, are creative and live a joyful life. (Emotion Picture Festival FP5 viewer, 2009)

I'm pleased when I watch a film that dismisses stereotypes when this wasn't in filmmaker's mind. By depicting the reality of disability they break down stereotypes and they don't need to make a special effort. (Emotion Picture Festival MP6 viewer, 2009)

Yes they challenge stereotypes and in some cases I've been shocked myself. I wouldn't dare to say things this way but this is how they try to fight stereotypes. If I was making a film I wouldn't do it that way, I would go with originality. I still believe that they challenge stereotypes, and if the screenings went beyond this festival, it would be great! (Emotion Picture Festival MP7 viewer, 2009)

Films can help people understand the difficulties. Here in Greece there are many issues whereas abroad there is more access, have you noticed that? (Emotion Picture Festival FP8 viewer, 2009)

I believe that films challenge stereotypes because people start to become more familiar with disability. It used to be something that would cause fear. Disability is a reference to people's nightmare. When you see a person with disability you realize that this can happen to you, but for most people this is a nightmare and since they don't like nightmares, they don't like disability either. Here they realize that disability is not a distinct part of ourselves and they don't have to become disabled to understand this. They also see disability as a social phenomenon that requires a right approach so that it doesn't turn into a nightmare but into a positive experience. (Emotion Picture Festival MP17 viewer, 2009)

Disabled viewers that considered documentary films as having little or no effect on challenging misconceptions and stereotypes, were based on the argument that documentary films are not widely screened. Some disabled participants raised the concern that documentary films can reproduce and reinforce misconceptions, particularly in cases where the viewers have not a good understanding of disability matters. They also felt that documentary films are addressed to a specific group of viewers (eg. people who perceive themselves disabled or professionals who work with disabled people), and they were selected according to specific criteria for accomplishing the festival's purposes. The suggestion that documentary films can potentially challenge misconceptions ascribed to disability was dismissed by the argument that breaking down stereotypes is a matter that relies entirely on practices of education and state:

The festival's aim is to break down stereotypes, but my concern is whether we get the "heroes of life" image from this festival. There aren't any heroes of life, everybody might have to face his/her disability at some point in our lives. Non-disabled people are not going to be non-disabled for ever. The disability movement seeks equality, real equality, access, education, employment, social and personal relationships so that we can have a normal life with no discrimination. (Emotion Picture Festival MP1 viewer, 2009)

Documentary films contribute to making people realize the difficulties [of disability] and how these could be dealt, but I don't think we'll get this impact here because the group of viewers here is very specific. Documentary films should be screened more widely. (Emotion Picture Festival MP2 viewer, 2009)

There are and there will always be stereotypes since the required education is missing. Sometimes films challenged stereotypes. (Emotion Picture Festival MP10 viewer, 2009)

Yes films highlight stereotypes and sometimes reproduce them. I don't expect from a film-maker or an actor to change a situation, these are matters for education and the state. For example, I don't think that a film will have a negative impact by presenting stereotypes; this is not the root of the problem. A film is just a small wheel of the machine that perpetuates these matters. (Emotion Picture Festival FP13 viewer, 2009)

No I wouldn't be honest if I was saying that films break down stereotypes. These films have been selected according to this festival's subjective criteria. Some people brought these films specifically to this festival, and this is not necessarily a bad or a good thing. I don't believe that the world's history will change its direction due to these films. (Emotion Picture Festival FP15 viewer, 2009)

The question about the differentiation between disability films and disabling films proved to be a difficult one in terms of translation. "Disabling" was the word that was the most challenging to translate in Greek because it required finding a way that would give

the same meaning as English, avoiding at the same time traps of not being politically correct in a context where people were quite alert and protective about the use of term “ανάπηρος” (anaperos) which is the Greek word for disabled. The choice of a periphrastic definition secured quite an accurate translation that also avoided any pitfalls of political correctness. The issue, though, with the periphrastic definition was the risk of dictating an answer or a specific direction that could influence interviewees’ responses. In this case, I decided to choose a periphrastic way that would allow interviewees to express their own understanding of disabling films. Consequently, the disabled viewers described the disabling films as the films that:

- Depict the “catchy” image of disability
- Focus only on disability
- Focus on psychological effects of disability
- Depict disability as disease or bad fortune and the plot solution is a divine intervention or a miracle cure
- Promote the idealisation of disability focusing on special abilities
- Will be on TV on 3rd December (International day of persons’ with disabilities)
- Depict disabled characters as martyrs or heroes
- Reproduce stereotypes
- Are bad films that make you leave the room in the middle of screening.

In contrast they describe the disability films as the films that:

- Depict the real image of disability
- Raise matters of discrimination
- Focus on barriers set by society and non-disabled people's attitudes
- Depict reality, which might be shocking in cases but educates the audience.

Disabled viewers had a clear understanding of the differentiation between the disabling and disability films. They mention particular differences and characteristics of their content and the types of depictions. They were also very specific about their expectations when they chose to watch a documentary that focused on disability. Thus, they expected to see a different approach where pity has no place. They were concerned to have represented an authentic image of disability that can have educational impact, depicting disabled people speaking to their own realities. Disabled viewers expected that films will focus on ways of dealing with reality and not so much on their daily routine which can change the depiction to a modern freak show or personal tragedy story. Participants

clearly stated that films should be clear of editing approaches that create a melodramatic depiction. The expectation of seeing personal and sexual relationships on the wide screen was one of the popular answers. At this point, the disabled viewers challenged the stereotype that projects them as only being attracted to other disabled people, and they asked for films that negotiate personal and sexual relationships in a wider spectrum. Generally, disabled participants wanted documentary films to unfold extensive content. Specifically, they expected that documentary films that focus on disability will go beyond the common motif of a disabled person's biography, and try to depict stories of people from different countries who are or became disabled. In this way, they averred that documentary films should negotiate disability on a cross-cultural basis where cultural and societal matters could be discussed. In this context, participants also wanted films to depict disabled and non-disabled people in an equal and balanced way:

I haven't thought about it. To be honest I was hoping to see beautiful girls and think: "Ah! I would like to meet her!" I was impressed because I watched a reality that I am concerned about daily, but don't dare to speak of them. I don't dare to mention these issues especially to non-disabled people, so when I watch a film, I am a viewer and someone else discusses these matters. There are important issues so I am pleased when I watch someone else bring them up the way I would. For example, how tiring an impairment could be or how specific some of your movements should be. I would like to see these issues depicted. Love is also a big issue. Of course I would like to be in a relationship but not necessarily with someone who is disabled. If I watch a story like this in a film, it would be a relief for me. Again I would like it to be real, the way it happens in real life. (Emotion Picture Festival MP7 viewer, 2009)

I would like to see the reality and ways of dealing with it. I would like to see the ways in which non-disabled filmmakers approach disability. I wouldn't want to see a melodramatic approach. You know, a picture full of pity, which is usually used in TV depictions. (Emotion Picture Festival MP6 viewer, 2009)

I expect to see another point of view depicted. People with disabilities don't get the chance in daily life to express themselves and speak out about anything they would like. I would expect a film to present this and in addition to this to also say that all these people are not just their disabilities, but a lot more than that; this is very valuable. (Emotion Picture Festival FP5 viewer, 2009)

It depends on the theme and filmmaker's intention. I would like to see reality. For example, I saw a documentary about a child with autism filmed in Greece, showing the school bus taking him to the special school where he spent 8 hrs in classes and therapy sessions. After school his friends would come over his place to meet with him. This is not the whole story. I want to see the reality he experiences, and that's why we talk about documentaries and not fiction. I also expect to see what's going on in other countries of the world as well as the stories

of people who are not disabled from birth. As I said, I'd like to see what's happening in the real world. (Emotion Picture Festival FP13 viewer, 2009)

I would like to see an equal depiction of disabled and non-disabled people. Films show what a person with disability can do and viewers open their mouth surprised, thinking: "Ah! Look what the disabled character does!" I don't wish to see this. I'd be more interested in a film showing that all people have a place in this society regardless of whether they are disabled or not. All people can do the same thing and all have something to give; there could be something that a disabled person is good at and a non-disabled is not and vice versa. (Emotion Picture Festival P16 viewer, 2009)

For example, films that give priority to problems and issues that disabled people face. Films also depict how disabled people deal with society and vice versa. (Emotion Picture Festival MP17 viewer, 2009)

The films that were watched by the disabled interviewees were:

- ☞ Cost of Living-DV8 (FP5, FP13, MP14), (Friday 19.06.09, 21:40)
- ☞ Strand (MP2, FP13), (Friday 19.06.09, 22:15)
- ☞ A guide to taking a photo (FP13), (Friday 19.06.09, 22:20)
- ☞ Something like my eyes –Mine (FP13, MP14), (Friday 19.06.09, 22:40)
- ☞ Body of war (MP2, FP13, MP14), (Friday 19.06.09, 23:10)
- ☞ Blind loves (MP7), (Saturday 20.06.09, 20:05)
- ☞ Ecologia (MP9), (Saturday 20.06.09 21:00)
- ☞ Deep violet (MP7), (Saturday 20.06.09 21:05)
- ☞ Everybody from my courtyard (MP7, MP14), (Saturday 20.06.09, 21:25)
- ☞ Letter to Lou (FP4, FP5, MP7, MP14), (Saturday 20.06.09, 21:55)
- ☞ Including Samuel (FP4, MP6, FP8, MP12, FP13), (Sunday 21.06.09, 13:25)
- ☞ Mister Spazzman (FP3), (Sunday 21.06.09, 19:30)
- ☞ White Sound (FP3), (Sunday, 21.06.09, 21:02)
- ☞ Forbidden Acts (FP3), Sunday 21.06.09, 21:10)
- ☞ Prodigal sons (MP12), (Sunday 21.06.09, 21:20)
- ☞ Charm of harm (MP9) (Sunday 21.06.09, 22:50)
- ☞ Erotica Italiana: The Disabled Person's Kamasutra (MP2, MP9, MP10), (Sunday 21.06.09, 23:35)
- ☞ The trap (MP1) (Monday 22.06.09, 18:30)
- ☞ Antoine (FP5) (Monday 22.06.09, 19:05)
- ☞ Waves of the Aegean (MP1, MP14) (Monday 22.06.09, 22:30)

👂 Please listen to me (MP16, was screened in 2008)

👂 The Pirate of time (MP1, screened in 2008)

It is clear that the disabled viewers attended mostly the evening screenings on Friday, Saturday and Sunday, and this was usually the busiest slots of the event. According to their few comments for some of the selected films, they liked the *Letter to Lou* and *Including Samuel*. They also expressed some strong views about *Body of war*:

I was impressed by the *Letter to Lou* and *Including Samuel*. These films were quite direct and also full of strong emotions, smoothly combined. I felt that I could find a way to express my disability through them. I believe that many elements of these films could inspire other filmmakers. If you are creative, you can find inspiration from very specific things in life, and this is what this festival means to me. (Emotion Picture Festival FP4 viewer, 2009)

I've been here since the first day but I've been watching only the films that were screened at the open cinema area of the museum. The one that I liked a lot was the *Letter to Lou* which was about a blind child. I've been saying to the organisers that this film should get an award. (Emotion Picture Festival FP5 viewer, 2009)

Letter to Lou was a complete film and could influence the viewers. There were many issues addressed. I think that's the one I liked most. It also depicted the effort made by the father and mother. (Emotion Picture Festival MP7 viewer, 2009)

Body of war was a really good film, a film that functions as a denouncement. I knew what I was about to watch in this case. There wasn't really any film that I didn't like. (Emotion Picture Festival FP13 viewer, 2009)

I've also watched the *Body of war*, but I didn't like it that much. The *Waves of the Aegean* and *Letter to Lou* were really good films. There is lack of films that don't rely on an approach that represents disabled people as pitiful: for example *Body of war* presents a war veteran that got paraplegic in a "Oh! Poor me!" way. I wasn't really disturbed by any of the films. The positive thing about documentaries is that they address issues in the most bizarre way. And only by sitting and watching a documentary about specific themes you get a lot. (Emotion Picture Festival MP14 viewer, 2009)

Finally the themes that disabled viewers would choose to make a film about disability include:

🎬 Love, sex and relationships

🎬 "My type of disability".

🎬 Issues of daily life through art and with a sense of humour.

🎬 The way society makes people disabled.

🎬 Unemployment

- 🎬 Access
- 🎬 Disguised discrimination.
- 🎬 Non-disabled people's response to disability.
- 🎬 Sci-Fi animation.
- 🎬 Something dark and extreme about disability that would break motifs of idealisation.
- 🎬 Something that viewers would like to see on the screen.

In the disabled viewers' choices if they were to make their own films about disability, there is a clear rejection of idealisation and sensationalism of disability. The desire for making films that will be provocative and taunting, in order to challenge stereotypes and misconceptions, is central. Disabled viewers also wanted to tease out political matters, such as unemployment and accessibility but also some undiscovered fields, such as types of disabilities, for which there is lack of representation – and not only in reference to films. Other undiscovered fields are an alternative construction of society, as suggested in Sci-Fi films, and non-disabled people's choice of themes related to disability. Both fields are suggestions for constructive dialogue in tackling disabling practices and perceptions. The alternatively built Sci-Fi society opens up numerous possibilities for flexibility that the use of technology could offer, breaking down many of the barriers that disabled people face. It could also alter perception of environment, technology and the potential of allowing people to make the most of their abilities, whereas a static disabling society is more restrictive. Asking the non-disabled audience what they want to see when it comes to disability is a clever response that targets non-disabled viewers' lack of awareness and of course their primal and impulsive response to disability, namely, their curiosity. This curiosity has been historically and culturally problematic when applied to approaches of disabled people, so non-disabled people are asked openly what they want to know about disability. By posing this question, it is the first step to erase any myths, mysteries and misconceptions ascribed to disability. At the same time, by exposing the non-disabled people's lack of knowledge and understanding, the disabled people's position on social dialogue is empowered – an outcome that is achieved by applying the practice of reverse discourse.

There is a hidden discrimination – this is what I experience. This discrimination is related to relationships and love life. If it gets presented, it is presented in an extreme way for example through some documentaries that could be considered pornographic. They don't touch the emotional side of it. Most people are aware

that disabled people are able to have a sexual life, the point is how disabled people experience the process of getting into relationships, the rejection or the acceptance. How someone can flirt and say:” Hi! I'm “X” and I'm disabled”. (Emotion Picture Festival MP1 viewer, 2009)

I would tease issues like these in Danezi's film: *The Trap*. That is, how they make us disabled. Even though there is an impairment, we have much more to show and give, but they prefer to keep us in “*The Trap*”. I've been looking for a job for two years now. I send my CV via e-mail; some of the potential employers weren't bothered at all to reply to me and these few times that I've been offered a post, the place wasn't accessible. So is this a trap or not? (Emotion Picture Festival FP5 viewer, 2009)

My film would ask people to care more and improve things in Greece. Physically able people should think that they might have to use a wheelchair at some point. Some people don't care about those who can't walk or have difficulties and this bothers me. (Emotion Picture Festival FP8 viewer, 2009)

That's a difficult question. I would talk about the discrimination that many people practice and it's not quite visible. You know, there is a type of discrimination that comes up as “help” or “support” to facilitate our life by other people. I have many ideas: sexual relationships could be another theme but not in the way presented through *Erotica Italiana*. Viewers, including myself liked this film, but my approach would be more emotional. (Emotion Picture Festival MP9 viewer, 2009)

I would show how people respond to disability and how they see disabled people's efforts for achievement. (Emotion Picture Festival MP12 viewer, 2009)

It's difficult...I would make a film about what I'm dealing with at the moment and that's access. Access to rights for disabled people, access to employment, education, medical cover. All these problems and it's not just about stairs, it's about bureaucracy. But I understand that bureaucracy affects everybody in Greece, not just people with disabilities. (Emotion Picture Festival FP13 viewer, 2009)

It's hard to answer, I haven't thought about it. Themes related to disability are daily issues and difficulties, sexual relationships, something that nobody has talked about is the non-disabled people response to disability. This is a theme that hasn't been explored because film-makers are afraid to approach it. What are their fears, what are their feelings when they see a person with disability, what would they do if they were in their shoes? These are things that most people think when they encounter a disabled person. (Emotion Picture Festival MP14 viewer, 2009)

I would make a film containing big doses of sci-fi and animation. I would love a combination like this. I would not do something compromising; I would prefer something radical and different from what we are used to. Some of the characters would be disabled but I wouldn't focus on this or stereotypes. (Emotion Picture Festival FP15 viewer, 2009)

I would focus on the people's mentality towards disability. Most people believe that disabled people are not able to do things that they actually are able to do. Technology helps a lot in our days. Those who haven't lived close to a person with disability believe that disabled people are useless. I would try to change this, not sure how, maybe by getting these people to live with a disabled person. (Emotion Picture Festival MP16 viewer, 2009)

I would make a film like those film-makers made depicting reality without idealising it. Some films idealised some matters. I would go darker not because I am a pessimist, but because I want to shake people up the way I've been shaken up. I am not easily moved as a person but here some films managed to shake me up by depicting stories to their extreme. I like the extreme and I believe that when you want to make people understand you have to present stories in an intense and powerful way. (Emotion Picture Festival MP17 viewer, 2009)

As the *Emotion Pictures- Documentary & Disability International Festival* was an innovative event for Greek standards, the general sense that comes out of the disabled viewers' interviews was the need for growth and expansion. In general there was a sense that such documentaries are viewed positively, but according to the interviewees there was still room for further development in terms of disability documentaries becoming more popular and expanding their connection to a wider public, either in terms of audience, but also in terms of stakeholders involved in education, politics, arts and the media. Disabled viewers recognised the benefits of an event that was newly introduced to Greek society, as it was the main focus for filling the gaps in representation of disability in the Greek media. It also served to initiate social dialogue about disability during and after the festival. What is more, disabled viewers tended to appreciate the fact that the festival organisers tried to promote cross-disability and cross-cultural representations based on more authentic or, as they mention in many cases, "real" images of disability. It became clear that disabled viewers expected to watch films, and particularly documentaries, that avoid the repetition of stereotypical representation that rely on the motifs of negative imagery, and they also spotted the narrative trap that many documentaries fall into: a disabled person's biography where the personal stays personal, and this way, reproduced the personal tragedy model, since it fails to become political.

5.5 CONCLUSIONS

Clearly the disability film festivals expanded their action beyond the artistic one, adopting an education role aiming for the change of social arrangements for people with

disabilities. As Frazee (2008), had warned the audience at the Unruly Salon sessions at the University of British Columbia in Vancouver, Canada:

There will be turbulence and majesty, encounters with the profane and the divine, illuminations that both affirm and unsettle. There will be nervous laughter, gut wrenching howls, pin-drop silence and riotous enthusiasm. There will be bafflement, resonance and revelation. And you will be changed. (Frazee, 2008, p.2)

I would agree that disability film festivals are the spaces where all the above reactions take place. People with or without experience of disability are exposed to stories and images that might affirm or might challenge their views, shock and surprise them, make them laugh, and give them new information. This impact is the first step to becoming aware of disability through its expanded and international dimensions.

Snyder and Mitchell (2008), see the disability film festivals as “depathologising contexts” that contribute to anti-stigmatising effort of disability communities. Sharing their views after participating in a few festivals as disability studies scholars and independent filmmakers, the authors describe their function quite clearly:

This agonistic, cross-cultural and cross-disability space becomes the site where the social implications of rights and policy-based initiatives are worked through for locals. This has been increasingly true as NGOs, and local, national and international government participate with private industry in the sponsorship of disability film festivals. (Snyder and Mitchell, 2008, p.12)

Vulnerable groups and arts seem to be some of the easy targets when it comes to funding cuts. With the excuse of financial crisis where budgets are squeezed, people with disabilities and artists are not considered priorities since, in strictly market terms, they are not “cost effective”. Within the frame of capitalism where people's worth is linked to their productive value, disabled people are not considered as good workers who will support the economy and make it profitable, so in this case, the system is not likely to invest in them. In addition, it can be argued that arts are not a great investment in days of socio-economic crisis and some of the reasons are that on one hand, arts are perceived as a luxury available to society under optimal economic conditions and therefore dispensable or, on the other hand, the arts can also be the medium of criticism and protest against any condition that brings oppression and violation of human rights, and therefore they are dangerous, making them disposable by those who have an interest in maintaining a particular status quo.

However, it is obvious that the support from the state makes the festivals larger and more social impactful in auctioning their mission. It also indicates the level of will of the state to participate in actions that empower its citizens, and can be viewed as a litmus test of democracy. The initiative on social dialogue and the community building through the medium of the image is considered as one of the important values of the festivals. As Snyder and Mitchell (2008) note in their analysis of depathologising context: “disability film festivals become a site for working through efforts to raise social awareness and return a sense of dignity to everyone impacted by disability issues” (p. 14). The authors clarify that documentaries that were made to serve educational purposes were characterised as “awareness” films by the audience. These films were depicting medical, rehabilitation and “pro”-care matters. It seems though that the independent production of documentary films shifted from that motif and are more interested in stories where people who have disabilities are the protagonists, raising their own voices for any matter of their lives. Snyder and Mitchell (2008) call these films “transgressive” because they reverse portrayals established by mainstream films, which depict people with disabilities as passive, dependent and unable to respond to society's expectations:

Disabled people become the agents of their own social integration by resisting the conventions of exclusion. In these films, disabled people check out institutions, fire their personal assistants, seek revenge upon insensitive bureaucracies, and pursue personal fulfilment apparently at the expense of everyone else's well-meaning efforts. Often such portrayals are seen as rejections of the beneficent “care” extolled by “awareness” films. (Snyder & Mitchell, 2008, p.13)

It can be argued that the programme of *Emotion Pictures Festival* successfully avoided the “awareness” genre promoting, in large part, the images that transgressive film presents, offering new ways of seeing disability. An additional contribution is the one in the shaping of collective identity, in a similar line to that of Queer Film Festivals. As Martha Gever (1990) had noted: “our identities are constituted as much in the event as in the images we watch” (p.201). White (1999) explains that “the festivals constitute a counter public sphere, providing a collective experience and a literal site of critical reception” (p.74).

Disability film festivals invest in pluralism, adopting an international character in most cases, and recruiting films through an open call. The range of representations is wide and the stories cover different cultures, genders, ages, disabilities and socio-economical

settings. The selection of films for screenings and awards unavoidably will be filtered by the criteria that each organisational body sets.

During my fieldwork, I witnessed an unofficial debate taking place about the selection criteria, especially for the competition part of the *Emotion Pictures Festival*. It was almost impossible for everybody to be satisfied with the results of the competitive section but a fair question was raised: regarding what criteria the jury applied its decision. Participants with a strong background in disability felt that the criteria were more inclined to film aesthetics and techniques than to knowledge of disability. The organisers tried to involve personalities with the appropriate skills and sound reputation in the festival jury, but nevertheless the non-disabled filmmakers and film critics outnumbered the disabled members of the jury. It was not the non-disabled status that was problematic but the lack of education in disability matters. This created a sense of juxtaposition, since some of the awarded films were not perceived by disabled viewers as empowering. Their narratives were based on stereotypical patterns, which once again aimed to tease out non-disabled viewers' emotions using disability. The depictions of the festival programme created a map of a puzzle that presented “new ways of *being disabled*”, yet some of the choices of the non-disabled, in large part, notably film experts who were members of the jury, created a dissonance. In the specific case of the *Emotion Pictures Festival* there was a discrepancy of representation in terms of authorising selection.

The initial intentions, as it was mentioned at the beginning of this chapter, were positive towards the social dialogue about disability. The organisers tried quite hard to give the festival the status of an event with high artistic standards, inviting filmmakers with important oeuvre in European and independent cinema. Undoubtedly, this initiative worked as a safeguard for the “film” element but at the same time it abated the “disability” element. Disability film festivals are the space where viewers are introduced to disability aesthetics and new ways of looking, so all the actions taken in this space should be coordinated towards its fundamental mission. Arguably, changing the ways of looking at disability and becoming familiar with disability aesthetics can lead to the development of inclusive thinking.

Siebers (2006), in his introduction to disability aesthetics, noted that making the influence of disability present in arts requires a revision of traditional conceptions of aesthetic production and appreciation. This process will also challenge established aesthetic presuppositions.

The *Other Film Festival* is also followed by the provocative question: “What are you looking at?”, officially established as the second title/slogan by the organisers. Surely this aims to challenge all the different, uncomfortable looks that disabled people have been receiving through encounters with non-disabled people. The interesting part is that disability film festivals can expose a variety of looks in the form of point of view in screened films and educate participants about ways of looking. According to Snyder and Mitchell (2008):

[...] multiple ways of viewing disability made available to audiences participating in disability film festivals play a key role in what could be called the politics of atypicality -the refusal to remain within the strict boundaries of medically and socially prescribed categories of sameness. (Snyder & Mitchell, 2008, p.14)

Viewers are exposed to a variety of depictions devoid of educational or medical context. Rick Randall, the artistic director of the *Other Film Festival*, interviewed by the filmmaker and participant of disability film festivals; Sara Tracton (2008), clearly stated that the selection of films was based on high production values and they avoided films that were didactic or focused on medicalising disability, (p.53). Disabled people come on the screen with their stories that in their generality are a close up to numerous human conditions. Disability Film Festivals offer the space for engaged staring encounters where disabled people guide the viewers on how to look at them and in this way - as Garland-Thomson (2009) notes in her analysis of staring, “move the audience towards a “newness” that can be transformative” (p.188). Harriet McBryde-Johnson, an American author, attorney, and disability rights activist, on “*Unspeakable Conversations*” of The New York Times Magazine in February 2003, stated: “It's not that I'm ugly. It's more that most people don't know how to look at me”. In McBryde-Johnson's tutorials on looking at the disabled body, viewers are invited to attend a range of “tutorials” at disability film festivals where disabled people's life stories come closer to the viewers'. This interaction, although virtual and mediated, allows viewers to become more familiar with the presence and actions of disabled bodies:

Both the films and the festivals challenge expectations and understandings of normative narratives, spaces and people, allowing for the raising of issues related to the place of disabled people in the world and the readjusting of perspectives on the subjects and on the systems that assign these definitions and categories. (Mitchell & Snyder, 2012, p.81)

This concludes what is described by Mitchell and Snyder (2012) as “the independent disability film festival circuit” (p.81) that supports and at the same time records the reactions to the “historical re-entry of disabled people into normative social orders” while challenging host governments to create, evaluate and reform their policies. Access and accessibility are matters that are always central within disability politics. Disability film festivals work towards the call for accessible cinema (Snyder & Mitchell, 2008, Tracton, 2008), where audio description, captions, print in Braille, ramps, moderated sound and light effects, the venue and its facilities, are designed and set in place to respond to the needs of a diverse audience. Tracton (2008) notes that “accessibility is about acknowledging all people as valued audience. Accessibility leads to opportunities for full inclusion and engagement in the arts”, (p.50). According to Mitchell and Snyder (2012) disability film festivals promote and support the independent disability cinema, a term that they use for the films included in the festivals’ programme and the conditions of viewing. The independent disability cinema exposes and critiques the “national normativities: the exclusionary social orders that dictate the local boundaries of physical, cognitive, sensory and aesthetic foundations of embodiment”, (p.83). In this way, disability film festivals suggest and engage alternative ways of being disabled and seeing disability as a counternarrative to social exclusion and discrimination that the oppression of normativity imposes on disabled people. As Mitchell and Snyder (2012) note:

...disability film festivals show disability as a strategy of referencing identity in the absence of a coherent and universally shared experience of embodiment. This strategy questions containment of any sort, fighting against the forms of identity-building that contribute to exploitation and exclusion. (Mitchell & Snyder, 2012, p.87)

The programme of film festivals include representations of a wide range of social and material dimensions of disabled bodies. This “tactical deployment of body chaos” (p.87) invites the audience to engage critically in questioning the national normativities and understanding the complexity of disability. Disability film festivals also embrace and promote the collective identity of disability by screening representations of different types of disabilities and avoiding practices of grouping and categorising these diverse depictions, as these would be practices of oppression. The audience, released from the tendency of becoming “diagnostic or therapeutic experts” (p.87), is exposed to this human variation and becomes more familiar with the diversity of unruly bodies. Disability film

festivals call their audiences to reflect on social and cultural norms. Viewers are engaged with a resistance to normativity, since they get exposed to the stories that disabled people and their advocates choose to say in order to demand more visibility, claim the position they want and occupy more public space in their local societies. This engagement initiates a discussion with strong political content and as such it is transformative, since it allows viewers to reflect on aspect of the politics of disability.



CHAPTER 6: FILM ANALYSIS

I've changed sides now. Normally, as a disabled person, you're always being stared at. Now, I am on the offensive. [...] and I'm saying: "Look! Look at me!"
– Sofia, *NoBody's Perfect*.

Don't let them spread silly rumours about me, or make me a god.
–Richard Bach, *Jonathan Livingston Seagull*.

6.1 INTRODUCTION

The discussion on representations and disability film festivals would be incomplete and irrelevant without the examination of the documentary films that composed the programme of the festival and shaped various representations. Following the set criteria, which were:

- a) award winning
- b) popularity with disabled viewers – interviewees
- c) researcher's own suggestions

nine documentary films were selected for critical disability studies analysis or crip analysis. In my analysis, I examine films individually but also comparatively where I find that there are commonalities in themes and discourse. Starting with the documentary film *Invitation to the Dance – Body and Taboo* I discuss the fluctuation of "otherness" in a dance project that aims to provoke taboos. *Letter to Lou*, the second film under analysis, is a father's confession letter to his disabled son. Importantly, the father is the filmmaker as, so he fill a dual role. In this visual confession, the growth of son and father unfolds by presenting different stages of understanding and living with disability. *Body of War* is an anti-war documentary film that depicts disability as a casualty. *Breadmakers* is one of the short documentary films that was selected for analysis and it depicts a case of supported training and employment. *Please listen to me* and *Including Samuel* are two documentary films that I examine together as they both negotiate the matter of educational inclusion and transition from lower to higher educational settings. *MasterPiece – Part I, NoBody's perfect* and *Shameless: the Art of Disability* are also analysed together. I consider their

representations significant for crippling stereotypes. Their social actors are crip killjoys who openly challenge notions of aesthetics, beauty, and normalcy by taking action for political and cultural matters related to disability. Nine documentary films narrate the stories of disabled social actors developing a cross-cultural and cross-disability frame of representations to the extent that the depictions of nine films can cover. These indicate the preferences of the festival's jury, disabled participants' and my own.

6.2 FLUCTUATION OF “OTHERNESS” IN A DANCE PROJECT THAT PROVOKES TABOOS

Invitation to the Dance – Body and Taboo/Einladung zum Tanz - Körper und Tabus

Gerhard Schick | Germany | 2006 | 89 mins

According to a very short description on the festival award page, “the film shows how art creates bridges between people with and without disabilities, between continents, races and cultures” (<http://www.ameamedia.gr/en/node/70>). The art of dance becomes the bridge between people with diversities. This is the aim of König's projects and the principle mission of the dance company she founded in 1995, DIN A13. By introducing new aesthetic categories in contemporary dance she challenges current visual habits and she also provokes pre-established ideas about physical disabilities and dance performance. König's dance projects aim to challenge several stereotypes and taboos - not just those related to physical disabilities- through a language of symbolic and poetic imagery. In the context of the development of a platform for an artistic dialogue on complex relationships between dance, contemporary art, society, otherness, disability and aesthetics, DIN A13 has developed a number of collaborations in different places around the world, such as Brazil, Ethiopia, Ghana, Kenya, Senegal, South Africa and Sri Lanka, with the support of the German Cultural Institute, the Goethe-Institut. The performance “Counter Circles” was the product from the dance project that took place in Kenya, Nairobi, with the participation of mix-abled dancers. In this context, the term “mix-abled” is used in a positive inclusive context for disabled and non-disabled dancers. I do not refer non-disabled dancers as able bodied because it has been proven, especially by dance project like “Counter Circles”, that dance, particularly contemporary, allows a big range of possibilities of movements and body performance so that all bodies can participate if they serve the repertoire of movements for each performance. The “able body” is stripped

off from its characteristics that at the same time impose limitations on other bodies and exclude them as non-abled. As it will be pointed by one of König's co-choreographer the participation of mixed-abled dancers offers an innovative and extended repertoire of movements, which also expresses and reinforces the politics of atypicality (Mitchell & Snyder, 2008).

In examining one of the basic discourse fragments of this film, the body, it is important to begin with Ondiege Matthew's statement who is the co-choreographer and the interpreter between Gerda's team and local dancers. Ondiege talks to the camera and admits that he was impressed because it was the first time that he saw disabled people turning up for contemporary dance. He believes that most of them had never tried contemporary or even simple dancing before. Ondiege considers the exposed and performing disabled body as a political action taken by individuals:

Showing the body is something very political in a way, not for everybody it is just free to portray something that has to do with their bodies. We have a lot of barriers to cross because by the time they come out to accept that they are part of life and they should be seen on equal level with other normal bodied human beings, and then accepting that they can perform, it is really a process. (Schick, 2006)

Clearly, Ondiege highlights that the political action of showing the disabled body presupposes a process of self-acceptance, claiming equal rights and the realisation of the ability for performing. What Ondiege describes can be defined as a coming-out practice within the frame of crip theory. The invisible disability becomes visible rejecting the oppression and the standardised frame of abilities that the compulsory able-bodiedness compels.

Gerda's methods for working with her inexperienced dancers also mirror coming-out practices. She is interested in finding out the potential of her dancers' bodies. They explore together how far they can go with their bodies, with Gerda first demonstrating movements that her hand can perform.

Later, as the group still explores body image and movements, Gerda asks them to pretend they are models exposing their beauty but also competing with the other models around. The group becomes creative: exposing body parts, posing, and trying acrobatic movements. Stephen, one of the disabled participants, puts his weak leg around his neck and he poses with pride. On another shot he uses a shovel as a mirror and a small broom as a comb even though he does not have any hair. Male participants are presented as seeming to adapt easily to the role of model and are confident with posing and exposing

body parts, performing handsomeness, charm and acts of masculinity. However, only the two non-disabled dancers improvise intensely upon the request of being competitive. Gerda encourages Lucy, the only female participant from the local team, to come out of her shell a little more, by telling her that she is sexy. Lucy responds to this by exposing the area of her left breast.

Gerda changes the exercise and everybody is asked to show a part of their body they do not like. Every participant shows the part or limb that he/she does not like. Most of the disabled dancers indicate the part affected by their impairment or body areas close to the impaired part which function in support to it. Gerda asks them to improvise exposing these particular parts as those that they are really fond of. Her method brings about the desired result as a different quality characterises dancers' improvisation and new movements come to the surface. This particular improvisation is an act of the body that becomes political. Impairments and flaws are embraced and demonstrated as beauty crafts, rejecting at the same time any "passing" (passing as non-disabled) strategies and the compulsory conception of the "normal" body. Gerda calls her team to proceed with a coming out act.

Ondiege enthusiastically emphasises that the unformed body of the inexperienced disabled dancers, creates images that do not exist in mainstream performance. He adds that disabled people have a rich movement vocabulary and this is a statement in accordance with the politics of atypicality and disability aesthetics. The disabled body breaks down the limitations set by the representations, and in this case, the performances of the body that are constructed and perceived as "normal". Disability offers new movement vocabulary that also adds to the development of new aesthetics beyond those standardised by the compulsory normalcy. Obviously contemporary dance as an open and flexible field can support these new developments, exposing its audience to this rich context of various bodies and expanded aesthetics beyond the limited boundaries of socially and medically constructed notions of sameness, beauty and ability.

These bodies that come out through Gerda's choreographies also question and challenge sociocultural beliefs that society uses to stigmatise their bodies. The dancers that participate in this project come from the informal settlements of Nairobi and most of them have been infected by poliomyelitis in their childhood. The description of the rehabilitation methods is interesting as it indicates the lack of access to medical facilities and the trust in more traditional practices. Patrick, one of the dancers, was infected by polio and his right leg was paralysed. He recalls a day that his mother dug a hole in the

ground and put him in, in order to straighten up his leg. Patrick comments that due to poliomyelitis and his impairment he was not allowed to attend school. Lucy also confesses to the camera that she had experienced the same therapeutic method. She was put in a hole, covered with soil and clay up to her waist. She claims that this 'cure' made her walk, as until then she would only crawl. Patrick on the other hand, feels that this cure did not change his situation even if he had stayed in the ground for two weeks.

It was not only the rehabilitation that relied on tradition but also the reasoning behind the cause of the impairment. Lucy openly wonders if the cause was a poliomyelitis aftereffect or witchcraft. She mentions that her mother believed that it was witchcraft inflicted by a woman who was jealous of Lucy's beauty, youth and body shape, which tends to differ from the current dominant Western perception of healthy body shape.

I can't tell about my leg. My mum said it was witchcraft. Yeah... There is another woman there. She saw me, I'm young, I'm beautiful, I'm fat... I don't know whether she put the egg, or what she did. My mum told me it was witchcraft. But I, myself, maybe. But...it's just polio. I think so. Because it started when I was young. (Schick, 2006)

Ondiege, who not only is the co-choreographer and interpreter but also presented as the commentator on socio-political matters that arise during the project preparation, confirms that disability, particularly when it affects children, is associated with curses and witchcraft. Prejudice of this kind stigmatises disabled children. Parents hide and isolate them from community and education, allowing the circle of prejudice, stigma and poverty to grow bigger. As Douglas notes from an anthropological (and perhaps a slightly Western Eurocentred) perspective:

[...] the ideal order of society is guarded by dangers which threaten transgressors. These danger- beliefs are as much threats which one man uses to coerce another as dangers which he himself fears to incur by his own lapses from righteousness. They are a strong language of mutual exhortation. (Douglas, 2001, p. 3)

The marginalisation and isolation of disabled children is a phenomenon observed across different cultures. The reasons that usually lead parents to isolate their children are various and derive from traditional exclusionary social settings, lack of awareness, unequal access to education, health systems and social provisions. As the social model of disability claims: the barriers are set by society.

Gerda and Ondiege proceed with the risky business of challenging taboos that haunt the society of Nairobi. Two eggs are laid on the floor to provoke the dancers. Stephen and

Patrick admit that they were afraid and experienced negative feelings. They did not want to touch them since they did not know where the eggs came from. They both related the eggs with voodoo practice. Ondiege explains to the camera that eggs are commonly used by medicine men and voodoo practitioners so there is a principal superstition around the egg. The aim of this provocative exercise was to check how dancers with different cultural backgrounds would reflect on and react to the eggs. Gerda reads the egg as a symbol of something forbidden, untouchable and linked to fear, so it is a taboo. As taboos are a popular part of Kenyan culture dancers share different daily human manners that are considered as such. Ondiege tries to push the discussion a bit further, questioning if the group as a group of dancers believes in taboo. There are different responses and one of the dancers' comments: "that's the main problem in Africa as a whole; bridging the gap between culture and this contemporary modern world, it's so hard" (Schick, 2006).

The views amongst dancers vary, most of them were aware of the established taboos of their culture but they doubted the punishment or vengeance effect in the case of not adopting them. Interestingly, all the examples of taboos and prejudice that were given by the dancers were related to women, either in the context of sex practices, menstruation or motherhood. Within this context the female body is the other body, constructed by numerous cultural misconceptions that aim to reduce the "disorder" this other body causes. The female body has been subject to interpretations of purity and impurity, pollution and cleanliness, holiness and sin; shifting extremely rapidly from one pole to the other depending on the sociocultural and religious positioning. Taboos are constructed provisions that aim to regulate unclarified notions of sanctity and sin. As Douglas (2001) comments taboos were inspired by the fear of malignant spirits and they were constructed to prevent their intervention. In the cases where the belief in evil spirits is deeply rooted, taboos become rules that indicate spiritual uncleanness.

Gerda takes the risky business further by adding two provoking scenes to the performance: one is homoerotic and the other depicts a rape of a woman. The most provoking, as it is a big taboo for Kenyan culture, is the homoerotic. In a close up, a hand strokes a man's arm that touches his torso. The hand goes up to the fingers, back down to the elbow and then up to the man's shoulder. As the hand goes from the elbow to the shoulder, the angle of the camera opens wider, showing Patrick and Adam, two of the local dancers, working on this act that is related to homosexuality under Gerda's directions. Marc, a professional dancer member of DIN A13, comments:

The homoerotic scene is the only one that could be called provocative. It directly addresses homosexuality, which is taboo, forbidden, illegal. Up to 14 years imprisonment. It's not an easy scene. (Schick, 2006)

Both Adam and Patrick had difficulties at the rehearsals but they realised that this act of physical affection was part of the performance. Homosexuality exists in Nairobi but in the closet as it is a major taboo. Eggs and homosexuality were combined in a symbolic act of breaking down taboos in the final show and everyone that participated in the dance project is determined to take the risk. The homoerotic scene develops to a cleansing with eggs act. Adam first breaks an egg on his chest, in an intense and provocative movement and then Patrick applies yolk on Adam's upper body. Marc also breaks one more egg on Adam's back and both dancers apply it mimicking movements of washing. The scene functions as a representation of a ritual of catharsis, in the sense of purification and intellectual clarification, as interpreted from Aristotle's definition of Greek tragedy and commonly met as a practice in performing arts. Odienge comments that breaking the egg is a key point because it actually symbolises the breaking of the taboo. He explains that it is an act of cleansing somebody from something horrific and traumatic. This specific scene has a double meaning as it functions as a healing process and a "coming out" performance. This time the performing bodies represent other than normate sexuality: the forbidden as illegal, well hidden, penalised and deemed as hideous. Through the cleansing act they make a statement for seeing these other bodies clean from prejudice and constructed misbeliefs inspired by fear and inflicted notions of normalcy.

Schick's documentary supports disability aesthetics and the politics of atypicality by presenting the collaboration of DIN A13 Dance Company, with local dancers in Nairobi, through the filming of the different stages of project development: audition, improvisation, rehearsals, and participants' reflections. My analysis examines the particular discourse fragments that arise from Schick's documentary: the performing body, taboos, social inequalities and shifting status of "otherness".

The film opens showing a wheelchair of an unusual type that looks more like a handmade tricycle. A physically disabled man is crawling to reach it on a very narrow path in an informal settlement. A woman is carrying his sandals, bag and a bowl with water. The man washes his feet sitting on the wheelchair with the woman's help, before putting his sandals on. In a voice over he talks about the opportunity he is given to dance. For him it is an opportunity to express and to explore what is in him. A tune with an African touch covers his trip from informal settlement to town. We watch him driving his

tricycle chair by turning the handles, which move the bike chain of the chair. It seems quite impressive how the chair moves on the muddy streets of the slum. A crowd of pedestrians and a truck are moving on the same road at the same time, creating an image of a chaotic passing with no safety arrangements, neither for pedestrians nor for the man on the wheelchair. In a voice-over the disabled man comments:

Life here in Kenya is a great challenge. You cannot rely on anybody. You need to fight for your own life...to make a living and if you are not hard working you'll not achieve anything here. (Schick, 2006)

We still watch the man driving his tricycle on a busy main road. The tune makes the bridge for the scene that introduces Gerda König, the German disabled choreographer. We watch Gerda sitting in a moving car and in a voice-over she explains the aim of the trip in Kenya. Already from the scenes of travelling on the roads of Nairobi, an interesting and unexpected sense of contrast is created between the black Kenyan disabled man and the white German disabled woman, as Gerda is presented as being safer and in luxury, in comparison to the Kenyan disabled man on the handmade tricycle. Here the characteristics of disability and sex are surpassed by race and class. Of course not just by definition, the access to a safer, faster and more effortless transport is not a privilege guaranteed by the fact that Gerda is white but more by the fact that Gerda is a white disabled female choreographer, who comes from a Western European country with a stronger economy, which also funds Gerda's projects in different countries. The matter of social inequalities and how these are reflected on the participants' views, is highlighted by Gerda herself and her team, in scenes that follow later on the film's structure. This points to the intersectional nature of marginalisation and injustice.

From the first scene of the documentary with Stephen, one of the disabled dancers crawling in a narrow muddy path to reach his wheelchair, an image of poverty and a sense of lack of quality of life is created. The documentary is full of scenes that highlight the contrast between poverty and quality of life. Landscapes that combine a mixture of big buildings on one side of the road debris and detritus on the other, chaotic traffic where pedestrians, cars, trucks and wheelchair users move in the same lane, informal settlements by landfills where people pay high rents for really small makeshift rooms, are only some of the indications of social inequalities that characterise Nairobi. It is important to note that these are also the living conditions of the disabled dancers who participate in the dance project. Gerda and the two white dancers of DIN A13 Dance Company, Gitta and

Marc, experience these inequalities and reflect on their position as white Europeans in relation to the rest of the group.

Gitta: What will they think? These Europeans, these Germans come here, spend thousands of Kenyan shillings on props and then discard them. I did feel uneasy about that, because it's something that is unimaginable for them.

Marc: What is crazy about this work is that you get to know people very well because of the intensive and often the very personal nature of the work. You get to know one side very well but nothing about their lives. This predicament is very discernible here, it's plainly apparent because we often can't comprehend their stories. If people say, "I grew in a slum", I haven't got the faintest idea what that means. (Schick, 2006)

More striking though is Gerda's reflection which declares a shift of hierarchy and status:

During the day it's fine in town but you are always wary. You feel you have to look around and be careful. They distrust you too. You are somehow inside and also outside. Everywhere there are security centres where you are safe, surrounded by barbed wire and security staff. I can't tell whether in our fortress here I'm on the inside or on the outside, whether this is freedom or isolation. These questions occupy me because you are always confronted with them. I definitely get the feeling that because I'm white, and I have a motorized wheelchair, I have a higher status. They make a clear distinction between me as a white European woman who is disabled, and the disabled who live here. In certain situations I got the feeling that I wasn't seen as disabled or inferior, simply because I'm European and white. That was really strange. (Schick, 2006)

The race, skin tone and a technologically advanced assistive medium, are the characteristics that classify Gerda with a higher status amongst the black male and female disabled people who participate in her project. Gerda seems surprised by this classification as she probably carries the experience of the disabled female wheelchair user who in Western culture has been, and still could be, subject to discrimination and be ascribed with a status of inferiority. However, from the very first scenes of the film, this reading does not seem to be unexpected. Just by comparing the make of the two wheelchairs, Stephen's handmade tricycle and Gerda's electrically motorised one, immediately there is a reading of differences in social background and assistive provisions. Even though someone could claim that Stephen's physical disability is not as severe as Gerda's, as he presents higher level of mobility, the unequal access to facilities and assistive technology creates a schema of representation that depicts Stephen as the "other" with a lower social status. In contradiction, to all previously mentioned taboos

ascribed to women in Kenya, Gerda's race and - determined by presentation - class overrule her gender within the "inside-outside" context.

Images of newly built accommodation in protected areas with wire fences and CCTV cameras, contrast with the overcrowded informal settlements by the landfill and depict what Gerda experienced as "inside-outside" positioning. However, there are some very crucial differences between the experience of DIN A13 team and that of the local dancers. Firstly, for the team of the white Europeans, it is a visitor's experience that comes with the knowledge of a different socio-political and cultural system and with the benefits of their country's stronger economy. Their experience is temporary, as it will come to an end when they leave Nairobi. In contrast, the "inside-outside" positioning is the living condition for the local dancers and they need to deal with it daily as it has an impact on their lives. Wired fences and CCTV definitely do not guarantee safety and freedom, they are practical actions of division and control; the result of the violation of human rights. According to UNICEF for the year 2006 which was also the year that the documentary was released, 46% of people in Kenya were living below the poverty line and the latest Human Development Report of United Nations Development Programme indicates that 43.37% is the percentage of the population that lives on an income that is estimated to be below \$1.25 per day per capita. Disabled people are reported as one of the social categories most affected by poverty. Living below the poverty line manifests as a violation of human rights and brings human life to a vulnerable state. Obviously, Gerda, Gitta and Marc's experience is an outside view of those who had the privilege to be accommodated "inside" the properly built and securely protected areas. On the contrary, local dancers' experience is an inside one as they deal daily with the "outside" the safety net world.

Secondly, there is also a difference in participation and decision-making. Gerda and the two dancers from DIN A13 arrive in Nairobi to set and present a dance project through an organised collaboration that is fully supported by cultural and funding institutions of their country. Gerda is the founder and owner of the dance company and her two colleagues are professional dancers. As it has been mentioned Gerda works internationally on projects that question pre-established ideas on dance, body, disability and aesthetics. The documentary does not really give much information on Gerda's background and achievements but through the scenes of auditioning, decision-making, planning, coordinating and reflection, a strong and creative personality unfolds. The image that the film shapes is that of a professional and experienced choreographer, with

a very clear plan of the performance, quick in suggesting alternative options and creative with improvisation, ideas and outcomes. Her methods also seem to be very effective in developing the required levels of trust and communication within the group and transferring her ideas to the dancers through reflection that finally becomes embodiment. No doubt this is a very powerful realistic representation of a disabled woman in action and control. As some of the disabled participants commented, Gerda inspired them first of all to take part in her project and secondly to take ownership of their talents and abilities.

However, considering the “inside-outside” social structure, it is unavoidable not to question “whose voice” is raised. According to Kapoor (2008):

When we act in accordance with personal, professional, organizational interests, our representations of the Other say much more about us than the Other, or at a minimum, they construct the Other only in as far as we want to know it and control it. (Kapoor, 2008, p.50)

Filtering through a postcolonial approach shall we be more critical on these cultural collaborations/interventions where the distinction between dominance, paternalism and friendship, professional interests and empowering the “other” is quite blurry? It would be inadequate to jump to ultimate conclusions just from the reading of an edited documentary. The reason that makes me sceptical about the matter of decision making, is that even though there is a well-organised and creative effort of breaking down stereotypes, the dynamics of the different “inside-outside” status between the organisers and the participants leave traces of uneasiness. My argument about decision-making does not refer so much to the actual development of the dance performance that would seek a different type of collaboration and artistic project. My aim is to stress that empowering marginalised voices requires their participation in decision-making. The documentary makes it clear that Gerda is a white disabled woman with a strong voice coming from a society where there is a level of access to decision-making, whereas the disabled dancers who live in the informal settlements, the designated “outside” space, are excluded. Stephen’s accident evidences this. A vehicle hit Stephen and his wheelchair and he was left with no support and no access to medical care because he could not afford it. His co-dancers’ comments on Stephen’s accident confirm a reality of unequal treatment that leaves them in a passive position.

The hazy and uncomfortable sense of “inside- outside” inspired Gerda for creating the closing act of the performance. All dancers are on the stage, trying to reach, step by

step, a big cage made of wire. Stephen sits in the cage and every time the others get closer he shouts: “stop”. As they reach the cage they leave it wide open for him as a symbolic act of liberation but Stephen keeps shouting “stop” with an obvious increased anxiety. Adam, crawling from one open side of the cage to the other, approaches Stephen, when he gets really close to him, Stephen turns his face to the audience and shouts loudly: “stop!” as a final but strong cry for ending all types of discrimination.

6.3 GROWING TOGETHER: A FATHER’S CONFESSION LETTER

Letter to Lou (Lettre à Lou!)

Luc Bolland | Belgium | 2006 | 80 mins

Letter to Lou is a documentary that narrates a father’s account of his experience of parenting a son with a developmental and sensory disability. There is literature on fathers’ accounts of parenting disabled children that have been developed in a slow pace since the 1980s. Hornby (1992), mentions seven common themes that occur from fathers’ testimonies: first comes the initial reaction to the realisation of having a disabled child, second is the process of adaptation to disability and fathers’ existential conflicts. Negative feelings towards the professionals involved for child’s care and support is the third theme. Fourth is the stress of caring for a disabled child in relation to the impact on fathers’ lives and their relationships with wives/partners and other children. Finding suitable support and resources for long term care is the fifth theme. Sixth and seventh matters occur from reflections on personal insights such as expressing positive and negative feelings for their disabled children and acknowledging personal growth as an outcome of parenting a disabled child.

Luc Bolland is Lou’s father and also the film-maker. He filmed the first six years of his son’s life reflecting on his thought and feelings about being Lou’s father.

My Little Lou, my little Prince, this film tells the story of the first six years of your life, the story of a blind little boy, mentally different. This is the story of a daily struggle to make you want to leave the inner world you have created to protect yourself. Our world frightens you and looks much too complicated, aggressive and demanding to you. This is the story of your life seen through my eyes as a father and filmmaker. (Bolland, 2006)

Lou was diagnosed with septo-optic dysplasia in the early stages of his development, medical terms difficult to understand, for a developmental condition that was even harder to accept and deal with.

-“Your son suffers from a very rare congenital malformation of the brain (1 case out of 10 million births). It’s an orphan disease called septo-optic dysplasia syndrome.

-I’ll explain to you: Your son’s optic nerve is atrophied. As a consequence, he’s blind”

-We suspected it.

-“That’s also because of this syndrome that Lou is thirsty all the time. His hypophysis is underdeveloped.”

- I beg your pardon?

-“The hypophysis is a gland in the brain which regulates the whole hormonal system. In the case of Lou, it’s not enough developed. As a consequence, his body doesn’t retain water and he dehydrates very quickly. It occurs frequently with this symptom but don’t worry, this can be controlled very well by the daily intake of medicine and regular tests.

- And one more thing...Lou has no septum.”

- No what?

-“Septum. It’s a membrane separating the two hemispheres of the brain, of which we don’t know the precise usefulness. Some children grow up normally without this membrane but other children suffer from a more or less serious mental handicap. We cannot yet predict Lou’s future intellectual capacities. At the earliest, a diagnosis will be possible when he is an adolescent.” (Bolland, 2006)

While we hear Luc in a voice-over re-enacting his dialogue with doctors describing Lou’s medical case, and also his reaction to the diagnosis, we watch different shots of Lou when he was a baby. In the last two frames he is held by his little sister and his mother enjoying some happy moments of affection. The image and content of the voice over, create a juxtaposition. Watching Lou in these shots it is impossible to match the diagnosis with this baby that shows no sign of any type of impairment. The voice over that inform us about Lou’s medical case is accompanied by a tune which is quite mellow and very significant of Luc’s change of feelings regarding his son’s development. Luc presents the medical description as the answer that caused more questions in his mind. Medical tests were required, as he and his wife had noticed that their son’s development and responses did not follow the standards of his age. The report of results caused shock and frustration; full of medical terms, hard to understand and even harder to relate to this vague prediction of his son’s future development. The description of Lou’s diagnosis reflects the medical

model of disability, which objectifies the person by defining every individual through standardised medical labels. Labels that support the terrifying effect of a diagnosis, since they are constructed by a language not widely-known, which causes more confusion but at the same time hides a content that sounds strong enough to foreordain a child's life.

Luc recalls the moment of getting the news of his son's condition as a very confusing and frustrating experience. He confesses that it took him time to show his feelings, hiding behind his camera, filming family moments pretending that everything was fine. Lou's first birthday was the day that became the tipping point for Luc's emotional state.

That's too much! That evening my anger explodes....and turns against you. To my rebellion, the violence of my words, you oppose your "joie de vivre" (joy in life). I'm the only one to complain. Being so down in the dumps I'm destroying myself, causing you inevitable harm. I have to react, to decide whether to indulge in my suffering or to embrace life. (Bolland, 2006)

Grief and anger, frustration and guilt, the typical and most common feelings about disability, which actually are not so much a reaction to disability itself but rather to the constructed expectations of creating a healthy and "normal" new life, imposed on parents. A child should fulfil their expectations and dreams that are actually influenced by sociocultural norms. Even though giving birth to healthy children it was more imposed on women as a mother's primary mission, status of complete manhood was also judged upon the fact of being a father of strong and healthy children. This expectation derived from the demand of sustaining the system of the society whether the society needed warriors, workers or consumers. Disability is the transgression, the contravention of this constructed and stereotypical mentality, which can be found in different cultures and periods, initially as the primal need to protect the tribe, then a eugenic ideology and currently as an essential requirement for surviving in a society that follows and covers the requisitions of capitalism and neoliberalism.

Fathers' responses to their child's diagnosis have been recorded as invariably very intense (Herbert & Carpenter, 1994, Hornby, 1992). Dealing with a diagnosis could also cause a personal crisis and the process of adjustment can be turbulent and long lasting (Harrison et al, 2007; Hornby, 1992). Lou's sisters' approach to their disabled brother is interesting as a contrast. They include him in their games and daily activities, as there is no need of adjustment or reflection. They support him and they try to teach him songs, words and games that help him with his development. All come naturally with no hints

of concerns about their brother's disability. The two girls, also children, due to their age have not been infused with or adopted the constructed expectations created by the oppressive notion of normalcy yet. They approach Lou as their baby brother who they can play and have fun with. They can teach him new things but they also learn anew vocabulary from him; of movements, behaviours and mannerisms. Instead of questioning Lou's status of "normalcy", the girls approach him as the person who adds all these new experiences to their family life. This approach could be read in the same line with Siebers' (2006) perspective on the presence of disability in culture; it makes the art world richer as it offers a new potential for future development. Even further, the living experience of disability seems to be perceived by these two girls as a new experience, full of rich stimuli beneficial for their development. Luc finds his daughters' approach comforting and empowering, so when he reflects on a scene where his two daughters appear to lie on the floor next to their brother, imitating his mannerisms in a playful way, he comments: "Boland dynasty".

As the film depicts Lou's first six years, Luc confesses that he goes through different phases of adaptation and existential conflicts. As Lou's development follows a slower pace than the one that is set as "normal" by medical and measurable standards, Luc experiences the cancellation of his expectations and he cannot avoid the comparison with his two older daughters. In order to observe from distance and also from a de-sentimentalised angle Luc uses his camera as a filter. He decides to film only on occasions that he considers important, as it seems pointless to him to create visual records for his blind son. The camera is the tool that creates space for distance but also contributes to observation, which seems to be important for Luc in order to manage his son's disability. What becomes problematic for him, more as a father rather than a filmmaker, is –as he calls it- the "image world". Luc comes across new challenges that lead to existential conflicts; what is the point of creating an image world for a son who is blind? As an extension of this question, there is probably a hidden and deeper pseudo-question; how a father, who is a filmmaker and to whom the image is so important, will transfer his passion and his being to a blind son that will care less about image.

Luc expresses his anxiety by referring to challenges such as teaching his son how to walk and finding new, particularly tactile and empirical ways for explaining nature and the world. The documentary depicts the family dealing well with all these challenges. Luc also participates in his son's empirical learning which relies a lot on fun activities at home,

in nature and during holidays by the sea. Using humour also is a great method and stimulation that motivates Lou and makes him respond.

It is clear from the very beginning, even from the title “Letter to Lou”, that the documentary narrates the father’s personal difficulties in dealing with disability. Even though the film is full of images and scenes that focus on Lou, Luc’s confessions are a non-disabled person’s accounts of encounters with disability so closely and personally. He goes through all the different phases, including depression, trying to deal with the sociocultural constructions and societal barriers that present and translate disability as a personal matter. The only clear reference to societal barriers is made when Lou becomes quite confident with his mobility but he does not use a white cane yet. Luc realises that his son will have to rely on them, as the streets are not accessible and there is lack of signalisation for blind people. At this point there is a small shift from the personal responsibility to societal; Lou’s father makes a brief manifestation that barriers are set by the society too because it excludes disabled people through the limitations that it sets. Even though Luc makes a last effort in his epilogue to give his film a political sense by stating that he decided to share the story of Lou’s first six years for the children like his son “to find a place in our society” (Bolland, 2006) and to disrupt the compulsory sameness, the context of his film remains a personal account of a father’s growth, stated as an outcome of parenting a disabled child:

[...]Your expressiveness, so rare by blind born people is surprising. You are an open book. Absolute sincerity as you cannot imitate other people, like we do. You’re fascinating me more and more. As I’m taking these pictures, a crazy challenge imposes itself upon me. Forgetting everything sight has taught me. Starting from rock-bottom again. Rebuilding my own perception of life from yours. Entering your world, limited to the close things that you are able to touch, but open to all the sound perceptions. In order to be your guide, as every parent is, after all. I’m learning life again, on your side. (Bolland, 2006)

[...]Your difference has made me see life from a different point of you, on this planet where we are made to think that everybody must be alike. Because, you see, my little Lou, we also have our fears: fear of the unknown fear of the other. In front of that, I only have two weapons: faith and love. (Bolland, 2006)

Luc’s effort to change his own filters of seeing his son is central in the film. It is interesting that on one hand, he becomes more optimistic when Lou shows signs of what Luc understands as “normal” (eg. facial expressiveness, walking with confidence, walking on the sand, role-play that involves direct interaction), on the other hand, he realises that he needs to deconstruct and re-evaluate his knowledge of “normal” and

perception of life. In contrast, the depiction of Lou, apart from what we learn from his father's concerns and the slow motion scenes where the camera focuses on his compulsory mannerisms, shows a personality characterised by the typical elements and challenges that come with infancy and childhood. Certainly there is a developmental condition, the septo-optic dysplasia, which affects Lou's development but the film definitely supports an image that goes beyond the disorder and illustrates the child's complex personality and talents.

The documentary seems to be a puzzle of family videos and scenes that were intentionally filmed in order to put together significant moments of Lou's first six years. Luc's confessions and reflections on a voice over, on one hand shifts the focus from Lou's depiction to Luc's thoughts and feelings about his son's action. The voice over definitely supports the idea of addressing a *Letter to Lou* but it also sentimentalises the depiction of Lou.

However, as it was mentioned before, as the film develops, delineating Lou's personality and his musical inclination, there are points where the viewers can distinguish between the two positions; Lou's character and Luc's thoughts and feelings. It is also made clear in a number of scenes, when Luc is behind the camera talking to his son, and in some cases it becomes obvious by the movements of the camera. In the process of adaptation to Lou's repetitive motor mannerisms Luc depicts some of these movements in slow motion and also in regular frequency throughout the duration of the film. This decision of editing helps the viewers to become familiar with this element of Lou's behaviour, accepting it as part of his identity. The film also depicts a smooth and natural connection between some of the repetitive movements and Lou's musical talent. Rhythm and music function as sensory stimulation for the blind boy but he also shows a genuine interest. Luc captures his son interest through different stages: first, Lou is presented as a focused listener, secondly, he tries a rhythm that he had listened to by an African drumming group, and thirdly, as he gets older he becomes interested in melody and singing. Viewers watch all these stages that define a process where Lou internalises stimuli from his daily activities and expresses them through music. His talent seems to be significant for his father in his choice of the closing scene which shows Lou playing the keyboards and improvising a short song about animals and his love for his mother. Two readings occur here, one is that Lou's musical talent could be perceived as compensation for his disability but since it is not central to the narrative structure of the film, it would be unfair to relate this depiction to the *super cripp* stereotype. However, the documentary

slightly flirts with it by investing space and time on this “extra” skill. A second reading is that this scene serves the sentimentalised mode and the manipulation of viewers’ emotions. In a voice over, Luc creates an emotional epilogue that is completed with the scene of the blind child singing about his love for his mum, a common recipe to move the audience.

The majority of the activities take place within the family environment. Most of the scenes are filmed at home or during summer holidays by the sea. All the family members appear in the film but Lou and Luc appear as the main characters, with Luc’s voice being the stronger voice. Lou’s mother has an interesting part, as she appears the one in control of his nurture, showing her affection and patience from the first day and through the whole film, even in challenging moments. Even though she is presented as the strong member of the family, who deals admirably well with the challenges that come with their son’s disability, she is the person with no voice as we see her talking on only a few occasions, always addressing to Lou and never the camera. Luc recognises and appraises his wife’s mothering skills and very characteristically he admits that he felt lost when she was away for a few days.

An interesting point, in the context of connections, is the lack of information on networks for support. Luc expresses a few times his anxiety of finding new ways in order to approach and teach his disabled son. The documentary presents him and his wife coming up with creative ideas and a number of fun activities that not only offer empirical learning and different experiences to Lou but they are also beneficial and enjoyable for the whole family. As Lou reaches pre-school years we watch again while his parents support him with introductory preparation for learning the Braille system and improving his mobility skills based on orientation exercises. Although scenes where Lou attends regular medical tests are part of the film, we are left with no information on any type of other professional guidance or support. Even Lou’s schooling is mentioned only very briefly through a scene where the school bus gets him at home and the preparation for Braille alphabet. There is no reference to which educational setting he attends. It also remains a mystery if he attends music classes. So apart from his family and doctors, it is quite unclear what are Lou’s other connections.

On the other hand, Luc admits that he sought professional help when he struggled and became depressed. In addition to this, as a parallel activity he decided to create a blog about Lou, his condition and the experimental ideas that he practiced daily to support his son’s development. This action and the film show a clear need for communication and

the development of supportive networking. It seems that Luc chooses the personal to become public as the approach that could alter notions of life, fear and living, and this is his personal way of seeking inclusion for his son.

6.4 DISABILITY AS CASUALTY: A BODY OF WAR TAKES PAIN TO ACTIVISM

Body of War

Phil Donahue & Ellen Spiro | USA | 2008 | 87 mins

Body of War is an anti-war film where the damaged body is depicted as the casualty that serves the arguments against the war and soldiers' recruitment. Disability becomes the "you don't want this to happen to you" argument, since it encloses the experience of daily suffering. As it is described in the first synopsis the documentary depicts Tomas' coming home story illustrating: a) the daily experience of his disability and the management of his changed body, b) his activist involvement against the war in Iraq and Afghanistan, c) his relationship with his fiancé and d) the construction of the pro-war propaganda during the presidency of George W. Bush.

What is problematic with the development of *Body of War* is the management of disability, which drifts between the effort of living an active life and suffering from a changed body daily regulated by pain. Historically, the depiction of war veterans was problematic in that dealt with acquired disability, the perception of the damaged body and the new self but at the same time, it had an impact on empowering the audience's anti-war feelings and claimed more rights and provisions for disabled veterans' rehabilitation (Norden, 1994, Safran, 2001).

In *Body of War* we watch Tomas in a dilemma of dealing with and denying his disabled self, seeking ways to return to his heteronormative masculine able body. Even though he takes action as an anti-war motivational speaker exposing himself as a living casualty, he clearly expresses grief and frustration about his disabled body. Tomas is screened as keen to carry on with his life and his relationship with his fiancé Brie but it seems that instead of accepting the changes in his body and looking for practices that will serve his altered bodily in reality, he insists on adjustments that will live up to what was known and accepted by him as heteronormative bodily functions.

Charmaz and Rosenfeld (2006) in their work on reflections of body and images of self note that:

People with chronic illness and disabilities confront tensions between body, self and identity that everyone faces (barring an early and sudden death); however, they experience these tensions in accelerated, intensified, and magnified form. These tensions (1) arise in such problematic concerns as maintaining a valued self, controlling information about body and self, and overruling images that others impart and (2) bring often tacit oppositions into view: visibility vs. invisibility of physical status, bodily control vs. failure, autonomy vs. dependency, victory vs. defeat, and acceptability vs. unacceptability. (Charmaz & Rosenfeld, 2006, p.37)

Body of War brings some of these tensions to the surface, as Tomas intentionally makes his impaired body, the failure of bodily control and his dependency on non-disabled persons, particularly his fiancé, visible; showing though at the same time his difficulty to value his disabled self. Twice he confesses openly to his frustration and grief about adapting to his disabled body and new self-image:

There are a lot of times that I sit in my back bedroom, lying in bed, just...crying with very little control. Usually it happens after my body does something to show how much disagrees with me. It happens sometimes when I watch people walking down the street. I am jealous of people that can walk. (Donahue & Spiro, 2008)

[...]You know, you see a guy he's paralysed in a wheelchair and you think "he is in a wheelchair", you don't think about, you know, stuff inside is paralysed. I can't cough because my stomach muscle is paralysed so I can't work up the whole coughing energy, I'm more sensitive to urine infections and there is that grey area of erection downside of this story. (Donahue & Spiro, 2008)

Since the film focuses on this type of confession it recreates the image of the war veteran as self-pitying, a common stereotypical depiction that was ascribed to war veterans by Hollywood productions (Norden, 1994).

Sexual pleasure and other bodily functions, like urinating and particularly penis erection, are part of the narrative structure of the film. Tomas' expressed his anxiety for assisting his body to respond to heteronormative expectations of male sexual performance. Very early on the film narrative Brie writes to "Crip College" website with a query about accidental bowel movement because Tomas is concerned that it might happen on the day of their wedding. There are also scenes where Tomas searches on the Internet for assistive medicine or tools that can help him with penis erection. He openly describes the functions of a few of the available options and Brie explains the complications with a penis pump in front of the camera. Assistance for body regulation

and functions continues in situations where Tomas is active. Brie, who clearly has taken over the role of personal assistant, keeps changing bags for Tomas' cooling jacket that helps to regulate his body temperature and pressure, she checks his daily doses of medication and blood pressure. In a quite explicit sequence of scenes his mother under his guidance supports him to urinate in his catheter in the back of their car. These depictions could represent what Siebers (2008) describes as new realism of the disabled body. According to the renewed acceptance of bodily reality, pain and accounts of corporeality differ from the one dictated by compulsory normalcy becoming part of theorising disability. These representations, though they are manipulated in order to support the anti-war context of the documentary, construct the image of damaged body once again, a live example of casualty.

Bobby Muller, a Vietnam veteran, is the only voice that represents the new realism in the documentary. Tomas meets with him seeking some advice on dealing with his disability and bodily complications. Bobby is ascribed the disability mentor's role as he has been using a wheelchair for thirty-six years after being shot in his spine. He comes up with sound perception of disability management by war veterans in several aspects. Firstly he confirms that wheelchairs should always be on the front line in anti-war demonstrations because "that's the visual! They have to hand the visual". Secondly, in a firm and direct manner, he tells Tomas off for having a "short trip" in rehabilitation and he should work more with his body. Bobby realising Tomas' personal resistance to rehabilitation, even if Tomas does not express it directly, also gives him political justification in terms of his rights, he reiterates that Tomas deserves more rehabilitation and medical treatment: "If I don't fight the system I will die!" Thirdly, the rehabilitation chat also includes talk about reconstructing the damaged sexual body. Bobby is presented as being more aware of and comfortable with his bodily reality and redefined sexual self; offering a number of suggestions to Tomas in order to become again sexually active. It should be noted that the discussion is still based on the heteronormative expectations of male sexual performance but Bobby's perspective is less rigid than Tomas' and gives examples of the new realism of body. Cheryl Marie Wade (1994) reflecting on the ragged edges of the disabled body states:

These blunt, crude realities. Our daily lives. [. . .] We rarely talk about these things, and when we do the realities are usually disguised in generic language or gimp humour. Because, let's face it: we have great shame about this need. This need that only babies and the "broken" have. [. . .] If we are ever to be

really at home in the world and in ourselves, then we must say these things out loud. And we must say them with real language. (Wade, 1994, pp.88-89)

On one hand, Tomas and Ellen Spiro do choose to use the real language, which as Safran (2001) suggests, could also be educational for an audience with no similar experience, providing openly accurate level of information about the reality of disability. On the other hand, this real language is used for constructing the reality of a damaged body that becomes the agent of anti-war manifestation, reproduced this way the stereotypical image of a self-pitying but heroic disabled veteran.

The documentary supports an anti-war message that directs its viewers through the development of a political argumentation based on scenes of the debate in both houses of Congress and the vote-by-vote tally for authorising the invasion of Iraq. The editing of the film positions these scenes in order to create a high contrast between what is said in the pro-war debate, and Tomas' reality, which consists of the puzzle of a strong counter-argument raised by war veterans and their families.

The film depicts Tomas being active in the public domain as a motivational speaker and anti-war activist. Even though he is still in the process of finding the balance between the old and new self, he is presented as keen to carry on with his life. According to Brie's testimony, Tomas struggled to find meaning in his life while he was in rehabilitation and he is described as quite disinterested during that period of his life. On film though he is presented as quite active and determined. In his private domain, he lives with his fiancé Brie and is also surrounded by his family, especially his mother. Brie is presented as very supportive, always on Tomas' side providing the care he needs. We see them getting married and before that Brie talks to the camera about her decision:

I think I would be stupid not to question myself: "Can I handle this?" but he is very charming and he is very caring. And I told him when he was in rehab that I was going to marry him, I didn't ask him, I just thought he should know. (Donahue & Spiro, 2008)

Their relationship deteriorates in less than a year from the day of their wedding and they separate. Tomas admits that every encounter would escalate in to an argument. They tried therapy but it did not work so they had to end their marriage. He admits that he hesitated in ending his marriage earlier as he was not sure if he could make it on his own. On the other hand, Brie, who had taken the role of personal assistant and -as she defines it- "roommate", claims that one of the basic reasons was that she had a more active life outside their house than Tomas, because she was working and she was socialising with

her friends. At the point where the film informs the viewers about the ending of Tomas' wedding there is a shift in the narrative climax. Tomas had been asked to participate in a number of events making connections and networking with military families and other veterans in the public domain of activism. At the point where the film informs the viewers about the end of Tomas' marriage, there is a shift in the narrative climax. It had become obvious though the lack of employment or other occupation and aspects of social life. The documentary shifts from a depiction of a fully active life to a sequence of scenes where Tomas is presented alone in his house, moving in an almost empty dining room and sleeping on bed full of newspapers, tissues, and an ashtray filled with cigarette butts. An atmosphere of loneliness and isolation is created preparing the viewers for sad news and empowering the stereotypical image of isolated self-pitying disabled person.

As it was mentioned at the beginning of the analysis of *Body of War*, the film serves an anti-war content drawing upon the depiction of a young male veteran who has to deal with a damaged body. Even though there are elements that potentially could represent the complexity of managing an acquired disability and the new realism of disabled body, disability is mainly represented as the painful casualty that comes with the epiphany for political action against the war; a political action that is actually moved by the nostalgia and desire of a non-disabled male body.

6.5 EXTRAORDINARY BODIES IN CONTROL OF MAKING: AN EXAMPLE OF TRAINING AND SUPPORTED EMPLOYMENT

Breadmakers

Yasmin Fedda | Scotland | 2007 | 11 min.

Breadmakers is a short documentary depicting the operations in a bakery where people with learning disabilities get trained with the support and guidance of support workers. In a relaxing environment every individual shares responsibilities and takes ownership of their role's duties, and this seems to be the evidence of the documentary; the challenge of the discriminatory and exclusionary misconception about people with learning disabilities abilities and particularly their ability to participate in labour.

According to Marx's (1976) definition:

Labour is, first of all, a process between man and nature, a process by which man, through his own actions, mediates, regulates and controls the metabolism

between himself and nature. He confronts the materials of nature as a force of nature. He sets in motion the natural forces which belong to his own body, his arms, legs, head and hands, in order to appropriate the materials of nature in a form adapted to his own needs. Through this movement he acts upon external nature and changes it, and in this way he simultaneously changes his own nature. He develops the potentialities slumbering within nature, and subjects the play of its forces to his own sovereign power. (Marx, 1976, p. 283)

Through the act of labour, the human bodies intervene to the limiting qualities of nature, realising also the human potential of worker's body. As Gleeson (1999) defines it: "the act of labour socially embodies human beings" (p.42). Labour is structured by power relations and in this context, the preservation of ruling interests led to practices of social division and categorisation through which some identities are valued, and others oppressed and devalued. These practices produced the "rejected body" of the "lower orders" of society which actually were described as something less than human (Gleeson, 1999, Soper 1995). Marx (1976) suggested that people with weak bodily characteristics were positioned in the lowest level of the sphere of pauperism. Physical weakness, according to Marx, was a principal cause for a worker's labour ability to be devalued.

In these hierarchies that were formed to serve capitalism and the interests of the ruling class, the disabled body was not always excluded as the "rejected weak body". However, the construction of industrial society created particular limitations making the disabled body subject to regulatory practices.

Oliver (1989) notes that industrialisation brought limitations not only through the changes in ways of working, but also through the impact on social relations with the development of industrial proletariat and the changes in communities. Disabled people became subject to exclusion because the ways of working ascribed them the inability to participate in the work process and the new forming of communities led to the extinction of social roles such as beggar or 'village idiot'(Oliver, 1989). Disability stands as a problematic by-product for industrial societies. It is a by-product of the new working and living conditions and also of the labour accidents, it is problematic because as Abberley (1987) notes disabled people were classified as non-productive and in a capitalist context the problem is:

[...] how to return them to productivity, and, if this is not seen as economically viable, how to handle their non-productivity in a manner which causes as little disruption as possible to the overriding imperative of capital accumulation and the maximisation of profits. (Abberley, 1987, p. 16)

In order to control those who were not or could not be productive, with as little disruption as possible, workhouses and asylums and through the years the establishment of specialised institutions develop (Oliver, 1989). These establishments not only controlled the non-productive individuals but also functioned as “visible monuments to the fate of others who might no longer choose to subjugate themselves to the disciplinary requirements of the new work system” (Oliver, 1989, p.10). Of course, in our days policies have changed establishments, conditions and practices, so workhouses, asylums, and institutions became sheltered workshops, supported employment, day centres and supported/independent living but the issue is that the concerns about disabled people’s exclusion and dependency are still similar even if the language is different. Oliver (1989) claims that “the issues are still the same; disabled people are likely to face exclusion from the workforce because of their perceived inabilities, and hence dependency is still being created” (p.11).

Breadmakers are trained and work at the Garvald Bakery, which is based in Edinburgh. Garvald is a company with charitable status that runs support projects for people with learning disabilities, inspired by the work of Rudolf Steiner and particularly his social therapy approach and ideas about curative education. According to Steiner’s “fundamental law” of social life:

The well-being of a community of people working together will be the greater, the less the individual claims for himself the proceeds of his work, i.e. the more of these proceeds he makes over to his fellow-workers, the more his own needs are satisfied, not out of his own work but out of the work done by others. (Steiner, 1917)

Steiner’s approach was based on the idea of a healthy environment where each human being is a spiritual individual at work that could reach its potential and create its own destiny through creativity and the principle of mutuality. Under this approach and socio-ethic principle, he developed new ideas in diverse areas such as agriculture, medicine, visual and performing arts and social life. Creativity is central for Garvald day services. The bakery, in line with Steiner’s ecological and sustainable perspective on agriculture, produces a wide range of fresh organic bread and rolls that are delivered daily to local wholefood shops.

The documentary was made based on the technique of observation, without voice-over or still shot. The sound design was also very important to reflect all the sounds and noises in the bakery and to reflect a busy, proud and creative work environment where

people with and without disabilities supported each other. Different sounds from the operations in the bakery are put together creating different rhythmical patterns made of stamping labels or sticking prices on bags. These patterns are a significant element of the narrative structure. We watch a worker stamping the bags for the bread with the details of the bakery. After every stamp there is a cut with a shot where another worker weighs dough and then throws it on the table. Stamping the bags and the dough falling on the table, both produce sounds that create the rhythm of the work patterns in the bakery. One more rhythmical pattern is created by the combination of shots of the two main tasks: stamping receipts of the orders and putting labels with the expiry date on wrapping bags. The playful mixture of sounds produced in bakery into a rhythmical pattern is interested in terms of the filmmakers' observation on repetitive patterns in movements and sounds. Her decision to manipulate sound and image in order to create a playful audio-visual product could also be interpreted as an act of disrupting the repetitive patterns in work place that also function as patterns for normalisation. According to Nirje (1969), there are eight basic facets of normalisation:

- 1) the normal rhythm of the day
- 2) the normal rhythm of the week
- 3) the normal rhythm of the year
- 4) the normal development of the life cycle
- 5) normal economic conditions
- 6) normal environmental conditions
- 7) normal respect
- 8) normal sexual patterns.

Thus, in these terms, a repetitive rhythm of the day and the week could come with the practices of work but it could also be significant of practices of normalisation, that are also applied through work, which leave little space for initiative and flexibility contradicting the development of creativity which is meant to be central at the bakery. On the other hand, the creation of these rhythmical patterns matches the playfulness demonstrated by some of the bakers.

The documentary presents all the workers, with males in the majority, participating in the operations of the bakery and occupying different posts. Most of them are involved in the making of bread and preparing rolls, weighting, cutting and rolling the dough. It is a hands-on procedure with which the workers are quite familiar and have control over their responsibilities. Apparently, the responsibilities are shared amongst workers

according to the requirements of the production and the other functions of the bakery. The interesting part that the documentary regards is the high level of ownership of duties that the workers present so very little guidance by support workers takes place. The low level of guidance creates the sense that the bakery is basically run by the trainees so in some scenes like those depicting the dough preparation and workers putting the trays in the oven, it is hard to distinguish the trainees from support workers as they all occupy and perform the bakery worker's role.

Autonomy is performed by the trainees who cover other posts at the telephone orders desk, at the counter for making the packaging, the counter for packaging the bakery products, and activities that involve cleaning and transferring equipment or carrying trays with bread to vehicles for delivery.

Mutuality and cooperation is expressed through sequences of scenes where workers stand side by side around a big working unit rolling dough, and during their tea break where some of them share the preparation, and then all together to enjoy it, sitting around a table.

However, there is a shift of dynamics in a few scenes where the support workers make suggestions or guide the trainees to proceed with other activities. Even though support workers' intervention is minor, in each occasion where trainees' actions are disrupted, they are marked with the status of the supported member as the control of initiative is transferred to support workers' hands.

Clearly the film gives out the image of a micro-community created in the bakery establishment. In this type of micro-community members with learning difficulties are presented to participate fully, since the conditions and duties of work are suitable and probably fairly adjusted. Further, the lack of competitiveness as a condition imposed by the rules of market, allows these members to work in a relaxing and friendly environment, where respect and cooperation are core values. Such an environment is essential in order to serve the aims of the establishment which by definition is meant to invest in the empowerment of self-esteem, confidence and skills. *Breadmakers* depicts the micro-community of the bakery as a paradigm if not of a success-story, probably of a good practice towards inclusion through vocational training. This is well documented through the image of confident trainees with learning disabilities taking over responsibility and having the control of making duties, and particularly of making a principal and vital type of food, basic for feeding the nations in most cultures; the bread. Another element of making this depiction empowering is that the bakery is presented in a neutral status. There

is no information on founding and establishment, so if you are not aware of the project, or you have not read the films reviews, you miss the detail that the bakery functions as a project of a charity organisation.

The omission of this background has its own benefits as this allows the documentary to depict an image focused on disabled and non-disabled workers' performance breaking down a few stereotypes that derive from a reductionist approach, based on deficit, to people's with learning disabilities abilities. A clear picture of action and productivity is screened proving the viability of this employability project, especially to viewers with no previous references or low expectations.

This appears good and well, but the issue is that inclusion and disabled people's rights, in this case the right to employment, are still at stake. Beyond the beneficial dynamics of the micro-community in a wider spectrum, the bakery is what is currently named a "community" type of sheltered workshop, founded and run by a charity company. Sheltered employment has been criticised (Gill 2005, Taylor 2002) as one more practice that leads to exclusion and dependence on the grounds of low or zero payment, dead-end placement due to the lack of transition to employment planning, and incentive to keep the most productive users under pressure for receiving funding from public and charity sources. Employment remains a field of discrimination and exclusion for disabled people. There could be arguments based on the grounds of changes in the field, such as reasonable adjustments to employers' provisions (Disability Discrimination Act 1995), emphasis on the vocational training (National Dossier 2005), work placements and supported employment for disabled people. I would agree that these practices are provided to facilitate access to employment but I would be cautious as these reforms usually are well wrapped with an "equal opportunities" discursive framework, however they also come with reforms in welfare benefits that require reassessments for disability allowances based on "fit to work" criteria. In current times of neoliberal economics the redistribution of provision is determined by market interest. Under these terms and conditions the claim for a "society for all" becomes a utopia. As Oliver (1989) had predicted in his analysis on the creation of dependency in the frame of industrial society:

There are no government incentives to create barrier-free work environments, nor can Ford claim a grant if it wants to make its assembly line usable by all the potential workforce. Neither can other manufacturers wishing to design machinery or tools that are usable by everyone, regardless of their functional abilities, seek government assistance. There are virtually no attempts in modern industrial societies that are targeted at the social organisations of work, at the

demand side of labour. And given the size of the reserve pool of labour that currently exists in most industrial societies, it is unlikely that such targeting will occur in the foreseeable future. (Oliver, 1989, p.11)

All in all, *Breadmakers* exhibits a sound evidence of abilities and possibilities in relation to employability and employment for people with learning disabilities. In their first reading, the representations of this documentary can be approached as an example that introduces and supports the employability projects for adults with learning disabilities. *Breadmakers* could be perceived as a killjoy in terms of challenging the misconceptions in relation to disabled people's abilities and skills, and also in terms of suggesting an employee-centred approach in these neoliberal times. However, behind this promising image a number of questions should be examined from the agenda of politics for accessing employment and welfare provisions.

6.6 EDUCATION ON THE FRAME: MATTERS OF INCLUSION AND TRANSITION

Please Listen to Me

Marianna Economou | Greece | 2008 | 52 min.

Including Samuel

Dan Habib | USA | 2008 | 58 mins

Both films *Please Listen to Me* and *Including Samuel* negotiate matters of educational inclusion and transition from primary education to secondary. These films depict the stories of two boys with cerebral palsy, Costas and Samuel, who come to deal with similar issues in relation to their education but from different perspectives. Costas' story brings up the dilemma that a student with physical disabilities and his family face when it is time for transition from primary to high school. The dilemma derives from the "choice" of attending a special educational setting or mainstream. Actually, there is not much space left for choice, as the lack of accessibility in mainstream high school and his family's low expectations put Costas under pressure. He wishes to attend the mainstream high school, as his sister does, dreaming of receiving all the benefits that a mainstream setting can offer, mainly aiming at making more friends and improving his social life. In order to convince his family to get him enrolled for the school of his dreams, he shows his willingness to take full responsibility for overcoming all the obstacles that come with

an inaccessible setting. In reality, the responsibility is shared with his family and in a way the dilemma between special or mainstream school (“regular” is the term used in the documentary), becomes a personal matter that comes with the heavy load of personal responsibility for counterbalancing an inaccessible educational system:

On their way to visit the Special High School:

Mother: This is the right school for you. I hope you have the sense to say that “this is the right school for me”, not the regular school where they will push you and knock you down. Did you hear what Angeliki’s head teacher said? “If he falls Mrs Danopoulou, the responsibility is yours.” Should I have this anxiety daily?

Costas: My³ responsibility, not yours.

Mother: Parents have the responsibility, not you.

Costas: The responsibility is mine, mine. (Economou, 2008)

After their visit:

Costas: The lady (the headteacher) stuck up for me. If you want to know. (She said that) I have the ability to go to a normal school.

Mother: Can’t you understand that over there they have the railings and the toilets and the helpers? Who would help you in the other school?

Costas: On my own, on my own! (Economou, 2008)

Including Samuel turns Samuel’s story to a disability rights matter, taking his parents’ concerns a little bit further, giving space to different voices; disabled and non-disabled students, disabled activists, teachers, parents and academics, and developing Samuel’s inclusion as a discourse, making the personal political at the same time:

Dan (Samuel’s father): As he gets older, how accepting will his classmates be? How patient will his teachers be? Will they know how to include Samuel? Will they be willing to try? We want Samuel to be fully included in our school, our community, our family, in every aspect of our lives. (Habib, 2008)

Dan: We’re working to give Samuel a deep sense of belonging and self-confidence, to be proud of himself and proud of his body so that if he faces prejudice, if some kids give him a hard time as he gets older, he has that inner strength to fend it off and know that he’s going to contribute a lot to this society. [...] Samuel brought disability rights movement into our home, and every day it brings new questions. (Habib, 2008)

Costas attends the special primary school of Spastics’ Society Athens (recently renamed to Cerebral Palsy Greece, however in the film at the entrance of the main

³ Emphasis added by the writer.

building we read on a sign in Greek: “Society for Spastics’ Protection”) for students with cerebral palsy where his timetable also includes sessions of physiotherapy and lessons are delivered in small number groups so teachers are able to meet the individual’s learning needs. This kind of flexibility is one of the benefits that special education settings could offer both at primary and secondary. Samuel attends the Beaver Meadow Elementary where all students share the same classroom and an inclusive educational programme is applied. Samuel’s teacher Mrs O’ Brien, one of the voices that contribute to the discourse of inclusion, recognises the benefits of inclusive education and approaches it as a civil right in the frame of a democratic society:

Mrs O’ Brien: Every child has their own way of learning. Inclusion is the best way for every child to learn, not just the child who comes in with a speech issue or the child who uses a wheelchair or a child who is ESL, who doesn’t know the English language and joins your classroom. Every single child has a multiple way of learning, and we need to discover those ways. I don’t think inclusion builds community. I think not having inclusion takes away community. When children leave the classroom and don’t come back for hours, I don’t think you have that community anymore. (Habib, 2008)

However, she also sees the challenges of transition to higher educational level:

Mrs O’ Brien: When I look at my classroom, I see a smaller version of life and I think if children learn to accept within the classroom differences and challenges, they’re going to accept them in life. Inclusion is easier in our grade level. I think when you get up to the higher-grade levels, it’s much more difficult. (Habib, 2008)

A few other voices confirm Mrs O’ Brien’s assumption, so the puzzle of challenges that put inclusion at stake, are reflected by testimonies of teaching staff of the Pembroke Academy, a public high school in New Hampshire, which works towards inclusive education in partnership with the University of New Hampshire Institute on Disability. The testimonies reflect a mixture of positive attitudes and frustration, as some feel that inclusive education gives them the freedom to apply new teaching methods that benefits all students in class whereas others feel unprepared to find the balance between the demands of delivering the mandatory sections of curriculum and disabled students’ individual educational needs, claiming a discrepancy between these two teaching requirements.

Cheryl Jorgensen and Jan Nisbet, two of the academic voices of the documentary representing the Institute on Disability of University of New Hampshire, pinpoint that the demands for the teaching profession have changed but the definition of inclusion has also

changed and this requires planning in terms of curriculum design, instructions for delivery, use of technology and classroom management. Considering the pressure imposed on planning by the neoliberal approach for funding that supports cost-effective practice, Nisbet notes that “students with disability are charged as the most expensive in education but as citizens of America, this becomes a civil rights issue” (Habib, 2008).

With no doubt inclusion is a civil right issue but the application of educational inclusion has been quite problematic. Allan (2008) mentions that inclusion has almost become the stimulus that is given a kick for confusion, frustration, guilt and exhaustion in the world of education and this seems to be an international case. Zoniou-Sideri and Vlachou (2006, just two years before the distribution of the documentary *Please Listen to Me*) in their study on Greek teachers’ beliefs about disability and inclusive education, indicate that secondary education teachers chose special-segregated education more frequently than pre-school and primary teachers. The study indicates a number of restrictive and conflicting beliefs towards inclusive education, as teachers recognised the value of inclusion in terms of improving the functions of mainstream/ ordinary school and tackling the marginalisation of disabled pupils. At the same time, though, they viewed special-segregated education as the establishment that provides secure “shelter” for disabled children covering also the inability of mainstream education to respond effectively to their needs. Teachers believed that inclusive education:

- a) would not broaden existing curricula
- b) would have no impact on peers’ academic achievement
- c) will mainly be beneficial for disabled pupils’ socialisation and social acceptance development and not for their cognitive development (Zoniou-Sideri & Vlachou, 2006).

Inclusive education has not been applied effectively in Greece yet, and in our current years of austerity the cuts of funding and provisions bring more obstacles. The introduction of inclusive education in Greece was doomed to be problematic, because it relied on the import and imitation of inclusive education practices from western countries without the involvement and active participation of disabled people, parents and other professionals (Lampropoulou & Padelidou, 1995).

However, inclusive education seems to be misunderstood, poorly interpreted and ineffectively applied internationally. Slee (1998) argues that “for many, inclusion connotes a linguistic adjustment to present a politically correct facade to a changing world” (p.131), and Armstrong, Armstrong and Spandagou (2011) add that:

To a large extent problems related to the implementation of EFA (Education for All) are related to economic disparity between countries; cultural imperialism which often means that countries of the North dictate the pace and direction to countries of the South; a lack of political will at a global level to do what is right in terms of equitable distribution of resources; and a lack of political will at country levels. (Armstrong et al, 2011, p. 36)

The social actors of the documentary film *Please Listen to Me* are totally aware of the camera - something that changes the dynamics in scenes where interaction takes place - and they address to the filmmaker behind it in several cases. Some dialogue, especially between Costas and his sister do not seem to occur naturally and spontaneously leaving a sense of re-enactment. Even if Economou wanted to be the observer behind the camera that follows Costas during his decision-making journey, it becomes quite obvious that she became a participant that all social actors were aware of. The positive element and filmmaker's achievement is that filming was allowed in schools, during guidance and consultation meetings amongst Costas, his mother and teaching staff, and for the final students' show at the special primary school. The fact that teaching staff and head teachers had accepted to be filmed for a documentary that did not follow the typical educational mode, is also an innovation as it is not common for the Greek educational community and teaching staff become quite conscious and introvert at the appearance of a camera.

Including Samuel is a parental advocacy documentary film that includes evidence material like Samuel's photographs from various moments of his life, black and white photos from equal rights protests, newspaper articles, and interviews with people that have taken significant action towards inclusion. The documentary is developed in a tight structure organised by chapters. Questions posed by Dan, who is Samuel's father and the filmmaker, and his wife Betsy set the structure of the film. The narrative starts with Samuel's story but it continues with other disabled students' stories, disabled activists statements and teaching staff's views, thus delineating the inclusion discourse. The documentary is a puzzle of home videos, interviews and scenes filmed in the schools mentioned and classrooms.

In this context, both films negotiate the complications of inclusive education but the frequency of crip killjoys (Johnson & McRuer, 2014, Ahmed 2010) is different. In the documentary *Please Listen to Me*, Costas acts as a killjoy showing a crip wilfulness by refusing to take the place that he is given. For support the Head teacher of the Special High School confirms Costas' capacity for attending the mainstream high school. Clearly

Costas is the dissident, the one who is unseated - getting in the way of the others that insist on preserving the “happiness” of special-segregated education.

Including Samuel represents a few killjoys and this is the consequence of the fact that Habib shifts the personal to political and acts as killjoy himself. Seeking answers to his questions, he makes connections with disability activists Keith Jones and Norman Kunc. We watch them both taking action in public spaces representing strong voices of the disability rights movement. They are both willful and unseated getting in the way of the others by claiming the places they want and challenging discriminatory notions of belonging:

Keith Jones: People really did not have high expectations for students with disabilities. How the hell do I develop a positive self-image if from the time I get off the bus to the time I leave, I am being told because of my physical presence, because of the physical condition of my being, that I have to be secluded, and stashed away and talked to in a demeaning manner or talks to in a way where there’s no expectations about me doing anything? And then you want me to succeed? You want me to go out and be aggressive and be a product of society and produce and to put into this economy, but from the time I’m born to the time I die, I am being told that I ain’t shit?”

Norman Kunc: What do we do to get that sense of belonging? Well that’s when I think we rely on prejudice. Because if I hate the same guy you hate, we must be friends, if we call someone retarded or stupid or fat or faggot, we’re on the same side. How do you build a sense of belonging without relying on a common enemy? And without simply trying to be nice to each other. How do we authentically build a sense of belonging in our schools and our community? (Habib, 2008)

Killjoys are the voices that are raised for the support of disability rights in Habib’s film by getting in the way. The viewers are guided from a personal story to a political matter. Unfortunately this is not the case for *Please Listen to Me*, Costas stands alone with others who are seated at the table where his transition is discussed, reminding him of his deficits and his limitation, keeping the matter of transition as personal, an outcome of Costas’ “personal tragedy”. Since his family remains seated at the table of “personal tragedy”, a circle of low expectations is developed keeping Costas isolated and dependent. The film highlights that the only spaces where Costas acts is home and his school. He seeks companionship from his sister’s friends, he spends his free time playing videogames on his own and this is his main fun activity and he receives physical support from family members to walk around. The building and the flat where he lives is inaccessible as there are many steps at the entrance and the flat is small with narrow corridors. The picture that we get of his family is of a working class family that struggles

to find other resources beyond public and welfare provisions. Since these are very limited and inefficient in Greece, the family seems trapped in the circle of low expectations and unable to support Costas to build new connections.

In contrast, Samuel is depicted taking action in various spaces beyond school and home, enjoying a full social life and different fun activities. His family's approach is different, as they seem to have access to more resources. They expand Samuel's and their connections as they become killjoys through their involvement with the disability rights movement. They do not just get in the way all together as killjoys refusing to be seated where bad practices of "happiness" dictate but they also pass on the message that the implementation of education for all, and in extension, society for all requires a shared responsibility of involvement, participation and cooperation like every application of a democratic procedure.

6.7 CRIPPING REPRESENTATION: KILLJOYS IN ACTION!

MasterPiece – Part I

Stefanos Mondelos | Greece | 2007 | 25 mins

NoBody's Perfect

Niko Von Glasow | Germany | 2008 | 84 mins

Shameless: The Art of Disability

Bonnie Sherr Klein | 2006 | Canada

Three documentaries that invite viewers to have a good look at the social actors who proudly expose themselves, their personal stories and their unruly body in order to make a claim are: *MasterPiece – Part I*, *NoBody's Perfect* and *Shameless: The Art of Disability*. All participants act as killjoys and stand in the way of compulsory normalcy stereotypes and visual representations, claiming expanded understanding of beauty, bodily aesthetics and the political right of making their existence present, either in relation to employment, sexual relationships, demanding compensation from Grünenthal GmbH, the company involved in thalidomide scandal, or promoting disability culture.

Stelios plays along with the iconic representations of James Bond, starting his autobiographical narration of crippling with this popular stereotype of handsome masculinity: "My name is Payias. Stelios Payias. I was born on 20th of February 1971 in

Thessaloniki. Do you understand me when I speak? Make an effort. I'll also try to speak more clearly.” (Mondelos, 2007) Stelios, as he defines it, has spastic quadriplegia caused by icterus which developed in nuclear after the fifth day from his birth. He starts the narration of his personal story by presenting his academic achievements, which include a Master's in Informatics and Management, speaking foreign languages and IT skills, and other achievements awarded with distinction. Stelios informs the viewers that he is not as independent as he would like because he can't find a job, but this does not put him off being active practicing a number of interests, including adapted skiing and sailing, and expanding his knowledge on IT and programming. While we watch Stelios dressed in his tuxedo holding a big toy gun, the sound effect here is a gun shooting, he talks about his interest in cinema. He likes adventure, spy, war and science fiction films. He is into James Bond's stories with fast cars, high technology, gadgets, beautiful women and irresistible charm. This challenges the viewers to expand the established representations of the James Bond icon and see the new version performed by Stelios. Could viewers recognise the irresistible charm of Stelios' face?

Filmed in a studio with a white background this time, and a woman's shadow on it, Stelios talks about women:

Women are very tender to me and it seems that they like me. If this proves that I am charming?! Maybe they think that they are not in danger and therefore they feel free. However, I am equally dangerous for them as any other man. (Mondelos, 2007)

In a close up shot, Stelios asks the viewers: “I don't know if I am handsome. What do you think?” (Mondelos, 2007). In order for the viewers to think about his question, a sequence of Stelios different facial expressions, for posing purposes, follows. Stelios gives his answer again in a close up screen, and he keeps a straight face: “Beauty is in the eye of the beholder”, (Mondelos, 2007). Just after this line the title: *Masterpiece, Part I* comes on the screen, apparently as a provocative answer to Stelios' question.

This short documentary, clearly plays with notions of constructed beauty and aesthetics and by depicting Stelios in many close-ups, introduces new images to viewers, allowing familiarity with disability image and its aesthetics to be developed. Stelios' challenging viewers' perceptions of beauty and charm and with Mondelos supporting technically, this challenge functions as a response in a parallel line to McBryde-Johnson's statement: “It's not that I'm ugly. It's more that most people don't know how to look at me” (McBryde-Johnson, 2003).

An interesting element is that Stelios seems to be in control of his story through the autobiographical narration, addressing to the camera directly and in extension to viewers. In addition his metaphorical reference from *Jonathan Livingston Seagull*: “Don’t let them spread silly rumours about me...”, (screen fills with a close up on Stelios’ face) “... or make me a god. O.K Fletch? I am a seagull. I like to fly, maybe” (Mondelos, 2007).

NoBody’s Perfect is the second film where the participants, twelve thalidomide victims also act as cripp killjoys refusing to take the seat that a pharmaceutical company, with heavy historical associations with Nazis’ eugenic practices and experiments, arranged for them. They ask not just the viewers but the public to have a good look at them in order to gain knowledge. As Garland-Thomson (2009) states:

[...] Staring is a conduit to knowledge. Stares are urgent efforts to make the unknown known, to render legible something that seems at first glance incomprehensible. In this way, staring becomes a starrer’s quest to know and a staree’s opportunity to be known. (Garland-Thomson, 2009, p.16)

Glasow, also a thalidomide victim, invites eleven adults from Germany and the U.K. to participate in a nude photo project for a calendar publication that will raise awareness of the thalidomide case and compensation claims from Grünenthal GmbH. Even though, the idea of this project started almost as a CBT exercise for Glasow to come to terms with personal concerns of self-image, it develops in to a practice of visual activism. The twelve nude stills showing the models in actual size were exhibited publicly outside the Roman-Germanic Museum (Römisch-Germanisches Museum) in Cologne, receiving comments that cover the two poles of reactions from “nicely erotic” to “repulsive and distasteful”:

Woman: Not repulsive or anything. I think they are just lovely. Very erotic but nicely erotic.

Man: A naked man with crippled arms, is really just repulsive. And children walking by can see them. I don't like it.

Cameraman: Why? He was damaged by Thalidomide. Why can't he show himself naked?

Man: I can't say off the top of my head. Of course I have nothing against Thalidomide victims, but I find it tasteless to show it in public.

Younger man: They're strong people. That takes courage. They must be strong people to show themselves like that. (Glasow, 2008)

These comments reflect what Garland- Thomson (2009) describe as bad and good staring, drawing upon Sontag’s (2003) work *Regarding the Pain of Others*. “Bad staring leads to the ethical dead end of *schaudenfreude*, of taking satisfaction in someone else’s

misfortune” (p.186), affirming at the same time that “this is not happening to me”. Bad staring fails to achieve the transition from the place of discomfort, shock or fear to empathetic identification. Good staring encloses readings mobilised into political action that allows the development of ethical relations. “If starers can identify with starees enough to jumpstart a sympathetic response that is then *translated into action*, staring turns the corner toward the ethical” (Garland-Thomson, 2009, p.186).

What also worked as a strong motivation for the participants of Glasow’s project, apart from the political action against Grünenthal GmbH that did not respond to compensation claims, is the empowering act of staring back:

Sofia (one of the participants): I’ve changed sides now. Normally, as a disabled person, you’re always being stared at. Now, I am on the offensive. I’ve done these photos and I’m saying: “Look! Look at me!” (Glasow, 2008)

Crip killjoys of *NoBody’s Perfect* keep getting in the way of various oppressive positioning through the whole film. Mat Fraser, who is also one of the participants, refuses the publisher’s suggestion to offer the product of the photo shoot for charity purposes.

Mat: Hold on how they are going to advertise it? “Come and see twelve really sexy, middle age, people, some of them have got weird arms and legs, but you know...whoaaw!! Get the calendar now!”, that I am up for but... “Oh! It’s such a great project and you’ll be doing great things...” I don’t want to be part of that! Just because it’s disabled people, it should not be automatically a charity event.

Niko: But she likes that because she is going to sell more copies.

Mat: Right, ok. I don’t want any of my money to go to charity. I want the money.

Niko: Good, good point.

Mat: Why does it always has to turn to a big orgy of compassion? (Glasow, 2008)

Mat Fraser has very sound views on being on control of his actions and choices for participation as a disabled person and actor. He jokes about investing his payment from the project on a “thalidomide toilet” that apparently requires the application of specific technology, making a few points at the same time about disabled people’s right; firstly of refusing the charity model that immediately positions their lives as being in need and dependence, secondly of receiving payments for the projects they participate, thirdly of decision making that supports and empowers their independence. Fraser, Glasow and the rest of the participants express very strong political voices, some of them are also politically active, they inform and educate the viewers not only on the thalidomide scandal but also on the image of disabled body and disability aesthetics, illuminating the

complexities of disabled people's personalities and lives, countering a fixed homogenised depiction of disability.

Shameless: the Art of Disability also supports the image of complexity as a counternarrative to homogenization elucidating an insight of disability culture and activism. As the documentary presents them; Bonnie Klein, the earnest filmmaker, Catherine Frazee, writer, disability guru, Persimmon Blackbridge, visual artist, writer, "bad girl", David Roche aka "Reverend Dave", humourist, and Geoff McMurchy, artistic director of KickstART Festival, the "Renaissance guy" get together for a pyjama party where the main fun activity is called "Stereotype Smash" and "Killer bingo". All the guests have picked fiction films that depict stereotypes ascribed to their disabilities. The "gang" of five has several meetings as they all collaborate for the KickstArt Festival. Through their self-presentation and art, they create a context representative of disability culture in Canada. The documentary deals with various crip narratives as the participants and the filmmaker talk openly about their disabilities, their own stereotypes and the process of changing views, dealing with others' stereotypes, their relationships with partners, their art and their political action.

What is central to Klein's and the others' artwork is that disability is "a valued human condition", and as Klein notes in her introduction at Ryerson University Disability Arts Launch: this "is a revolutionary insight. It goes-contradicts everything we are taught and everything we fear" (Klein, 2006). As Frazee (2008) highlights at the opening of Unruly Salon series, change is the outcome of encounters with disability culture. In her speech for KickstART Festival she notes:

It moves us. It impassions us. It emboldens us. Disability art for many of us, the stuff and business of our everyday and particular lives. [...] Do not underestimate the power of what has happened here. Disabled artists and creators have pushed back the demons of shame and humiliation. [...] It may even feel like fun and games but that is what is so deliciously subversive about our cultural revolution. (Klein, 2008)

Roche also affirms this on the stage addressing the last lines of his show to KickstART Festival audience:

I know that I look differently to you than when you first saw me. I appreciate that and I thank you. But you know what? You look different to me too because I've learned to have faith in myself that I have caught at least a glimpse of my own inner beauty that has opened up this wonderful door to me, where now I am more able to see the beauty of others. (Klein, 2008)

In several cases the participants come out as kill joys interrupting the stories that normates' fixed ideas imposed on them. First, Persimmon Blackbridge shows the camera her scars on her arm claiming "Invisible Disabilities". In another scene talking to Klein about her learning difficulties and her father's corrective method of hitting her in order to make her normal.

I was raised to think if I made it through the high school it's doing good. Not everyone has that. So I feel like you know here I am on the camera justifying myself, telling you that I really do have a real learning disability. I'm not just making it up to be able to get away with being a bad person... (Klein, 2008)

Next, Catherine Frazee in a scene from her speech at the Genome Canada Symposium challenges the fixed and tight canons of genetic and medical science:

My profile characterized by a disrupted, mutated or absent gene on the short arm of chromosome 5. Born just two years after the invention of amniocentesis and therefore before its widespread use in Canada. I am therefore a fugitive from the laws of genetic science. The problem is not that I cannot walk. The problem is that I find myself living in a society which is premised in the most fundamental ways upon the assumption that everyone, or everyone who matters, does walk in that quaint if rather laborious bi-ped sort of way. (Klein, 2008)

The third cripple killjoy is Geoff Mercer talking about the connotations of return to "normal" world behind the 2004 "Courage to come back" award that he received:

[It was] very well produced and a nice award. Overall I have to say it was a little too inspirational for my taste. A lot of crying and- almost encouraging people to cry. They put Kleenex on every table. [...] I don't want to be put in a place like upon this pedestal or something that I have to behave and always "be". I want to be bad too. I don't want to have to uphold this vision or image of inspiration or virtue or whatever. (Klein, 2008)

Shameless: the Art of Disability clearly depicts the transformative processes and knowledge that activists- artists offer through disability arts and their active presence within disability culture, bringing this way into surface the complexities and richness of the valued human condition that is called disability.

The main question that *Masterpiece- Part I* addresses is if we can see disability through aesthetic terms. The film attempts to address that in our society there is a specific aesthetic frame where disability does not fall in line with because it is non-eligible. With his film, Mondelos and Stelios highlight that in order to define the position of disability towards current aesthetics, either society needs to change the aesthetic rules and include disability, or preserve the existing order and exclude disability. Thus, through this documentary viewers are asked if they can change and widen their aesthetic criteria.

James Bond has been dominantly constituted as the perfect male icon for decades, so how does our society perceive it when a man with quadriplegia takes Bond's place? Stelios has the right, as every individual, to represent himself and talk about matters of his life the way he wants, even if this happens through irony, sarcasm and humour. Mondelos chooses this approach against the romantic "feel good" or "super hero" depictions created by Hollywood.

Stelios seems to keep himself busy with a number of interests and hobbies, most of them taking place at his home. Adapted skiing, sailing and photography are the most significant activities he is involved in outside home. He lives with his parents because he is unemployed and this affects his independence. Even though he talks about meeting women, he is not in a relationship and he does not share any information about his social life or friends, apart from his interest in going out and socialising. According to his self-presentation his connections are mostly built within family life and outdoors activities. It becomes quite clear though that the obstacles against his independence are placed by societal restrictions and fixed ideas, based on deficit, about disabled people.

Glasow wanted to overcome his own fears of acknowledging his disability and his self-image. For Klein *Shameless: The Art of Disability* was also an insight of her new identity and body as this was her first film since recovering from strokes:

Making the film really brought me full circle back to my whole self which includes being a filmmaker in the long run. I mean I was a filmmaker without disability. Then I was a disabled person without filmmaking and now I'm a filmmaker with disability. And I, in fact made a film- almost- with the disabilities. (Klein, 2008)

Both films follow a similar structure, with their filmmakers participating fully in the film behind and in front of the camera. They both give a short introduction of their films in scenes and are presented taking action in discussions. The films are based on interviews between the filmmakers and the individuals that they collaborate with their projects, scenes of several meetings for organising either the photo shooting for the calendar or for the KickstArt Festival, scenes of work in progress and of the outcome of the projects. Klein focuses a little bit more on participants personal lives as part of crippling the stereotypes associated with disabled people's love and sex life. Glasow also poses questions to his models about partners and their sex life but only Kim Morton is presented with her partner on film. Glasow's film serves up the idea of familiarising the viewers with disability and initially includes many slow close-ups on limbs affected by

thalidomide and as the film reaches the day of the photo shoot, the nude models' body parts. The aesthetic of the photo shoot and filming creates an elegant but sensual artwork where disabled bodies are appreciated as beauty, charm, sexiness and assertiveness countering constructed notions imposed by compulsory normalcy.

Klein also chooses an "in your face" approach of filming, showing reactions and responses to disabled body. The participants, with no shame, as the film title declares, let the camera focus on their bodies, first Persimmon Blackbridge shows the scars on her arm, then Geof Mercer is unconcerned about being filmed while he gets spasms on his legs, David Roche takes his dentures out of his mouth to become more grotesque for an acting exercise and he also explains in to detail the condition that affected his face, Catherine Frazee is filmed while being severely ill and Klein herself while she loses her balance and takes a slow fall. These scenes, clear from any element of sentimentalised or aestheticized editing, add on the realistic depiction of disability as a living condition with all the complexities as it is. This "in your face" open and honest depiction, as it is, clear of the impact of the privileged gaze, breaks down the image of the disqualified "extraordinary" body as they inform about the embodiment of different types of disabilities and the physicalities of different conditions. Through this approach, the viewers are put in a position of applying good staring and experiencing familiarity with disabled bodies, become obvious.

Glasow, Klein and their guests cover a big range of activities and connections. Even if the filmmaking was the trigger to make connections amongst them, for some it was also an opportunity to talk openly about the experienced oppression imposed by others and how they came to terms with accepting their selves and feeling comfortable about their body-image. The connections are built upon a context of sharing, collaborating and taking action for raising awareness, erasing misconceptions and claiming rights. The scene of dinner with all models at Glasow's film and the pyjama party in Klein's film, might give the sense of a small "Thalidomide" and "Disability arts" communities, but since all the members act as crip killjoys through their participation in activist projects, they reach out to the wider community claiming the place they want to occupy.

The majority of the films' social actors are presented living rich lives that include a wide range of personal and familial relationships, careers, professions, artistic and political action, athletic and scientific achievements. A complex representation as such counters the stereotypical motif of disqualification; damaged bodies-invalid lives. It

actually affirms disability as valued human condition that can have a rich role in art and life.

6.8 EVALUATION OF REPRESENTATIONS

Expanding Safran's (2000) method for evaluating negative and positive representations in films that depict disabled characters, I will attempt a brief evaluation of the documentaries analysed. Safran developed this method as an assessment tool that could be used in schools for educational purposes. In the context of supporting the use of films as an effective teaching tool to increase understanding of a wide range of disabilities, Safran created a simple and easy to use format based on the division of negative and positive depiction. Even though, this format is an excellent pioneering example for assessment of cinematic representations, it is clearly a product of the "negative imagery" methodological approach, as I mentioned in the literature review, it was an important first attempt to analyse representations but it has been criticised as simplistic and sterile approach (Mitchell & Snyder, 2000). In addition, an evaluation as such following a multimodal discourse analysis would also seem very simplistic missing the complexities, positionalities and actions that unfold.

However, an overall assessment is important, as it will point where the selected documentaries stand in terms of constructing an image that responds to the complexities of lives and personalities of disabled people, and also to the political matters related to theme "disability". Following Safran's (2000), format which is partly based on the guidelines issued by the Institute for Information Studies (1979) in Washington DC, the evaluation criteria was expanded, adding questions that examine if disabled people are, or act as *crip killjoys*, if the film achieves political building central to disability matters and if the content of the documentary involves crippling stereotypical representations. The numerical marking that Safran suggests can be useful and practical for pupils' understanding, especially if they proceed with classification requirements for distinguishing negative from positive representations on a quantitative basis, but a qualitative assessment will be more suitable for the purpose of my thesis. The evaluation is meant to give a synoptic review of the contextual level of representations and is set on flexible checklist format (see Table 1). Comments are added if extended reasoning is required, as Safran's evaluation was developed for fiction films, where depictions were

products of filmmaker and screenwriter's choices. In the case of documentaries, representation is not only the filmmaker's choice but how the disabled person's actual living condition influences their depictions. The interrogation point is used when filming and editing techniques manipulate the representation in ways that either information is not given (eg. *Breadmakers*) or the filmmaker's approach comes in contradiction with disabled person's representation, creating a paradox (eg. *Letter to Lou*).

The films: *Invitation to the Dance*, *MasterPiece- Part I*, *Including Samuel*, *NoBody's Perfect*, and *Shameless: the Art of Disability*, offer rich material negotiating various dimensions of disability discourse. They focus on the complexities of disability and successfully shift the narrative context from personal to political, investing in the achievement of political and relationship building and giving an insight of socio-culturally situated identities. The political building comes as a natural development since the social actors are crip killjoys and the film-makers invest in this role. The crip killjoy's view is integrated in Glasow and Klein's approach because they are crip killjoys and they act as such since the films are part of their involvement with visual activism. Schick, Mondelos and Habib adopt this approach in-relation to the crip killjoys they film. *Breadmakers*, *Please Listen to Me*, *Body of War*, and *Letter to Lou* also raise important matters for discussion but there are discrepancies of political building central to disability matters. They present their main characters with complex personalities but the representations remain in the frame of the personal story since the connections with political reasoning are discounted or mentioned only slightly. There could be an argument, that *Body of War* is rich in political reasoning. The issue the film negotiates, is that of anti-war political engagement, based on the connection of disability with disqualification; a life not worth living. If documentary films are meant to serve a polemic; in this case disabled people's place in our societies, they should invest more on political building aiming for the "personal is political" transition, that will contribute in viewers' political engagement and in the transition from bad staring to good staring.


	<i>Invitation to the Dance</i>	<i>Breadmakers</i>	<i>Please Listen to Me</i>	<i>Body of War</i>	<i>Letter to Lou</i>	<i>MasterPiece Part I</i>	<i>Including Samuel</i>	<i>NoBody's Perfect</i>	<i>Shameless: The Art of Disability</i>
Disabled persons who are central characters	2 women - 3 men Physical disabilities	3 women - 9 men Learning disabilities	1 boy Cerebral palsy	1 man Acquired disability due to injury	1 boy Septo-optic dysplasia	1 man Cerebral palsy (spastic quadriplegia)	1 boy Cerebral palsy	6 women - 6 men Physical disabilities	3 women - 2 men Various acquired & by birth disabilities
Disabled persons: Have a complex personality, with full range of emotions (Safran, 2000)	✓	?	✓	✓	✓	✓	✓	✓	✓
Interact as equal (Safran, 2000)	The film exhibits a fluctuation of inequalities.	✓	✗	✓	✓	✓	✓	✓	✓
Are part of the mainstream, e.g. hold a job, are family members, or students in general education (Safran, 2000)	The film exhibits a fluctuation of inequalities.	✗	✗	Partly	Partly	Partly	✓	✓	✓
Provide insight into societal barriers (Safran, 2000)	✓	✗	✓	✗	✗	✓	✓	✓	✓
Are shown in personal relationships, expressing sexual needs.	Some of them.	✗	✗	✓	N/A	✓	N/A	✓	✓
Are/act as cripp killjoys.	✓	✗	✓	✗	?	✓	✓	✓	✓
The documentary engages with the politics of disability.	✓	✗	✗	✗	✗	✓	✓	✓	✓
The documentary supports the crippling of stereotypical representations.	✓	?	✗	✗	?	✓	✓	✓	✓

Table 1. **Evaluation of representations**



CHAPTER 7: CONCLUSIONS

Disability film festivals usually close with an award ceremony where some filmmakers leave satisfied and others somewhat disappointed, but definitely everyone has something to discuss regarding their experience. Reflection and report for the next event and recommended development are vital. My role as a researcher is not about deciding on the awards. I am far more interested in the evaluation of representations and their content, and the tools we have for proceeding with this. Thus, in order to shape a temporary closure of this thesis I conclude by re-visiting my seven sub-questions and assessing whether these have been addressed:

- 1. What difference does disability theory, crip theory and killjoy feminism make in the construction of disability through current documentary films, and what do they reveal?**

Sieber's disability theory is by far a more holistic perspective. This is because as it puts forth three critical agendas. More importantly, it takes the theoretical perspectives beyond the contrast between the medical and social models of disability. Primarily, disability theory offers a theoretical frame based on critical disability studies, which challenges certain assumptions about the body made by critical and cultural theorists. It also further develops the theoretical grounds of disability studies as it intersects with the fields of cultural studies, literary theory, queer theory, gender studies, and critical race studies. The intersectional basis of disability theory gives us an expanded frame to understand a complex embodiment that combines social and corporeal factors. Disability theory also talks openly about pain that a percentage of disabled people experience and which has been silenced in order to maintain focus on societal barriers. Siebers re-introduces pain as a living condition that should also be considered within the agenda of identity politics. The renewed acceptance of bodily reality updates the politics of disability opening up the space for various aspects to be taken forward, thus offering a multidimensional understanding of the complexities of disability identity.

Secondly, disability theory extends the discussion about the representation of disability beyond the frame of social constructionism. Siebers (2008) takes into account

the mimetic theory of embodiment and notes that “a focus on the disabled body encourages a more generous theory of representation that reaches from gestures and emotions to language and political representation” (Siebers, 2008, p.2).

Siebers inserts the body into debates about identity politics and suggests that identity could be perceived as an embodied representational category. Thus thirdly, disability theory considers disability as a minority identity where disability should be perceived as product of societal barriers. Declining the political circumvention of claiming disability as positive identity, Siebers (2008) suggests that:

[...]people with disabilities insist on the pertinence of disability to the human condition, on the value of disability as a form of diversity, and on the power of disability as a critical concept for thinking about human identity in general. (Siebers, 2008, p.3)

Crip theory also includes an intersectional basis and questions cultural locations and socio-political constructions that reproduce compulsory heterosexuality and compulsory able-bodiedness. Perceiving heterosexuality and able-bodiedness as norms creates an authority that influences depictions of what shifts away from these norms. The established oppressive references and their criteria are challenged by crip theory as it rejects pathologisation and politicises access. Crip theory also looks at *coming out* as a political act because coming out does not only change the discourse but it also shifts validity for two reasons; firstly because invisible disabilities become visible, rejecting strategies of “passing” (passing as non-disabled). Secondly and most importantly, disabled people perform their coming out stories in their own voices, instead of being talked about by others.

The theoretical background that both disability and crip theory offer is flexible and wide enough to examine the complexities of disability as an important matter, and even more so, the complexities that come with representations of disability in documentary films. The element of intersectionality that both are based on and their interconnections with cultural locations and socio-political constructions widen the spectrum of the aspects they reach, offering, in this way, a flexible multidimensional theoretical perspective suitable for examining the content of current documentary films that depict disability matters.

Considering that documentary films are meant to depict current or historical perspectives based on cultural and socio-political evidence, disability and crip theory are the current most suitable theoretical developments within disability studies for examining

and discussing the content of these films. Furthermore, the latest update of crip theory that adds the status of crip killjoys and the importance of crip wilfulness, drawing upon Ahmed's (2010) work on feminist killjoys, could function as a criterion for checking the level of political content of documentary films. I have argued that it is critically important that documentary films manage to depict the shift of personal becoming political. They otherwise would reproduce depictions trapped in the personal tragedy or charity model, where societal barriers, lack of policies and violation of rights are either silenced or passed as the disabled individual's fate.

One more advantage of disability and crip theories are that they effectively support a multimodal discourse analysis of films as they offer a strong theoretical framework for analysing building tasks such as socioculturally-situated identity and relationship building, as well as political building, contributing to the development of a comprehensive analysis.

2. How do disability film festivals function towards disability culture and inclusion?

As Titchkosky (2008) notes: "we never come to imagine and perceive disability 'purely,' we perceive disability through our cultural assumptions" (p. 76). Disability film festivals are the spaces where these cultural assumptions are put into work. Firstly, disability film festivals function as the spaces where disability aesthetics are promoted and flourish. Secondly, they are the spaces where crip killjoys take action. This action is quite broad because it is represented in films. It also attaches particular political messages to artistic performances and collaborations, discussion panels and workshops but it can also be expressed within the formation of disabled activists' groups. When disability film festivals engage with and are organised by disability communities, they definitely are the cross-cultural and cross-disability spaces that offer depathologising contexts as described by Mitchell and Snyder (2008), and this contributes to changing the ways of seeing disability. Disability culture through its means of expression leads the audience of disability film festivals to develop a better understanding when it comes to disability matters and to become familiar with the politics of atypicality. This process is transformative and offers many benefits for the inclusion of disabled people. Disability film festivals are the spaces where critical reception takes place as the audience is exposed to multiple ways of seeing disability. These multiple ways enable viewers to see and at some level understand the complexity of disability matters. Consequently, a new

perspective is on offer that supports the development of political thinking required for working towards rights and social justice.

3. What are the themes of documentary films that negotiate disability and what are the representations they shape?

I approached an answer to this question through the methods of written festival, collecting the programmes and interviews of artistic directors' of disability film festivals and most particularly of the *Emotion Pictures-Documentary & Disability International Festival*. The programme of the festival includes mainly documentary entries that cover a wide range of disabilities: learning disabilities, visual and hearing impairments, autism, mental illness, physical disabilities, disfiguration, dwarfism, amputation, cerebral palsy. It also included degenerative illnesses such as muscular dystrophy, neurological disorders, Tourette syndrome, Thalidomide victims, war and poverty victims, epilepsy, dementia. It is important to highlight that the focus is not on exploring the different types of disability through a medical gaze aiming to make the audience diagnostic experts. On the contrary, this diversity of unruly bodies is presented free from the fixed and inflexible frames of categorisation that is also another form of oppression for disabled people. The variety of themes also gave a diverse approach on disability issues. The themes of selected documentaries negotiated issues related to education, rehabilitation, independent living, supported employment, activism, civil rights, sexual relationships, awareness against stereotypes, disability aesthetics and poetry. Some of the films were portrayals of families with children with disabilities, or of athletes and artists with disabilities, thus unfolding some personal stories and personal achievements of living with disabilities.

Considering that the majority of disability film festivals have an international context, since they include in their programme films from all over world, and also that the themes of documentary films are not limited to a specific type of disability, I suggest that the representations are cross-cultural and cross-disability. In this sense documentary films that focus on disability shape crip representations in terms of exposing matters related to compulsory normalcy. Documentary films shape crip representations when they invest in political building and are based on an investigation of the theme where personal matters are perceived as political. Viewers are most definitely exposed to crip representations when the stories depicted are crip killjoys' stories.

However, I need to stress that in many cases documentary films fall into the trap of reproducing traditional stereotypical images due to editing choices and approaches. The reason behind this type of filmmaking is usually filmmakers' intentionality which reflects their lack of in-depth understanding of disability and the politics related to it. As the programme of disability film festivals is quite rich in the number of documentary films, there is an unavoidable mixture of crip representations and representations which insist on traditional stereotypes.

4. How do these representations differ from existing media and cinematic models and how do they contribute in filling the gap between representation and disabled people's actual experiences (as much as this can be ascertained)?

Documentary film, as genre, offers different representations than the fiction films. The reasons are that the factual character of it draws more attention to what is depicted and what unfolds. Documentary film represents and engages with the world we occupy by offering familiarity, illustrating, and in many cases, supporting the interests of others by making a case or an argument. The offer of familiarity and the development of arguments are the key elements that create representations of different context and meaning in comparison to those produced by media and fiction films. Through documentary viewers are invited to participate in mediated staring encounters that, within the particular frame of disability film festivals, contribute to the production of good staring. Garland-Thomson draws on Sontag's (2003) work *Regarding the pain of others* and notes that "bad staring satisfies supposedly salacious curiosity and leads to the ethical dead end of schaudenfreude, of taking satisfaction in someone else's misfortune" (p.186). Good staring though, reaches out and can produce ethical relation when it becomes political action; "if starers can identify with starees enough to jumpstart a sympathetic response that is then translated into action, staring turns the corner toward the ethical" (p.186). Disabled filmmakers and viewers recognise familiarity as an important key to change the viewers' approaches to disability. The time of mediated interaction that audiences engage with representations of disability allows viewers to become familiar with disabled characters, the image of disabled bodies and matters of civil rights.

The representations of disability in documentary films are also different because most of them invest in a political building for the themes they negotiate. Depictions of

crip killjoys who are conscious of their political identity, speak out and take action, are depictions that ask for political engagement, and as such they can produce good staring.

5. What are some of the ways in which disabled people respond to the representations of disability in documentary films?

Disabled viewers were satisfied with the extended range of types of disability and the variety of themes covered by documentary films that were included in the disability films festival's schedule. Some of the viewers also believed that representations of disability in documentary films challenge stereotypes as they depict original stories of actual disabled people and unfold disability as a social phenomenon. They also recognised familiarity as one of the beneficial functionalities of documentary films. Viewers stated that representations of documentary films familiarise viewers with disability, even if in some cases they were shocked by the represented original stories. This shock has effectively a positive outcome in changing the way of thinking about disability. Familiarity as a practice that leads to good staring and political action is highly valued by disabled viewers.

However some disabled viewers spotted limitations in the representations of documentary films and opinions were also divided about these particular representations having the power to break down stereotypes. These interviewees felt that documentary films had no impact on challenging misconceptions because they were selected according to specific criteria set by the festival's objectives. Thus, the representations produced were very particular. The interviewees also pointed that, actually, documentary films can potentially reproduce more misconceptions when viewers are not aware of disability matters and politics. The disabled viewers who participated in this study and who saw documentary films having very little effect on challenging misconceptions stated that breaking down stereotypes is a more extensive task, where education and state play the most important role in influencing critical outcomes.

6. What are the limitations in the representations of disability in documentary films and what alternative representations do disabled people envisage?

The disabled viewers that considered documentary films having little or no effect on challenging stereotypes based their argument on their belief that documentary film is

not a popular genre and as such documentary films are not widely screened. They also felt that scheduled documentary films for disability film festivals addressed to specific group of viewers (e.g. people who perceive themselves disabled or professionals who work with disabled people), that in one way or another were already involved in disability matters. In addition, they pinpointed that documentary films were selected according to specific criteria for accomplishing the festival's purposes in that the representations were also specific. Biographies that would mainly focus on disabled characters' daily routines were described as representations that were lacking in interesting narrative and political engagement. These documentaries were seen as commonplace, almost traditional representations for documentary films and they were not popular amongst disabled viewers. The interviewees made suggestions for films that will negotiate disability on a cross-cultural basis where cultural and societal matters can be discussed. Participants also wanted films to depict disabled and non-disabled people in an equal and balanced way. Disabled viewers made specific suggestions about alternative representations. The most popular were personal and sexual relationships, for which participants noted that the misconceptions of disabled people as asexual or as compatible only with other disabled people should be explored. Other suggestions included themes such as society's perceptions of disability and non-disabled people's response to disability, this way shifting the focus on barriers deriving from society and prejudice, unemployment, access and disguised discrimination. In relation to filming approaches disabled viewers proposed the use of humour but also dark and extreme frames that will break patterns of idealisation. Artistic videos and sci-fi animation were also suggested as an alternative resource of representations.

7. What might disabled people's views be about disability film festivals?

Visibility and social dialogue are two of the benefits of disability film festivals that are highlighted by the disabled viewers. They pinpointed that disability film festivals give them the chance to see films that are not usually depicted on national T.V. This way representations of disability find a space to unfold that no other organisation offers. The fact that many screenings were followed by Q&A sessions with film-makers was acknowledged very positively by disabled viewers. They perceived the opportunities for interaction and dialogue that the disability film festival offered as an important initiative on social dialogue and community building through the medium of the image. They felt

that during the festival, disability matters were approached and disabled people had the chance to address their art and their issues in relation to inclusion and access to society. They tended to be more excited, however, with the fact that disability culture and politics were also discussed in a cross-disability and cross-cultural frame. This is because artists, film-makers and disabled people from different parts of the world attended the festival and its discussion panels. For disabled viewers visibility was the step that led to familiarity which was required for the audience's political engagement with disability matters.

The only concern that was addressed was that the disability film festivals usually attract a specific audience which is consisted of viewers who either are disabled or are people who related to disabled people, either as family members or as professionals. Disabled viewers felt that there were only a small percentage of non-disabled viewers who attended the festival and had no previous relation or interest about disability. Even in this case, the majority of disabled people hoped that the popularity of the festival would grow and, as a consequence, the visibility of the disability community and familiarity with it would also expand.

7.1 IMPLICATIONS & IDEAS FOR FURTHER RESEARCH

My research was set out to explore the representations of disability in documentary films. I suggest that when representations of disability in documentary films are under examination, we need to take under consideration a level of complexity that comes with:

- a) disability
- b) the construction and functionalities of representations through systems of communication, and more particularly,
- c) the impact of documentary films on the functionalities of social representations.

In this case, a theoretical framework is required that reflects intersectionality and criticality in order to respond to this level of complexity. I assert that the theoretical framework that draws upon disability theory and disability aesthetics, crip theory and crip wilfulness, and practices of good looking particularly useful and effective for regarding representations of disability not only in documentary films, but also in other cinematic genres, mass media, adult's and children's literature and graphic novels. Theorising through intersectionality and criticality is an effective approach as it responds to the

complexity of documentary films and at the same time attributes the required emphasis to the political and socio-cultural matters related to disability. Even though my initial guide for selecting this perspective was to address all the matters involved, I settled on to a theoretical framework that takes into account the current developments of critical disability studies. I find that it also contributes to this discipline because it develops the discussion on disability and filmic representations beyond the traditional theoretical approaches that are based on dualisms and which lead to a sterile analysis. These theoretical strands encourage the examination of political building and other cognitive, interactional and inter-textual achievements that a documentary film reveals and I consider them very important since they make the difference in guiding the audience to political engagement.

In this context, I updated Safran's (2000) educational tool addressed to students for the evaluation of fictional portrayals of disability, adding statements to the evaluation form that refer to political building and crip killjoys. The *Emotion Pictures - International Documentary and Disability Film Festival* distributed educational audio-visual kit about disability issues to numerous schools and municipalities across Greece. Unfortunately, there are no data of evaluation and outcomes of this initiative, leaving a discrepancy in relation to the educational impact of documentary films that focus on disability. I believe that such initiatives should be repeated. The creative modelling of multimodal critical discourse analysis that I employed for analysing films, in combination with the evaluation tool I developed drawing upon Safran's idea can be used for educational sessions with students and professionals. Against this background, I hope to have expanded on them, as tools for future analysis, contributing in this way to the field and its growth.

A further contribution can be asserted: There was a discrepancy that occurred due to the cessation of funding to the *Emotion Pictures - International Documentary and Disability Film Festival*. This impacted the evaluation of the suggested guidelines and policies for improving the portrayal of disability in Greek mass media. In conjunction with the festival an international conference, organised by the Greek Secretariat General of Communication, was taking place with a focus on *people with disabilities and mass media*. The conference addressed issues related to depictions, access and legal frameworks. Every year the organisers distributed an edition with the papers of previous events, but there was not an official evaluation of application or outcomes of suggested frameworks and guidelines. It would actually be of great value to examine whether there are any applications and what their impact might be.

A field that remains unexplored and I believe to be of a great interest for a researcher, is the field of Greek documentary films that negotiate disability matters. The earlier work that is popular within Greek disability community is the documentary film titled *Struggle of the Blind* filmed by Maria Papaliou, the artistic director of the *Emotion Pictures- Documentary & Disability International Festival*. The *Struggle of the Blind* was distributed in 1978 and there is no recorded research about disability documentary films before that year and for the following twenty years until 1998. This is when Grammatikos' *Night flowers* became very popular to the Greek audience, particularly within the Greek educational community. This is because the film narrates the story of a blind young student who attends the High School for the Blind in Athens. Greek documentary films that were filmed the first 8 years of the 21st century became more popular due to the festival and thus gained more attention by the viewers. I believe that a review of documentary films of 20th and 21st century would add to our knowledge on depictions of disability. The creation of a database would be useful for students, researchers, professionals, and for the disability community at large.

Generally, I find that there is a similar gap of knowledge and information in the wider field of depictions of disability in documentary films. A historical review is needed to put into perspective the different types of documentary films that were produced in particular historical periods and to highlight the shifting in the context of representations (eg. from educational documentary films that served the propaganda of eugenics to depictions that promote visual activism). A study that would aim on the classification of different types of documentary films that were produced through the years and were focused on disability matters would contribute in offering the required historical perspective in the matter of representations, and again in creating a data base of the most significant films for every period.

7.2 FINAL WORDS

Roche: "I know that I look differently to you than when you first saw me. I appreciate that and I thank you. But you know what? You look different to me too [...]"

(Klein, 2008)

Even though the *Emotion Pictures - Documentary & Disability International Festival* does not exist as an organised event any longer, it managed to plant a few seeds for transcendent political action of collective voices and activism at the time, and this definitely defines it as a space where crip killjoys take action. As a reaction to austerity and exclusion, two activist groups were organised by people with disabilities, who were also involved in the organisation of *the Emotion Pictures - Documentary & Disability International Festival*: the “Movement of artists with disabilities” and the “Movement of people with disabilities for emancipation- Zero Tolerance”.

The “Movement of artists with disabilities” was founded in 2010 and its aim was to bring together artists with disabilities and all those who historically have been marginalised according to the criteria of compulsory normalcy, in order to promote their art work. The group also aims to secure accessibility to art and other spaces where people with disabilities take action and participate in all activities or events related to matters of disability. According to the statement of the group, disabled artists support political and social rights for disabled people through their work.

Along similar lines, the “Movement of people with disabilities for emancipation- Zero Tolerance” was founded in 2011. It is a group with political and activist character that was shaped after the death of a man who lived with the support of an iron lung. His death was a result of the power company turning off the electricity to his house due to an outstanding power bill.

In June 2010, nine people with disabilities occupied the Department of Social Security for two days. They refused to leave until the Federal Minister agreed to meet with them to discuss their demands. Both groups, the “Movement of artists with disabilities” and the “Movement of people with disabilities for emancipation- Zero Tolerance”, take action at festivals, events and protests against racism, fascism and discrimination that takes place in Athens. They also run events, film screenings and performances at the “Embros” theatre, which has been characterised as a free self-managed theatre and it is an accessible and open space for citizens’ activism. Since some of the people involved in these actions had particular roles for *the Emotion Pictures - Documentary & Disability International Festival* and the formation of these two groups of disabled activists takes place the year that the funding for the event was ceased, I consider these two groups and their action as the after-effect of the festival, something that I am intrigued to explore further.



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APPENDICES

APPENDIX A: RELEASE FORM

Representations of Disability in Independent Documentary Films.

INTERVIEWS

My doctoral research is concerned with representations of disability in independent documentary films. The topic will be researched through collection of data from different sources. The first source is international documentary festivals focusing on disability, from which the documentaries will be chosen. The second source is the interviews with documentarists, directors and film-makers and the third, and most crucial one, is the interviews with disabled viewers. My research aims to analyse the image of disability as it is formed through the independent documentary films, as well as positing the viewpoints of disabled viewers on a topic which greatly concerns them, especially since they have the double role of actors and viewers.

The interviews are based on open questions which will be sound-recorded or filmed according to the wishes and agreement of the participants. All regulations will be adhered to regarding ethical commitments and protection of private data, under which this research is conducted and which have been set by the Scottish Educational Research Association and Stirling Institute of Education. A written agreement will be requested of the participants regarding their involvement in this research however, those participants maintain the right to withdraw the said agreement during or after the completion of the interviews.

The content of the interviews will be analysed and catalogued in the final research thesis. Anonymity and all other regulations for the non-delineation of particular persons and the protection of personal data will be adhered to at all times of handling the interview material.

In the case that you would like to share any questions or thoughts, you can contact me via email on: maria.tsakiri@stir.ac.uk, Otherwise, you can phone me on the following numbers: 6971958207, 00441786466141.

Thank you very much for your time.

Maria Tsakiri
PhD student,
Stirling Institute of Education,
University of Stirling.

I am informed as to the aim of this research as well as the regulations regarding data protection, to which this research commits. I am also aware of my right to withdraw my participation during or after the completion of the interviews. I wish to participate in the interviews which are an integral component of the research Representations of Disability in Documentary Films.

APPENDIX B: RELEASE FORM TRANSLATED IN GREEK

Αναπαραστάσεις της αναπηρίας στις ανεξάρτητες ταινίες ντοκυμαντέρ.

ΣΥΝΕΝΤΕΥΞΕΙΣ

Η διδακτορική διατριβή μου αφορά τις *αναπαραστάσεις της αναπηρίας στις ανεξάρτητες ταινίες ντοκυμαντέρ*. Το θέμα θα ερευνηθεί με τη συλλογή δεδομένων από διαφορετικές πηγές. Η πρώτη είναι οι λίστες των διεθνών φεστιβάλ ντοκυμαντέρ με θέμα την αναπηρία από όπου συλλέγονται ντοκυμαντέρ. Η δεύτερη είναι οι συνεντεύξεις με ντοκυμαντερίστες, σκηνοθέτες, κινηματογραφιστές και η τρίτη και πιο βασική οι συνεντεύξεις με θεατές με αναπηρία. Η έρευνά μου έχει σκοπό να αναλύσει την εικόνα της αναπηρίας όπως σχηματίζεται από τις ανεξάρτητες ταινίες ντοκυμαντέρ αλλά και να κατατεθούν οι απόψεις θεατών με αναπηρία για το θέμα αυτό που τους αφορά άμεσα εφόσον πλέον έχουν το διπλό ρόλο των πρωταγωνιστών και των θεατών.

Οι συνεντεύξεις βασίζονται σε ανοιχτές ερωτήσεις και θα ηχογραφηθούν ή θα βιντεοσκοπηθούν ανάλογα την επιθυμία των συμμετεχόντων. Θα τηρηθούν όλοι οι κανονισμοί περί ηθικών δεσμεύσεων και προστασίας προσωπικών δεδομένων στους οποίους υπόκειται η έρευνα αυτή και έχουν τεθεί από το Scottish Educational Research Association και το Stirling Institute of Education. Θα ζητηθεί να παραθέσουν γραπτώς οι συμμετέχοντες/-ουσες τη συγκατάθεσή τους για τη συμμετοχή τους στην έρευνα, ωστόσο έχουν το δικαίωμα να ανακαλέσουν τη συμμετοχή τους είτε κατά τη διάρκεια ή στο τέλος των συνεντεύξεων.

Το περιεχόμενο των συνεντεύξεων θα αναλυθεί και θα καταγραφεί στην τελική γραπτή έκθεση της έρευνας. Ανωνυμία και λοιποί κανονισμοί για τη μη σκιαγράφηση συγκεκριμένων ατόμων ή αποκάλυψη προσωπικών δεδομένων θα τηρηθούν σε όλες τις περιπτώσεις διαχείρισης του υλικού των συνεντεύξεων.

Σε περίπτωση που επιθυμείτε να μοιραστείτε οποιοσδήποτε απορίες ή σκέψεις μπορείτε να επικοινωνήσετε είτε μέσω ηλεκτρονικής αλληλογραφίας στη διεύθυνση:

maria.tsakiri@stir.ac.uk ή τηλεφωνικά στους αριθμούς: **6971958207, 00441786466141.**

Σας ευχαριστώ για το χρόνο σας,

Μαρία Τσακίρη,
PhD student,
Stirling Institute of Education,
University of Stirling.

Είμαι ενήμερος/-η για το σκοπο των συνεντεύξεων, καθώς και για τους κανονισμούς προστασίας δεδομένων στους οποίους υπόκειται η έρευνα αυτή. Επίσης γνωρίζω το δικαίωμά μου ν'ανακαλέσω τη συμμετοχή μου κατά τη διάρκεια ή στο τέλος των συνεντεύξεων και κατόπιν τούτου επιθυμώ να πάρω μέρος στις συνεντεύξεις που αποτελούν μέρος της έρευνας *Αναπαραστάσεις της αναπηρίας στις ανεξάρτητες ταινίες ντοκυμαντέρ*.

APPENDIX C: INTERVIEW QUESTIONS FOR VIEWERS

Interview Questions for disabled viewers

- 1) Could we start by describing why did you become interested in attending the screenings of the Disability Film Festival?
- 2) Was there any previous knowledge on disability in films?
- 3) Which films did you see? Which films did you like and why? / Which films did not you like and why?
- 4) What impact do you think these films will have?
- 5) What do you expect from a film about disabled people?
- 6) How would you define: a) a disability film and b) a disabling film?
- 7) There are many misconceptions and stereotypes related to disability. How do the films respond to this challenge posed by these?
- 8) Is there full representation of all types of disability in the list of films?
- 9) If you were asked to make a film about disabled people what issues would you address?
- 10) What do you think of non-disabled people making films about disability? /What is the difference between a disabled filmmaker and a non-disabled filmmaker?
- 11) Is there anything you would like to add that we have not covered? / Is there anything you would like to ask me?

APPENDIX D: INTERVIEW QUESTIONS FOR VIEWERS (GREEK VERSION)

- 1) Πείτε μου για ποιο λόγο αποφασίσατε να παρακολουθήσετε τις προβολές του φεστιβάλ.
- 2) Είχατε κάποιο ενδιαφέρον για το αντικείμενο ντοκυμαντέρ και αναπηρία πριν το φεστιβάλ;
- 3) Ποιες ταινίες είδατε; Ποιες σας άρεσαν και γιατί; Ποιες δεν σας άρεσαν και γιατί;
- 4) Τι αντίκτυπο πιστεύετε, θα έχουν τα ντοκυμαντέρ αυτά στο ευρύτερο κοινό;
- 5) Εσείς τι περιμένετε να δείτε από ένα ντοκυμαντέρ για την αναπηρία;
- 6) Πώς θα ορίζατε ένα ντοκυμαντέρ για την αναπηρία και ένα ντοκυμαντέρ που δημιουργεί αναπηρία;
- 7) Υπάρχουν διάφορα στερεότυπα και προκαταλήψεις γύρω από την αναπηρία. Πιστεύετε ότι τα ντοκυμαντέρ που προβάλλονται στο φεστιβάλ / που είδατε τις προκαλούν;
- 8) Θεωρείτε ότι υπάρχει πλήρης αντιπροσώπευση όλων των αναπηριών στα ντοκυμαντέρ που προβάλλονται;
- 9) Υποθετικά, αν σας ζητούσαν να φτιάξετε ένα ντοκυμαντέρ για την αναπηρία, τι θέματα θα θίγατε στο ντοκυμαντέρ σας;
- 10) Ποια η γνώμη σας για το γεγονός ότι δημιουργοί χωρίς αναπηρία φτιάχνουν ντοκυμαντέρ με θέμα την αναπηρία; Υπάρχει διαφορά μεταξύ δημιουργών με αναπηρία και δημιουργών χωρίς αναπηρία;
- 11) Υπάρχει κάτι που θα θέλατε να συμπληρώσετε;

APPENDIX E: INTERVIEW QUESTIONS FOR FILMMAKERS

Questions for filmmakers:

- Could we start by describing how you became interested in doing this film?
- What kind of questions did the film set out to address? (Why these questions?)
- Can you say something about how you decided on who and what you would include in this film?
- Did you have to take specific decisions about the approach of filming? Why these decisions were important for the filming process?
- When you were collecting information for making the film were there any surprises? How did you react? What did this mean for the film?
- Tell me about the filming process. What were the most challenging aspects of this and how did you approach it?
- Was there any previous knowledge /research on disabled people's experiences?
- What impact do you hope the film will have?/ What has been the impact of this film?
- Looking back, if you were to do this film again would you do anything differently?
- There are many misconceptions and stereotypes related to disability. How do you respond to this challenge posed by these?
- How does this film sit in relation to very popular films with disabled people as main characters?
- Finally, how would you say this film sits in relation to other films in the field of disability, public awareness and social inclusion?
- Is there anything you'd like to add that we've not covered? / Is there anything you would like to ask me?

APPENDIX F: SYNOPSES OF FILMS FROM THE PROGRAMMES OF EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM FESTIVAL AND OFFICIAL WEBSITES OF FILMS

- Invitation to the Dance – Body and taboo /Einladung zum Tanz - Körper und Tabus

Gerhard Schick | Germany | 2006 | 89 mins

Invitation to the Dance won the First Prize for Best Documentary Film at the first event of *Emotion Pictures – Documentary and Disability Festival* in 2007.

Synopsis:

The 39-year old dancer and choreographer from Cologne, Gerda König, suffers from muscular atrophy. Since her body doesn't produce any muscular tissue, she lives a life without power⁴ in her arms and legs. She depends on the electric wheelchair. But on stage a fascinating personality is unfolded. The movie not only shows the artistic genesis of the dance piece, "Counter Circles" in Nairobi, but also offers an unusual insight into eastern African culture and way of living. Five disabled and non-disabled dancers were chosen for the performance, most of them coming from the slums of Nairobi. In addition, there were two dancers of the permanent German ensemble. (<http://www.ameamedia.gr/en/node/84>)

- Letter to Lou (Lettre à Lou!)

Luc Boland | Belgium | 2006 | 80 mins

Letter to Lou was awarded with Second Prize for Best Feature-length Documentary (over 30') at the event of *Emotion Pictures – Documentary and Disability Festival* in 2009.

Synopsis:

Lou is a little boy who only sees through his heart. He was born blind and mentally different, something that has forced his parents to adjust to a new reality. But beyond all this, Lou is a little prince, cute, mischievous and full of humour. The audience is offered the opportunity to follow Lou's first six years, through the eyes of the filmmaker, his father.

(<http://www.ameamedia.gr/en/node/85>)

⁴ I am quoting the original text from festival's website but for more accurate translation, the term "strength" should be used instead.

- Body of War

Phil Donahue & Ellen Spiro | USA | 2008 | 87 mins

Body of War was awarded the First Prize for Best Feature-length Documentary (over 30') at the *Emotion Pictures – Documentary and Disability Festival* in 2009.

Synopsis:

An intimate and transformational feature documentary about the true face of war today. Meet Tomas Young, 25 years old, paralyzed from a bullet to his spine - wounded after serving in Iraq for less than a week. *Body of War* is Tomas' coming home story as he evolves into a new person, coming to terms with his disability and finding his own unique and passionate voice against the war. *Body of War* is a naked and honest portrayal of what it's like inside the body, heart and soul of this extraordinary and heroic young man.

(<http://www.ameamedia.gr/en/node/85>)

Synopsis from official website of the film:

Body of War unfolds on two parallel tracks. On the one hand, we see Tomas evolving into a powerful voice against the war as he struggles to deal with the complexities of a paralyzed body. And on the other, we see the historic debate unfolding in the Congress about going to war in Iraq. On a parallel track, *Body of War* follows the historic deliberations in Congress to grant President Bush authority to invade Iraq. During the fall of 2002, both Houses debated the Joint Resolution to Authorize the Use of United States Forces against Iraq (H. J. Res 114). The House of Representatives adopted the resolution on October 10, by a vote of 296-133. The next day, the Senate passed it by a vote of 77-23. In the film, scenes of Tomas speaking out against the war are interspersed with the packaged debate in both houses of Congress, and the vote by vote tally in the U.S. Senate. (The vote on this resolution remains highly controversial five years later. In the current presidential campaign, the vote comes up again and again.) The foremost voice of restraint in Congress was Senator Robert Byrd, Democrat of West Virginia, the longest serving senator in U. S. history, first elected in 1958. His eloquent opposition to this momentous resolution is vividly captured in *Body of War*. (<http://www.bodyofwar.com/>)

- Breadmakers

Yasmin Fedda | Scotland | 2007 | 11 min.

Synopsis:

At a unique Edinburgh bakery, a community of workers with learning disabilities makes a variety of organic breads for daily delivery to shops and cafes in the city. The workers interact using individual expressions, repetitive speech and sign language, revealing intricate social relationships with each other and their support workers. The featured bakery is part of a centre inspired by the ideas of Rudolf Steiner where the workers realise their potential for self-discovery and creativity in a social environment. (<http://www.ameamedia.gr/en/node/86>)

Awards:

- Black Pearl Best Short Documentary Award – Abu Dhabi International Film Festival, 2008 (Dubai)
- Best Short Documentary Prize – Emotion Pictures – Documentary and Disability Festival, 2008 (Greece)
- Sundance International Film Festival, 2008 (UK)
- Best Short Scottish Documentary Award – Edinburgh International Film Festival, 2007 (UK)
- Nominated for BAFTA Scotland Best Short Film Award, 2007 (UK)

- Please Listen to Me

Marianna Economou | Greece | 2008 | 52 min.

Please Listen to Me received the Second Prize for Best Feature-length Documentary (over 30') at the *Emotion Pictures – Documentary and Disability Festival* in 2008.

Synopsis:

Costa's deep desire to go to a mainstream high school and not to a special school reveals how differently the members of his family comprehend, experience and manage Costa's physical disability. The film follows the psychological anguish, the dilemmas and conflicts that the choice of school causes to the family. At the same time, the film unravels Costa's special relationship with his sister - a definitive relationship for them both. "If I fall, I have the strength to get up. If they tease me, I will not cry. I want to make friends. Let me be responsible for myself". (<http://www.ameamedia.gr/en/node/86>)

- Including Samuel

Dan Habib | USA | 2008 | 58 mins

Synopsis:

The story of Samuel and four other families who have children with disabilities, including autism, schizophrenia and cerebral palsy. An extraordinary, realistic chronicle of the struggle waged by these families but also of the joy they derive. The director admitted that it was through his son that he was forced to face his prejudices head-on. 'When I saw people who didn't look like me, or talk like me... I often saw them as less smart, less capable, and not worth getting to know. Is that how the world would see Samuel?' (<http://www.ameamedia.gr/en/node/85>)

- MasterPiece – Part I

Stefanos Mondelos |Hellas | 2007 | 25 mins

MasterPiece- Part I received the Special Jury Prize at the *Emotion Pictures – Documentary and Disability Festival* in 2007.

Synopsis:

Stelios Payas is the “Masterpiece”, not only because of the interest he attracts through his zest for life, although he is quadriplegic, but also for the opportunity he offers us to re-examine the commonly accepted canons of aesthetics. Given that disability does not seem, by definition, to conform to these, Stelios challenges us to discover new aesthetic concepts, so that disability and beauty are not mutually exclusive. (<http://www.ameamedia.gr/en/node/84>)

- NoBody’s Perfect

Niko Von Glasow |Germany | 2008 | 84 mins

Synopsis:

The documentary film NoBody’s Perfect follows Niko von Glasow as he looks for eleven people who, like him, were born disabled due to the disastrous side effects of Thalidomide, and who are prepared to pose for a book of photos. And to pose naked - to allow those who regularly throw furtive glances at Thalidomiders and other physically disabled people, to take a good, long look. In the process Niko discovers many fascinating characters who work in such diverse areas as politics, the media, sport, astrophysics and acting. Characters who have

learned to live with their disability to an impressive level of “normality”. With a darkly humorous touch, and no deference to political correctness, NoBody’s Perfect explores the specific problems which these twelve extraordinary people have faced during childhood, adolescence and adulthood, and shows them reacting with curiosity, enthusiasm or (like Niko himself) horror towards the project. As the film approaches its climax – the photoshoots – von Glasow completes the picture with scenes showing his unsuccessful attempts to make contact with the chemical company Gruenthal, to talk about Thalidomide and its effects. Von Glasow presents an impressive portrayal of the sensitivities and feelings of disabled people, and our society’s reactions to them. (<http://www.nobodysperfect-film.de/en/filminfo.html>)

- Shameless: The Art of Disability

Bonnie Sherr Klein | 2006 |Canada

Synopsis:

Art, activism and disability are the starting point for what unfolds as a funny and intimate portrait of 5 individuals. Director Bonnie Sherr Klein (Not a Love Story and Speaking Our Peace) has been a pioneer of women’s cinema. SHAMELESS: The ART of Disability marks Klein's return to a career interrupted by a catastrophic stroke in 1987. She turns the lens on the world of disability culture and the transformative power of art. [...] The film tracks this motley gang of five while they create and then present their self-representations. As we get to know each of these remarkable people driven by a passion for art and transformation, the everyday complexities and unexpected richness of life with a disability are exposed.

([https://www.onf.ca/film/shameless the art of disability-edu](https://www.onf.ca/film/shameless_the_art_of_disability-edu))

APPENDIX G: EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM FESTIVAL POSTERS 2007 & 2009.



Retrieved from <http://www.ameamedia.gr/en/node/67>



Retrieved from <http://www.ameamedia.gr/en/node/65>

APPENDIX H: THE OTHER FILM FESTIVAL POSTERS



Retrieved from: <http://otherfilmfestival.com/wp-content/uploads/2012/07/Other-Film-Festival-Program-2008.pdf>



Retrieved from: <http://disabilityincontext.blogspot.co.uk/>

APPENDIX I: PHOTOS & LINKS FOR TRAILERS OF EMOTION PICTURES-DOCUMENTARY AND DISABILITY FILM FESTIVAL



Retrieved from: <http://www.snf.org/en/grants/grantees/g/greek-film-festival/emotion-pictures-festival-%E2%80%93-educational-material/>



Retrieved from: <http://www.snf.org/en/grants/grantees/g/greek-film-festival/emotion-pictures-festival-%E2%80%93-educational-material/>

EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM

FESTIVAL 2007 TRAILER: <http://www.youtube.com/watch?v=UBGi0UnmzgY>

EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM

FESTIVAL 2008 TRAILER: <http://www.youtube.com/watch?v=yjgkTW8dXp8>

EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM

FESTIVAL 2009 TRAILER 1: <http://www.youtube.com/watch?v=UOMKNDYRxDk>

EMOTION PICTURES- DOCUMENTARY AND DISABILITY FILM

FESTIVAL 2009 TRAILER 2: <http://www.youtube.com/watch?v=itEVTrIDWhg>