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## 9 Disability @ the Movies: Toward a Disability-Conscious Bioethics

What continues to concern me most is what will and what will not constitute an intelligible life,  
what will and will not be considered to be “real”.  
(J. Butler, *Gender Trouble* 1990)

### 9.1 Introduction

The relationship between disability, cinema, and bioethics is a love–hate affair. Bioethics shares with the disability rights movement its commitment to patient autonomy over and against medical paternalism (Asch 2001, 297–9). Nevertheless, mainstream Anglo-American bioethics has shown little or no interest for the topic of disability and the impact of impairment on everyday life (Kuczewski 2001). When attention has been given, discussions have been mostly limited to quality-of-life analyses or decisions at the beginning (e.g., prenatal screening and abortion), as well as at the end of life (e.g., requests for assistance in dying) (Kuczewski 2001, 36). The reason for this is that bioethicists have focused mainly on fashionable topics or cutting-edge technologies, such as gene editing, moral enhancement, and assistive robots (Kuczewski 2001, 36). The inattention and indifference for everyday problems of people with disabilities explains the continuing tensions between bioethics and advocates of the disability rights movement (Amundson and Tresky 2008; Ouellette 2011). Unlike Anglo-American bioethics, European bioethics is much less procedural and more teleological (Schotsmans 2015). This means that it does not focus only on principles such as autonomy and nonmaleficence but is also concerned with people’s dignity, integrity, and vulnerability. Unfortunately, for a long time, the presence of European bioethics on the intercontinental scene has remained rather limited, with the result that the (individualistic) autonomy-oriented approach has largely prevailed (Schotsmans 2015).

Unlike mainstream bioethics, film narratives have rarely ever ignored disability. In fact, compared to race and gender, disabled bodies are almost “obsessively” present on the screen (Chivers and Markotic 2010, 1; Mitchel and Snyder 2001, 51–2). Still, the striking fact is that despite this prevalence, the presence of disabled characters is often overlooked by the audience in the sense that viewers seldom recognize disability as a feature of the film (Longmore 2003). The reason for this is that disability is used as an (invisible) narrative “prosthesis”: stories rely on disability for its melodramatic power

to evoke emotions of fear and compassion but rarely ever focus on it as an experience of social, cultural, and political dimensions (Mitchell and Snyder 2001, 48).

In other words, both cinema and bioethics make disabled bodies invisible. Or yet, they exclude them from the boundaries of the real: of those whose lives can be counted as culturally viable. The American philosopher and gender theorist Judith Butler calls this process a regulatory mechanism of de-realization (Butler 2004). This can occur in two ways: through omission (exclusion) or through the mode of visual representation itself (Butler 2004, 147). Although, Butler's work does not explicitly deal with disability (Samuels 2002, 59–61)<sup>1</sup>, her theoretical framework constitutes a valuable key to better understand the problematic relationship between disability, bioethics, and cinema. Disabled bodies become unreal in bioethics due to exclusion and, in cinema, due to the way in which they are represented.

In this paper, I argue that it is possible to come to a disability-conscious bioethics (Ouellette, 2011) through cinema. Films can play an important role in bioethics curriculum as they can change the way in which future health professionals and scholars within bioethics look at people with disabilities. This is especially the case for the educational system within the European tradition, wherein bioethics is not just a method for ethical decision-making but is also guided by an anthropological approach that uses ethical principles to protect the development of the human character (Adachi and ten Have 2015; Schotsmans 2015).

I want to explore the possibility of such a disability-conscious bioethics by revisiting Martha Nussbaum's notion of moral imagination (1990) and Butler's concept of re-signification (1997). I start with illustrating the individual and social models of disability through a brief discussion of a film fragment with Judith Butler and disability rights activist Sunaura Taylor. In the next section, I explore Nussbaum's work on the role of literature in the cultivation of our empathy. I then transpose this framework to cinema. I examine the stories and cinematographic language that have encoded disability throughout the history of film. In the last section, I focus on the portrayal of disability in more recent films and I argue, following Butler, that images can be re-signified or interpreted in unexpected ways and, thus, give rise to alternative meanings of disability.

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<sup>1</sup> Butler is a professor in the Department of Comparative Literature and the Program of Critical Theory at the University of California, Berkeley, CA, USA. She has made significant contributions to gender-, sexuality-, and feminism-related issues. Still, in her most recent work, she focuses also on human rights, antiwar politics, and mourning.

## 9.2 What *can* a body do?

*Examined Life* (Astra Taylor 2008) is a documentary film featuring eight living philosophers, among whom is Judith Butler. We see her “going for a walk” together with Sunaura Taylor in the streets of San Francisco, one of the most disabled-friendly cities in the world. Taylor was born with a neuromuscular disorder and sits in a wheelchair. Butler and Taylor start their conversation by considering the question: what *can* a body *do*? This is a quite unusual question in the history of philosophy (Abrams 2011, 74). In fact, most philosophers have occupied themselves with *what* the body *is* (Abrams 2011, 74). Both feminists and disability activists have viewed the latter question with suspicion, as the discrimination of women and people with disabilities has often been justified by referring to their “weak” and “impaired” bodies. Asking what the body can *do* draws attention away from the essence of the body and shifts the focus to capabilities and possibilities (Abrams 2011, 74–5). Still, in the video fragment, two different meanings are given to this question: “what is a body *able* to do?” and “what is a body *permitted* to do?” (Abrams 2011, 75).

The first formulation brings Taylor to the difference between the medical and the social models of disability. The medical model views disability as a lack of ability to perform *normal* human activities due to physical or mental impairments. Disability is defined as a *personal* problem that needs to be managed individually by providing people special treatment and services. Rehabilitation medicine is meant to alleviate discomfort and restore functioning (Banja 2015, 562–3) to allow a person to lead a satisfying life. Wheelchairs or prosthetic limbs, for instance, correct persons’ impaired bodies and enable them to function “normally”. Traditionally, bioethicists and policymakers have adhered to the medical model of disability (Asch 2001).

The social model presents a radically different view on disability. The inability to participate in society is no longer considered to be a personal issue but collocated in societal and environmental barriers that inhibit people with impairments from leading a “normal” life. Examples of social disabling restrictions are limited access to health care, education, employment, public spaces, independent living, and transport, as well as the stereotypical images conveyed by cultural products, such as films, TV, social media, and so on. This inaccessibility reinforces social unacceptability. Taylor gives us a concrete idea of this social discrimination: she remembers that when she was little and “walked” without her wheelchair, people compared her to a monkey because her body was perceived as transgressing the norm of ableism (Abrams 2011, 79). This example clearly shows that there are important social constraints to people’s ability to move and that the question “what *can* a body do?” is closely connected to issues of normalization.

This brings us to the second formulation: what is a body *permitted* to do? (Abrams 2011, 79–80). This question has to do with societal norms and expectations regarding

embodiment, which limit what can be considered to be real and acceptable. Taylor challenges these norms, for instance, by using her mouth for activities for which other people use their arms and hands, such as cooking, cleaning, painting, and even picking up a coffee cup, and this causes discomfort in an “ableist” society as ours (Abrams 2011, 89). On the other hand, asking for assistance with basic needs is a provocative act as it challenges the assumption of autonomy, independence, and self-reliance. In their conversation, Butler and Taylor interrogate these dominant norms of “able-ism” and emphasize the importance of recognizing vulnerability and interdependence as a common human condition of both “able” and “disabled” persons (Abrams 2011, 85–9). They remind us that disability is a fundamental part of human life and that, sooner or later, most of us will experience some kind of disability in our lives.

### 9.3 Moral imagination @ the movies

In our contemporary society, images are everywhere. The power of visual culture on public opinion is much greater than that of words. This may explain why Italy’s national organization for people with Down syndrome decided to launch a video on World Down Syndrome Day to raise awareness for this condition (Coordown 2016). The film *How do you see me* takes the form of an internal monologue of a young woman who sees herself as an ordinary person who goes for a run, works in a restaurant, hangs out with her family and friends, laughs, and cries. The video features the American actress Olivia Wilde, but the voice is of Anna Rose Rubright, a young woman with Down syndrome, who only appears at the very end of the movie to ask: “This is how I see myself, how do you see me?”. The project aimed to overcome the stereotypical view that people with this condition cannot lead fulfilling lives. Although the film was reviewed positively by parents and various media, there were also critical voices (Perry 2016). According to some disability activists, the fact that Anne Rose is visually erased reinforces the idea that disabled bodies should not be seen (“unreal”) and that disabled persons (should) see themselves through the (ideal) eyes of able-ism. Many people with disabilities have been confronted with statements such as, “I do not think of you as disabled, you’re my friend!” or “I don’t see you as disabled, I just see you as a person!” (Garland-Thomson 2016; Hitselberger 2016). Despite the best intentions, these words risk undermining the value of disabled lives. Karin Hitselberger (2016) puts it as follows:

How you see me matters. See me as me. See me as a daughter, sister, friend, writer, and student. See me as smart, strong, outgoing, and capable. See me as all these things, but see me as disabled, too. See my chair, and acknowledge that it changes the way I experience the world. See my disability, and understand that is an integral part of who I am. See me, and realize that I don’t have to erase my disability in order for any other part of me to shine through.

The main difference between Sunaura Taylor and Anne Rose is that where the former emerges as a woman, a thinker, and an activist with physical impairments (Abrams 2011, 87), the latter emerges as a person *despite* the fact that she is disabled. Although Taylor is not defined by her physical disabilities, as viewers, we are nevertheless aware of the fact that she has limited movement in arms and legs (Abrams 2011, 87–9). At the same time, however, we do not see her as a disabled person trying to become abled. She has her own, distinct abilities (Abrams 2011, 87–99). We can imagine how it is to live with a neuromuscular disorder: it not only affects how she moves but also how she interacts with people around her.

This leads us to the need for moral imagination. In *From Disgust to Humanity: Sexual Orientation and Constitutional Law* (2010, xvii), Martha Nussbaum writes:

It is possible to view another human being as a slimy slug or a piece of revolting trash only if one has never made a serious good-faith attempt to see the world through that person's eyes or to experience that person's feelings. Disgust imputes to the other a subhuman nature. How, by contrast, do we ever become able to see one another as human? Only through the exercise of imagination.

Nussbaum argues that moral imagination is encouraged by the activity of novel reading (1990, 166). Literature is nourishing because it expands our empathy and knowledge: it gives us access to the thoughts, feelings, and dreams of those different from ourselves; it enables us to live multiple lives and to take on their viewpoints. Afterward, it becomes more difficult to find these “others” disgusting or abhorrent. This is why reading a novel is never a trivial activity; on the contrary, it is subversive (Nussbaum 1991, 879): it urges the reader to question dogmatic conventions, to challenge social prejudices, and to move beyond preconceived generalizations. For the same reason, Nussbaum believes that literature has an important role to play in public life: it “will steer judges in their judging, legislators in their legislating and policymakers in measuring the quality of life of people both near and far” (Nussbaum 1991, 879).

Nussbaum's invitation to enlarge our moral imagination by reading novels should not be interpreted as a rejection of traditional ethical theories; on the contrary, literature and moral theory are complementary. Still, literature is not the only vehicle to stimulate moral imagination. Similar to novels, films allow people to approach moral questions in various directions as they offer us an endless amount of stories and lives to experience. The interest in cinema as a source to strengthen our moral capacities is evidenced by the growing number of authors publishing on this topic. Further, various movie festivals and university courses incorporate feature films in the student curriculum (Penn, Stanford, and Yale Universities) in order to encourage and enhance students' thinking about important ethical issues (DiBartolo and Seldomridge 2009).

## 9.4 Disability stereotypes on the silver screen

Cinema and disability constitute a strange combination for many of us. Still, as stated above, disability has never really been absent from the silver screen. The problem is not that people with disabilities have been underrepresented, but rather that the film industry has conveyed a pronounced stereotypical image of these people by showing little or no interest in disability as a condition of life. They have been – to use a term of Judith Butler – de-realized. In *The Cinema of Isolation* (1994), the American scholar Martin Norden puts it as follows:

The movie industry has perpetuated or initiated a number of stereotypes over the years as part of the general practice of isolation—stereotypes so durable and pervasive that they have become mainstream society’s perception of disabled people and have obscured if not outright supplanted disabled people’s perceptions of themselves (Norden 1994, 3).

Until the 1990s, people with disabilities were rarely ever featured as protagonists but were set apart from the other characters in the film to highlight a physical and symbolic separation between them and the rest of the “abled” society (Norden 1994, 3–4). This process of isolation is not only enacted by the plot of the film but also by the so-called cinematographic language (framing, lighting, editing, and sound) (Norden 1994; Ellis 2008, 35).

In his work, Norden traces the history of the way in which physical disability has been represented in American films. He distinguishes three historical periods: (1) from the birth of cinema to the end of the 1930s; (2) from World War II (WWII) until the 1970s; and (3) from the 1970s until the mid-90s (when his work was published). In the first period, people with disabilities were depicted as monsters, criminals, or comic characters whose bodies were used to arouse pity, compassion, and fear in the audience (*The Hunchback of Notre Dame*, Wallace Worsely, 1923; *Freaks*, Browning, 1932). Many movies conveyed the message that these people should be excluded from society because their deformed bodies were considered to be a reflection of the deformation of their soul. For those with a permanent disability, there was no other way out but death. This might also explain the interest in storylines that revolved around characters with curable disabilities (*City Lights*, Charlie Chaplin 1931). After WWII, the return of many disabled veterans, young men who had put their lives at risk to protect the nation, urged a different, more sensitive representation of disability. As a result, films from the mid-1940s onward portrayed people with disabilities no longer as criminals or freaks but as people who were engaged in a personal battle (*The Men*, Fred Zinneman 1950), much like the medical model of disability. They insisted on the need to fix disabled people, instead of making society more inclusive. The implied message was that reintegration and success in society are only possible when based on the tenacity to overcome adversity and that self-pity can only lead to social exclusion (Norden 2014).

Films belonging to the third period were not so much concerned with the theme of rehabilitation but focused more on social struggles. This shift in representation should be understood in the context of the Rehabilitation Act of 1973, which ensured equal opportunities for people with disabilities and gave rise to the so-called social model of disability. Still, despite this progress, many films of the 1990s still took a rather paternalistic and normalizing approach. In *Rain Man* (Barry Levinson 1988), for instance, Raymond's autism is somehow compensated by the supernatural gift of his phenomenal memory. Likewise, Tom Hanks' mental retardation in *Forrest Gump* (Robert Zemeckis 1994) turns him into a kind of spiritual guru. Still, the film portrays Forrest as an inherent asexual being, continuing the trope that people with disabilities are not – and should not be – sexually active.

Throughout his book, Norden thus shows us cinema's long history of stereotyping disability and urges the audience to reflect on these stereotypes, which are at once the *result* and the *cause* of society's negative attitudes toward disabled people. These preconceived notions enact a kind of normative "violence": although disability is represented, the way in which it is framed ("put on screen") inhibits us from imagining it as a meaningful and viable ("real") way of life. Or yet, persistent sociocultural norms, such as autonomy and invulnerability, have enabled us to turn disabled bodies into anomalous, deviant bodies that do not matter. Given this violence of de-realization in films, we should reflect on the interaction between film and society and ask ourselves what role – if any – films can have today in challenging these stereotypes.

## 9.5 Disability in contemporary cinema: from isolation to inclusion?

More than 2 decades have passed since the publication of Norden's famous book. Since then the field of disability studies has grown consistently (Jarman and Kafer 2014). This may explain why the American president Donald Trump sparked a worldwide outrage during one of his election campaigns, when he mocked a disabled journalist by making spastic movements with his arms. This awkwardness in laughing at disabled people is not just a matter of political correctness but shows a change of mind-set regarding how people perceive disability. Still, this does not mean that societal prejudices have disappeared or that disability is no longer used as a trope to make fun of people in the media. Hence, it is important "to trace out the longstanding tradition of representational strategies" (Snyder and Mitchell 2010, 195) that continue to denigrate people with disabilities. Although many scholars have criticized the negative *narrative* portrayal of disability in movies, much less attention has been given to cinematographic *language* and the relationship between the audience and the actor's *body* (Snyder and Mitchell 2010, 181). Films, in fact, heavily rely on the representational power of the body. This is especially the case for those genres, such as comedies, melodrama, and horror movies, for which success

depends on the capacity to generate sensations in the bodies of their viewers (Snyder and Mitchell 2010, 183; Williams 1991, 702). In these so-called “body genres”, the disabled body plays the role of (1) producer of fear and trauma (horror), (2) the victim of bodily disintegration (illness melodrama), and (3) the metaphor of loss of bodily control (comedy) (Snyder and Mitchell 2010, 186). This need to communicate intense emotions to the audience might explain the long-term, almost obsessive, interest of the film industry in disability, especially in the period of the origins when cinema had few other means at its disposal to evoke strong reactions.

This raises the question whether films of recent years have managed to overcome this visual and narrative rhetoric and are “finally moving with times” (Cox 2012). Let us start with *The Sessions* (Lewin 2012). The movie tells the story of journalist and poet Mark O’Brien, who was paralyzed by polio as a child and is since then confined to an iron lung. At the age of 38, he decides to lose his virginity and hires a sex therapist to initiate him into the world of sexuality. The film has the merit of tackling the taboo of sex and disability but the comedy genre risks masking the complexities that disabled people face in the sphere of intimacy. *Rust and Bone* (Audiard 2012) tells the love story of Ali, a single father with no money, and Stephanie, a young woman who loses both legs after a tragic accident while training orcas in a tourist park. In the sex scenes, Stephanie’s impaired body is shown quite explicitly (although they are computer-generated images), but the movie’s true focus is more on Ali’s emotional disability. Despite Stephanie’s gradual self-empowerment, the film has been criticized for minimizing the difficulties of being a double-amputee woman and for ignoring the fact that disabled women are often targeted as easy sexual preys (Shapiro 2013). In Michael Haneke’s *Amour* (2012), George takes care of his wife Anne, who has had a stroke and gets worse every day. The movie has the merit of associating disability with old age, highlighting the fact that in an aging society such as ours, we will all become disabled one day. Although the couple’s love seems to be able to face all difficulties, in the end, the only way out of Anne’s permanent disabling disease is death. Likewise, in the much-debated movie *Me before You* (Sharrock 2016), the romance between Will – a paralyzed young banker – and Louisa, his caregiver, is not strong enough to withhold Will from his desire for assisted dying. For many disability activists, the message of the films seems to be that disabled people are better dead as their lives are not worth living.

Many other recent films have disability at the center of the plot, to mention just a few: *Avatar* (Cameron 2009); *Still Alice* (Glatzer 2014); *The Theory of Everything* (Marsh 2014); and *The Bélier Family* (Lartigau 2014). They all have received both positive and negative critiques from the disability community because although there – finally – seems to be a real interest in the lived reality of people with disabilities, the way in which their lives are portrayed is not always as complex and realistic. Moreover, most of the time, the disabled character is played by a nondisabled actor. In this way, “the audience can rest comfortably assured that the central character may appear to be disabled but isn’t really a disabled person” (Davis 2013, 40) and can, in fact, go back

to his or her “normal” life. And as many scholars have pointed out, playing a disabled character is one of the safest ways for abled actors to get an Oscar nomination for nondisabled actors (Chivers and Markotic 2010, 6), probably because of the effort that interpreting such a character requires.

Nevertheless, there are some important exceptions (Davis 2013, 40). In 2014, the Ukrainian film *The Tribe* (Slaboshpytskiy 2014) was considered to be one of the most controversial and challenging disability movies ever made. Acted entirely by deaf actors in Ukrainian sign language and without subtitles, the film forces the audience to focus on the characters’ expressions and perceive communication in a new way. Still, although the language of the film is innovative, the plot – a criminal gang engaged in robbery and prostitution in a boarding school for deaf children – repeats the trope of violence and disability and does not tackle the real issues that deaf children face.

## 9.6 Conclusion: the power of re-signification

The relationship between disability and the film industry has changed considerably over the past 120 years. Characters with disabilities are no longer just a prosthetic vehicle of emotion (isolation) but have taken center stage in the main plot (inclusion). This may explain why, unlike in the past, disability is increasingly recognized as a dominant film feature by the audience. This does not mean that all stereotypes have disappeared: in many movies, disability is still framed as a challenge that needs to be overcome, whether through the plot (the disabled character has a special gift) or the cinematographic language itself (use of nondisabled actors). Still, overall, both the narrative and the language have become more complex in the sense that they move beyond the monotone characterization of disabled people as villains, victims, or heroes. Of course, one could always ask for a “truer” image – although one could question to what extent fictional stories should adhere to the truth – but the fact that the lives of people with disabilities are put onto screen should not be underestimated. Following Butler’s logic of re-signification (1997), I believe that viewers can interpret movies in many unexpected ways that are beyond the control of the filmmakers. This is testified by the various contrasting viewpoints about the movies analyzed in the previous section. These discussions are fruitful in challenging stereotypical frames of representation and therefore movies can – despite all their limitations – encourage our moral imagination of what it is like to live with a disability. Hence, they can play an important role in bioethics education, which is increasingly moving from problem-solving toward influencing students’ attitudes, behaviors, and characters (Adachi and ten Have 2015, 7). Changing the way in which future health professionals and scholars within bioethics look at people with disabilities is an important step to arrive at a more disability-conscious bioethics.

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