FIRST STEPS

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BFA, Emily Carr Institute of Art and Design, 2001

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

MASTER OF APPLIED ARTS

in

Media Arts

EMILY CARR UNIVERSITY OF ART + DESIGN

2009

ABSTRACT

This paper examines the development of my thesis documentary film, First Steps, which portrays my experiences with a progressive disability, and situates my work in relation to different theoretical approaches to the representation of disability in film. The normative western construction of disability derives from legal, scientific, and medical models that tend to focus on repairing the handicap or curing the underlying physiological illness. This model of representing disability figures prominently in mainstream American film, and I discuss a number of the prevailing cinematic stereotypes about disability to expose how film helps to shape social perceptions about disability. I will consider these dominant discourses alongside alternative humanistic and socio-political discussions found in critical disability studies to consider how both discourses produce expressive possibilities, but also have their own limitations. Working through these different theoretical approaches in relation to the history of American film, I will explain how my own documentary negotiates both models of disability in an effort to find a balance between them and produce an authentic narrative of how I have experienced the onset of multiple sclerosis.

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Introduction

My first short film, Olivia's Puzzle, was completed and exhibited in its first major festival just after the World Trade Center towers were attacked in New York City in September, 2001. Subsequently, I moved to New York from Vancouver to start my first full-length film, Lest We Forget, which focuses on the racial profiling of South Asians, Arabs, and Muslims in the United States after 9/11. During production of this film, I noticed that my walking slowed and sometimes became off-balance. In 2005, after a series of tests, I was diagnosed with multiple sclerosis, and learned that I had been experiencing the disease's more hidden symptoms for years before that. Primary-progressive multiple sclerosis, the type that I was diagnosed with, is not treatable by medication normally prescribed for the disease. This slow progressive disease is having a massive impact on my life, causing my walking to become more difficult and labored, and distorting my vision. In addition, some of my other symptoms include fatigue, spasticity, and a slow degeneration of the use of my right hand. I can best measure the changes in my vision in relation to my depth of field: the further away something is, the blurrier it is. During the daytime, objects in the sunlight have a vibrating luminance in their outlines. When I get overheated, which happens often, an overall graininess washes over my field of sight, similar to the visual quality of a Super-8 film projection. These changes in my vision have been difficult for me to cope with because of the ways they compromise my filmmaking.

These symptoms are now noticeable to others, although in the years first following my diagnosis, I tried my best to keep my disabilities invisible. However, through my own changing relation with the world, I gradually became more aware of people with disabilities, becoming especially attentive to the accommodations, devices and aids that they must use, as well as their overall outlook on life. Before my diagnosis, like most people, I paid very little attention to such issues. Gradually, I came to see things differently. I slowly started looking around me and saw as if for the first time how public spaces were modified to accommodate disabled people, as with ramps and lifts. I also began to seek out advocacy groups for people with disabilities, and looked at their participation in and portrayal in the media. I became interested in the disability rights movement, and discovered links between the struggles of disabled people and various other social movements. Along with these explorations, I became progressively acquainted with disability theory, and discovered a long-running history, discourse, and debates around disability and society.

My thesis film, First Steps, spans the course of several months as I try to find ways to continue to walk to the best of my ability and cope with my proliferating symptoms. The story follows my journey as I come to better understand the disease and explore coping mechanisms for the future. I began the research process by looking into the history of disability and changing twentieth century policies and attitudes toward disability, as well as the dynamic forms of activism that took shape over this period. Learning about these social and political discourses around disability has been significant in the development of First Steps, and continues to influence my film work.

Defining Disability

The question that was central to my film was surprisingly simple, but has multiple and complex answers: what is disability? There are two opposing views I considered. The medical model of disability focuses on curing the disability and the underlying illness, suppressing the disability through medication. In contrast to the medical model, disability studies looks at the social dimensions of living with disability, focusing on isolation, oppression and discrimination, as well as forms of resistance to the social and economic restrictions placed on people with disabilities. Kim and Jarman observe,

> Socially positioned outside of the parameters of both cognitive and physical normalcy, people with disabilities in the modern Western context have inevitably been caught up in systems of charity, rehabilitation, or institutional confinement. (53)

Disability is commonly juxtaposed against the able-body, producing a polarized binary model of human health and ability. In this way, modernity relies on disability to define and draw the boundaries of normalcy (Davis 76). Edward Said suggests that the modern capitalist nation-state dictates the idea of normalcy via the creation of accepted social norms which are often expressed through dominant media and take shape in opposition to a denigrated "Other" (443). Film has become one of these dominant media, and I argue that representation of disability in cinema over the last century has helped to entrench and expand stereotypes about disability that contribute to the exclusion of disabled people from the social privileges and protections of normalcy, both on discursive and material levels. One of popular cinema's greatest influences on the representation of disability in society is in its reliance on the medical explanation of disability to the neglect of the social model.

The social model of disability, which has its origins in critical thought of the last half of the twentieth century, "holds that disability is the outcome of social barriers that restrict the activities of people with impairments" (Thomas 570). The social model of disability separates impairment from disability and contends that it is social barriers that completely define disability. Thomas writes,

> The view that society disables people with impairments, and that it is this problematic societal response that constitutes disability, meant that disabled people's political struggle should be directed toward changing society and winning control over their own lives. Thus it was a question of revolution rather than reform…a question of an emancipatory strategy rather than a 'compensatory' one. (571)

As this model distinguishes between disability and impairment, it has been critiqued over the years by various postmodern disability theorists who argue that the body and embodied states of impairment are relevant when conceptualizing who is disabled. "People," write Shakespeare and Watson, "are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial" (17). Although the social model of disability is important in its own right for advocating political action and social awareness, it is an incomplete engagement in that it does not go far enough to politicize bodily impairment itself (Cole 2). As Cole suggests, this line of thought separates the confrontation with social disability from that with bodily impairment. This artificial separation of the different modes through which people live with disability is one I continue to challenge through my own films on disability. I contend that disability has to be viewed in light of biological, social and cultural forces acting together on disabled bodies, and cannot be understood in relation to any one of these factors in isolation.

Looking more closely at how disability is produced socially and culturally as "Other" provides insight into how disability functions as a pervasive but often invisible form of discrimination. Disabled voices have rallied to be heard over time, entering the public sphere by fighting for substantive equality. In the 1970s, the disability rights movement emerged, taking its example from the American Black civil liberties movement of the 1960s. After a long history of struggle, the movement led to legal gains as well as the creation of disability studies and a disability arts movement. Disability rights activists have joined other disadvantaged groups and activists from cultural and racial minority groups, women, aboriginal peoples, and queer communities. Like feminized, queer and racialized bodies, the disabled body is situated as a deviant "Other" in contrast to the biologically "normal" body. It is against this normative baseline that art and aesthetic practices position the disabled body as a form of resistance, innovation, and self-expression.

Historical Approaches To Disability

The history of the treatment of disabled people brings to the forefront issues of inequality. For most of the twentieth century, erasure of people with disabilities has been achieved through cultural practices that include institutionalization, isolation, prosthetic masking, concealment, segregation, exile, eugenics, quarantine, incarceration, and genocide. Under Adolf Hitler's Nazi regime, a mass eradication of disabled people was enacted. Between 1933 and 1945 in Germany and its occupied territories, more than 260,000 people with disabilities, both young and old, were murdered in the context of the Nazi euthanasia program. Public health agencies, private physicians, schools, and treatment centers were obliged to report every person with a disability to authorities.

Once turned in, they were either killed or used as test subjects for various cruel and extreme experiments by Nazi scientists. These experiments involved bizarre and inhumane acts such as forcibly removing a person's teeth, removing blood and replacing it with gasoline, and various genetic experiments (Lifton 4). Along with Blacks, Hispanics, Jews, gypsies, Slavs and homosexuals, disabled people were targets of a state dedicated to exterminating all forms of racial and biological difference. The representation of disability as a direct threat to the health of the nation under the Nazis exemplifies the ways in which dominant modes of representation have direct impact on the lives of people living with disability.

Popular cinema was often used by the Nazi regime lobby public opinion. The 1941 German film Ich Klage An, directed by Wolfgang Liebeneiner, is a striking example of narrative fiction used as Third Reich propaganda to justify killing disabled people in Nazi Germany. In the film, a doctor's wife contracts multiple sclerosis and asks to be handed over to the government because she no longer wishes to live. Despite its high production quality and talented cast, Ich Klage An remains banned in Germany and around the world due to its highly contested ideological bias. This was the first film to portray multiple sclerosis and it does so in an unambiguously denigrating manner in support of the Nazi definition of what constituted authentically "valuable" German lives, in contrast to "lives unworthy of life," which included persons with disabilities (Poore 22).

At the same time, the struggle over how to represent disability was becoming more prominent in North America as well, where the U.S. head of state waged his own personal lifelong battle to hide his disability from public view. Franklin D. Roosevelt was permanently paralyzed from the waist down at the age of 39 due to a bout of what was believed to be polio.[1] He refused to believe that he would not recover, however, and was quoted by his physical therapist as saying, "I'll walk without crutches. I will walk into a room without scaring everybody half to death. I'll stand easily enough in front of people so that they'll forget I'm a cripple" (Gallagher 43). He insisted on presenting himself as non-disabled to the general public. Appearing in the media or at public events, his strategy was twofold: he carried himself with the confidence befitting a leading political figure, and maintained an image of self-sufficiency by always appearing seated and banning all images that would disrupt public expectations of physical normalcy. It is possible that his determination was informed by the negative treatment of people with disabilities by Nazis in Germany and abroad—Pro-Nazi papers in the U.S., for example, used Roosevelt's disability as leverage for their own lobbying during the war (Poore 8).

Interestingly, Roosevelt's personal struggle with disability was not only later a subject of interest in the news media, but was taken up by popular culture as well. The film <u>Sunrise at Campobello</u> (1960) follows Roosevelt from the time he contracts polio, to his faltered walking, to the speech that began his career in politics, and highlights the tension between public image and private disability. It becomes evident from these examples how important disability was in shaping both Roosevelt's own self-perceptions, and the popular social imaginary of what disability is. Researching these historical episodes, I began to think more about how media representations can have direct political effects on the bodies of disabled people, and I became increasingly interested in how popular cinema contributes to shaping public opinions on issues of disability in society.

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[1] A 2003 study suggests that in fact it was more likely that Roosevelt suffered Guillain-Barré syndrome (Goldman, A.S. et al. 237).

Disability in Art Practice

My research into artistic production within the disabled community explores how disabled artists locate their own bodies in relation to the normalized able–body, and helps me to position myself as an artist in conversation with discourses of disability. Within the disability community, art practice strives toward self-empowerment through its own modes of reflection, aesthetic theory, and forms of expression. Practicing artists within this community are finding ways to enact art-making that translates their experiences as disabled people for other audiences, thus providing embodied perspectives on living with disabilities. Before looking at disability and its representation in dominant cinema, I will briefly survey disability art, which has been an important inspiration for me in my own creative expression.

The University of British Columbia's Unruly Salon series is an ongoing series of presentations from artists with different kinds of disabilities – an actor who is blind, a dancer in a wheelchair and a filmmaker in a scooter, for example. On the subject of multiplicity in disability representation, W. J. T. Mitchell states:

> Whatever disability studies becomes, it will have much to teach us about visibility and temporality, about forms of mediation, representation, and their evolution over time. We should not suppose that a ready-made theory of visual culture or a prefabricated politics of representation can simply be "applied" to the question of disability. We should understand, rather, that disability poses questions for all of us, especially for the "able-bodied" who take their "-ability" for granted. (6)

Mitchell points out that disability studies are complex and comprise multiple perspectives, but at the core seek an alternative to mainstream voices. He conveys the importance of not relying on the “able-bodied” voice to speak on behalf of the disability community, and the need for alternative voices to present a diversity of perspectives on disability in society.

The Unruly Salon featured the work of filmmaker Bonnie Klein, who produced the feature documentary Shameless: The Art of Disability after sixteen years of not working in film at all due to the effects of a life-altering stroke. She states on the National Film Board of Canada website, “I am a documentary filmmaker who has made films about people who are invisible or misrepresented in traditional media and has tried to share the tools of production so people can shape their own images, lifestyles, and disabilities to produce a complex and subtle exposé of disabled art production” (Klein 2006). In the film, she stages interviews and a roundtable discussion with members of the disability arts community including Catherine Frazee, the renowned disability studies scholar; Persimmon Blackbridge, a multi-talented visual and performance artist; Geoff McMurchy, a dancer and graphic artist; and Dave Roche, an internationally-known humorist and storyteller who draws much of his material from his facial appearance. In Klein’s film, the artists speak about their philosophies on disability culture, while critiquing each other’s work and relating them to overarching themes in disability art. Similar to the artists highlighted in Klein’s film, who worked on related themes through diverse art practices, I contend that it is crucial for an artist to critique his or her own works by deconstructing them and placing them in conversation with works on related themes. Following Klein’s lead, then, I realized that it is essential for me to examine the portrayal of disability in my own medium: popular film. My encounter with Klein’s work set me in motion to investigate the history of disability in popular film.

Disability in Popular Film

> From the first horror films to modern-day renderings, physical and mental disabilities have been shown to connote murder, violence and danger.
>
> British Film Institute (Reiser 1)

The British Film Institute website and Martin F. Norden, in Cinema of Isolation, identify four distinct eras in the portrayal of disability in American film during the 20th century, which I outline below.

Era 1: Before World War II

From the very advent of film, people with disabilities were typically “Othered” through their difference and seen as repugnant and abnormal. As silent movies relied heavily on visual signification, they often appealed to visual modes of difference. One third of commercial films in Hollywood created before 1919 that are still in existence featured disabled characters. Rather than portray them in a positive light, they tended to be devalued and depicted as human novelties (Norden 48). With the rise of the feature film in the second decade of the twentieth century as the standard-length format, disabled actors continued to appear in front of the camera. With the exception of Helen Keller, playing herself in her 1919 film biography Deliverance, disabled characters were “fixed” by filmmakers, who consistently reproduced scenarios that focused on normalization or “cures” for disabled characters. Limiting themselves to an able-bodied agenda supported the medical model of disability while disabled actors were miraculously “cured” though editing, careful cinematography, and costuming. When portrayed on screen pre-World War I, people with disabilities were typically reduced to roles in the “freak show” trope that fascinated moviegoers and proved lucrative for the movie industry. New York Times reporter Barry Keisling tellingly titled a 1921 article on the industry's fetish for freak shows, "Lucrative Ugliness: Good Looks In The Movie Industry, But A Cauliflower Ear Is A Steady Job" (Norden 50).

Alongside the idea of freaks as entertainment, early cinema exhibited a trend depicting disability as erasable. The 1910 adaptation of A Christmas Carol took Dickens's implied cure of Tiny Tim's lameness at the end of his novel to a new level by making it explicit in the film. By the conclusion of World War I, many films began to depict disabled characters conquering their disabilities or having them cured – a phenomenon traceable to the social adjustments required by the sharp rise in cases of impairment due to the Great War. Approximately 35 % of films showcasing disability between 1912 and 1930 depicted characters overcoming their disabilities (Reiser 3). Alongside this development, the 1920s paved the way for the rise of the "evil disabled character." Disabled hunchbacks, for example, were popular villains in such movies as The Hunchback of Notre Dame (1923) and The Magician (1926).

By the advent of World War II, many disabled characters were common enough as to be recognizable archetypes in popular film, composing a staple cast of stereotyped characters still evident in cinema today. Some of the most prominent of these figures are the *obsessive avenger*, seen in Captain Hook in Peter Pan (1924), the disabled cast of Freaks (1932) in their vengeance scene, or Long John Silver in Treasure Island (1934); the *sweet innocent*, as for example Tiny Tim in A Christmas Carol (1938); and the *noble warrior*, often in the form of disabled veterans who experience difficulties adjusting to normal life upon their return home, as in The Big Parade (1925) and The Four Horsemen of the Apocalypse (1921).

Era 2: After World War II

Films showing disabilities tended to be more rehabilitative after World War II, focusing on disabled characters learning to better integrate with society. Many of these films focused on veterans returning from the war, such as <u>Pride of the Marines</u> (1945), <u>Till the End of Time</u> (1946), and <u>The Best Years of Our Lives</u> (1946).

Although these films set disability in the context of larger social issues, the treatment of disability focused largely on individual experiences and did little to counteract generalized and persistently demeaning stereotypes about disability. Rather than change elements of their lives to fit with their disability, the emphasis was put on characters modifying or rehabilitating themselves to get as close as possible to their old lives before the war and before they became disabled. This narrative of overcoming disability to return to a semblance of normality contrasted with social work approaches to disabled soldiers returning to society. These veterans were actively encouraged to find new ways to function with disability and integrate themselves into society through adaptation and self-improvement.

Era 3: 1950s-60s

Due to rising censorship during the McCarthy era, many film production houses chose to avoid controversial topics and pre-emptively self-censored their films, and the production of films depicting disability decreased. Although some films portrayed people with disabilities overcoming their disability (e.g. <u>Reach for the Sky</u> [1956] or <u>The Miracle Worker</u> [1962]), in the 1960s the depiction of "disabled villains" remained. James Bond films particularly propagated this stereotype, casting many disabled antiheroes. Other examples of films with people with disabilities cast in negative roles include Peter Pan (1953), Dr. No (1962) and Dr. Strangelove (1963).

Era 4: 1960s-Present

Recent film history has shown a wide range of portrayals of people with disabilities. Many more nuanced and sensitive portrayals of disability issues have been addressed in films such as Passion Fish (1992), My Left Foot (1989), Rain Man (1988) and The Elephant Man (1980).

The British Film Institute website identifies a recent trend in film in which characters fake a disability for their own ends, to gain sympathy, or to feign innocence. In Something About Mary (1998), for example, a character fakes cerebral palsy to win a woman's sympathy. In The Usual Suspects (1995), Kevin Spacey's character also fakes cerebral palsy, as does Edward Norton's character in 2001's The Score. The widespread depiction of cerebral palsy by the film industry is partly due to the fact that the neurological disorder produces highly visible symptoms, and is an effective way to visualize disability and simplistically symbolize difference. This trope of representation is part of a diversifying portrayal of disability in film that nonetheless continues to objectify disability as deviance, and also often as degeneration, whether physical or moral. The element of deception that is associated with characters who fake disability to achieve selfish goals reflects social misperceptions about disability, and propagates social desires for the ability to turn disability on and off at will, as though it were just a performance, rather than confront its lasting demands on those whose lives are shaped by disability.

Undoubtedly, some progress has been achieved in portraying disability in film since the times of Ich Klage An. From sympathetic or empathetic perspectives, the inclusion of difference and universal humanity in film begins to raise the status of disability in popular consciousness. However, disabled characters continue to be largely portrayed by able-bodied actors, perpetuating the impression that the disabled are not capable of representing themselves and require others to represent them. Whittington-Walsh states:

> A film would never be made today casting Anthony Hopkins, garnished in make-up, portraying Nelson Mandela—it would be a moral outrage, and yet this is continuing to happen to the most marginalised and oppressed group. (2)

Whittington-Walsh brings up the issue of the cinematic and societal "Other" in film. Although the film industry has made some efforts to become more politically informed over the years in terms of the treatment of minorities, curiously, this has generally not been the case with people with disabilities. As Whittington-Walsh writes above, Mandela would never be portrayed by Hopkins, yet it is acceptable for Al Pacino to portray a blind man in Scent of a Woman (1992), or for Tom Hanks to portray a mildly mentally disabled man in Forrest Gump (1994), and indeed, these actors are praised all the more highly for taking on such challenging roles. Disability thus becomes a vehicle for cinema to show off its compelling powers of illusion, more than an opportunity for advancing social justice.

In this way, popular American film propagates stereotypes about disabled characters by turning disability into a performance rather than embodied reality. The closest mainstream audiences get to disability is through actors portraying it, rather than seeing actual disabled people, who remain invisible in the mass media. Some of the most obvious examples of these include The Hunchback of Notre Dame (1939), Charly (1966), To Kill a Mockingbird (1969), Rain Man (1988), My Left Foot (1989), Forrest Gump (1994) and Sling Blade (1996). All of these films, which utilize non-disabled actors in the roles of disabled characters, have been repeatedly featured on North American television, and each of them has garnered at least one Academy Award. In essence, people with disabilities in narrative popular film have become a commodity. Additionally, in each of these films, the disabled character is extraordinary or is portrayed as a savant. "If a person with a disability is successful, or seems to have a good life, he or she is seen as brave and courageous or special or brilliant" (Charlton 52). This reinforces their ostensible difference as they are perceived to be "out of the ordinary" in socially redeeming ways, which thus seems to make up for their deviance from normative modes of embodiment. Furthermore, this consistent portrayal of disabled people as savants diminishes the lives of ordinary people with disabilities in society.

"Movies matter in the sense that they create a cultural backdrop for any discussion we, as a society, have regarding policy" (Pavlides 52). This is significant as "movies offer people a way to explore the unfamiliar in a safe environment. Therefore, if someone has not had direct experience with individuals with disabilities, film depictions may be his or her primary source of information" (Black and Pretes 1). By extension, these depictions contribute to shaping the way in which disabled people in society are treated by those around them.

> If movies portray individuals with disabilities as dependent victims or sullen objects of pity, then classmates, coworkers, and community members may be more

> likely to "see" individuals with disabilities through this lens. Moreover, these images influence the perceptions individuals with disabilities have of themselves. (Norden 3)

In addition to being fakers, villains or savants, disabled film characters are also frequently stereotyped as isolated, self-sacrificing, asexual, and violent (Whittington-Walsh 3). *They are isolated.* In Rain Man, Arthur lives in a mental institute. In To Kill A Mockingbird, Atticus Finch and the sheriff decide Boo Radley, due to his disability, is best left in the simplicity of isolation. *They are self-sacrificing*. Linked to the idea of the savant, disabled characters sacrifice themselves in order to save non-disabled characters (Norden 103). In both To Kill A Mockingbird and Sling Blade, the disabled characters save children's lives against threatening attackers. Forrest Gump saves his partner Jenny from abusive boyfriends. These characters are only allowed to "avenge" other "normal" persons, never the discrimination or injustices they have experienced themselves. *They are asexual or sexually inferior.* In My Left Foot, the main character, Christy, is frustrated from having cerebral palsy and being unable to find a partner. Forrest Gump immediately ejaculates when he touches Jenny's breasts. Raymond (Rain Man) and Karl (Sling Blade) are unresponsive to efforts to introduce them to potential partners. Finally, *they are violent*. In Straw Dogs, the disabled character saved by Dustin Hoffman unknowingly strangles his love. Boo Radley is the murderer in To Kill A Mockingbird, even though he comes across afterwards as harmless and "childlike", and Karl (Sling Blade) kills his verbal tormentor, Dole, in a vicious and lengthy murder scene with a lawnmower blade. These marginalizing and degrading stereotypes are consistently manufactured by mainstream media and the industry has profited greatly from it. From the 1930s to the 1990s, the percentage of Academy Award-winning films with physical disability themes rose from 3% to 44% (Safran 14). These films have brought numbers that rallied competitively in box-office sales, while not greatly changing the way that disabled people are perceived or treated in society.

Finding exceptions to these marginalizing norms of representation is difficult. One notable exception is the film Freaks, directed by Ted Browning in 1932, which was a mainstream film that advocated normalizing the way in which disabled people are perceived. The intention of the film was to show disabled people as they are. Upon its release, it had a disastrous run at the box office and was blamed for contributing to the end of Browning's career and pushing the all-disabled actor cast back to isolation. Placed into MGM's vaults, the film was hidden for twenty years in the United States and forty years in England. The reason for the banishment is not because of the disabled actors *per se* but because Browning and his actors demonstrated no shame in showcasing their diversity (Whittington-Walsh 1).

After studying the historical context of film and disability, I have come to feel that it is very important in my own work to counter mainstream depictions of disability in order to foster dialogue and understanding with the audience. As I have suggested above, fiction film's portrayal of disabled people has consistently misrepresented and stereotyped us. As a documentarian, I have a strong interest in how disability has been portrayed to mass society by popular media, especially in cinema. Similar to films such as the Celluloid Closet (1995), which surveys homosexuality in Hollywood, and Color Adjustment (1991), which surveys race relations in primetime television, my thesis film and future film projects are dedicated to addressing the portrayal of disability in film. By making references to the history of disability in cinema and showing archival footage from these films, I am motivated to personalize disabled characters and avoid stereotypical portrayals. First Steps is the beginning of my contribution to improving social awareness about disability, and I hope to continue this critical engagement with disability in my future work. In sum, then, the film First Steps looks at the implications of the medical and social models of disability, and examines how my own personal experiences relate to both these models and also exceed them in the complex specificity of my life with disability.

Disability, Race and Film

As a documentary filmmaker who made several documentary films with an able body, I am now reinventing my place in film culture as a disability artist. The major initial hurdle for me was my own resistance to defining myself in relation to the label "disabled." The disabled body represents what Rosemarie Garland-Thomson in her book Extraordinary Bodies refers to as the "freak show" (23). Garland-Thomson writes, "Disability is the unorthodox made flesh, refusing to be normalized, neutralized, or homogenized" (23). Perception of permanent physical change is mentally more difficult to deal with than the "luxury" of the temporary disability. In "Seeing Disability," W.J.T. Mitchell descriptively elaborates on his experience of having a temporary disability:

> The luxury is twofold: 1) the knowledge that this is temporary, thus entitling me to all sorts of temporary indulgences—being waited on, having an excuse not to work, not to answer mail and phone calls, or meet deadlines; 2) the time out of time, like those long stretches of boredom on transatlantic flights when one can avoid conversations with seat partners and sink into the world of some utterly

> distracting novel that one does not have to read for professional reasons—the ultimate regression into childhood for an English professor. (1)

Coming to the realization that my own disability is no longer invisible, the sense of becoming "Other" is also becoming permanent and part of my overall identity.

My initial response to my diagnosis was to enter into a deep psychological struggle against being typecast into another kind of "Other." After all, as a person of color, I already had experienced oppression – not only as a person of colour but as a South Asian male of colour living in New York City after 9/11. To this day, I am the one chosen in "randomized" searches of bags or person by Canadian and American immigration when passing through airports. Once, I had a whole aircraft deplane their passengers after they hadn't searched me. As a social subject, I am problematically embodied as a man of color and a man with a disability—doubly marked as an outsider. These intersecting categories of race and disability overlap to form a multilayered and often-unpredictable experience of suspicion and marginalization. I become reduced to generalized identity categories, while my own particularity as a subject is easily erased.

Disability identity amongst people of color has, for the most part, remained unaddressed within the disability movement and disability studies. The lived experiences of young men of color remain almost absent from disability identity literature:

> The few studies concerning a young people of color disability group indicate that they tend to present challenging needs and issues including poverty, lack of formal education, limited work histories, drug dependency, ethnic minority status, and teenage parenthood. (Hernandez 118)

Aware of my privilege as a male with higher education and a successful artistic career to date, I recognize that the issues I face are different than those faced by the young men referenced in Hernandez's study. The case study included 50% Latino and 50% African-American young men with disabilities. The study indicates that one of the foremost outcomes of acquiring disabilities for these young men was the increased attention to their own health, well-being and survival. However, I did find some overlaps between my experience and those of the young men of color in the study. For example, the young men discussed how disability became a turning point for them in the way they view their lives, and I feel that I have similarly been deeply changed by my experience with my disease. Personal goals such as my career have become paramount for me, including my decision to make First Steps. This film is important for me, not only for my career as a documentary filmmaker, but also as a means to channel my thoughts, feelings and experience with multiple sclerosis in a creative manner. Similar to my past work, this film examines different dimensions of social exclusion and oppression, and seeks to bring forward the narratives of the disadvantaged by asserting space for their stories in the public sphere.

Disability, Race and *First Steps*

As a person of color, I have used the medium of film as a tool to tell the stories of racial groups with whom I identify. In my film Olivia's Puzzle (comparing two girls of Indian origin living on different continents), and Lest We Forget (investigating backlash towards South Asian, Arab, and Muslim people after 9/11), my own visible ethnic and racial origin gives me insight into the experiences of the participants in my films. I have used my experience as a South Asian born and raised in North America to creatively explore cultural hybridity, identity formation, and outsiderness in my subjects. My first film, Olivia's Puzzle, addresses the issue of retention of ethnic identity in a host country (Isajiw 420). The film compared two Indian girls, both eight years old, and showed how their environmental differences affected their upbringing. One of the girls grew up in Goa, India and the other was born in Ladner, British Columbia. The film focused on Olivia from Canada, who had misconstrued perceptions of India and, consequently, her own ethnic identity. By looking at the overall production process of this film, I can acknowledge that by comparing and contrasting these two South Asian girls, I am also looking at my own identity through the camera lens by viewing others like me. I am creatively bridging together two identities – one as a South Asian and the other as a North American filmmaker. Like South Asians living in New York after 9/11 such as those I profiled in Lest We Forget, I, too, felt the eyes and actions of racial profiling and commented on this by interviewing those from the targeted communities after 9/11. In First Steps, I undergo a similar process – bringing together my documentary career with disability culture. It is a method of self-understanding that relates to the bridging together of two identities, a process I began with Olivia's Puzzle.

There has, however, been a paradigm shift from my previous work while making this film. Unlike race, one's relationship to disability is individual. Whereas race cannot be washed off, relationship to disability is something that is negotiated by a person's own description of their physical or mental disability, whether the disability is visible or not, and whether – or how much – a person chooses to disclose. Unlike the permanence of racial colour, up until recently, my disability has been something that I have had the option of keeping invisible. It was when I began walking with a cane that I realized I could no longer keep my disability invisible to others around me. As I acquire more assistive devices, such as walkers and scooters, it becomes clear that my earlier desire to "pass" is not going to be easily maintained or even possible over time. In essence, there is a change of my physical self taking place, which in turn affects my overall identity. I became increasingly aware of my own attachment to the perception of the human body and disability that is set by a medical model, but have subsequently become disturbed by this model of isolation and objectification. According to Siebers, "the medical model situates disability exclusively in individual bodies and strives to cure them by particular treatment, isolating the patient as diseased or defective" (743). For this reason, I have worked in First Steps to find more balance in my sense of identity, incorporating both the medical and social models of disability.

Representing (My) Disability in My Own Films

I have witnessed a major shift in my self-conception since being diagnosed with multiple sclerosis. Within sociological discourse, identity incorporation is the process of developing a new identity within society. Isajiw defines identity "as the manner in which a person locates themselves psychologically in relation to one or more social systems and in which they perceive others as locating themselves in relation to those systems" (128). Social inclusion and exclusion assume two main forms – one in the way others treat a person and the other in the way that someone perceives how s/he is treated by others. Alongside this, there is a combination of emotional factors that involve feelings of willingness and a desire to enter into interpersonal relationships with others and feelings of freedom and acceptance in interacting with them. With the evolution of my own disability from being invisible to becoming visible, and my movement toward taking up a subject position as a disabled young man of color, I have had to deal with changes in my own self-perspective, such as, the need for emotional connectedness with others in my day-to-day conceptions and interactions.

My desire to better understand my own disability as well as the broader socio-political implications of disability was a major reason for me to make my documentary. However, it took several years to conceive this film project, partly, I believe, because I was most likely in denial of my changing physical self. Beginning with denial of my diagnosis and eventually moving through the various stages of loss at a slow but steady pace, First Steps is part of my acceptance of multiple sclerosis.

Although, in some ways, First Steps is different from my previous work, it is still connected thematically through its focus on marginalization and difference. At first, I was hesitant to accept my own physical changes, and found myself unable to discuss them with others. Understanding that I am still coming to terms with my own situation, I investigated others' relationships with their disabilities and their artistic practices. This was a way for me to find others who have creatively bridged the two worlds—their artistic life with their disability. For example, Bonnie Klein waited sixteen years before being able to start the production of Shameless: The Art of Disability. She created a community of disabled artists around herself that helped inform her practice, while gaining their confidence to act as subjects in the film.

I believe that documentary filmmaking is a tool for filmmakers to discover their own philosophy. Exploring a subject in its entirety for the purpose of discovery and understanding is what ideally draws a filmmaker to his or her subject matter. It is a craft that overtly manifests the artist's subjectivity. Being a documentarian embodying the very content and subject matter of my film, the relationship between subject and filmmaker in my work draws closer, breaking the mold of the 'objective' observer. In First Steps, there exists a larger representation of myself as a disabled person sharing theoretical and artistic interests within a larger community. It is important to ask myself: how do my own social, class, racial and age categories factor into my portrayal of the self in the autobiographical documentary?

It is also important for me to think about who will be viewing my film. One of the venues that could potentially screen First Steps is disability film festivals such as the DisThis Film Series in New York which specifically targets audiences interested in disability. Such festivals effectively raise questions about filmmaker perspectives and disability that are not asked frequently enough (Snyder and Mitchell 1). It is important that earnest films about disability also get showcased in mainstream film venues to counteract dominant Hollywood stereotypes about disability. In this vein, I am happy that First Steps was screened at both the Tribeca Film Festival and the Vancouver International Film Festival in 2009. Broadening the exposure and circulation of a diversity of representations of disability will help to educate viewing publics, and will help save people (and filmmakers) with disability from having to incessantly explain themselves.

In her paper "Encounters In Camera: Autobiography as Interaction," Susanna Egan suggests that the "point-of-view" of the autobiographical documentary filmmaker moves beyond objectivity to embodying subjectivity, but then moves further to embrace multiplicity in perspective. "Film may enable autobiographers to define and represent subjectivity not as singular or solipsistic but as multiple and as revealed in relationship" (Egan 4); this was an approach I embraced with First Steps. As a split-subject (subject and creator), I move through my own film both in front of and behind the camera. I am making editorial choices on the progression of incidents that are included in the film, but at the same time, I am inspired by and incorporate the perspectives of others who have helped shape my self-understanding, both as a filmmaker and as someone with multiple sclerosis. As Bonnie Klein did with Shameless: The Art of Disability, my intention is that First Steps carries multiple perspectives on the same topic and provides contrasting ideas as well as complementary perspectives.

In Lest We Forget, I chose subjects that I was aware would help carry forward the themes I wished to communicate. Whether the subjects chosen were complementary or antagonistic to the overall argument of the film, each subject was intentionally selected to convey a perspective integral to the overall development of the film. The use of interviews, for example, provides testimonial narratives, which I use, following Latino American filmmaker Chon Noriega, as the preferred vehicle "to give voice" to communities. In the hands of Aboriginal-Canadian documentary filmmaker Alanis Obomsawin, interviews effectively anchor her own role as a filmmaker with that of the social protagonists in her film. These interviews implicitly acknowledge collaboration between the subject and the filmmaker as she records and edits the material, and I find this a significant model for my own work.

In my own experience as a split-subject—in terms of being both behind the camera as director and in front of it as subject—I found that the filmmaker-subject relationship is deeply interwoven. This makes the production less difficult in some ways, but also requires extra effort on my part as I play multiple roles. I am making a film about learning to show myself to the audience and what I am learning on my journey.

There are two distinct stories told in the film. One is about how I am learning to handle the disease: "I want to walk," as I say at the beginning of the film. The other is about how I am learning to cope with the effects of the disease on my career: "I want to keep telling stories and making films," I say, as the second premise introduced early in the film.

Community and Making *First Steps*

When creating a documentary about a marginalized community, it is important to consider issues of exploitation and the ethics of making of the film. From the perspective of a filmmaker with a disability, my argument is that it is less exploitative as long as the process is made in consultation with the community portrayed in the film. I believe that, based on the work of documentary filmmakers with a similar philosophy (such as Bonnie Klein), my film will be better realized, from production to distribution, when it is done with community engagement. My research for the film has led me to engage with and participate in MS support groups, both young and old, in Canada and the United States, and this has exposed me to the diversity of individuals and life situations implicated with MS.

Through the film production, I have been able to meet staff members of the National Multiple Sclerosis Society that have allowed me to share my viewpoints on being a young person with MS. Through them, I attended a photo shoot in Colorado, and I was on a billboard in Times Square as the model for MS Awareness Week this year. I attend group for people with multiple sclerosis between the ages of twenty and forty, and plan to integrate the sorts of roundtable discussions we have into my future film work. I have started a non-profit organization called When I Walk Inc., whose purpose is to create media that promotes advocacy and awareness about multiple sclerosis.

Production Changes for *First Steps*

In making First Steps, I have changed my approach to documentary filmmaking in several respects. I had to adapt to changes in my body, which resulted in technical changes as well as changes to the more traditional aspects of documentary filmmaking.

Adaptations in Filming

First Steps takes my prior shooting philosophy in an entirely different direction. Celluloid film is a medium that I am more comfortable with, but the camera is heavier. With multiple sclerosis and my consequent imbalance and clumsy movements, I am not able to achieve hand-held smooth tilts or utilize crab dolly shots as I once did. Now, even mounting the Super 16mm camera on my shoulder has become precarious to my physical balance. Having found a lightweight, high quality video camera, I am able to change the way I shoot.

First Steps is shot on digital video with a professional high-definition camera. This allows for much more footage to be shot than with film, and at a lower cost, and it makes it easier for others without technical camera experience to assist me in the shooting process. In this case, I have challenged my relationship with the camera and the techniques that I used to depend on. I became an actor in my own documentary.

In Front of the Camera

First Steps puts me in front of the camera for the first time, rather than solely behind it. This gives me the feeling that I am losing some control as filmmaker.

However, this feeling is counter-balanced by the realization that I have the power to act as a character in my own story, and I have gained comfort and pleasure from the "acting" element of making the documentary, which gives me a sense of liberation. It is both challenging and rewarding to put myself and my vulnerabilities on screen in this way.

According to Jim Lane, author of The Autobiographical Documentary, there are three significant characteristics of the autobiographical documentary. First, it reveals how documentary can be a site of autobiographical subjectivity. Second, placing the self in the film complicates how the non-fiction film represents the real world. Third, the form of autobiographical documentary has established an array of its own formal possibilities in the cinematic storytelling form (6). While making First Steps, I noticed the mobility and freedom of creating an autobiographical documentary: it has helped me realize my own subjective voice as an authority. I have also changed the way I organize my creative process partly due to my different physical capacities. For example, my subject becomes constitutive of my process, as I now rarely film scenes spontaneously but instead organize every aspect of the crew, setting, and even shot lists before shooting. These adjustments alter both the world of representation and the formal possibilities available to me in my filmmaking. These aspects of autobiographical film give me a new sense of control and nuance in my expression as my method changes in tandem with my abilities.

First Steps is best classified under the documentary category of "participatory." It welcomes direct engagement between filmmaker and subjects, and the filmmaker becomes part of the events being recorded, such that the filmmaker's impact on the events being recorded is acknowledged and often celebrated (Nichols 12). Similar to

Nina Davenport in her Always a Bridesmaid, Never a Bride (2000) or Morgan Spurlock appearing in Supersize Me (2004), my presence in the film will be critical of the journey that the viewer takes. Both Davenport and Spurlock integrate humor and lightheartedness in their socio-political subject matter. Similarly, I plan to move through my personal stories by combining them with informational prose.

Roger and Me is another example of documentary making in the "participatory" category. In his 1989 film, Michael Moore gathers information by meeting with and interviewing people who live in economic disparity in Flint, Michigan. Moore follows a collector from the police force as he repossesses houses from unemployed persons, and discovers otherwise inaccessible information simply by being there as dramatic events unfold. First Steps has a similar strategy in that the individuals I meet move my own personal story forward as I learn from them and come to progressively map out the future development of the narrative. These interactions allow me to look at specific issues of disability in society, functioning as an on-camera investigator by interviewing others. For example, on-camera, I attended the West End MS Support Group in Vancouver and recorded them speaking about various issues that the MS community faces such as accessibility and advocacy.

Conclusion

First Steps is foremost a personal story. The film acts as a way to bring issues related to disability to the general public. It celebrates the progress our society has made towards the betterment of disabled people's lives, but is also mindful of the mistreatment and violation of basic respect and rights that we continue to face.

While my past films, Olivia's Puzzle and Lest We Forget, were conceptually autobiographical, First Steps evolved into a more explicitly autobiographical and self-referential documentary. This shift has carried its own challenges, but also encouraged me to explore new modes of filmmaking. My film highlights the interaction between my self and my environment, bringing together both a discussion of the bodily experience of disability and how such disability fits into a complex interplay of social forces. These forces determine which individuals or groups are labelled "normal," and which "abnormal;" which sort of body is unmarked or marked as deviant; and who is labelled as "Other." Beyond the autobiographical documentary form, my aim with First Steps is to take a critical look through the filmic lens into these very social, cultural and biological structures that interact to create both notions of disability and the material experiences of living with it.

My hope is that my film work on disability provides information, inspiration and a forum for discussion for those affected by multiple sclerosis and their supporters. It is crucial to view the film as not only a critical tool that examines issues of disability and "Otherness," but also as a personal testimonial that challenges dominant social and cinematic conceptions about disability and its apparent limitations. In other words, against a history of distortion and erasure of disability, my film restores agency and self-determination to my own marginalized status as a disabled subject and filmmaker.

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