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Editorial: Isolation: A Diary of Subtle Discrimination

Megan A. Conway, PhD
RDS Managing Editor

Although I am a self-described white lady of excellent education and moderate means, I follow with interest developments in ethnic studies, women’s studies and social justice because they so often resonate with my experiences as a person with a disability and a professional in the area of disability studies. A recent article in the New York Times, “Students See Many Slight as Micro-Aggressions” (March 21, 2014) caught my eye because in discussing how seemingly innocent comments can convey subtle forms of discrimination, the author lead with:

“A tone-deaf inquiry into an Asian-American’s ethnic origin. Cringe-inducing praise for how articulate a black student is. An unwanted conversation about a Latino’s ability to speak English without an accent.”

Tone deaf? I realize this is a common figure of speech, but still. It amazes me that an entire article about the expression of micro-aggression via the use of language in higher education could so blithely ignore this obvious stereotyping of deafness as equated with ignorance.

But language is really just the tip of the iceberg here (no offense to icebergs). Many of us with disabilities in professional roles have been waking up to the fact that just because we have advanced degrees and know a lot about a lot of stuff does not mean that we have shed discrimination like an unwanted Christmas sweater (apologies to Aunt Gladys). In fact, just as with women and ethnic minorities who have banged their heads firmly against the glass ceiling as they climb up the professional ladder, we are experiencing a profound dose of “ouch” (even more painful for those of us who may have more than one “minority” identity).

Mary Rowe, in a still-relevant article published in 1990, “Barriers to Equality: The Power of Subtle Discrimination to Maintain Unequal Opportunity,” describes how overt prejudice has been replaced by more subtle forms of discrimination that nurture persistent inequalities in education and the workplace. Even though blatantly telling someone that they have been denied promotion because they are a woman is no longer acceptable in the United States, as happened to my mother-in-law in the 1970’s, actual prejudice still persists and results in the same mechanisms of exclusion. Writes Rowe:

“[Micro-inequities as] mechanisms of prejudice against persons of difference are usually small in nature, but not trivial in effect. They are especially powerful taken together. (As one drop of water has little effect, though continuous drops may be destructive, one racist slight may be insignificant but many such slights cause serious damage.) Micro-inequities work both by excluding the person of difference and by making that person less self-confident and less productive.”

I have to confess that I am still mulling over (o.k. I am still mad about) a recent experience that brought these issues home to me. At the grand gala of a recent conference focused on disability, I secured my usual table up front near both the stage and my assistive listening device. For those of you who don’t know me, I am both legally blind and severely hard of hearing (aka deaf-blind), and I am always worried about missing something, which is fruitless since I miss half of everything no matter what. Anyhow, I kept waiting for someone to join me at my table. I know other people are often shy

about sitting up front. And I know my wheely colleagues likely couldn't even get up front. But I observed as the tables around me filled with people. And no one sat down at my table. Do I have lice? I wondered. Is there food in my teeth? The conversational buzz around me increased as people talked and laughed, and there I sat alone. I peered around, trying to recognize someone that I knew. I knew I knew people there, but I couldn't see where they were sitting and no one approached me. A wave of isolation and loneliness settled in. Then the program started, and the speakers talked about inclusion, and access, and recognizing diversity, and I didn't know whether to laugh or cry. I put on my dark glasses, just in case. Finally I had enough. I gathered my things. Then I noticed a sign on the center of the table, "Reserved." Reserved? Reserved for who? For me? Special me? Surely not. Whoever the table was reserved for, they didn't show up.

Whether you call it "micro-aggression," "subtle discrimination" or "micro-inequalities," the impact of being treated with disrespect or even just lack of awareness is damaging to the individual and hard to prove. How do you confront and correct colleagues who talk behind your back about how you are "arrogant" when you speak your mind about social justice issues that are important to you not because they make you look pretty but because to you they are intensely personal? Who do you complain to when you sit alone at a meeting in a room full of people who assume that isolation is your choice, when in actuality you cannot see/hear/move to join them? It is easy for people to make excuses that shift responsibility away from them and onto the person being discriminated against: "You need to learn to tone down your opinions," or, "Oh, that was unintentional." But one after another, these "micro" events build up into one giant iceberg that blocks the path to success.

I took the liberty of substituting "people with disabilities" for "minorities and women" in an article posted by Bowling Green State University, titled, "Subtle Discrimination". The results highlight the striking nature of discrimination, no matter the reason:

"Subtle Discrimination"

There are a broad range of subtle behaviors and events that perpetuate inequities for people with disabilities in post-secondary education...

Condescension: the apparent refusal to take people with disabilities seriously, as students and colleagues, which is communicated through posture, gesture, and tone of voice.

Role stereotyping: the expectation of behavior that conforms to the disability role stereotype.

Disablist comments: expressions of derogatory beliefs about people with disabilities such as statements of "inferiority," "not intelligent," and "not serious."

Hostility: avoidance, expressions of annoyance, resentment, anger, jokes, and innuendoes.

Exclusion: unintentional and intentional oversights denying people with disabilities access to events.

Denial of status authority: the covert refusal to acknowledge a person with a disability's position or their scope of authority (e.g., bypassing the individual and going to their supervisor).

Invisibility: the failure to recognize the presence or contributions of people with disabilities.

Double standard: differential evaluation of behavior as a function of disability attribution (e.g., regarding an able bodied person's non-academic experience as "enriching" and that of a person with a disability as indicating a "lack of focus.")

Tokenism: the discretionary inclusion of one or few people with disabilities.

Divide and conquer: the use of tactics that maximize the social distance of people with disabilities from each other (e.g., informing the individual that s/he is superior to others of the protected class in ability or achievement).

Backlash: the rejection of men and women who support efforts to improve the status of people with disabilities.

Am I being subtle enough? You be the judge.

Popular Culture and Disability

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Forum Introduction

Disability is popular. Whether as source of fear and/or fascination, what it means to have a disability has been a subject of continual popular interest. These contradictory impulses are reflected in the way that disability has been—and continues to be—represented in popular media.

When we say that disability is popular, we mean this in at least two ways:

(1) Disability is a source of popular attention: media audiences are very interested in the experience of disability and looking at media that would purport to allow them the vicarious experience of disability, with a host of media products and programs addressing this interest. (2) We also mean to stress that *disability* is, in a very real sense, created in the popular. That is, the social meaning of bodies with disabilities is fashioned in the process of representing them in circulated media. It is through this ritual of popular forms that many people (both with disabilities and without disabilities) formulate their ideas of what it means to have a disability.

Disability Studies has of course concerned itself with how this constructed nature of disability has been hidden and how instead the “medical model” of disability has been used as a way of attempting to control *the story* of disability, buttressing current distribution (or lack thereof) of social power. As such, popular media has often offered well-defined cultural scripts of what it means to have a disability. Scholars including the late Paul Longmore and Martin Norden have offered valuable roadmaps of the recurrent stereotypes that have formed ideas of disability in popular media, particularly film: the avenger, the freak, the monster, the inno-

cent, all caricatures that do their best to reduce the complex and organic experience of disability to simple object of pity, scorn, or fear.¹

While media circulating in popular media has certainly been complicit in reinforcing and helping articulate the repressive structures that support ableism, they do not always do so. At the same time that they have been culpable of images and forms that have encouraged discrimination and exclusion, popular media continues to be a powerful public place in which these same limiting cultural scripts are often challenged and perhaps reimagined.

Cultural Studies pioneer the late Stuart Hall stressed the importance of the realm of popular culture. While many critics and scholars have been dismissive of popular media, Hall suggests we pay closer attention. Popular culture matters. It is the unstable ground on which an essential battle is being waged. A constant conflict both for and against tradition, both for and against established orders and structures of power. Hall suggests that it is from this unstable maelstrom that culture (and its future forms) emerge. Popular culture has at its center “the changing and uneven relations of force which define the field of culture.”²

So this issue of the Review of Disability Studies asks us to take popular culture seriously, to consider some of its forms and how they might participate in a conversation culture is having with itself about what disability means. It is a conversation in which new, potentially transformative and empowering forms may be emerging. This special issue assembles some of the most provocative glimpses into this interna-

tional dialog. The works gathered here consider the shifting places where the plastic concepts of disability meet the equally shifting ground of popular culture.

In “Precarious Inclusions; Re-Imagining Disability, Race, Masculinity and Nation in *My Name is Khan*,” Nadia Kanani invites us to examine the ways in which disability and popular culture intersect with cherished notions of masculinity and nation in the realm of Bollywood film. Similarly, in “Keep It Right - *Homeland*: The Female Body, Disability, and Nation,” Jollette Rouleau considers how post-9/11 fears of nation negotiate with concerns of race, gender and sexuality in the popular American television program’s imagining of disability. In the essay “Body Vandalism: Lady Gaga, Disability and Popular Culture,” author Christopher Smit invites us to consider unexpected ways in which the global media popstar Lady Gaga may serve as a powerful popular site to redefining disability. And the essay “The Legacy of 19th Century Popular Freak Show Discourse in the 21st Century *XMen* Films” by Fiona Pettit adds an important historical dimension to this issue with her consideration of the ways in which historical forms of popular culture continue to resonate in new forms and contribute to the precarious social identity of those with disabilities.

It is our hope that the essays in this issue contribute to the continued investigation of the ways in which popular forms inform the frames by which we know the body, and most importantly, how popular engagement with these frames may transform both the popular and disability, offering perhaps glimpses into better things to come.

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Popular Culture (with Russell Meeuf) (2013). Dr. Raphael lectures at the University of Hawaii at Manoa and serves as technology faculty for the American Community Schools in Athens, Greece. He is co-editor of the new journal, *DIS/ART: The Journal of Disability Culture and the Visual Arts*. His scholarship is also informed by his own practice as a digital artist.

Holly Manaseri, PhD holds a doctoral degree in the Cultural Foundations of Education specializing in the area of Disability Studies from Syracuse University. She has conducted educational research and evaluation studies for the UH Center on Disability Studies in the area of Interdisciplinary Studies, place-based education and has extensive experience in the development of collegiate curricula in the area of Disability Studies. Most recently, Dr. Manaseri has participated in the development of the undergraduate Disability Studies program at the University of Hawaii at Manoa and is currently developing an Inclusive Education Certificate at Leeward Community College for paraprofessionals. As a former public school principal, she has been involved in the practical application of inclusion and as a parent to a son with complex medical needs, she has been a active advocate for inclusive schooling. Dr. Manaseri has had presentations accepted on how portrayals of disability in media intersect with inclusive education policy at the international PopCaanz conference in Australia and New Zealand.

Endnotes

¹ See Longmore’s seminal essay “Screening Stereotypes: Images of Disabled People in Television and Motion Pictures” in *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple UP, 2003; and Norden’s *Cinema of Isolation*. New Brunswick: Rutgers UP, 1994.

² See Hall’s “Notes on Deconstructing the Popular,” originally published in Raphael Samuel’s *People’s History and Socialist Theory*. London: Routledge & K. Paul, 1981.

The Legacy of 19th Century Popular Freak Show Discourse in the 21st Century X-Men Films

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Abstract: This essay seeks to tease out the narrative similarities found in nineteenth-century freak show literature and in the *X-Men* films of the twenty-first century. Both of these forms of popular entertainment emphasize the precarious position of people with extraordinary bodies in their contemporary societies..

Key Words: freak, *X-Men*, disability

In terms of the narrative similarities between the nineteenth-century freak show and the *X-Men* films, there are two key components that this paper will explore. There exists a striking similarity in how certain freak show performers and mutated characters in the *X-Men* speak about their condition. Additionally, there is a degree of resonance between how ‘normal’ or non-normative bodies speak of the freak, the mutant, or the “other”. This paper addresses the narrative relationship to demonstrate the legacy of popular nineteenth-century freak show discourse.

During the winter season of 1898-1899, the popular Barnum and Bailey Circus, dubbed the “greatest show on earth,” exhibited in London at the Olympia theatre. The show was a huge success and was regularly featured in numerous popular periodicals. In the middle of this season, the freak show performers, who made up a large portion of the circus, held a protest against their designation as “Freaks of Nature”, and instead adopted the title of “Prodigy.” They explained: “In the opinion of many some of us are really the development of a higher type, and are superior persons, inasmuch as some of us are gifted with extraordinary attributes not apparent in ordinary beings” (Man about town, 1899, p. 41). The performers acknowledged that they had extraordinary attributes, but sought wider

recognition of their superior traits. Freak show performers represented a broad spectrum of physical otherness, from sword-swallowers and tattooed women to bearded ladies, elastic-skinned men and armless wonders, and many variations of uncommon corporeality in between. While the media coverage of this protest and the exhibition itself continued to vary the terms used to reference the performers, the notion of their ‘ordinary’ and ‘normal’ attributes, received regular attention. Indeed, the normalizing of freak show performers through their everyday actions, alongside an emphasis on their extraordinary attributes, was an important convention in freak show discourse that has been brought forward to popular narratives of disability and otherness in the twenty-first century. In this paper, I will consider how the legacy of these freak show narratives resonate in the twenty-first century through the unlikely format of the superhero films based on the *X-Men* comic book series.

Simply put, the *X-Men* movies (*X-Men*, *X2: X-Men United*, *X-Men: The Last Stand*, *X-Men Origins: Wolverine*, *X-Men: First Class*) feature a world where humans and Mutants struggle to live together peacefully. However, the relationship between these two spheres of the population is often strained and far more complex, with the attempts for a peaceful coexistence ranging from cooperation to genocide. Indeed, the second film in the trilogy, *X2*, begins with a voiceover by the character of Charles Xavier remarking that “sharing the world has never been humanity’s defining attribute” (Shuler Donner, Winter & Singer, 2003). The Mutants are essentially human beings with a genetic makeup that has evolved and mutated to produce a being with exceptional abilities. These extraordinary attributes range in their visibility and strength.

From the shapeshifter, Mystique, whose natural body is blue and scaly, to the telepath, Charles Xavier, who has no visible trace of his ability written on his body. Due to their extraordinary traits, the mutants are exploited, ostracized, pitied, feared, and glorified. While they have extraordinary attributes, these features often impair the Mutants and make it difficult for them to participate in 'normal' society. The Mutants themselves are divided in their approach to this treatment. While those who side with Magneto seek revenge on a society that struggles to accept the Mutants, the other Mutants, the X-Men, who side with Professor Xavier, take measures to be accepted in 'normal' society and exploit their extraordinary attributes only for good. Despite being fiction, these fantastical bodies employ cultural narratives and offer, as Aaron Taylor has noted, "A site of departure for typical ways of thinking about and categorizing the body" (Taylor, 2007, p. 347). Narratives of otherness due to physical difference are rife within these films, and this paper aims to link these narratives to their historical roots in nineteenth-century freak show discourse.

Both the nineteenth-century freak show and the *X-Men* film series are forms of popular entertainment accessed by wide-ranging audiences in their contemporary periods. Freak show histories have demonstrated how the variety of exhibition and performance venues (including travelling fairs, circuses, and shop-fronts) used by the showmen, as well as the multiplicity of print representations (such as newspapers, children's magazines, and trade journals) allowed broad and diverse audiences to engage with and consume freakish bodies throughout the nineteenth century (Durbach, 2010; F. Y. Pettit, 2012; Toulmin, 2006). Similarly, the *X-Men* also have a strong print and visual culture presence, originating as a comic book series from Marvel in the 1960s and later developing into films in the 2000s. Film scholars have noted the success of *X-Men* films in terms of their "blockbuster" status, and, indeed, the overwhelming influence of the comic book genre in the filmed

entertainment industry (McAllister, Gordon, & Jancovich, 2006; Weltzien, 2005, p. 230). Due to the extent of their reach, both the freak show and *X-Men* have brought extraordinary bodies to the fore of their contemporary popular culture.

Central to the popular engagement with the freak show and the *X-Men* is the perceived otherness of the bodies on display. These two forms of popular entertainment showcase extraordinary beings that represent a minority population separate from the general populace. As such, they are seen as the exception, the opposite to "normal". It is through the variations of this narrative in the shows and the films that brings this analysis into the realm of disability studies. As Gary Albrecht, Katerine Seelman and Michael Bury have explained, "The history of disability studies in the Western world reveals that from early times, disability has raised questions of normality, theories of difference, the perceived threat of difference to the established order, and institutions and mechanisms of social control" (Albrecht, Seelman, & Bury, 2001, p. 5). From the fraught relationship between the *X-Men* and their society to the freak show's challenges to perceptions of normality, this analysis will demonstrate the value of disability studies in understanding the legacy of popular culture narratives from the nineteenth-century in the twenty-first century.

Background

There have been several studies on the legacy of the Victorian freak show in twentieth- and twenty-first century disability studies. These works have demonstrated how the notion of "otherness" created within the shows has continued to attach itself to cultural representations of disabled bodies through time.

Integral to the question of difference or deviance is the notion of "normal." A key debate within disability studies and studies on the freak show centers on ideas of social inclusion and

otherness. In her analysis of the continuation of freak show performances in the twenty-first century, Elizabeth Stephens notes that “dominant cultural concepts of the body as a natural and coherent entity emerge in and through the exhibition of bodies identified as chaotic, unstable, and exceptional” (Stephens, 2005). This same point on the creation of normality simply through comparison is regularly addressed by Disability Studies scholars. Indeed, as shown in David Turner and Kevin Stagg’s *Social Histories of Disability and Deformity*, there is a very diverse history of who has been considered disabled and deformed through time and how those people were (un)able to engage in their contemporary societies. Turner explains “What connects these disparate histories and experiences is a shared element of stigma and separation from what dominant cultural and medical discourses define as ‘natural’ or ‘normal,’ leading to devaluation and socially imposed restriction” (Turner, 2006, p. 4). In the nineteenth-century, the freak body was used by both medicine and popular culture as a site to define and circulate notions of normality.

In his seminal study of the history of freak shows, Robert Bogdan highlighted that freak was a “social construction” rather than an inherent attribute of the performers (Bogdan, 1988, p. xi, 1996). This means that freakishness was woven into representations and exhibitions of the freak show performers, rather than an instant assumption made upon viewing a person with a disability or deformity. One of the most pervasive examples of this is the attempts to make the ordinary and everyday actions of the performers seem extraordinary due to their appearance. For instance, an 1889 interview with the freaks performing in the Barnum and Bailey circus explains, “that but for one particular trick which Dame Nature has played each one of them, these sports of Fortune are just men and women, with the feelings and habits, the likes and dislikes, the occupations and amusements of the rest of the world, with, of course, certain inevitable limitations” (Goddard, 1898,

p. 493). By highlighting the everyday aspects of the performers’ lives and comparing them to the “rest of the world”, this article makes their “normal” attributes seem extraordinary and freakish. Rather than normalizing the performers through this acknowledgement of their similarities to the readers, it makes it seem incredible that the freaks are in fact “just men and women.” This notion of otherness, despite the similarities, is a key narrative that has continued in popular culture discourse on disability.

Further, Rosemarie Garland Thomson, has described “freakery” as “a single amorphous category of corporeal otherness [...] constituting the freak as an icon of generalized embodied deviance” (Garland Thomson, 1996, p. 10). She situates the freak show as a cultural site for reinforcing normalcy. She explains, “the freak’s bizarre embodiment could assuage viewers’ uneasiness either by functioning as a touchstone of anxious identification or as an assurance of their regularized normalcy” (Garland Thomson, 1996, p. 11). This was brought out in the freak show not only through the physical appearance of the freak performers, but also largely through the narratives cultivated and sold in the shows. Garland Thompson argues that the symbolism of deviant bodies has continued through time, taking on new narratives to serve the contemporary notions of normalcy.

Traces of nineteenth-century freak show narratives are numerous in the X-Men films and are woven into the storylines and dialogue. These range from more obvious references, such as the mutant characters being called freaks, or performing as novelty acts in circus sideshows, to more nuanced references which will be teased out here. Rather than provide an in-depth analysis of each film’s engagement with disability narrative, I hope to introduce some of the key themes which exhibit the legacy of freak show narrative. Primarily, these are brought out in the films through notions of evolution, mutation, and social exclusion, all of which are supported

and expounded by the concepts of deviance and normalcy.

Evolution

Underscoring the creation of Mutants in the films is the theory of evolution. Throughout the first three films, evolutionary theory is regularly referenced. For instance, one of the opening scenes in the second film, *X2*, shows the students from Xavier's school having a lesson on the evolution of man in the Neanderthal exhibit of a museum. Also, the first film begins and second film ends with the same speech on the importance of evolution to human survival: "Mutation. It is the key to our evolution. It has enabled us to evolve from a single-celled organism into the dominant species on the planet. This process is slow, normally taking thousands and thousands of years, but every few hundred millennia evolution leaps forward" (Shuler Donner, Winter & Singer, 2000, 2003). Further, in *X-Men: First Class*, we also learn that Professor Charles Xavier achieved his doctoral degree for his expertise in gene mutations, based on the theory of evolution. This conceptualization of evolution permeates the storylines of the *X-Men* films as a means to explain the origins of the Mutants' abilities. Rather than ever giving a comprehensive explanation, the films assume the audience's familiarity with evolutionary theory. In a similar manner to the Victorian showman's manipulation of popular understandings of evolution as a means of selling his freak performers to curious audiences, the *X-Men* films also rely on viewers' knowledge of evolution to understand the formation of mutants.

In the nineteenth-century freak show, evolution was regularly traded on as a freak narrative. Indeed, some acts were even touted as the missing link between man and ape. However, as the freak protest demonstrates, many freak show performers did not see themselves as lower down on the evolutionary scale, even though they had performed this role in the shows. Instead, they were of a "higher type" and "superior persons"

("Man about town," 1899, p. 41). In a similar vein, many of the Mutants consider themselves to be of a separate and superior species from Humans. The character of Magneto employs this narrative throughout the films and goes to great lengths to remind Humans of their frailty next to the extraordinary attributes of Mutants. During the opening scenes of the first *X-Men* film, viewers are introduced to Magneto's belief in Mutant superiority:

Charles Xavier: Mankind is evolving.

Magneto: Yes, into us[...].

Magneto: We are the future Charles, not them [Humans]. They no longer matter (Shuler Donner, Winter & Singer, 2000).

Indeed, throughout the films, the characters who wish to hurt humans, and are therefore depicted as the villains, often frame their justifications for their actions on the narrative of mutant superiority and human simplicity. Magneto reassures one of his recruits in *X2* by stating: "You are a god among insects. Don't let anyone tell you different" (Shuler Donner, Winter & Singer, 2003). While many of the mutant characters are shown to struggle to adapt to their society, being a Mutant is often portrayed as something to be proud of, at least from within the Mutant community.

While the nineteenth-century protestors did not cite evolutionary theory as the root of their superiority, the employment of the same narrative on extraordinary superiority in the *X-Men* films provides an interesting comparison. Marlene Tromp and Karyn Valerius have described the necessity of interpreting "freakishness" within the performer's social context and "particular cultural moment" (Tromp & Valerius, 2008, p. 4). With this in mind we can understand why the nineteenth-century freaks would not use evolutionary theory to explain their superiority. In that period, evolution was more regularly used to justify the differences between races, frequently making the non-white races inferior and more closely related to ape than man. By

contrast, the *X-Men* films use contemporary understandings of evolution to explain the existence of a higher, superior type of human. In the films, Mutants are the result of evolution leaping forward, whereas in the heyday of the freak show, freak performers were represented by showmen as proof that “normal” humans had evolved. However, the protest against the name of freak and the performers’ justification for this, are more closely aligned with the Mutant narrative in the *X-Men* films. The narrative supporting the protest pre-empts the twentieth-century move towards more empowering discourse surrounding difference.

Human or Animal

A more direct link between the nineteenth-century use of evolutionary narrative in freak shows and the *X-Men* films can be seen in Logan’s animalistic traits and the language surrounding this in *X-Men Origins: Wolverine*. On top of his body’s regenerative ability, Logan is also able to grow claws in between his fingers, has an acute sense of smell, as well as extraordinary climbing abilities. The first part of the film demonstrates that Logan regularly used his abilities and his short temper to kill. His Mutant name, Wolverine, furthers his animalism. Throughout this film his bestial qualities are referenced in recognition of his proximity to the animal kingdom. For instance, the military scientist, Striker, who uses Mutants for experimentation in the creation of an ultimate weapon, convinces Logan to use his animalistic skills to kill his own brother, Viktor. He says, “I can’t take Viktor down myself, Logan. To kill him you’ll have to embrace the other side. Become the animal” (Shuler Donner, et al. & Hood, 2009). In another scene, Logan’s girlfriend attempts to calm his animalistic instincts, which become particularly aggressive when he is angry, by reminding him, “You’re not an animal, Logan. You have a gift” (Shuler Donner, et al. & Hood, 2009).

Logan’s animalism is reminiscent of the narratives in the freak show surrounding both

“missing link” acts and “wild boy” exhibits. Both of these types of acts merged human and animal characteristics to produce a freakish creature. In 1894, *Illustrated Chips* mentioned two such creatures in a series on “Freaks of Nature.” The first was the “Man-Monkey” from Africa, which by the description seems to have been a primate rather than a human (“Freaks of Nature IV,” 1894, p. 6). The second was a child called “Peter, the Wild Boy,” “A creature who was half a boy and half an animal. Half a monkey would perhaps be a better term to apply to him” (“Freaks of Nature VII,” 1894, p. 3). Both are described as being neither completely human, nor completely animal. However, it is likely that the Man-Monkey was actually a monkey and that Peter was a human. Due to the contemporary debates and popular understandings of evolution, freak showmen were able to trade on the similarities between man and animal exhibited through primates and get audiences to question animalistic features in humans.

Mutant Experimentation

In their overview of Disability Studies, Albrecht, Seelman, and Bury note that “disability is both a private and public experience” which may be “a shameful condition to be denied or hidden” for some, but also “a source of pride and empowerment – a symbol of enriched self-identity and self-worth” for others (Albrecht et al., 2001, p. 1). It is this notion of pride and enriched self-worth that we see in the freak protesters and in the Mutants. However, as David T. Mitchell and Sharon Snyder have demonstrated in their review of Humanities studies of disability, negative imagery is pervasive in literary and filmic representations. Quoting Paul Longmore’s work on television and film representations, they note that oftentimes, “Disability is a punishment for evil; disabled people are embittered by their ‘fate’; disabled people resent the nondisabled and would, if they could, destroy them” (Longmore qtd. in Mitchell & Snyder, 2001, p. 197). Throughout the films, the character of Magneto and his dislike for non-

mutants falls in line with Longmore's analysis. At the same time that Magneto encourages the Mutant's sense of self-worth, he also propagates a strong hatred for the 'normal' humans. So, both of these conceptions of disability, empowered pride and embittered resentment, resonant in the *X-Men* films through the Mutants.

Magneto's hatred towards non-Mutants stems from his own horrific experiences and from the constant reinforcement that Mutants are "other." At the beginning of the first film and elaborated in *X-Men: First Class*, we learn that as a child Magneto lost his family in a German concentration camp and he was subjected to cruel experimentation. The use of Mutants for scientific study and experimentation is also a powerful theme in *X-Men Origins: Wolverine*. In *Wolverine*, Logan and many other Mutants are taken to an island run by the US military and are used for experimentation. These storylines are entwined not only with Eugenics and the World War II atrocities enacted on 'othered' bodies, but also with narratives from the nineteenth-century medical relationship with freaks. Since the origin and complexities of many of the conditions exhibited by freak performers' bodies were still unknown, they attracted a great deal of interest from the medical community. In attempts to legitimize the shows, showmen would often invite medical practitioners to hold private audiences with the freak performers. As the famous case of Joseph Merrick and the surgeon Frederick Treves has shown, when freaks became the subjects of medical practitioners this relationship could easily lead to further degradation and humiliation for the performer in the name of science (Durbach, 2010, pp. 33–57). Further, freak bodies offered opportunities for the development of medical practices, such as the separation of conjoined twins (F. Pettit, 2012, pp. 74–78). At the crux of this medical interest in freaks and in the experimentation on the Mutants, is the narrative of difference.

A Cure for Difference

Both freak show histories and Disability Studies have argued that the concept of an "other" or a deviant body has worked to reinforce notions of "normal" bodies. Through the freak show, the notion of normalcy was brought out by the freaks enacting everyday activities, and it was the "inflated language that [made] them remarkable even as it invites pity and admiration" (Garland Thomson, 1996, p. 10). The ordinary is made to seem extraordinary because of the "cultural premise of irreducible corporeal difference" seen on the freak's body (Garland Thomson, 1996, p. 10). Indicated in the article interviewing the Barnum freaks, described above, this was a common narrative used to sell freak shows. The author, Arthur Goddard, stresses that "with the one particular reservation in each case, they are just men and women, normal and healthy, 'even as you and I'" (Goddard, 1898, p. 496). So, without their freakish corporeality, the freak performers were 'normal' people, but their bodily difference would always be "other."

This same narrative is echoed in the *X-Men* films. In the final part of the trilogy, *X-Men: The Last Stand*, a cure is developed to suppress the "Mutant X gene", transforming the abnormal Mutants into normal humans. The language of the announcement is reminiscent of Goddard's article: "These so-called Mutants are people just like us. Their affliction is nothing more than a disease, a corruption of healthy cellular activity" (Shuler Donner, et al. & Ratner, 2006).

The release of a cure for mutation sparks anger from all sides of the Mutant community. Magneto, in particular, actively ignites hatred for humans and recruits scores of Mutants to attack the labs creating the cure. The Mutants who side with Charles Xavier, the X-Men, work to stop Magneto and try to prevent the humans from being harmed. However, even the X-Men are angry by the notion that they are a problem in need of a cure. Storm, one of the leading members of the X-Men, rails against the Xavier's

explanation of the cure to one of his students, “No Professor, they can’t cure us. You want to know why? Because there’s nothing to cure. Nothing’s wrong with you or any of us for that matter” (Shuler Donner, et al. & Ratner, 2006). Storm’s pride and empowerment from being a mutant echoes Albrecht, Seelman and Bury’s description of disability (above) and highlights the prevalence of disability studies discourse in the *X-Men* suite.

Mutant and Proud

The most recent *X-Men* film (at the time of writing), *X-Men: First Class*, which chronologically pre-dates the trilogy, highlights the struggle for Mutants to feel empowered by and proud of their extraordinary abilities, and also feel a part of society. This is particularly brought out by the character of Raven, who later adopts the name of Mystique. In her natural state, Raven has blue skin, red hair and yellow eyes. Through her ability she is able to transform into other forms and often adopts the appearance of a Caucasian female with long blonde hair. Recognizing that society would struggle to accept her in her natural form, Raven’s friend Charles Xavier recommends that she adopts a ‘normal’ appearance when out in public. In an argument with Charles, Raven challenges his recommendation and mocks the use of the phrase “mutant and proud” she overheard in his flirtatious conversation with another woman: “Or is it only with pretty mutations or invisible ones like yours? But if you’re a freak you better hide” (Shuler Donner, et al. & Vaughn, 2011).

Later in the film, Raven toys with the idea of trying a normalizing serum developed by another character, Hank. The two discuss their shared wish to look normal. However, by the time the serum is ready to use, Raven’s self-image has altered again and she encourages her friend to adopt a similar empowering narrative. In answer to Hank’s admission, “I don’t want to feel like a freak all the time,” Raven protests: “You’re beautiful Hank. Everything you are, you’re perfect.

Look at all of us. Look at all we’ve achieved this week, all we will achieve. We are different, but we shouldn’t be trying to fit into society. Society should aspire to be more like us. Mutant and proud” (Shuler Donner, et al. & Vaughn, 2011).

This point brings us back to the empowering message behind the freak protest of 1898. Rather than wishing to hide due to the fear of not being accepted by ‘normal’ society, the freaks were vocal about their extraordinary traits and demanded a greater respect be paid to them. So too, do the Mutants.

Conclusion

In the nineteenth-century, the freak show was a ubiquitous entertainment in popular culture. Many of the narratives from this mode of entertainment, particularly those surrounding the concept of physical otherness, continued to proliferate and transform in popular culture through the twentieth and into the twenty-first century. In the *X-Men* films we can see numerous similarities between the narratives of otherness represented by the mutants, and disability narratives with roots in the nineteenth-century freak show. Interestingly, little focus is placed on the only traditional representation of disability in the films; that is, Charles Xavier’s use of a wheelchair. Rather than following traditional representations of disability, the *X-Men* films demonstrate that disability narratives are present in our contemporary popular culture in even the most unlikely of places. While this essay has only been able to examine a handful of these instances in the films, it has opened the possibilities of exploring non-standard contemporary representations of disability narrative.

All of the *X-Men* films employ a narrative of conflict between the “normal” humans and “abnormal” mutants. In these films, the people living with differences don’t necessarily see them as problematic, but their position in society is affected by their differing attributes. While some of the mutants struggle to accept their

difference, there is an underlying, empowering theme, which Barnum and Bailey's freaks also employed in their protest. This common theme is the belief in the power and strength of difference. Rather than accepting a marginalized and inferior position in society, these groups of 'others' choose to reinforce the equality, if not superiority, their extraordinary attributes entitle them to have in society, a theme that resonates strongly with Disability Studies today.

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Keep It Right - *Homeland*: The Female Body, Disability, and Nation

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Abstract: This article will look at how *Homeland*'s main character, Carrie Mathison, is used as a metaphor for the current cultural state of fear in the post-9/11 United States by demonstrating the effects of internalized sexism and ableism within the representation of a disabled woman's experience in the articulation of her gender, race, disability, and sexuality.

Key Words: feminism, disability, *Homeland* (TV series)

Introduction

This article will consider Episode 1 of the first season of *Homeland* (entitled "Pilot"), which premiered on October 2, 2011 in the US. *Homeland* is set in the anti-terror movement, where terrorists present a menace to homeland security.¹ This article explores constructions of race, gender, and dis/ability in a reflexive analysis of the series that interrogates these identity categories and reconceives normativity in relation to the body, asking what it means socially to "be normal." In this paper, these norms are understood as being inscribed in discourses – the means of representation coding our experiences of the world in order to structure and share them to a larger scale (Hall, 1997).²

To further develop a thesis, this analysis will start by pointing out some key moments. The series opens on the lead character, Carrie Mathison, driving a car in the streets of Baghdad. In the first three minutes of the show, she defies her boss, trespasses illegally on a local prison, and interrogates a prisoner who is awaiting execution. Mathison bribes the inmate into revealing some clues about the next terrorist attack on American soil and creates a diplomatic crisis when she is discovered in the prison – because of which, she is forced back to Washington to

do administrative work, isolating her from her contacts.

Ten months elapse, taking us through the opening credits, where we meet again with Mathison in a completely different setting. Here, we are introduced to her within the private sphere. We witness her rushing to get ready in her empty but disorganized house that is decorated with cardboard boxes full of paperwork. An over-the-shoulder shot takes us to her bathroom where she changes and cleans her genitals – a simple act that is sexually coded and emphasized by the fact that she only goes home to do so. Mathison then dresses quickly in a suit and leaves her home. When in contact with other people, she is depicted as the outsider. Her boss notes the fact that she is habitually late (thus separating her from her peers) and introduces the subject of their urgent meeting: Nicholas Brody, an American soldier taken hostage eight years before in Iraq, has been found alive in Afghanistan.

Mathison is visibly shocked where the rest of the agents applaud and rejoice. She recalls her discussion in the Iraqi prison 10 months earlier and confides in her closest friend and supervisor, Saul, explaining that the Iraqi prisoner she interrogated disclosed that an American prisoner of the war had been "turned." She is convinced that Brody is this American traitor and she decides, despite a warning from her mentor, to pursue her intuition and investigate him. Ten minutes into the series, we have an incredible terrorist plot with no narrative basis except the intuition of a woman that the audience has been led to believe is not entirely well suited to her job or status. This tension is formally elaborated through a constant alternating editing, building Mathison and Brody's identities in different spaces simultaneously.

Nicholas Brody's character, on the other hand, embodies the white, able-bodied, male, marine hero of a long-lasting war – far from being believed to be a potential terrorist. We first see him in captivity, being discovered in a hidden trap somewhere in Afghanistan. His first words in the series are “I'm an American,” reinstating his heroic identity. We follow him through his naturalization steps, under both strict military surveillance and the multiple cameras of every American news channel. His heroic character is built on a foundation of post-traumatic stress disorder, which locates him and Mathison in a kind of binary opposition – as this article will further explore.

This paper argues that in *Homeland*, the body of main character Carrie Mathison is used as metaphor for the current cultural state of fear in the post-9/11 United States by demonstrating the effects of internalized sexism and ableism within the representation of a disabled woman's experience.³ Internalized oppressions (e.g., ableism) are those that are culturally coded as character traits or specific to a particular gender, race, or ability/disability (Hall, 1997). Mostly, they are oppressions entangled within a society or a culture without being criticized or even acknowledged. This article will discuss the ways in which the articulations of Mathison's gender, race, disability, and sexuality locate her in a specific intersection, explored via how she dresses, speaks, and acts and in relation to Brody's gender, race, disability, and sexuality. Here, articulation is understood as the recognition of the particularity of each oppression as well as interactions among them, which are specific to her character, and their effect. As Slack explains,

“Articulation is, then, not just a thing (not just a connection) but a process of creating connections, much in the same way that hegemony is not domination but the process of creating and maintaining consensus or of co-ordinating interests” (1996, p. 114).

This paper argues that these articulations make Mathison the moral gatekeeper of American white supremacist cultural hegemony,⁴ deployed and reinforced within Stuart Hall's regime of representation (1997). Hegemony requires that ideological assertions become self-evident cultural assumptions. This regime refers to, as Hall (1997) explains, the framework in which “representation connects meaning and language to culture / uses language to say something meaningful about, or to represent, the world meaningfully, to other people” (p. 15). Therefore, Mathison's character becomes the link between culture and meaning: there is a cultural state of fear post 9/11 that she embodies through her gender and her disability, and her actions are set up to counteract those fears and prevent any other attacks from being made.

Furthermore, it is imperative to apply the regime of representation as a critique of ableism, wherein disability is discussed but only as something to overcome or be erased (Palmer, 2011) in order to preserve the symbolic order of white ableist heteronormativity.⁵ The symbolic order refers to a concept developed by psychoanalytical theorist Jacques Lacan, who argued that the symbolic order structures social conduct. Feminist film theorist Laura Mulvey demonstrated that the symbolic order in classical film is obtained by condemning deviant conduct (often, the woman is deviant through her sexuality, and her domestication via marriage or her death brings back the symbolic order). In this article, the symbolic order of white ableist heteronormativity refers to multiple concepts articulated together, exemplified by the tension between Occident and Orient – between “white Americans” and “Arabs”; the implied deviance of Mathison's mood disorder; and finally the compulsory heterosexuality and able-bodiedness working together to “(re)produce the able body and heterosexuality” (McRuer, 2010, p. 97). Moreover, this analysis will consider the ways in which *Homeland* portrays the female body as a metaphor for the United States' homeland, strategically deploying gender and disabil-

ity to symbolize state security against racialized and ethnicized invaders. It will look at how the main characters of the series, Carrie Mathison and Nicholas Brody, are formally depicted and constructed as binary oppositions of each other in relation to gender and abilities.

The analysis will first look at how gender and disability are constructed in such a way as to deploy Mathison as a contemporary re-articulation of the hysterical woman. Secondly, it will look at how the representation of disability in popular culture nourishes the idea of compulsory able-bodiedness and compulsory heterosexuality as discussed in queer and disability studies (Butler, 1993; McRuer, 2010; Rich, 2004) by building a tension between gender and disability within the concept of normalcy (Davis, 1995). These questions will be addressed in the second section of this article.

Invisibility and Transcendence of the “Hysterical Woman”

Carrie Mathison refers to herself as having a “mood disorder,” which it is implied would threaten her position at the agency were it to become well known. In the first 10 minutes of the show, we see Mathison take some kind of green pill hidden in an aspirin bottle. Ten minutes later, her secret is discovered by Maxim, Virgil’s brother, both being her two closest allies in her illegal investigation of Nicholas Brody. From this discovery and onward, we know Mathison has a secret, and we are led to doubt her ability to act and think “sanely.” While this secret could compromise her job, we also understand that it’s making her good at it. A precisely gendered and ableist scheme of power relations is now set, which locates Mathison in a complex relationship to other characters.

She is the only woman in her surroundings and she is thought to be “crazy” because of her pills. First, her action of taking the secret pill is marked as suspicious when Maxim and Virgil find the pill and start inquiring about its con-

tent. Thus, to keep her social status, she must pass as able-bodied or “supercrip.” Tanya Titchkosky, in Withers (2012), defines “supercrips” as people who can avoid:

“Attending to disability by attending fully to their ability to participate in society, as normally as possible ... [who] ultimately and inevitably signify having a ‘positive effect on others,’ ‘contributing fully to the community,’ and ‘maximizing their potential.’ . . . The stories of the abled-disabled demonstrate that even disabled people are able to fit in and take up an appearance, which shows that their conduct is undoubtedly oriented to an unquestioned normalcy. Through this way of conceptualizing disability, disability becomes the space in which the value of normal shines forth without ever having to be directly spoken of, and disabled people are held to be asserting their individual ability (value) when they can be seen as oriented to serving this normal order” (p. 69-70).

Mathison can pass because her disability is mostly an invisible one. She also embodies the “supercrip” by virtue of the fact that her disability is the key to her passing: it’s what makes her able to work and think as she does. Later in the episode, Virgil confronts Mathison with the pill, having discovered that it is clozapine, an antipsychotic used with patients who are “unresponsive to conventional neuroleptics” (CPS, 2001, p. 376). He asks her if she’s “crazy,” to which she replies that she’s dealing with it:

Virgil: Just tell me I’m not out here risking federal prison on behalf of a crazy person.

Mathison: I am crazy.

Virgil: It is not funny. If anybody at the agency finds out about this. . . .

Mathison: I’ve got a mood disorder, okay. . . .

Virgil: I looked it up Carrie! Clozapine is an antipsychotic!

Mathison: I'm dealing with it. I've been dealing with it since I was 22.

Virgil: Does Saul know?

Mathison: God no. No . . . nobody does. Don't act so shocked, I mean, it can't come as a complete surprise.⁶

These examples serve to define Mathison as deviant and demonstrate how she navigates her marginalization.

Homeland's diegesis is strategically constructed so that the spectators know from the narrative that Mathison is dealing with a mood disorder that can be referred to as "crazy," as Mathison points out in this dialogue. As feminist film studies theorist Teresa De Lauretis (2004) explains, narrativity is a mechanism of coherence (p. 266). Therefore, it contributes to the depiction of the "crazy" woman audio-visually but also spatiotemporally.

First, internalized sexism mostly manifests itself through Mathison's work. The most obvious example of such is when she approaches Saul in a sexually suggestive way demonstrating how, as a woman, her primary weapon against oppression is through her body via men's sexual satisfaction. Moreover, her disability locates Mathison as weak, feeble, and irrational (for example, when Virgil describes her as being "intense" or when she reacts very emotionally to David telling her what to do). It is interesting to notice that the characteristics she displays are socially undesirable and mostly associated with femininity – again, her gender and disability enact these intersections of oppressions.

Her ability to transcend her gender issues is only available to her as a white woman; she is the only white woman directly involved in the investigation, in opposition to Saul and David, who are her ethnicized and racialized male counterparts, and Brody, the white male terrorist. In the following section, this analysis focuses on her sexuality being used as a weapon within a masculine industry, complicated by the con-

struction of mental health/disability through the archetype of the hysterical female.

Gender and Disability in Popular Culture

In *Homeland*, this construction of Mathison's gender and disability to create the archetypical hysterical woman reinforces the ableist and sexist regime of representation in popular culture. Mathison is portrayed as an archetype of the hysterical woman, and her gender and her sexuality enable her to act as the gatekeeper of morals and white heteronormativity in popular culture. The hysterical woman archetype, as embodied by Claire Danes' portrayal of Mathison, has a very long history in film and media (Doane, 1988), but she is also important in the history and development of allopathy. Since the 17th century, women have been pathologized as "neurasthenic" and "hysterical" (Foucault, 1976). The commonly held belief informing medical science was that women were mentally more fragile than men and therefore unable to participate fully in social life.

As mentioned, irrationality and vulnerability are seen as undesirable and often associated with femininity and feminine sexuality. Mathison's sexuality must be passive in order to be non-threatening to her male counterparts (Doane, 1988). In *Homeland*, Mathison's gender and disability construct her as being both irrational and vulnerable, and these characteristics therefore serve to justify her irrational behavior and sexuality. As alluded to previously, Mathison embodies this hysterical woman partly based on her promiscuous sexuality. When it comes to women, this promiscuity can be associated with having mental health issues – or, more specifically, with hysteria and Freud's definition of what this type of diagnosis implies for female sexuality (Heath, 1992, p. 51), such as sexual desire, insomnia, irritability, and a tendency to cause trouble (Maines, 1999). When Saul discovers Mathison's illegal monitoring of Brody's house, Mathison attempts to protect the

investigation from being shut down by stating that she would do anything to prevent him from reporting her, clearly implying a sexual offer. He rejects and shames her paternalistically, marking her sexuality as a main weapon in her battle to gain and maintain power.

When Saul rejects Mathison's attempts to gain security and cuts off communication with her, she is then depicted as entering into an irrational, emotional state. She listens to loud jazz music, takes a pill, and tries unsuccessfully to calm down. The camera movements in this scene could also be described as hysterical. As Doane (1988) puts it, hysteria condenses where paranoia decomposes (p. 198), and here, we have access to more narrowed shots picturing Mathison constantly within frames (the frame of her bed, the frame of her closet, the frame of her door). The frames contribute to this idea of constraining her – hysteria condenses her emotions as well as her body into narrative and cinematic frames. The camera frantically follows Mathison's actions. Frustrated, she begins to repeatedly change her clothes, intermittently trying to calm down, and finally leaves the house for a nearby bar where she attempts to seduce a stranger. This precise action reminds us of the beginning of the episode, where Mathison comes home in the early morning, changes out of evening clothes, cleans her genitals, and dresses in clothes more suitable for office work. Her promiscuous sexuality can be understood as a direct effect of her emotional reactions, which leads us to understand it as related to her mental health issues, a work tool, or both; but it is difficult to imagine that her pleasure factors highly.

Her interaction with Saul leads the spectators to understand that she uses her body and her sexuality to achieve her goals (in this case, to prevent him from denouncing her) but that she is at once revered and detested for this. Earlier in the episode, Saul had gotten Mathison entry to Brody's debriefing, asking her, "Will you behave yourself?" Not too long after the alleged meeting, David and Saul have a paternalistic conver-

sation about Mathison, helping us understand the structure of the power relations taking place between the three of them:

David: You kicked Carrie Mathison into my debrief this morning, I'm curious – was it her request or yours?

Saul: Hers. Frankly, I'm surprised you didn't assign her yourself. She is the only one in the section who's ever been to Iraq.

David: It's not her résumé I have a problem with, it's her temperament.

Saul: What happened?

David: She turned a routine follow up into a cross-examination. She kept trying to connect Brody to Abu Nazir. It's always Nazir with her.

Saul: I won't deny, she can be a little obsessive on the subject.

David: Is there something I should know Saul?

Saul: Not that I'm aware of.

David: Because the last time I heard her like this, she bribed her way into an Iraqi prison, causing an international crisis.

Saul: I appreciate your concerns. Carrie has learned her lesson. We both know how good she is.

David: What did I tell you when I agreed to give her one more chance?

Saul: You said only if I agreed to do the babysitting.

David: I said it would end badly – for both of you. You've got a big blind spot where she is concerned. Trust me, I did too. Now my wife lives in Palm Beach and I only see my kids twice a year.⁷

This exchange implies that David and Mathison have a history together that led David's family away. It then confirms Mathison's representation of the hysterical woman, as dangerous

and fatale. If Saul were to accept her sexual offer, his safety would be compromised.

Later, in the bar, her interaction with the stranger can be understood in the same manner: when Mathison is about to leave with her conquest, she is enlightened by watching the finger patterns of the jazz musicians playing. This triggers a memory of Brody's right hand during his television appearances. The space in the bar is organized in order for us to understand Mathison's observation; a television showing news coverage of Nicholas Brody is located close to the live musicians. Her sexual behavior, directly linked to her disability and gender, is the first reason for her presence in this bar, and it is her presence in this space that enables her to understand that Brody's hand movements are potential evidence that he is attempting to make contact with terrorists. Her deviant sexuality is producing and reproducing the American cultural anxiety and puritanism about women's sexual freedom, upholding American cultural hegemony. Her sexual agency literally serves to protect and reinforce Brody's cultural identity and thus the American cultural identity as a whole.

Naturalizing Mathison or Using Her as a Weapon?

Often in media representations of the hysterical woman, the ultimate goal is to naturalize the subject. Strangely enough, in *Homeland*, the dialectic is different; if the goal were to identify Mathison as a hysterical woman, it would then follow that the entire series is set upon naturalizing her by either normalizing her or killing her – a consequence that has been specifically applied to deviant characters such as women, homosexuals, queers, or “freaks” in traditional Hollywood cinema (Russo, 1987). Here, Mathison's hysteria is the key to the premise; neither her death nor her naturalization would prevent the United States from being attacked. Thus she requires her specific disability and gender and the interaction of these in order to successfully

conduct an investigation that undermines the terrorists' plot.

If this analysis is extended beyond the first episode of *Homeland* to include a macroscopic view of the entire series, it becomes evident that there is a connection to both tragic endings available to hysterical women. In Season One's ending, Mathison is controlled and treated medically for her mental health issues (later identified as a bipolar disorder), locating her within the scope of naturalization. She is taught to behave according to certain standards of normalcy: she eats well, sleeps well, takes her medication, and avoids participating in stressful work situations. When she finally learns that her “delusions” were actual facts and that she was correct in following her hunches, she makes peace with her pathologized behavior and tries to reintegrate into a more socially acceptable way of life. At the end of Season One, while Mathison knows that she is leading a good investigation, she is also convinced that she is leading a destructive way of life. She wants to get better and to “learn to be normal.” However, the CIA still needs her knowledge, and moreover, it is her “dangerous” delusions that allow for the continuation of the investigation into Abu Nazir (the series' equivalent of Osama bin Laden).

Season Two locates a stabilized but still fragile Mathison – who, at this juncture, is no longer a CIA agent – into a very complicated plot, where Brody turns out to be a new informant in the war on terrorism. At the end of this season, almost all the characters die in a terrorist attack with the exception of Brody and Mathison. Although her sensitivity is back and her out-of-control mood disorder reappears, Mathison is still alive. Her own “normal” state (as characterized by mental health issues, which is depicted as abnormal by other characters throughout the episodes) is the main reason why she can lead the investigation and continue to find clues that will help prevent the next attack.

Season Three literally uses Mathison's disability as a weapon against the "Middle East." The narrative of this season works primarily to blur the lines surrounding Mathison's behavior and response to the CIA's investigation into the bombing of Langley. In terms of her gender, she's now pregnant with Brody's baby, a difficult reality she is unable to deal with. The ending of this season marks a very important step regarding Mathison and Brody's relationship. While he dies (his death consolidates a CIA plan to take over the government in Iran), Mathison lives. She does not want her baby, but it is too late for her to take action. These observations help us to understand how both disability and gender interact in *Homeland* to display a complex representation of disability in popular culture.

The Male Gaze and the Ableist "Stare"

This representation of the disabled woman supports two types of gazes as defined by feminist film theorist Laura Mulvey and disability theorist Vera Chouinard: the male gaze (Mulvey, 1975) and the ableist gaze (Chouinard, 2012). The former refers to the woman as spectacle in classical Hollywood cinema, wherein female characters are portrayed as to-be-looked-at. According to Laura Mulvey and Mary Ann Doane, the woman is the object of scopophilia (the desire to look), thus gendering the roles of the spectators: men are the beholders of the gaze, the active heroes, whereas women are the obstacles to men's quests. To overcome these difficulties, men must either tame women or kill them. Sarah E. Chinn (2004) builds on this paradigm in her discussion of "the look" (p.196), wherein desire and desirability are constructed through who is looking, who can look, and who is and is not being looked at.

In disability studies, the ableist gaze, or as Rosemarie Garland-Thomson (1997) calls it, "the stare" (p. 26), objectifies people with disabilities and deems them vulnerable, pitiful, and endangering to the abilities of others. Vera Ch-

ouinard argues that the ableist gaze is a direct consequence of the concept of compulsory able-bodiedness as developed by Robert McRuer (2006). It is this ableist gaze that subjects the disabled character to her cinematic fates: she is either someone to overcome or someone to kill in order to protect able-bodiedness, thereby allowing for the continued subjugation of disabled subjects under the dominance of an objectification by the able-bodied. Nicholas Brody's character is constructed in such a way as to amplify Mathison's disability. Our first introduction to Brody is via footage of his "liberation"; found in a hidden closet, dirty and with very long hair and a beard, his first lines in the episode proclaim that he is American. Before he arrives in the United States, we follow his journey back. He is shown showering, shaving, and receiving a haircut. This process delineates the binary opposition between Orient and Occident, savage and civilized, dirty and clean (Hall, 1997). Moreover, when viewed in comparison with the depiction of Mathison's hygiene at the beginning of the episode, it becomes clear that this scene acts to further binarize able-bodied male and disabled female, between the active soldier held captive eight years in Iraq and the suspended, and therefore more passive, CIA agent having sexual intercourse with strangers to cope with emotional stress.

The "stare" also operates to desexualize the disabled person, reinstating able-bodied heterosexuality as the norm. Sarah E. Chinn (2004) discusses how both gazes relate to sexuality and objectification and locate the disabled female body at the center of desire and repulsion, to be looked at and to be controlled (p. 197). In *Homeland*, Mathison's disability and sexual promiscuity endanger national security because of her role in the CIA's investigation of terrorist attacks. Her sexuality is expressed as a symptom of her disability, therefore locating her again outside of the realm of acceptable social behavior where she is expected to conform to the stereotype of the desexualized, obedient, disabled woman. She acts as the gatekeeper of the nation

through her sexualized and disabled body. With a concept like compulsory able-bodiedness, McRuer complicates the intersection of sexuality and disability, arguing that “both systems work to (re)produce the able body and heterosexuality. But precisely because they depend on a queer/disabled existence that can never quite be contained, able-bodied heterosexuality’s hegemony is always in danger of being disrupted” (McRuer, 2006, p. 97). Mathison’s sexuality is not only a threat to the security of the state, it is a threat to the entire structure of able-bodiedness.

Sexual Opposition Between Mathison and Brody

While this essay focuses on the events of Episode 1, it is worth noting that from Episode 5 (“Blind Spot”) and onward, Mathison and Brody develop a sexual relationship. At this point, her sexuality is again not related to pleasure but to work. She physically attempts to bring back Brody into the state, into the nation, by bringing him literally into her body. She has the responsibility to reintegrate him; it is her duty to respond to the terrorist plot as the sole moral guardian of the United States.

This representation of sexuality and disability as articulated in Mathison’s character contributes to a broader pop-cultural representation of disability in which able-bodiedness and heterosexuality become compulsive, and a tension is created between gender and disability within the concept of normalcy. Signs of this are present throughout the episode as Mathison is pressured to become “normalized,” in other words, able-bodied, feminine, with a sexuality used to defend the state, rather than for pleasure. This representation is reinforced by the antagonistic construction of Mathison and Brody’s characters, set in opposition in order to reinforce this regime through their eventual sexual relationship. Mathison is deviant because of her gender and her disability, but this deviance can be reformed if she is the one to reform Brody.

Furthering this discussion of sexuality, Brody and Mathison’s different situations also contribute to these binary oppositions. The violent sexual intercourse between Brody and Jessica (his wife) seems to act as a means of addressing the trauma of violence and torture that Brody has been subjected to and depicts the hero as having a troubled mind. This scene reinscribes the woman as the passive object, helping the post-traumatic stressed hero to reintegrate into the nation, through this expression of violent masculine sexuality. The white woman, again portrayed as the moral gatekeeper of white heteronormativity, complies with this role and refrains from objecting to it. At first, Brody’s post-traumatic stress disorder can be articulated as a disability that affects his reintegration into the state, but in an effort to conform to masculine gender norms, he “mans up” and overcomes his disability in less than five episodes – the instant he meets Mathison at a veteran meeting and their relationship begins. Brody’s experience of the post-traumatic stress disorder portrays him as vulnerable and, as the male character, having to overcome it through dominant and violent sexual intercourse.

This scene, as witnessed by Mathison (and by extension, the spectator) in her living room via camera system emphasizes the idea that this woman, as a CIA agent, has a more passive role than the male soldier. Furthermore, when Mathison confronts Brody in a routine debrief about Abu Nazir and the death of his fellow hostage, we begin to understand Brody’s role in the terrorist plot. What the spectators see of Brody is significantly different from what is shown of him within the diegetic world of the series: Brody is the hero of the social sphere, where Mathison’s investigation is relegated to the private sphere. She acts out of her jurisdiction and everything else seems to contradict her story. Brody (who is male and passing as able-bodied despite clear signs of post-traumatic stress, which could also identify him as a “supercrip”) is on display as a war hero in the public sphere, where the disabled female experience is of no one’s interest;

she is a failed CIA agent who did not prevent previous terrorist attacks on American soil. Her conversation with Saul leads the spectator into understanding her obsessive attitude toward her investigation:

Mathison: I am just making sure we don't get hit again.

Saul: I'm glad someone is looking out for the country, Carrie.

Mathison: I'm serious. I missed something once before, I won't, I can't let that happen again.

Saul: It was ten years ago. Everyone missed something that day.

Mathison: Everyone is not me.⁸

Conclusion: *Homeland's* Submission to the Regime of Normativity

Stuart Hall states that the regime of representation shows how normative characteristics are being produced and are producing shared meaning into popular cultures, (for example, using stereotypes to ridicule, simplify, and reduce individual differences to essentialized characteristics). In *Homeland*, this regime manifests itself through the representation of the disabled woman, inscribed by codes of shared meaning such as the hysterical woman. The articulation of race, gender, disability, and sexuality developed within this analysis display what Hall (1997) calls a power play over representation (p. 254). In *Homeland's* regime of representation, disability is depicted as representing the able-bodied experience as necessarily existing in opposition to the disabled experience. In her article "Disability, Gender, and Difference on *The Sopranos*," Kathleen LeBesco (2011) considers the regime of representation as a key factor in the comprehension of normalcy. The conditioning of the ableist regime of representation serves to "conflate body ideals with our concept of what is physically 'normal,' increasing the number of people whose bodies are regarded . . . as socially unacceptable. . . . What is sorely needed is a rep-

resentational universe that begins to approach the complexity and wealth of real corporeal difference" (LeBesco, 2011).

Inevitably, the regime of representation influences – and is influenced by – popular culture. Popular television series such as *Homeland* contribute to the general coding of disabled and gendered experiences. To extrapolate this thesis, Mathison becomes a bearer of white ableist American heteronormativity in the state of fear that has drastically changed the United States and the Western world in the post-9/11 era. This is evidenced in the show's depiction of the obsessive "24/7" news coverage of Brody's story, a phenomenon referred to by media and political science theorists as the "CNN effect" (Robinson, 1999). This concept postulates that the existence of a 24-hour international news channel could have a major impact on foreign policy and general opinion towards international relations. This effect is included in *Homeland's* narrative, showing masses of journalists and camera people filming every step of Brody's return to the United States. Lots of television screens are shown to emphasize this constant coverage, and these "on-the-spot" shots are even edited into the editing of the actual episode. However, Mathison's mental health issues, her tapping of Brody's house with cameras and microphones, and her theory regarding Brody's implication in the terrorist attack after years of torture and captivity in Iraq are considered justifiable, despite being extraordinary measures of surveillance. Her sexuality is used as a tool to get information for her investigation on terrorism and later as leverage to bring Brody back into the nation, symbolizing how compulsory heteronormativity must be respected in order to reinstate the moral order of American's hegemony over non-Western, non-white cultural invaders. Therefore, Mathison's white female bipolar disorder embodiment symbolizes the "unstable" American nation-state post-9/11 attack.

By presenting a complex intersection of race, gender, and ability within a mainstream

popular cultural format, it seems *Homeland* is a missed opportunity for resistance in the representation of disability and female sexuality. In a television series where the main character is both female and disabled, we are given a rare representation of difference. However, the reinscription of harmful stereotypes around these identities unfortunately serves to contribute to the marginalization and oppression experienced by disabled women. By locating Carrie Mathison within the ableist and male gaze, creating a regime of representation wherein as a disabled woman she is expected both to conform to traditional, patriarchal notions of femininity and also to transcend these in order to maintain white cultural hegemony and reform the male characters, the show unfortunately reproduces the cultural context it could have challenged, which begs the question: Is there space for negotiation and resistance within the dominant cultural regime of representation or does the format of the latter automatically reinforce itself in order to maintain the forms of oppression that serve its hegemonic agenda?

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² As Lennard J. Davis (1995) puts it, "We live in a world of norms. Each of us endeavors to be normal or else deliberately tries to avoid that state. We consider what the average person does, thinks, earns, or consumes. . . . There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated" (p. 23). Judith Butler (2004) also describes a norm as "not the same as a rule, and . . . not the same as a law. A norm operates within social practices as the implicit standard of normalization. Although a norm may be analytically separable from the practices in which it is embedded, it may also prove to be recalcitrant to any effort to decontextualize its operation" (p. 41).

³ Regarding Carrie Mathison's character specifically, I strongly suggest looking into a Saturday Night Live sketch written about Homeland, focusing mostly on her gender and disability in order to be "funny." This sketch is an example of how sexism and ableism are internalized and accepted in order to make fun of and ridicule some identity traits (see NBC.com, Saturday Night Live, Season 38 Episode 1627 aired on November 11, 2012).

⁴ Cultural hegemony is a concept defined by James Lull after Gramsci's theory of hegemony. Lull mentions that Gramsci's theory of hegemony, therefore, connects ideological representation to culture.

⁵ Sarah Palmer cited McRuer in her discussion of Avatar, stating that "McRuer notes that definitions of able-bodiedness are articulated in negative terms as in 'free from disability' so that able-bodiedness is always dependent on disability in same way that heterosexuality is definitively dependent on homosexuality (385). While such a binary implies two choices, people are socially compelled to adhere only to one, rendering the expectation that everyone at all times desires to be able-bodied" (Palmer, 2011).

⁶ Homeland, Episode 1 "Pilot," 00:42:50

⁷ Homeland, Episode 1 "Pilot," 00:39:25

⁸ Homeland, Episode 1 "Pilot," 00:44:00

Endnotes

¹ Since before but much more reinforced after the terrorist attacks on September 11, 2001, various legislation was passed in the United States in order to prevent any kind of bombing or assassination related to political terrorism.

Body Vandalism: Lady Gaga, Disability, and Popular Culture

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Forum Articles

Abstract: This essay investigates the employment of disability by the pop star Lady Gaga. Working through different illustrations of disability in her videos it is argued that Lady Gaga ushers in a new aesthetic and political platform on which disability can be redefined. In particular, the author argues that Lady Gaga unconsciously performs within the space of what Siebers has named a disability aesthetic in which the different bodies reformulate the expectations and desires of the art object. The context of popular culture is explained as a necessary component of this reframing.

Key Words: disability, Lady Gaga, aesthetics

“To what concept, other than the idea of disability, might be referred modern art’s love affair with misshapen and twisted bodies, stunning variety of human forms, intense representation of traumatic injury and psychological alienation, and unyielding preoccupation with wounds and tormented flesh?” –Tobin Siebers, *Disability Aesthetics*

Introduction

The body of Lady Gaga has been tortured, bruised, beaten, bloodied, hung by the neck, and killed. It has limped using crutches, been propelled by haute couture wheelchairs, and disemboweled by a lover. All in public. All in performance, as a product to be bought and sold in the pop culture marketplace. The corpse has been painted with the brush of sexuality, glamorized, objectified, and graphically presented as the consumable flesh of female celebrity. Indeed, the body-imperfect, the transitional body, is fixed to Gaga’s aesthetic story. This painful creation in her videos, photo shoots, and films hasn’t always been original, but the residue of its parts smacks of a novel aesthetic blend of the

controversial, beautiful, and ugly. Her performative essence, in other words, has consistently been the changing, unstable, disabled body.

Popular discourse surrounding Lady Gaga, fueled by legacy media platforms like TV and print news, as well as a Gaga-promoted social networking site (littlemonsters.com), an extensive network of bloggers, academic/pop psychology websites (i.e., *Gaga Stigmata*), and various new media platforms of criticism, have created a rich fabric of explanations, interpretations, and predictions about the star’s popular meanings. Through rumors that she was a hermaphrodite and wild speculations about her drug use, Lady Gaga has been extremely successful in keeping us talking, keeping us buying, keeping us firmly planted in our spectator positions. The spectacle of Lady Gaga actually thrives on a shifting set of meanings, a pseudo-flexible textuality that some find fascinating while others find it absolutely ridiculous. Camille Paglia (2010), for example, snorted the following in her often quoted *Sunday Times* discussion of the Queen of spectacle: “Gaga is in way over her head with her avant-garde pretensions... She wants to have it both ways – to be hip and avant-garde and yet popular and universal, a practitioner of gung-ho show biz.” Trained in art theory and musical performance at the Tisch School of the Arts, Gaga admittedly had a unique bag of experiences, concepts, and vocabularies to pull from when she emerged on the music scene in 2008 with her first CD, *The Fame*. Paglia concludes however that this education was merely cursory, the detriment of which has been a thinly drawn line of artistic development in otherwise clichéd pop sensibilities.

Attempting to gauge whether her art is either popular or avant-garde (and not both?) seems an insufficient approach to the work be-

ing produced by Lady Gaga and her team (referred to as the Haus of Gaga). This approach, however, does point out that Paglia and other critics of Gaga are misguided in looking at Lady Gaga through well-worn, ideologically specific, and firmly institutionalized systems of meanings. Feminism works well to illustrate the ways in which transgressive artists like Gaga can confuse traditional glossaries of political, cultural, and aesthetic movements. Several pieces have been written about the potential feminism in Lady Gaga in the past couple of years, all of which argue that the star offers, at best, a confused understanding of female empowerment (Bauer, 2010; Williams, 2010; Quinlan and Fogel, 2011). These articles and blog posts too easily conflate social and cultural performance with that of marketplace, consumer driven performance: critics seem unable to distinguish between political realities and artistic vision. This is not to say that pop artifacts carry no political significance, but rather that they play with them to create an aesthetic experience. Lady Gaga performs a sort of feminism, but does not easily fit into the historical trajectories that even second or third wave feminism presents. J. Jack Halberstam (2012) has it right in her book *Gaga Feminism* when she argues that the form of feminism embedded in the work of Lady Gaga, “Is a scavenger feminism that borrows promiscuously, steals from everywhere, and inhabits the ground of stereotypes and clichés all at the same time” (p. 5). In an interview with *The Chronicle of Higher Education*, Halberstam (2012) discusses Lady Gaga’s use of feminism as a fluid act. Discussing the polysemic nature of Gaga’s music video for “Telephone,” she says:

“This lack of resolution or moral outcome feels right for contemporary feminism, as does Lady Gaga herself as a contradictory figure who offers much as a symbol of contemporary feminism. It is this figuration that interests me much more than Lady Gaga’s own politics, which can veer toward a gender essentialism that is

problematic for feminism and for queer politics.”

Here, Halberstam not only identifies the discomfort some feminists feel in interpreting Lady Gaga, but celebrates it as a potentially important sign of contemporary feminist inquiry and its own distaste for easy answers.

So the relationship between Lady Gaga and feminism is one based on a clash between pre-conceived politics and contemporary cultural experience, between political ideals and popular culture. That relationship is mirrored in the connections between Lady Gaga and the disabled body. As discussed below, Gaga’s relationship with disability has been met with rancor and contempt, as well as pride and celebration: people with disabilities have been both naysayers and advocates for the ways Gaga has appropriated the experience of disability into her products. What’s most interesting about these reactions are the ways they illuminate different approaches to defining disability in popular culture. Accordingly, just like her stretching of the accepted meanings of feminism, it’s argued here that Lady Gaga presents a potential re-approaching to the way we understand disability within the landscape of consumer culture. This new understanding of pop disability is seen in a discussion of Lady Gaga’s poaching and redistribution of disability as style as well as her destruction/disabling and reforming of the perfect, sexualized, consumable female body.

Lady Gaga’s Disability Images

Recently, there has been an online circulation of a paper Lady Gaga supposedly wrote under her real name, Stefani Germanotta, while attending the Tisch School of the Arts at New York University in 2004. Although she was attending Tisch as a musical performance student she reportedly was able to take credit hours in art criticism, history, and theory. This paper, in which she analyzes some of the aesthetic philosophies of Spencer Tunick, one of her first major



Figure 1: Lady Gaga, “Paparazzi” Video
(photo from <http://crabbygolightly.com/wordpress/guaranteed-to-sexually-satisfy-lady-gaga-at-the-vmas/8341258/>)

art influences, shows an early, somewhat naïve, interest in the ways bodies make sense:

“The terms of the human body, some might say, are determined through a theoretical dissection of both the private environments and public atmospheres in which we live. By terms, the rules and evaluations of bodily condition, I mean to establish a division of perception... However, it is in the freeing of both natural and artificial bodies that art is created. Some artists depend on the predisposition of their subjects to provide the work with its primary message and meaning, other artists rely on a temporal and physical freedom, an ability to use objects while also freeing them of their social significance and thus endowing them with endless possibilities of form.”¹⁷

The fact that the source of this quote cannot be fully authenticated means very little for the current discussion of Lady Gaga and disability. In fact it adds to the play between authenticity and fakery that looms beneath the discussion

below. That she wrote a thesis on Tunick, was exposed to the curriculum at Tisch, and found community in this arts scene delivers as much significance as we choose to afford it. The quote pinpoints the centrality of perception in our understanding of human bodies, as well as the ways our expectations of said bodies permeate our subsequent consumption of them. As such, this paper and other potential assumptions made about her art education at the very least provide an attenuated context for her employment of disability.

The earliest presentation of disability in the work of Lady Gaga seems to be located in her 2009 video for “Paparazzi.” Gaga finds herself temporarily disabled after being thrown from a balcony by a lover who performs the violent act to feed the voyeuristic groveling of photographers; returning from some sort of celebrity rehab, lifted by an African-American limousine driver out of the backseat, Lady Gaga is transferred into a bedazzled wheelchair designed by B. Akerlund. In an interview about the design of the “Paparazzi” props and outfits, Akerlund



Figure 2: Lady Gaga as Yui (photo from <http://w4walls.com/lady-gaga-wheelchair/>)

describes her process of transforming the wheelchair into a Gaga-artifact:

“Gaga called me and said she wanted to be in a wheelchair. She wanted me to design it and not the prop department. I took it upon myself to drive to East L.A. and exchange the wheels for some low rider ones. I ordered some Gucci fabric and handed it over to my genius friend/designer Michael Schmidt so he could embellish it with Swarovski crystals. Originally, we made a metal logo that read ‘Gaga’ on the wheels, but she disliked the font and we ended up exchanging it for the Chanel logo.”²

Completing the tableau of disability are a bejeweled neck brace, polished aluminum crutches, and a designer, corrective corset created by the French designer Thierry Mugler (Figure 1). Beyond these props of disability, or alternately “disabled things,” Lady Gaga per-

forms disability through her own body, convulsing in the wheelchair, walking with the crutches, exhibiting a crooked stance and severe limp, an emotionless face throughout. The video also portrays other women who are either disabled or dead, all of which pieced together secure the aesthetic theme of body decay.

Disabled or transitional bodies continued to be a repeating theme in the music videos and photo shoots of Lady Gaga, especially after the release of her second CD *The Fame Monster* in late 2009. Even a cursory glance at her videos from 2009 forward shows a repeated presence of Kristeva’s (1982) “abject body”—the body trapped between objectivity and subjectivity, the ever-changing, never static, traumatized being. She (always gendered as female, except the “male” performance by Gaga in her video for “You and I” in 2011) is there as the hatchling, twitching being, the large-eyed curiosity in the bathtub, the thin and emaciated body with the

spinal prosthesis in the video for “Bad Romance” from 2009. In 2010’s “Telephone,” the unstable body shows itself as the imprisoned, chained, and grotesque inmate of an all-female jail; in that same year for the video “Alejandro,” the transformative body is covered with some sort of protoplasm, a grotesque goo being caressed by her dancers. All the videos from 2011, including the title track from her *Born This Way* CD, “Judas,” “You and I,” and “Marry the Night” include some sort of different, transforming, mutated, and/or grotesque performance of embodiment.³

Besides the presence of the wheelchair and crutches in the video for “Paparazzi,” it should be pointed out that the different bodies present in these visual products are not immediately coded as “disabled” in popular culture. Indeed, the prosthetics, lighting techniques, costumes, and performances in these videos are more linked to a code of horror, one that viewers would no doubt recognize and link to an aesthetic of cinematic technique. Nonetheless, in an investigation of the ways Lady Gaga has employed the disabled body, it must be argued that all of these performances fall under the category of body difference, consequently placing them within the larger cultural spectrum of disability. But because these performances are primarily consumable products (i.e., they are to be downloaded/purchased, experienced as media and shared in the context of consumerism) they become intertwined with popular conceptions of disability itself.

Disability Chic

It’s not until Lady Gaga performs as a person with a disability on stage that the moniker “disabled” really gets injected into popular conversation. During a 2011 concert performance in Sydney, Gaga brought out a new character for only the second time, a wheelchair using mermaid, a bizarre creature she calls Yuyi (who would later play a significant role in the video for “You and I”) (Figure 2). Poaching Bette Midler’s

1980s performance of a mermaid in a wheelchair, Lady Gaga’s employment of the mermaid prosthetic and the manual wheelchair is meant to play on ironies of limitations, abilities, and confusion. Alexander Cavaluzzo (2011), writing for quasi-academic blog *Gaga Stigmata* describes Yuyi the following way:

“She [the mermaid] perfectly summates Lady Gaga’s project thus far, combining the spectacle of *The Fame*, the demonic metaphor of *The Fame Monster*, and the dichotomy of living halfway between reality and fantasy of *Born This Way*. She’s not a sultry siren floating through the crystal clear waters of a blue lagoon; she’s a grotesque aberration, a welding of woman and fish, inelegantly lying on a slab, carting herself around stage in a wheelchair, or writhing in a filthy bathtub.”

Here, under the lens of Gaga-criticism, the disabled mermaid is contextualized in a larger project of body play, self-actualization, and artistry. Evaluation from a lens of disability rights, however, was quite different.

Mainstream online sources like *E!* and the *Huffington Post* reported that disability activists in Sydney met Gaga after her performance with vocal demonstrations and egg throwing, protesting what they saw as being trivializing and mocking behavior (Grossberg 2011; *Huffington Post*, 2011). Several of her fans with disabilities tweeted their disapproval immediately after the performance. One wrote “Dear@ladygaga how about using your celebrity status 2 try 2 get us out of wheelchairs. Instead of cruising one. Cool!?” *E!* also quoted Jesse Billauer, disabled founder of the advocacy group Life Roles On as saying, “Since this isn’t the first time she has used a wheelchair in her performances, I invite her to learn more about the 5.6 million Americans who live with paralysis. They, like me, unfortunately, don’t use a wheelchair for shock value.”

Josie Byzek (2011) writing for *New Mobility* pointed out that many performers with

disabilities saw right through this act, offering harsh criticism. The celebrated poet and activist Leroy Moore, who has cerebral palsy, referred to artists who pretend to be disabled as “black face” equivalents, marking a striking connection between race and disability discrimination in popular culture. Moore went on to say:

“It doesn’t go deeper, it’s surface stuff... If you’re going to do that, contact real people with disabilities and get to the real issues, but don’t pimp it. For me it’s sloppy and very lazy music. And also it takes away from real artists who have disabilities. I wouldn’t care if there were enough images in music and TV that have real people with disabilities, but there are not.”

Such a reaction, while warranted, trivializes popular culture as “surface stuff,” while at the same time demonizes it as culturally transgressive. This confusion happens often in criticisms of popular culture: popular products are deemed superfluous and damaging all at the same time, a confusing and somewhat dangerous proclamation. Scholars of popular culture have been less likely to make that sort of argument since the early 1980s when leaders like Stuart Hall (1981) argued that our critiques of “the popular” be made within a vibrant consideration of production, consumption, and social experience. To limit our understandings of popular culture to variances of mass production, like Adorno and Horkheimer (1944, 2002) had, or to see the actions of consumption as completely empowering, like John Fiske (1989) would, ignores the geographical and historical specificities of popular culture and its potential as a source of political action.

Moore is absolutely correct when he implies that the wheelchair using mermaid is a shtick meant to create shock and attention. However, it can also be said that Yuyi is an extremely powerful product because it brings issues of disability into the mass cultural experience by way of the same shock and spectacle. *Bitch Magazine*

(2013) refers to Lady Gaga’s performances of body difference as *disability chic*, a process of using the different a disabled body as an element of style and message. In a post on the “Paparazzi” video, the *Bitch Magazine* writer argues that because Lady Gaga’s disability portrayal is temporary, the artist is playing loose with authentic experiences of individuals with disabilities. Working through Susan Wendell’s (1989) work on feminist theory and disability, the author points out that the disabled body performed by Lady Gaga is paradoxically both public and private, all at once visible and invisible, rendering the political message of this work insignificant:

“Disability can be “cool,” but only if it is temporary, not shown to the public, and that your eventual recovery from it can be portrayed through the timeless medium of dance! Oh, and be sure to have people of color around to assist you with your wheelchair and with your ‘recovery’-cum-dance routine.”

Although facetious, the criticism is quite clear. Lady Gaga performs a shameful presentation of disability, one tainted by impermanence and insincerity.⁴

Rather than lean heavily on what we might call a post-medical model of disability in which definitions of disability get tied up in rigid political structures, opening up our understandings of body difference to a more fluid conception of disability may allow us to reread Gaga’s performance in “Paparazzi” and elsewhere. Indeed, the term *disability chic* might be repurposed to highlight the positive ways in which Gaga is able to bring disability into pop culture conversations. Other disabled activists have been quite positive regarding the star’s employment of disability iconography. For example, media critic Terri O’Hare, quite soon after reports came out about the protests against Yuyi, blogged, “Are we going to snuff out all popular culture that has anything to do with disability if the performers are not disabled” (Byzek, 2013)? Continuing this enthusiasm for what Gaga is doing,

Bethany Stevens, a sexologist with a disability was quoted as saying, “I want to figure out how to connect what Gaga’s doing to transability, the fluidity of embodiment and moving away from this binary of ‘ability’ and ‘disability’ and allowing for people to play with these things, these attributes” (Byzek, 2013). Other fans with disabilities have shared positive reviews of Gaga’s *disability chic* through twitter and Facebook, blogs and websites, including the aptly titled *gagability* website.

What these and other examples of positive disability response show is that there is a growing understanding of the service Gaga’s employment of *disability chic* offers; by including the topic of disability in her work, Gaga helps disability be consumed alongside other popular aesthetic and political ideas. Although it would be a mistake to say that she is slipping disability into her work, clandestinely for example, it is fair to claim that because disability is not the central element, Lady Gaga’s popular art forms a space in which difference is exposed, disability is visible, and human difference is accepted without the normal pomp and circumstance of disability rights. Admittedly, hers is not a well articulated mission of activism for women or people with disabilities, a fact that many have bemoaned. However, by intertwining politics and entertainment in such a transparent fashion, Lady Gaga is able to usher in a sort of political consciousness without alerting her fans that such an act is occurring. Certainly, her mantra of “be yourself, you were born this way” hits a particular teenage angst right between the eyes: the little monsters get spoken to directly. However, her delivery of this anthem is accompanied by an invisible politics, introducing the rhetoric of rights for women, the LGBTQ community, and people with physical and cognitive disabilities.

Vandalism and Disability Aesthetics

Her success in being able to perform this type of political delivery comes from a unique

artistic vision, one that is almost completely centered on the body. The origins of this centralization of physicality can be traced to a larger, Christian tradition in which bodies are theologically attached to the concept of incarnation, in which the resurrected body of Jesus carries with it novel understandings/representations of liberation, freedom, and suffering. Consequently, having been brought up Catholic, Lady Gaga (along with many other contemporary artists) has digested particular theological and ideological messages about the importance of flesh. According to Eleanor Heartney (2004), author of *Postmodern Heretics: The Catholic Imagination in Contemporary Art, Catholicism after Thomas Aquinas* clearly advocated the Incarnation as a central truth of Christianity, out of which comes the centrality of the body in what she calls, the Catholic Imagination. Anchored by a belief in the lived experience of Jesus, the incarnation finds its importance in the crucifixion and resurrection of Christ, the elevation of the Virgin Mary, and, most importantly, the Eucharist, which, according to Heartney:

“...Solidified the role played by the body in the Mass, the central ritual of the Catholic faith. The mass is a reenactment of Christ’s Last Supper with his Apostles before his crucifixion (which itself was a celebration of the Jewish Passover). At the pivotal moment of the Mass, the priest, who assumes Christ’s role in the ritual, takes bread and wine, which symbolize the meal shared with the apostles, and turns them into the actual body and blood of Christ. The bread and wine retain their natural forms, but when consumed by the members of the congregation, replay Christ’s sacrifice and seal their commitment to Christ through a physical union with his divine substance” (p. 10).

Thus, those who are accustomed to this incarnational heritage, according to the author, remain fixated on or confused by the body throughout their work.

Although she does not speak directly about Lady Gaga, Heartney would no doubt place her into a category of “Catholics in conflict.” She points out, “Their conflict stems in part from mixed messages about sexuality and the body within Catholicism itself, many of which originate in a schism between the Catholic Church’s official doctrine, and individual Catholic’s imaginative sensibilities (p.22). Alongside discussions of work by Madonna, Robert Mapplethorpe, Felix Gonzales-Torres, and Andres Serrano, Heartney devotes an entire chapter to Lady Gaga’s artistic hero, Andy Warhol.⁵ The author points out that Catholicism could be seen in Warhol’s “obsessions with physical death and physical love, his transformation of ordinary objects into icons with multiple residences, his interest in the body and its processes and most of all, the conflict manifested in his work between the church’s official teachings and Catholicism’s subliminal messages” (p. 38).

This reaction to and obsession with the Catholic sense of physicality is evident in Lady Gaga’s employment of, not only her body, but the bodies of others in her work. A key to understanding the ways in which this “incarnational thinking” makes its way into Lady Gaga’s work is the flagellation of Jesus before his crucifixion. Biblical accounts of his torture point to the ways in which Christ’s body was transformed by physical abuse, scraping of the skin, and wearing a crown of thorns.⁶ Portrayals of the crucified Christ in Catholic churches are often realistic, highlighting the illuminati, the bloodied brow, and the pierced side of Christ as a way of indicating the importance of suffering before sanctification. Gaga’s body is often reformulated, sometimes quite violently. During her Monster Ball concert tour, for example, she ritually bloodied her torso during a performance of her song “Monster,” a stark juxtaposition with the otherwise sexualized body being performed throughout the concert. Indeed, her juxtaposition of the pop female body (think Britney Spears) with the grotesque, bloodied, as discussed above, disabled body, grants a strik-

ing visualization of the Catholic imagination described above (Figure 3).

Gaga’s employment of “incarnational thinking” is consequently linked to a process of disablement to gain power or redemption; in order to be redeemed of its cultural contamination, the female pop body must suffer in order to be transformed. And yet religious narrative only tells half of the story behind this work. The other half stems directly from what Tobin Siebers (2010) refers to as disability aesthetics. In a book of the same name, Siebers unearths a sophisticated disabled sensibility in the history of modern art. Through a grand study of painting, sculpture, and performance, Siebers demonstrates that the presence of bodies in art, specifically those bodies that reject the classical aesthetic tradition of beauty and perfection, create in art the undeniable acceptance and sometimes adoration of disability itself. He points out that:

“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. Rather, disability aesthetics embraces beauty that seems by traditional standards to be broken, and yet is not less beautiful, but more so, as a result. Note that it is not a matter of representing the exclusion of disability from aesthetic history, since no such exclusion has taken place, but of making the influence of disability obvious....disability aesthetics prizes physical and mental difference as a significant value in itself...Disability is not, therefore, one subject of art among others.... It is not only a personal or autobiographical response embedded in the artwork. It is not solely a political act. It is all of these things, but it is more. It is more because *disability is properly speaking an aesthetic value*, which is to say, it participates in a system of knowledge that provides materials for and increases critical consciousness about the way that some



Figure 3: Lady Gaga, Monster Ball (photo from http://starcasm.net/archives/54801/fp_5324049_lady_gaga_cwny_070210)

bodies make other bodies feel” (p. 3, 19-20, italics added).

Using this definition, it is clear that Gaga is operating within the spirit of such a disability aesthetic. Whether this participation is consciously done doesn't matter because the essence of aesthetics need not be one of artistic intention but rather found in this way that “some bodies make other bodies feel.”

Siebers' argument winds its way through the history of modern art, from early painting and sculpture, all the way through to contemporary artists. Though his project is one of modernity, the terms and concepts he applies to modern art practices undoubtedly assist contemporary studies of artists like Lady Gaga. Perhaps most useful is his discussion of art vandalism. In a fascinating chapter, Siebers uses the act of art vandalism to explore the ways in which art objects both reflect and deflect realism, as well as the ways our aesthetic expectations get formed by the act of

looking.⁷ Although he spends a good amount of time talking about the ways mental illness play a significant role in this history of art due to the cognitive abilities of the Vandals themselves, it is his more philosophical dissection of the practice of vandalism itself that connects to the work of Lady Gaga.

As stated above, one can easily see a visual (if not directly ideological) connection to the flagellation of Christ in many of Gaga's performances. It is suggested that this act of destruction is mirrored in Gaga's own distraction of the normalized, praised pop female body type. A more sophisticated approach to this act can be related to vandalism, specifically the tearing down of already accepted art objects. On the level of perception, Siebers points out that:

“Vandalized images often evoke the same feelings of suffering, repulsion, and pity aroused by people with injuries or disabilities, but they do it with an important difference. They divert the beholder's attention from the content to the form of the artwork. More conventional representations of disability may also generate emotional reactions in beholders, but they seem to erect a partition separating the real world from the work of art, as if its aesthetic status acted like a barrier against the fact of disability. This separation produces a “beautification” of disability...” (p. 91).

Above, several critics were quoted being quite critical of Lady Gaga's impersonation of disability, finding disrespect in her portrayal of people with disabilities. As Siebers describes here, these critics are expecting a sort of “conventional” relationship between art and life, one in which there is an immediate parallel between experience and representation itself. This is not what we see in the work of Lady Gaga. Rather, through the act of vandalism, Gaga rejects an interpretation of the body based on “real” content and instead draws attention to the form of the

body itself, making disability a performative and artistic element in and of itself.

Siebers continues by arguing that, “Art vandals breach aesthetic form, violating the analogy between art object and subjectivity, and yet they do not render this analogy ineffective. They transform it, replacing the original referent with a different idea of subjectivity—the subject with a disability” (p. 92). As a vandal, then, Gaga can reformulate the aesthetic driving the perception of disabled bodies by the nature of her destructive act: thus, by using disability to transform the ideal, pop female body (read, the work of art), she creates a new “style” of disability to be consumed in the realm of popular culture. By doing so, she opens up an aesthetic conversation (which then becomes the conversation of bloggers, writers, and responders) in which body difference can alter the very act of representation itself.

Consequently, the act of vandalism becomes an act of creation:

“...When an act of art vandalism does occur, something more revelatory than a thought experiment is unleashed—the occasion, disturbing and shocking, for an awakening. In the spectacle of the beholder of art turned passionate vandal arises the vision of a different kind of aesthetics, one in which people react powerfully to works of art that in turn affect the emotions, sensibilities, and perceptions of others. The works themselves are subject to an accelerated deterioration more akin to the human life cycle than into the glacial existence of museum pieces, and they evoke as a result the forms of truth and beauty, both shabby and sterling, found everywhere in the world of human beings (p. 99).”

The “everywhere” referred to here is no doubt perfectly encapsulated by the twenty-first century marketplace in which Lady Gaga has become a chief proprietor. In her work, the pop

female body becomes disabled, and consequently, in Siebers’ vision of things, more beautiful and more true.

Conclusion

The real power of Gaga’s vandalism, her body project, comes from the fact that it all occurs on the plane of popular culture. As such, disability finds its way into a lexicon of celebrity worship, star construction, mass marketing, social networking, and, perhaps most importantly, consumerism. As such, disability gains a position it has rarely had in the past—happenstance. This is not to say that it loses any of its political potential, nor its distinctiveness as a cultural marker. Indeed, it could be said that through the body reformulating in the hands of Gaga documented here, disability actually gains power. But it does so as a byproduct of popular consumption rather than as the centered subjectivity of representation that so plagues visions of disability in popular film and television, for example.

By employing the things of disability (wheelchairs, crutches, neck braces, etc.) and performing the tradition of disability aesthetics in her images, Lady Gaga brings to the public table the disabled body in a way it has never been delivered before. Although many would say that such grand conclusions can only come from a deep and far-reaching, critical interpretation of what some see as superfluous, spectaclad grandstanding, it has been argued here that there is at least a potential of true transgression when it comes to our definitions of physical and mental differences thanks to the work of Lady Gaga. Her bag of tricks and experiences includes all the right pieces: art theory, Catholicism, performance training, contemporary art inspirations, and an unflinching belief in individuality. When all of this is combined with good advertising and marketing strategies, it’s no wonder her work leads to new conceptions of disability and art.

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Endnotes

¹ At this point is impossible to substantiate whether this essay was actually written by Lady Gaga, by one of her staff at the Haus of Gaga, or by a fan posing as the artist. The author contacted the website that originally published the paper (brutishandshort.com) to substantiate its authenticity and is waiting for a reply from the original editor. The full text of the paper can be seen at <http://brutishandshort.com/a-paper-lady-gaga-wrote-in-u-grad/>.

² For more on the design elements of the "Paparazzi" video please see <http://jezebel.com/5285868/questions-about-the-high-fashion--domestic-violence-in-lady-gagas-video>.

³ The only exception in the videos from 2011 is the rather tame "Edge of Glory" in which Lady Gaga performs an homage to 1980s music videos, dancing around in a nondescript city, hanging out with 1980s icon Clarence Clemons while he plays saxophone on the track.

⁴ It should be pointed out that there are several illustrations that refute claims of disinterest in disability from Lady Gaga. Recently criticized for her purchase of a Ken Borochoy designed, \$2500 luxury wheelchair for her convalescence after hip surgery, the star continues to raise eyebrows when it comes to rehab technology. However, after she became aware of a fan who was suffering from a similar hip injury, Gaga not only gifted the wheelchair to the woman but also flew her to New York and promised to take care of all of her

medical expenses. For more on this story see <http://www.cinemablend.com/pop/Lady-Gaga-Gifts-Gold-Wheelchair-Fan-Pays-Her-Have-Surgery-54615.html> and http://www.newmobility.com/browse_thread.cfm?id=475&blogID=19. Lady Gaga has also recently reached out to her fans with mental disabilities, including one person with cognitive impairments from France whom she asked onstage during a performance of her song "Princess Die." Far from exhibitionist, the performance points to an understanding of the complicated lives being lived by her fans. For more see <http://ladyxgaga.com/post/32274224214/a-video-of-gaga-inviting-marcel-a-disabled-fan>. It should also be noted that people with disabilities are among those being targeted and served by Lady Gaga's Born This Way Foundation whose hope is to "... foster a more accepting society, where differences are embraced and individuality is celebrated. The foundation is dedicated to creating a safe community that helps connect young people with the skills and opportunities they need to build a kinder, braver world." For more see <http://bornthiswayfoundation.org/pages/our-mission>.

⁵ It is well documented that Lady Gaga consistently points to Andy Warhol as her artistic mentor. Her conglomeration of artists, scholars, and performers known as the Haus of Gaga mirrors Warhol's Factory system. She has been quoted saying "Warhol said art should be meaningful in the most shallow way. He was able to make commercial art that was taken seriously as fine art, to use something simple and shallow and take it to another planet. That's what I'm doing too." For more see <http://www.metrolyrics.com/2009-lady-gaga-inspired-by-andy-warhol-david-bowie-and-grace-jones-news.html>.

⁶ For specific passages see Matthew 27:28-31; Mark 15:16-21. Both sections are from the New International Version of the Bible.

⁷ Art vandalism can best be described as the conscious destruction of a work of art. Among the examples Siebers discusses are Hans-Joachim Bohlmann, a German with a disability who famously defaced a Rubens portrait of Archduke Albrecht, and other famous paintings; Robert Cambridge, who in 1988 shot Leonardo da Vinci's "The Virgin and Child with St. Anne and John the Baptist" with a sawed off shotgun; and Dennis Heiner who, in 1999, passed as a person with mental illness in order to place white latex paint of Chris Ofili's "The Holy Virgin Mary," a controversial painting of the Madonna adorned with pornographic cutouts and elephant dung (p. 87).

Precarious Inclusions; Re-Imagining Disability, Race, Masculinity and Nation in *My Name is Khan*

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Abstract: This paper will critically examine how dominant cultural scripts about disability are reinforced and complicated in the Bollywood film, *My Name is Khan* (Johar, 2010). An examination of the film's themes demonstrates that *My Name is Khan* allows for a nuanced analysis of disability, race, masculinity and nation.

Keywords: disability, race, nation

Introduction

In February 2010, the Bollywood film *My Name is Khan*, directed by Karan Johar, was released to a transnational audience. The film spans the pre and post 9/11 era and tells the story of an epic journey undertaken by protagonist Rizvan Khan, an Indian Muslim immigrant to the United States who has been diagnosed with Asperger's Syndrome. The film documents how the changing political climate in the United States at this time impacts Khan's life, and the lives of his family. *My Name is Khan* reflects on state-sanctioned violence and the ongoing discrimination against Muslims (and the South Asian diaspora), illustrating the links between criminalization, racial profiling, and the War on Terror. The film also comments on the devastation wreaked by Hurricane Katrina in predominantly African American communities, as well as the American state's inadequate response to it. In highlighting the racialized nature of citizenship in the United States,¹ *My Name is Khan* is a decidedly political, albeit fantastical, film.

My Name is Khan presents a different perspective of diasporic experience than many Bollywood films by focusing its narrative on the challenges faced by immigrants and racialized citizens in the United States. While Bollywood cinema is characterized by its focus on the dias-

pora's desires, and the anxieties associated with living in a global modernity (Punathambekar & Kavoori, 2008), the films infrequently engage with the day-to-day struggles faced by new immigrants, or their second generation children, in the West (Mishra, 2002). Rather, Bollywood cinema tends to re-imagine and re-produce the diaspora as a "successful," "integrated" yet "connected to its roots" community, a community that enjoys the full rewards of the American dream. As a result, these romanticized representations of the diaspora fail to account for the systemic racism, deskilling, and impoverishment experienced by racialized immigrants. However, Bollywood cinema remains in a position to challenge the distorted representations of racialized people that have become commonplace in Western media.²

Historical representations of Western encounters with the 'East' have cast the inhabitants of these areas as primitive, uncivilized, irrational, violent, dangerously sexual, and as the racial and cultural "other" to the civilized, rational, and morally superior white European (Said, 1978). Imperialist ideologies, which reproduced these discourses about the racialized other in art, literature, and academic publications, have been used to justify and legitimize Western territorial expansion (Said, 1978). These historic constructions of the racialized other continue to shape contemporary depictions of Muslims and South Asians in the West. In fact, the war on terror has led to an intensification of these orientalist constructions, and to the representation of terrorism as inherently linked to Islam, and to the racialized bodies perceived as Muslim (Mamdani, 2004; Puar & Rai, 2002). By centering and celebrating the object of the imperialist gaze, and exposing orientalist constructions of the racialized other, Bollywood

cinema has the potential to subvert the West's representations of the South Asian diaspora, and of the Islamic "other" (Thussu, 2008).

A preliminary viewing of *My Name is Khan* reveals that, like many Bollywood films, it elides the socio-political reality of many racialized people living in the United States. Certainly, at its core, *My Name is Khan* is a story about heroic overcoming, a story of love and human triumph. Rizvan Khan (who is depicted as autistic) is portrayed as overcoming the challenges his disability presents in order to participate in a nuclear family structure, contribute to a family business, and travel across the United States, by foot, bus, train, and plane, to meet the country's President. Khan also triumphs in face of the violence, intense racism, and Islamophobia that characterizes the period following 9/11, surviving both incarceration and brutal torture. Rizvan Khan's relationship with Mandira, his wife, also tells a story of triumph, as their marriage survives the presumed challenges of an inter-faith relationship and the pain of their son's death, the result of a brutal schoolyard beating by Islamophobic schoolmates. Finally, *My Name is Khan* tells a story of the United States' citizenry being able to overcome and overthrow the tyranny of the Bush era through the election of President Barack Obama. The centrality of this notion of overcoming to the film's narrative is underscored by the film's thematic song 'Hum honge Kamyab' a Hindi adaptation of one of the US civil rights movement's anthems, 'We shall Overcome'.

In spite of this overarching theme, *My Name is Khan* also provides a critical representation of American nationalist discourses of citizenship by confronting the precarious inclusion of racialized immigrants in the United States. This paper will examine these representations, and explore the contradictions that are central to the portrayal of disability, race, masculinity, and nationhood in the film. The first section of the paper will discuss the cinematic tropes of disability that are relied on in *My Name is Khan* to

further the film's narrative. It will argue that disability is used as a narrative device to underscore epiphanic moments in the film, and as a means of social critique. The second section of the paper will analyze how representations of disability, race, masculinity, and sexuality are simultaneously reinforced and disrupted in the film. This section of the paper will explore how the mutually constituted nature of disability, race, gender, and sexuality are rendered visible in the film, and how the relationships between these categories are articulated through constructions of the terrorist body. In bringing these discussions together, this paper will demonstrate that *My Name is Khan* allows for a nuanced analysis of disability and the nation. Moreover, it will illustrate that representations of disability in popular culture provide a critical means through which understandings of disability can be both troubled and enriched.

Representing Disability in *My Name is Khan*

Cinematic tropes of disability, broadly defined, have commonly relied on the spectacular and on narratives of exceptionalism in their portrayal of disabled characters. Although much of the research on filmic representations of disability has focused on Hollywood movies, there are clear parallels between these constructs and those employed in Bollywood film. As the works of Martin F. Norden (2001) and Paul Longmore (2001) on representations of disability show, popular culture's representations of disabled people have often spoken to the fears, prejudices, and misunderstandings about disability that are held by mainstream society. For example, depictions of disability in popular film have frequently associated disability with criminality or villainy, with loss of control and emotional maladjustment, and with the loss of humanity (Longmore, 2001). At the same time, some representations of disability, seemingly more positive characterizations, communicate well-worn stories of achievement 'against

all odds' (Longmore, 2001). While these narratives may seem more humanizing, they remain problematic in that their portrayal of disability as an individualized phenomenon constructs disability as a personal setback requiring emotional coping and acceptance. Furthermore, the representation of disability as an individualized problem to be overcome through grit and determination conceals the oppressive social forces that shape disabled people's experiences.

Representations of autism in mainstream cinema (in films such as *Rain Man* and *Mercury Rising*), although less frequently analyzed in disability studies, also rely on formulaic depictions of autistic characters. As Baker (2007) demonstrates, autistic characters are often portrayed in film as endearing, innocent, attractively quirky, and vulnerable, and as endowed with special powers or abilities, such as superhuman mathematical skills. These traits, regularly depicted as the redeeming qualities of an otherwise troubling character, are seen as features that distinguish autism from other forms of cognitive disabilities. In addition, since autism does not usually present in the visual terms required by film, excessive physical movement is often used as a means to signal disability in autistic characters (Murray, 2007). These popular representations of the quiriness, special abilities, and physicality of autistic characters bear little relationship to the experiences of most people labeled as autistic. Rather, they contribute to common misconceptions about autism, and do little to challenge the dehumanization that people with cognitive disabilities regularly experience.

In *My Name is Khan*, the narrative devices commonly used to tell the story of autism, and of disability more generally, are also present in the depiction of Rizvan Khan. Scenes picturing his childhood reveal that Khan has difficulty understanding social conventions, that the nuance of language can be difficult for him to understand, and that he dislikes physical contact, even with those people that he loves most. At the same time, Khan is portrayed as having the abil-

ity to "repair almost anything," anything mechanical that is. However, the representations of his skills at building and repairing complex machinery reduce Khan to an almost machine-like figure himself, robotic with exaggerated movements. His distinct walk, exaggerated and stiff, with his head leaning slightly to one side, and the comedic use of verbal repetition in the film, which Khan seems to do automatically, similarly contribute to the construction of a machine-like persona.

These common tropes of autism are relied upon in a scene in the film where Khan decodes a word-find puzzle, correctly identifying all of the hidden words before the other participants in the game are able to find even one. Significantly, Khan's decoding skills have not, up until that moment in the film, been revealed to the audience. Yet the scene produces no dissonance in the viewer, as it draws seamlessly on assumptions about autism that have become almost naturalized through popular culture. Fixing things, and solving coded puzzles, are presented as innate skills for Khan rather than something he learns over time. This portrayal, while reproducing common misunderstandings of autism, makes Khan legible to the audience as autistic.

Despite the use of these dominant tropes of disability, Khan is also portrayed in contradictory ways throughout the film. Although his disability remains visible, through visual cues and the use of verbal repetition, at many points in the film his disability is no longer the focal point. As is illustrated through Khan's interactions with many of the characters that are meeting him for the first time on his journey throughout the US, his disability or "quirks" elicit little or no surprise. In fact, disability in these scenes is rendered almost unremarkable despite the fact that the audience is made to feel that disability always structures Khan's behavior (again through cues such as verbal repetition or exaggerated movements). In this way, the use of disability as a narrative device in the film is complicated through the rendering of Khan's

disability as almost mundane at some points, and highly visible the next.

Disability, deployed in this manner, is often used to underscore epiphanic moments in film, moments that present a social critique and inspire self-reflexivity in the audience (Quayson, 2007). The use of disability to return the gaze on the audience and their potential inaction in face of national crises is one example of how disability is used for the purpose of social critique in *My Name is Khan*. The inadequate societal response to Hurricane Katrina, and the abandonment of impoverished black citizens by the state, is one of many social commentaries the film presents. The critique of the state's and of American citizens' inaction is clear in the scenes that depict Rizvan Khan's return to the fictional hurricane-hit town Wilhemina. Earlier in the film, Mama Jenny and Joel had taken Rizvan into their home in Wilhemina, Georgia, providing him with food, clean clothes, a place to stay, and a place to talk about the loss of his son.³ Upon hearing of the hurricane, soon after his release from a detention center, Khan rushes to Wilhemina and helps to rescue and rebuild the town. Khan's actions inspire other characters in the film to join him, leading to a dramatic scene where dozens of people are seen wading through chest-deep water, carrying food and supplies for the town's residents. Although disability in this scene is not rendered visible through the cues that were previously relied on, the audience is keenly aware that while Khan directs the rebuilding of town structures, it is his superhuman skill of being able to 'repair almost anything' that enables him to restore the town's infrastructure. At the same time his actions, all the more notable due to his disability, force the other characters in the film (and presumably the audience) to question their own indifference to the struggles of their neighbours.

Although the drama of such scenes are quite compelling, what is most intriguing about the contradictory use of disability in the film is the way in which it renders the relationship between

race, disability, masculinity, and nation visible. Of further interest is the way in which the film's narrative works to overcome the troubling excesses presented by the disabled and masculine Muslim body by portraying Khan as a respectable heteronormative and multicultural citizen and, thus, a viable protagonist. This complex depiction of Khan, and of race, disability, masculinity, and nationalism in the film, will be considered in the following discussion.

Re-Imagining Disability, Race, Masculinity and Nation through *My Name is Khan*

Through the cinematic representation of disability in *My Name is Khan*, we see that Khan's character is shaped through racialized, heteropatriarchal (heterosexual patriarchy)⁴, and nationalist orders. And yet, the film continues to challenge these depictions, calling our attention to the ways in which disability, masculinity, and race structure each other, while at the same time highlighting the ways in which the disabled, racialized, gendered and Muslim body must be disciplined in order to be folded into the racialized heteronormative nation (heteronormativity, in this context, refers to the racialized, gendered, and sexualized ideals that underwrite normative, state-sanctioned, middle and upper-class heterosexuality; see Cohen, 2007; Ferguson, 2007).

The opening scene of *My Name is Khan* begins with a dark screen that reads; San Francisco, November 2007. Next, we see a brown-skinned man sitting in front of the computer, typing and taking notes. A close up shot of the computer screen shows that he is looking up President Bush's travel itinerary. The scene shifts rapidly and we see the man again, carrying only a backpack, arriving at the San Francisco airport. He goes to the counter, purchases a ticket, and proceeds toward the security check. His walking is stilted, his body is stiff, and his head is cocked to one side. The man avoids other people in the

airport, deliberately walking at a great distance from them, swerving dramatically away from approaching travelers. Arriving at the airport security check, he stands in line waiting for his turn. The man seems nervous, rocking back and forth on his feet, playing with the rocks that he holds in his hand, and muttering to himself. As his utterances become clearer, we hear that he is repeating a prayer in Arabic over and over again, and while the prayer itself is more difficult to discern we can hear him say Allah several times. The woman in line in front of him also hears him speaking to himself and turns around, eyeing him suspiciously.

Not surprisingly, the man is quickly pulled out of the line by a security guard who directs him to an office. White male security guards search through the man's belongings with gloved hands, holding up his taqiyah (a Muslim prayer cap), thereby visually confirming the man is indeed a Muslim. We see the man in the next shot, his shirt and jacket have been removed but he is wearing an undershirt and pants. The security guards bend him over a desk and perform a physical search. The man squints and grimaces as the guards touch him, he's clearly distressed, extremely uncomfortable, angry even. The guards pull at the man's hair and repeatedly and forcefully push his head down, forcing his body to remain bent over the desk. He is then told to open his mouth and while one of the security guard probes his oral and nasal cavities violently, with gloved fingers, the restrained man looks wildly around the room. After the search the man continues looking distressed as he rocks back and forth on his feet.

The scene then cuts to the next shot, where the man is fully clothed again. The security guard in charge looks at the man's plane ticket; an Autism alert card with his name and picture has been included with his plane ticket and boarding pass. We know now that this man is Rizvan Khan. The guards have searched through his records and declared that he is 'clean'. Khan is told that he is free to go and the audience is

reassured that this seemingly suspicious character is innocent.

However, rather than responding gratefully to the guards, Khan states that his flight has already departed, that he's lost the money he spent on the flight, and that now he will have to take the bus to Washington, DC. The security guard, who until now has spoken in an aggressive manner with Khan, changes his tone and speaks to him condescendingly, demanding to know why Khan wants to go to Washington, DC. Khan tells him that it is because he wants to meet the President and convey a message. The guards laugh derisively and ask him whether his message to the president is that he knows where Osama bin Laden is hiding. Khan, however, responds to their mockery with sincerity, saying "oh no no no, that is not my message... I have to say to him. *My Name is Khan*. And I am not a terrorist" (Johar, 2010).

Through this dramatic opening scene, *My Name is Khan* can be understood as powerfully speaking back to mainstream discourses about terrorism that pathologize and criminalize Muslim men. In the absence of the well-known and widely circulated visual signifiers of the Islamic terrorist; the flowing beard, the turban, and the AK-47 (Rai, 2004), the film relies on other cues that enable the audience to read Khan as a potential threat. Certainly, Khan's research on the President of the United States' itinerary and his last minute ticket purchase become increasingly suspicious as he makes his way through the airport with only one small piece of luggage: a backpack. However, the most critical signifiers in this scene, the stilted walking, physically dodging other travelers while moving through the airport, the continuous reiteration of the same prayer, and the seemingly nervous gestures of rocking back and forth on one's own feet and playing with stones, illustrate how discourses about the terrorist body (that are racialized and gendered) are articulated with, and through, representations of disability and pathology. Indeed, it is specifically those behaviors that

render Khan legible as autistic in the film, the excessive physical movement, the avoidance of physical contact, and the verbal repetition, that allow the audience to know him as a potential terrorist in the opening scene. To be sure, disability is used as a narrative device in this scene, as in several others, to articulate a critique of the racial profiling experienced by brown-skinned men. However, what is most significant about this scene is how the mapping of constructions of disability, race, and masculinity are rendered visible on the presumably terrorist body.

The association of cognitive inferiority with irrationality, criminality, social threat, and madness has had a long history. To be clear, I am not arguing that cognitive disability, or autism, and madness are the same, but rather that these constructions are fluid and that they work with, and run through, each other. Cognitive disability and madness can be understood as being mutually constituted with race, gender and sexuality, (that is, as shaped through, and intertwined with, constructions of race, gender, and sexuality) (Jarman, 2012; Stubblefield, 2007; Waldron, 2002). Furthermore, a historical mapping of these constructs illustrates that cognitive inferiority and madness are linked to colonial tropes of both the immoral, perverse Oriental and the uncivilized, degenerate primitive (Rai, 2004; Waldram, 2004).

As Amit Rai (2004) has demonstrated, historic ideas about Muslim irrationality and the abnormal psyche have been drawn upon and revitalized in the construction of the Islamic terrorist. The figure of the Muslim terrorist, constituted through discourses of race, gender, disability, and sexuality, is posited against Western colonial notions of the 'normal' psyche (Puar & Rai, 2002). Moreover, the terrorist, whose genealogy lies in the racialized and sexualized monstrous figures of the eighteenth and nineteenth centuries, becomes, a projection of the racist fantasies of the West. The terrorist is thus represented as a perverse, homophobic, masculine-effeminate subject, produced through both

a failed masculinity and a failed heterosexuality (Puar & Rai, 2002).

The pathologized "psyche" of the terrorist has become the focus of multiple sites of investigation and fields of knowledge production, including the psy disciplines (psychiatry, psychology, and related disciplines). As Howell (2007) illustrates, the psy disciplines have specifically been called upon to render the terrorist, intelligible. Acts of terrorism, in this context, are understood as "...a symptom for the deviant psyche, the psyche gone awry, or the failed psyche; the terrorist enters the stage as an absolute violation" (Rai, 2002, 547). Critically, it is this particular framing of terrorism in relation to cognitive inferiority and madness that allows for the visual cues of cognitive disability, circulated through media and popular culture, to be linked to the embodiment of the terrorist.

It is also important to note that the terrorist figure is a regulatory construct, that is, a construct that allows for the disciplining of particular bodies. Depictions of the monster terrorist enable a disciplining of people of color with the view of creating docile patriots and good citizens (Puar & Rai, 2002). In particular, the construction of the monster terrorist demands a management of the body, and compliance to a set of normalized behavioral and social codes that become linked to the performance of good citizenship. As Puar and Rai state "such monsters, through their very example, provide patriotism with its own pedagogies of normalization" (2002, 136). In the film's opening scene, it is Khan's failure to comply with these normalized social codes, his failure to discipline his deviant racialized body, which brings him to the attention of airport security. In this scene, it is the excessive physicality of the brown-skinned masculinized body that inspires terror, and that renders Khan suspect.

Given these widely circulated representations of terrorism, the film *My Name is Khan* must contend with the spectre of the terrorist,

and with the construct of a pathological and perverse masculinity, that haunts Muslim and brown-skinned men. In this context, how does the film render Khan's disabled and racialized masculinity not only relatable but heroic? How is the threat of a dangerous, disabled, Muslim masculinity, which shadows Khan, contained? In the film we see that Khan becomes safely folded into the ideals of national citizenship, and relatable to the audience as a respectable multicultural citizen first, through the disciplining of his excessive sexuality and perverse masculinity, and second, by positioning him in relation to the bad and hate-driven Muslim male.

Narratives of degeneracy, sexual deviance, and sexual menace are common to the racialized constructions of cognitive disability (Jarman, 2012) and the Islamic terrorist. The normalized psyche, on the other hand, is linked to the proper performance of domestic life (Puar & Rai, 2002). The nuclear family unit, which has been a key iconography of the modern nation-state, has further embedded the links between sexuality and domesticity, connecting them to citizenship and patriotic duty. Importantly, because both the terrorist and the cognitively disabled individual have been so fully excised from the national body politic, their entry into spaces of domesticity becomes cause for moral panic. As a result, Khan's racialized, disabled, Muslim and masculinized body presents a site of considerable trouble, one that must be contained through a heteronormative family structure.

The contradictory construction and containment of Khan's potentially threatening sexuality is particularly evident in the depiction of Khan and Mandira's wedding night. The scene that follows Khan and Mandira's wedding shows Khan and Mandira sitting up in bed, fully clothed. Mandira turns to Khan, looking slightly concerned, and says, "Khan, we can't do this without touching." The apprehension Mandira feels is evident, as the audience knows that Khan does not like being touched. However, to both the audience and Mandira's surprise, Khan re-

plies, "I know, I know... yes I know, I have read it in this book; Intercourse for Dumbos." Mandira looks hesitant while Khan giggles and says "nice pictures." Mandira laughs also and Khan says to her, "I think we should do it. Now. I think we should do it now." Mandira shakes her head and interjects "one minute..." but Khan interrupts her with "Oh, no, no, no, not one minute. It will take longer than one minute." The scene ends with both Khan and Mandira laughing. The subsequent scene provides a montage of shots of Mandira, Khan, and Khan's stepson Sameer performing the happy family. Khan and Mandira are shown in their roles as parents and neighbors, living the idyllic suburban middle-class life. This picture of perfect domesticity ends with a shot of Mandira cooking and Khan saying to her, "Mandira, Mandira, can we have sex please?" Mandira asks him if he means right now to which Khan responds, "Now, now is good," giggles and walks away. Mandira looks down at the food she is preparing, smiles, and follows him out of the room.

What is remarkable about these scenes is that they are the only ones in the film where Khan is depicted as having sexual desires. Significantly, however, no actual physical intimacy, or even physical contact, is shown between Khan and Mandira. The exclusion of any behavior that can be read as sexual or intimate in these scenes is indicative of the anxieties surrounding Khan's sexuality. In fact, the threat posed by Khan's sexuality is hidden through his childlike innocence. The portrayal of Khan as having no knowledge about sex and no previous sexual experience (including having to learn about sex from a manual) distances him from representations of the sexually menacing cognitively disabled figure and from the degenerate and sexually perverse terrorist. In addition, by using Khan's disclosures of sexual desire as moments of comedic relief in the film, his sexuality is rendered as more or less impotent. Thus, despite being coded as a properly heterosexual couple, Khan and Mandira never conceive children of their own. This, of course, is a significant

departure from the normative trajectory of the heteronormative family unit.

In addition to his participation in the nuclear heteronormative family structure, Khan is represented as a respectable multicultural citizen and a “good Muslim” through the juxtaposition of his character with that of the “bad Muslim” and the terrorist. The film, while presenting a critique of the criminalization and racial profiling of Muslims living in the United States following 9/11, does not disavow the construction of the Islamic terrorist. Rather, the representation of Khan as a good citizen, and a pious and de-politicized Muslim, works to reify the distinction between terrorists and citizens, and between good and bad Muslims.

The construction of the Islamic terrorist relies on, and is sustained through, the construction of so-called “good” and “bad” Muslim citizens (Maira, 2009; Mamdani, 2004). As Mahmood Mamdani (2004) explains, the “War on Terror” has produced a binary construction of Muslims that allows for only two possible forms of citizenship for Muslim Americans. Good citizens demonstrate loyalty to the American nation-state, subscribe to American democratic ideals, and are constructed as enlightened and modern, whereas bad citizens, represented as pre-modern and traditional, are seen to pose a threat to the nation (Maira, 2009).

It is telling that the only character in the film that names the violence experienced by Muslims outside of the United States, referring to massacres of Muslims in both India and Palestine, is portrayed as a “Jihadist” and as a bad Muslim in the film. In this particular scene, Dr. Faisal Rehman, the bad Muslim, is represented as trying to incite men into action through his references to these massacres and through a misrepresentation of Islamic history. Dr. Rehman's comments, and his call to action, are seen as indicative of “jihadist” sentiment specifically through the invocation of a pathological hatred. Thus, as Jin Haritaworn argues, even when

“... the causes of hate are understandable, the hateful reaction and subsequent action are not, rendering it immediately atrocious...to hate is to reveal one's impulsiveness and irrationality as well as one's failure to perform oneself as a civilized subject...”(2013, 52). Hatred, in this context, becomes inherently associated with the bad Muslim. Furthermore, it is through this hatred, and the irrational violence that it is seen as potentially producing, that the bad Muslim is further constructed as a national threat.

Short as this scene is, it is critical in reaffirming Khan's respectability as a multicultural citizen in the film. Not only does Khan challenge Dr. Rehman's hateful speech, but later he also reports him to the FBI. In fact, it is specifically because Khan helped the FBI locate Dr. Rehman that he is released from a detention facility, where he was incarcerated and tortured after trying to meet the President. In spite of the persecution he has undergone, Khan's loyalty to the nation, and thereby his proper citizenship, is reaffirmed through his naming of the doctor as a terrorist and a bad Muslim. Significantly, it is through these actions that Khan is redeemed as the film's hero.

Conclusion

Popular culture is one way through which people come to know disability. At the same time, popular culture also limits what is imaginable, shaping discourses of disability by delimiting the terms of its existence. The representations of disability in *My Name is Khan* have made use of common cinematic tropes utilized in the depiction of disability in film. The reliance on these representations has led to the reproduction of common myths about disability and autism in the film, such as the notion that disability is a personal setback that must be “overcome”, and the association of autism with “special abilities.”

At the same time, a critical use of the visual cues associated with autism have allowed the film to represent the convergence of discourses

of race, disability, and masculinity through the figure of the terrorist, allowing for a re-imagining of the relationship between these categories. Through wide-ranging representations of disability, *My Name is Khan* illustrates that race, gender, sexuality and disability are mutually constituted, often at the service of the nation. Although the critical lens of the film remains constrained by a neoliberal multicultural narrative that continues to distinguish between good and bad citizens (and Muslims), *My Name is Khan* succeeds in both complicating understandings of disability, and its relationship to race, gender, and sexuality, and in highlighting the precarity of national belonging.

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Endnotes

¹ It is important to note that *My Name is Khan* offers no representations of indigenous people in the US, despite portraying the experiences of various other racialized groups living in the United States. By failing to include the experiences of indigenous people, the film can be understood as reproducing the American settler-colonial myth that there are 'no indigenous people left' in the US.

² Although Bollywood film has the potential to subvert orientalist representations of Muslims and the South Asian diaspora, the middle/upper-class Hindu male has traditionally been the focus of Bollywood films. Bollywood films have also frequently been used to promote Indian nationalist narratives (and are often influenced by Hindu nationalist narratives) (Gabriel & Vijayan, 2012; Khan, 2011). Unfortunately, a discussion of the political significance of these representations, and the use of Bollywood film to further Indian nationalist agendas, is beyond the scope of this paper.

³ Significantly, the depiction of Mama Jenny, a large, emotional, and maternal woman, is based on the cinematic and racist trope of the Mammy. Her son, Joel, is referred to as 'funny-hair' Joel by Khan and this racist

naming of Joel is used as a moment of comedic relief to lighten the drama in the scene. I would suggest that the racism in these encounters is rendered comedic, even innocent, precisely because it comes from the perspective of somebody who is understood as 'cognitively disabled' and who therefore doesn't know any better (relying on problematic stereotypes about autism and cognitive disability, in addition to racist tropes). Through these representations, blackness is turned into a caricature at the service of the narrative. Indeed, it is the caricaturization of blackness in the film that humanizes Khan's struggle and gives credence to his journey. For example, it is not until he is being cared for by Mama Jenny that Khan finally speaks about, and sheds tears over, his son's death.

⁴ I use the term heteropatriarchy to signify the combining of heterosexualization and patriarchy as governing principles of the nation-state; (see Alexander, 2005).

Physical Disability, Gender, and Marriage in Jordanian Society

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Research Articles

Abstract: In this article, three physically disabled Jordanian men discuss their perspectives on gender, marriage, family, and disability in Jordanian society. Their words reveal the contradictions with which they live. They refuse to marry disabled women even while they recognize their own stigmatization and oppression. They long for “real women” while absolving themselves of any guilt in the oppression of disabled women. They want wives who can provide the physical assistance they need while facing significant barriers to fulfilling their role as husband, father, and provider.

Keywords: disability, gender, marriage

I had thought of sexual love as an honor that was too great for me—not too great for my understanding and my feeling, but much too great and too beautiful for the body in which I was doomed to live. (Hathaway, 2000, p. 55)

In this article we take a tentative stance toward the social model of disability first articulated by the Union of the Physically Impaired Against Segregation (UPIAS, 1975) that argues disability is something imposed upon those with impairments, and that excludes people with impairments from “full participation in society.” As Tom Shakespeare (2010) points out, the social model neglects impairment’s influence on people’s lives and is unable to tease apart the impact of impairment versus the impact of social barriers. This second problem with the social model, that it ignores impairment, becomes fully evident in our data in which we explore what disabled men who have physical impairments have to say about marriage partners. Throughout, we use the term “physical disability” to refer to disabled people who have physical impairments of some type. “Disability” is used in the social model sense, as an oppressed social status,

unless it is in a direct quote from participants. In that case, participants sometimes seem to be referring to impairment while other times their concept of disability remains unclear or seems aligned with the social model. We leave you to interpret their meaning in these situations.

According to Zingale, (1984) disabled persons are still “seldom seen as normal human beings with a right to intimacy in personal relationships and to other things the able bodied take for granted” (p.1). Rubin, & Roessler (2008) and others (Finkelstein, 1993; Oliver, 1990; Swain, Barnes, & Thomas, 2004) report that from ancient times to now, disabled people have been stereotyped and stigmatized as asexual. Often, persons with physical impairments are among the most stigmatized because of their visibility (Falk, 2001; Goffman, 1963; Link & Phelan, 2001) and disabled women are more discriminated against than men. Disabled women are more often deprived of equal education and equal employment opportunities and they are less likely to marry (Abu-Habib, 1997; Britt, 1988; Emmett & Alant, 2006; Fairchild, 2000; Ghai, 2003). Being a woman and being disabled layers stigma over stigma.

In this article we report the results of a study that has sought to answer two questions that emerge from the lived experience of the first author, a physically disabled Jordanian man married to a non-disabled woman: (1) why do some physically disabled males refuse to marry disabled females? and (2) why do they want to marry non-disabled females? Since the answers to these questions are embedded culturally, we first provide a brief overview of disability, gender, and marriage in Jordanian society. Next, we touch on what the literature has to say about visibility and stigma. Then we present the study

and the interview data. Finally, we consider the interviews in light of internalized oppression and the materiality of disablement.

Disability and Gender in Developing, Middle East, and Arab Countries

While Islam is the majority religion in Arab countries, Jewish, Christian, and other religious groups also populate this region. Uhlmann (2005) observes that "Islam is ubiquitous in the Middle East...inflecting all aspects of life of Muslims and non-Muslims alike," creating a cultural milieu in which it is difficult to tease apart Muslim traditions and values from those of other religions. Given this reality, we culturally approach disability and gender in the Middle East and Arab countries.

Studies across the world reflect the tremendous oppression and hierarchy between disabled men and women based on gender. Being disabled and female in many societies creates "stigma upon stigma" (Britt, 1988). Chenoweth (1993) calls this a "double strike" (p.26). Fairchild (2002) states that "women with disabilities are often at a larger disadvantage due to a double discrimination, based on their gender and disability status"(p. 14). Saxton & Howe (1987) write, "There are many parallels between the oppression of women and of disabled people. Both groups are seen by others as passive, dependent, and childlike; their skills are minimized and their contributions to society undervalued" (p. xii). Hanna and Rogovsky (1991) surmise that people generally attribute physical impairment in men to peripheral factors such as war, injuries, or car accidents, while it is often believed to be inherited with women.

As reported by the United Nations: "Women in every society in the world remain economically, politically and culturally disadvantaged in relation to men" (Bryson, 2004). According to Abu-Habib (1997), disabled women in the Middle East seldom participate in making decisions about their lives. Even domestic policies

and national and international agencies neglect disabled women in their agendas. Historically, neither the women's movement nor the disability movement in the Middle East includes disabled women to a significant extent (Abu-Habib, 1997). The fundamental beliefs about women in Arab countries are that they are housekeepers, wives, and mothers. While both disabled men and women are marginalized, prejudged, and discriminated against in Jordan, disabled women are more vulnerable to abuse and more stigmatized than disabled men.

Arabic society is patriarchal, even in light of modernization (Uhlmann, 2005; Moghadam, 2004). Turmusani (2001) argues that disabled women in Islamic countries in the Middle East are devalued and given the lowest status. They face more challenges than do disabled men, often have no access to employment, and are kept hidden away. Impairment is synonymous with disability and is considered a stigma that causes shame that might extend to the entire family. Disabled women seldom marry because it is believed that they are not able to be mothers and housewives. Disabled women are twice as likely to be divorced. Studies in other developing countries have found similar results (Abu-Habib, 1997; Addlakha, 2007; Braathen & Kvam, 2008; Cheausuwantavee, 2002; Dalal, 2006; Dhungana, 2006; Ghai, 2003; Gray, 1999; Kiani, 2009).

In *Gender and Disability: Women's Experience in the Middle East*, Abu-Habib (1997) reports a case in Lebanon where two men disagreed about marrying disabled women. One of the interviewees believes that disabled women are not able to take on their household responsibilities. He rejects the notion of marrying a disabled woman, even if she could manage her responsibilities, such as carrying children. Another interviewee points out that even though he encourages marriage between disabled men and women and advocates for them, he believes disabled women are not fit for marriage, unlike disabled men.

A further example from Abu-Habib shows the inequality between men and women based on gender in Lebanon. Zeinab is not educated and she works in a sewing factory to earn money. Her brother wasted his own money and now Zeinab is responsible for the entire family and she is not allowed to get married because they need her money. Another Lebanese example is of two blind siblings: the father sent the boy to school while the girl remained at home. The girl, who now is a 29 year-old woman, said, "I shall never forgive him [her father] for this" (p. 46). Thomas and Lakkis (2003) describe the impact of gender differences on access to education and employment in Lebanon where disabled students are still attending institutions. The researchers interviewed 200 disabled graduates between 14 and 40 years of age in order to know to what extent the institutions assist students in education and employment. They found that even though disabled women academically achieve better, perform higher, their rate of employment is 35%, compared to 52% for disabled men.

Marriage Decisions in Jordanian Society

Jordanian society is patriarchal; therefore males dominate over females. According to El-Islam (1983), the hierarchical system in an Arab family is "male over female and older over younger" (p. 321). The Jordanian family is a social institution consisting of parents, brothers, sisters, and sisters- and brothers -in- law. Sometimes it is extended to include uncles, aunts, and cousins. Most of them live together in the same house, especially parents, children, and daughters-in-law. Even if they do not live together, the bond among the family members is very strong. Barakat (1993) described the Arab family relationship:

"The family is at the center of all social organization in all three Arab patterns of living (Bedouin, rural, and urban) and patriarchal among tribes, peasants, and the urban poor. The family constitutes

the dominant social institution through which individuals and groups inherit their religious, class, and cultural affiliations (p.98)."

Proposing marriage in Jordan is done in what is considered the traditional way and the authority of the family is critical in the decision to propose marriage or accept a marriage proposal. Male relatives, in particular, have significant influence over decisions about the women in the family (Moghadam, 2005). Turmusani (1999) reports that "the position of women in Jordan has improved in comparison to other Islamic countries, but is still different than that of men. For instance, women are not allowed freedom in choosing a husband" (p.109), Abudabbeh (1996) shows that a woman's decision in marriage is subject to her family's approval. Women are restricted from making important decisions related to their individual lives.

The values of the Jordanian society and those of Islam prohibit men and women from having intimate relationships outside of marriage. Such a relationship is considered taboo, shameful, and a terrible mistake. In order to get married, an older woman, usually the mother of the man, starts looking for a bride who meets her son's requirements and desires for a spouse. Both the man and the woman in question have a right to accept or reject each other but if the woman shows acceptance, the crucial decision is made by her family.

Visibility, Stigma, and Internalized Oppression

The meaning of disability "differs from one country to another or from one culture to another" (Rispler-Chaim, 2007). In Jordan, the term disability generally does not describe all disabled persons. On the contrary, it is more likely used to describe visible physical impairment. Visibility is an important criterion for what constitutes disability in Jordan. Jones et al (1984) point out that people with visible dif-

ferences, such as physical impairments, are the objects of stigmatization because they are visible in both homogeneous and heterogeneous societies. They are a vivid example of the difference between the categories of “abnormal” and “normal.” Goffman (1963) asserts that visual disability causes “discredited identity” (p. 4). Crocker et al. (1998) focus on the idea that with visibility, “stigma can provide the primary schema through which everything ... is understood by others”(p.507).

Ainlay, Coleman, and Becker (1986) suggest that visibility and stigma have a more disabling impact in cohesive societies like Jordan. The values and perceptions of homogeneous societies do not adjust to change and difference as readily as do heterogeneous societies. Solidarity among people, especially in the tribal affiliation system of Jordan, prevents any external factors from changing the perceptual beliefs about any phenomena. Therefore, any attempt to resist stigma may be meaningless, and stigma will remain with the stigmatized.

Ladieu-Leviton, Adler, and Dembo (1977) suggest that as a result of the impact of stigma on people, stigmatized individuals may agree with how society depicts them. Further, they may start to devalue and isolate themselves. If they admit that they have a stigma; they may not even try to reject or resist the vast majority of perceptions. This depiction has been identified as the “halo” phenomenon which means, “A spread of evaluation from characteristics actually affected by the injury, to other characteristics not necessarily so affected” (Ladieu-Leviton, et al., 1977). A common way the stigmatized person reacts is to practice stigma towards others. Not only is the stigma received, but also, the possessor contributes to stigmatization of others.

While physical impairment can be highly visible, some studies indicate that intellectual disability and mental illness also are stigmatized. In a study in Jordan, Gharibeh (2009) demon-

strates that, “intellectual disabilities, mental retardation, or mental illness are more stigmatizing than physical disability, while blind persons or persons with visual impairments are less stigmatized” (p.71). Gharibeh attributes stigmatization to a tribal tradition: “A tribe’s honor, and social standing [depend] on certain qualities that are thought to be passed on from generation to generation”(p. 71).

Stigma can contribute to the development of internalized oppression. Lipsky (1987) defines internalized oppression as “the turning upon ourselves, upon our families, and upon our own people the distress patterns that result from the racism and oppression of the majority society” (1987). Schwalbe, Godwin, Holden, and Schrock (2000) explain internalized oppression as “defensive othering among [the] subordinated” (p. 425), a process that involves the denial of the stigmatized self, acceptance of the normative standard, and abandonment of one’s identity. “The process, in each case,” write Schwalbe, et al.:

“...Involves accepting the legitimacy of a devalued identity imposed by the dominant group, but then saying, in effect, “There are indeed others to whom this applies, but it does not apply to me (ibid.)”

Rather than “blaming the victim,” Masson (1990) points out that “internalized oppression is not the cause of [disabled people’s] mistreatment. It would not exist without the real external oppression that forms the social climate in which [disabled people] exist” (Marks, 1999). As do the participants of this study, disabled people,

“...Harbor inside [them]selves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives (ibid.)”

The Study

This study took place from December 1, 2011 through March, 2012. Three participants were interviewed. To be included in this study the participants, met four criteria: (1) visibly physically disabled, (2) unmarried or married to a non-disabled woman, (3) financially independent of the family, and (4) unwilling to marry a disabled woman. The first author, a married, physically impaired Jordanian man living temporarily in the United States, conducted the interviews. He also did not want to marry a disabled woman and thinks of this as a paradox. Interviews were audio taped and then translated into English by a translator with fluency in both Arabic and English. Each participant was interviewed four times, and each interview lasted about forty minutes to an hour.

Participants were interviewed via Skype (Version 5.5) software, a free online application that enables the user to make voice and video calls. This was necessary due to the fact that the first author could not travel to Jordan. Interviewing people through the internet has been used in qualitative and mixed method research (Brownlow & O'Dell, 2002; Davis, Bolding, Hart, Sherr, & Elford, 2004; Meho, 2006; Olivero & Lunt, 2004). Brownlow and O'Dell describe the benefit of the on-line interview as "inexpensive, convenient and attractive to people who do not like face-to-face interviews."

Interviews were semi-structured and began with open ended questions about participants' marriage preferences, decisions, and experiences. Each subsequent interview consisted of follow-up questions seeking clarification or elaboration of previous responses and further probing for responses that could provide answers to the research questions.

The Participants

Jordan is a small country where it is easy to determine a person's identity if specific information is provided. Participants have concerns

about confidentiality. Therefore, we have been careful to provide only basic information about the participants. Born in 1976, Adam is single and lives with his family. He had polio as a child and now has post-polio syndrome. He uses leg braces and crutches to be able to walk. He has a master's degree in special education and intends to pursue his doctorate in the near future. He is an educational administrator in his community.

The second participant, Sami, is 34 years old and has post-polio syndrome. He uses a crutch to walk but does not need any other mobility devices. He was born in a rural community in Jordan where there were no medical or rehabilitation centers to treat him when he contracted polio so he was transported to Amman, the capital city, where he attended school and lived in a residential facility while he recovered. Sami is single and working in Amman where he holds several jobs as a handyman. He lives alone. Although he did not complete high school he earned a degree in electronic maintenance.

The third participant, Jamal, also is 34 years old. He has post-polio syndrome and is living in Amman with his wife and two children. He works as a prosthetic and orthotic technician.

Understanding the Culture Through A Person Who Is Rejected Many Times

The situation of disabled people in Jordanian culture is a significant focus of the participants' responses. They reported that the Jordanian culture portrays them as shameful, defective, dependent, abnormal, and stigmatized. Similarly, they reported that people stereotype them due to lack of awareness about the meaning of disability and disabled people's lives. The first participant, Adam, complained about the way the culture stigmatizes him:

"Jordanian culture has wrong beliefs about the life of disabled persons and disability. People think that people with

disabilities are abnormal persons. Our society still thinks that the disabled person is unable to do life's duty. It also believes that we have a limited potential with no talents."

The second participant, Sami, agrees about society's lack of awareness about disabled people who are marginalized and prevented from moving freely in marriage and in work:

"A disability in Jordan is not as good as in America or in Japan. There is still a lack of awareness about disability and disabled people. We are still ... marginalized. We do not have equal rights with others."

The third participant, Jamal, has been rejected in marriage many times, and believes that culture and people's attitudes are confusing and contradictory:

"On one hand, I see some disabled that are fully integrated, married, have jobs, and [are] educated. We have rights, duties, and privileges. On the other hand, disabled people seem to have less attention and consideration compared to non-disabled people. I see us deprived from many basic rights, such as the right of free mobility, the use of public facilities, and [it's] hard to marry."

Each participant's answers to questions depends on his unique situation, indicating that while there are some broad generalizations that can be made about Jordanian culture, disabled individuals also must be understood as situated within specific contexts. For example, Jamal's marriage with his current wife went smoothly though he had been refused so many times:

"You want to understand the culture through a person who is rejected many times; certainly it is something as shit. At the same time I, for instance, had gotten many remarkable privileges and positive attitudes. So, it depends on to whom you are talking."

We Are a Conservative Society

Marriage is important in Jordanian society and in Arab culture. The family is considered the most basic and important social unit (Moghadam, 2005). Intimate relationships outside marriage are not permitted and sexuality, particularly for females, is carefully controlled, making marriage even more vital for the expression of sexuality (ibid.). Adam says that:

"We are a conservative society and there is no intimacy between males and females away from marriage or outside the law. There are many illegal and illegitimate relationships between males and females, but hidden and no one knows about them. If they had been discovered, the woman's family would have punished her, or even killed her."

Sami agrees on the importance of marriage. He intends to create a family and have children. Having a wife will allow him to feel emotionally, physically, and psychologically comfortable. He explains:

"I need someone to be with me and talk to her ... to spend days and nights with her. Marriage to me means... means a lot. I want to have many children. I see marriage is also important in terms of an expression of sexual desire. Also, by getting married I will be intellectually and physically comfortable."

Jamal, who is married, wishes he had been married a long time ago. He has enjoyed his married life and believes his life has meaning now that he is married:

"Marriage is very important... it is important from all aspects, the spiritual, the psychological, and the social aspects. I have just realized the meaning of my life."

In Jordan, most often the marriage proposal is conducted in a traditional way. The mothers, sisters, sisters-in-law, and in a few cases, a friend of the man search for

a woman who meets the man's requirements."

As an example, Jamal said:

"My mother found a woman who has my requirements. After my mother told me about her, I went and saw her. I sat with her many times. I could say around four times. We talked and discussed general topics about life and about marriage expectations; I felt comfortable while I was talking to her. Then, we both said to our family, we agreed on marriage."

In contrast, Adam says he will not get married in the traditional way. He believes traditional marriage shows disrespect to women and considers them as a commodity. In addition, he believes that traditional marriage does not allow partners to understand each other. He reports that:

"We are subject to be rejected more than non-disabled persons because of the customs and traditions which are rooted in the mind of the woman and the parents in general. Society is still depicting us in [the] wrong way. So, disabled people need more time to explain who they are. The nature of my disability imposes me to crawl when I am not wearing the medical device. Such details [like] these are important for the wife to know and to accept it."

In Jordan, People Feel Ashamed Of Us

Participants all agree that several criteria must be met to find a marriage partner, who must have the correct social standing, education, financial status, and physical appearance. These emphases can present barriers to disabled people since all four criteria are interrelated. For example, if a disabled person cannot obtain an adequate education, he will not have good financial status or social standing. More than any other factor, all three participants attribute

disability, as they understand it, as a reason for being refused in a marriage proposal. Jamal expresses it here:

"Marriage is [the] hardest thing whether we have disabilities or not. When disability comes to marriage, it remains a large stumbling block which is very difficult for people to accept."

Jamal's proposals of marriage were refused 27 times until he found a wife whose family agreed to let her marry him:

"It is not [a] puzzle. It is obviously because of my disability. Why do you think somebody like me would be rejected? I have a flat, car, career, good income, [am] independent, and I'm good looking. I have all marriage requirements."

Sami shares this belief, and refers to disability as an "inflexible barrier" to marriage. He says that his rejections "apparently are due to my disability more than a financial matter. There are many who are poor but they are married." He mentions that money could be found through loans or family but there is no way to get rid of disability.

Marriage approval is controlled first and foremost by the woman's family even if the woman shows acceptance of a proposal. Participants stated that, based on their life experiences, the woman's family dismisses the marriage proposal more often than does the woman. Jamal says:

"Note that that most of the rejection was from the parents. Because when I sat with some women, they were showing a desire to marry me. They accepted me despite my disability. They did not show any reservations. But the parents, and in some cases the brother, oppose the marriage. I am talking from real experience that happened to me."

Sami elaborates on how the parents make choices on marriage. He talks about what hap-

pened to him when a woman indirectly asked her parents about marrying him. The parents rejected him because of his disability. He describes the way in which marriage confers status in Jordanian culture:

“Parents would like to boast of the groom in front of people. The family and woman like to be proud of [the] groom if he is educated, rich, good looking, or a high social class. In Jordan, disability does not bring pride and people feel ashamed of us. Parents may feel ashamed when their daughter's husband is disabled.”

I Am Ready For the Refusal

All participants expect rejection whether or not they have experienced a marriage proposal but they respond differently to the thought of rejection. Sami and Jamal find rejection acceptable and justified. Adam, who does not find it acceptable, says that he would understand that because of his disability he cannot easily find a wife and he could be rejected. Yet, he does not want to be rejected. He values himself and wants to avoid rejection and does not want to be judged by the family. For him, rejection is a very harsh word. However, he says that he would accept a traditional marriage, if:

“I get the green light from the woman and her family before I meet them. I want to be accepted before even they see me... Let me say that if there is rejection, I accept it if it is not because of my disability. Otherwise, I won't go and embarrass myself. I value myself. I don't want to be rejected.”

However, the other two participants say that being rejected due to their disability is justified. Sami says:

“It is normal to be refused. And I expect that. Then I get used to living in oppression and refusal. I am ready for the refusal. I may get a little bit upset if the woman and I were to love each other. I would

feel sad and it would be an injustice, but I have nothing to do, it is my fate and it is the life. All disabled people are oppressed and they must endure their fate.”

Jamal has the same reaction:

“Frankly, I have not [been] bothered much because I expected it. I adjusted myself to this rejection. There was not any problem to me. I was aware that as [a] disabled person, it will not be an easy decision. And I justify people's rejection to me in [the] matter of marriage.”

The participants reflect on suffering, pain, and anxiety when they talk about marriage. They say it feels unfair that it is so difficult for them to find a wife. Adam says:

“I lie [to] you or [to] myself if I say it is a normal feeling; absolutely not. I get very anxious when this topic comes to my mind because of rejection. Rejection is not easy. I don't want to hear the rejection word. I cannot imagine myself rejected even though I know I will face difficulties because of my disability.”

Sami feels anxious and worried because, as he says:

“My disability makes me feel insomnia and anxious when I think of marriage. I don't know what to do and who will accept me. It is hard to find one to accept me when I am poor and have disability. A disabled person in our society is not desirable as much as normal people.”

On the other hand, Jamal says that he felt anxious and worried after several marriage proposals were rejected but eventually he adjusted:

“I did not feel much anger or upset because I was expecting that [rejection]. Then, after the first and the second rejections, the fear and anxiety have disappeared and become normal. I was anxious. I was thinking of my luck. Will I

get luck with my wife or not? Will I live a happy life? Also, I was realizing that my disability will be a cause of rejection. But, the fear has gone after the first and the second attempts.”

A Disabled Woman Does Not Seem To Be Beautiful

Sami rejects marrying a disabled woman because she would not be a woman " like ... like ... a real woman." Sami also believes that most disabled women "know this fact." Asked what he meant by a "real woman," Sami states, "I see them abnormal ... incomplete. They are not a woman for, for marriage, procreation, sexual pleasure, or work at home. They are physically different." Sami has the same attitude about disabled men, however, he observes that being a disabled man is easier than being a disabled woman because men have choices about marriage. He refuses to marry a disabled woman because he does not see a disabled woman as fascinating or physically attractive:

“For me, a woman with a disability does not seem to be beautiful, seductive, or attractive. The non-disabled women are beautiful and charming. They give an aesthetic dimension that reflects the reality of women. There is a great pleasure while I am looking at her standing ... walking ... tying her skirt, or while she dances for me. Normal women are really, really different. Nobody, but I ... assume that. I assume that pregnancy is hard to a disabled woman to handle it. Also, I don't think her uterus can carry the baby. I guess so. ... Maybe she can. I don't know. I just guess.”

Jamal also refers to abnormality in his refusal to marry a disabled woman. He says that she had a near-invisible disability:

“When I saw her, I realized by my experience in the field of rehabilitation that she was abnormal. There was something,

something ... abnormal while she was walking. Her legs were such distorted or have ... deformities though she was wearing a long dress. I diagnosed her she did not walk normally.”

Jamal's heightened awareness of this woman's gait is indicative of the stigma he places on physical appearance. He says he is sure that the woman and her family realize that the rejection was because of her disability. Since he rejected her as a disabled man, Jamal believes he is not responsible for hurting the woman's feelings.

The participants admit that the visibility of impairment impacts their interest in disabled women because a disabled woman would make their own disability more visible and would increase people's stares. Digging, participants were asked whether they would marry a woman with an invisible impairment, such as mild hearing or vision loss.

Adam declares that he would never ever marry woman with a visible impairment. If he had to, he says he would marry a woman with a hearing impairment because it would be invisible or barely visible. Adam talks about the shame he felt when townspeople saw him with a disabled friend who has a "funny and strange" physical condition:

“He visited me here in my town. I live in a small town. It is a tiny and everybody knows each other. We went shopping, and everyone in the market was gazing at us. I felt so shamed and disgraced. I will not forget this situation. Until this moment, when I go to the same place, people ask me about him. In any event, such as wedding parties, some people still ask me about him and make fun of him because of his strange disability.”

Adam reports that Jordanians are "intruders" who want to "trace everyone's lives" and investigate private matters. He is used to people's stares, yet he would not be able to handle the

curiosity of people toward his life with a disabled wife.

Sami goes further saying that the more visible she is, the more physically severe her disability must be. He differentiates the visibility status as follow: “To be clear with you, I don’t care if my wife has a visible disability but I don’t [want] my wife to appear much visibly disabled.” Since he associates visibility with the inability to do what a wife is expected to do, he does not want to marry a visibly disabled woman.

If I Married a Disabled Woman the Burden Would Be Double

Jordan is not broadly accessible to physically disabled people. Therefore, physical ability is required for conducting life’s matters. While the participants are independent in their own lives and receive minimal assistance, they want to marry non-disabled women who can assist them and their children. This is consistent with the woman’s role in Jordanian culture, which is to take care of house, husband, and children. For instance, Adam does not pay attention to other criteria as much as his concern for having a woman who understands the details of married life with a physically disabled man. He believes that disabled women are as equal as non-disabled women yet he will not marry a disabled woman because:

“I still feel that I am a burden on my family and a burden on my brothers. They sometimes put on me the blankets when I sleep. They even warm up the car for me on cold days, besides to cooking, washing and shopping. So, if I married a disabled woman, the burden would be double. My family then will look after of both of us. I need a woman that has the physical ability to do the daily life. I want her cook, clean, buy for the house and so on. I want wife that might reduce my family’s burden not increase it. I don’t want her

as a maid. No, I want her to achieve the balance.”

Sami states as fact that a disabled woman definitely would cause a burden. He wants a wife who has the ability to conduct her traditional role as a housewife:

“Giving birth and routine tasks as a wife and a housewife are other reasons. Women with disabilities are not suitable to perform the tasks of daily life as they cannot get pregnant and give birth. A disabled woman is not valid to give birth or to be a wife. She is not valid for a disabled or a non-disabled husband.”

As did the two previous participants, Jamal says that a disabled woman is not appropriate for marriage because married life is hard. It requires physical effort. A woman must be able to take care of children and a house, an expectation cited by Moghadam (2005) who writes that the woman is required to play the role of nurturer and supporter while the husband “plays the instrumental role of earning the family’s keep and maintaining discipline” (p. 138). Even if a disabled woman was able to fulfill her role now, Sami believes that she would not be able when she got older:

“Unlike men, tasks of women in life are biggest a thousand times more than the tasks of the man. I see the activities and actions made by my wife. They are unbearable. Actually my choice to marry a non- disabled woman was 100% right. If my wife was disabled, in the future, we would need a third person to serve me and her. So, I wanted have woman I can count on her in everything such as: shopping, raising children, following children, taking care of house, and life’s affairs.”

Sami reflects the same understanding. He believes he causes suffering for his family. His point of view about disability is that “the suffering is ... inherent in the disability. I was a financial, psychological, physical, and social suffering

and burden.” Adam also believes that, consequently, a disabled woman would add suffering and be a burden on his family and on his life.

Sami was once told that his marriage choices were limited to disabled women. As a response, he chooses to marry a non-disabled woman.

“There is a story that happened to me years ago. An employee told me that ‘people who like you must marry a disabled woman.’ She hurt me. I did not know what to answer. She meant that being disabled means I did not have a right to have a normal woman as a wife. So, I decided to marry a normal woman because my marriage of a disabled woman would strengthen these convictions and beliefs.”

When asked for more details about what Sami means by “challenge” and in what ways he considers marriage to a “normal” woman a challenge, Sami answers with an insistent tone. Sami says, “I would like to tell them I was able to have one. People would be surprised when they found that I have done what they did not expect me to do.” Sami says that being with a “normal” wife would make him feel proud of himself:

“I challenge society, people's beliefs and everyone without exceptions. I want to answer every person and say that look to my wife. So, my marriage is a kind of ecstasy of victory, pride, and a reply to everyone. It is my weapon that I face the people with. And by which I can also overcome the physical barriers. But, if my wife had [a] disability, she would increase my disability.”

Jamal believes that if he married a disabled woman, he would always be doing things for her. He would be worried and anxious because she could not manage the home. He asks, “Why do I have to suffer while I can live in happiness?” and he says:

“In short the quality of life with non-disabled woman is better because the amount of suffering and fatigue is less and the amount of happiness is more. Now I do not suffer from anything and I feel relieved. My wife does all daily life tasks at home and takes care of my children. I feel less suffering and more happiness. I will not see medical devices in my face. I spend most of my life between medical devices. She doesn't need a medical device. No one will stare at us. We will not need assistance from outsiders. She helps me defeat the physical barriers. I really feel now my choice was great.”

People's attitudes receive considerable attention from the participants. Jamal refers to his public persona:

“When I go with her in a public place, wedding parties, visiting friends, or when we go to a restaurant, people begin to look at me in a positive way. I feel appreciated. But, if I had a disabled woman, I would have felt of people's pity toward us.”

Even though he is not married, Sami believes that people's attitudes would change for the better through marriage to a non-disabled woman because it would show his ability to marry an able-bodied woman:

“I would feel proud when I walk with her in public places. People will look at me and say to each other: look at that disabled man and how did he get this woman? How beautiful his wife is. It's kind of a challenge and self-proving...”

Adam expresses the same belief when he points out that a disabled woman would not bring pride. Rather, she attracts people's curiosity. He states that:

“Is it not enough that I have a disability? I cannot imagine myself with a disabled woman. And then people look at us. I

cannot handle that. Seriously, a disabled woman as wife does not fit me. Imagine if a disabled woman is next to me, certainly because of her disability she will be eye-catching. I am totally certain that people when [they] see us will ... wonder and say how we live our life. How we cook and take care of our home.”

Adam added that if his family found a disabled woman with “simple disabilities,” he would not agree unless she had a “simple” hearing impairment or simple physical disabilities because her disability would not be visible and she would be physically able to manage the routine housewife tasks:

“People’s attitudes prevent me from engaging with a disabled woman. People’s eyes haunt me when I am out; I want to avoid people’s deadly glances. Until this moment, I feel all people look at me. I’m even honest that I avoid being with other people with disabilities in a public place since I feel ashamed and embarrassed. My situation will be worse if my wife is also disabled. I am totally certain that people when they see us will ... wonder and say how we live our life. How we cook and take care of our home, wonder how we practice sex and how she becomes pregnant, or how she gives birth.”

Blind Man Leads Cripple

Adam says, “The blind man leads cripple,” which is a common Arabic adage meaning that the two are complementary to each other. The cripple can see and the blind man can walk so together they are able to do what needs to be done. To a degree, this adage speaks to the problem Shakespeare (2010) reports about the social model; that it ignores impairment. This adage points out the importance of physical support for people with impairments. Adam does not attribute his refusal to marry a disabled woman to her impairment but rather because she would not achieve the “physical balance” represented

by this saying. Adam believes that marriage and life’s requirements demand balance between the marriage partners. Adam says that he does not have any personal bias against disabled women but he wants to have a non-disabled wife so he can feel independent and avoid causing an “extra burden” on his family.

During the second interview, Adam says that he recently fell in love. He has concealed the affair for around 10 months and has just revealed this relationship proposing marriage. His marriage proposal was refused in the time between the second and third interviews. According to Adam, the woman’s entire family accepts him with the exception of her father who does not approve because he is a “cripple.” As is the tradition, the final word is the father’s. Adam says he is depressed and angry during the third interview. He does not want to talk about this rejection but a few days later he agrees: “I will talk. I need to talk. Let the world see what happened to me.”

“I found that I need to talk about it. I am very upset and I feel I am going to die. I need to talk. I am very upset because I always tried to avoid rejection. I have always dreamed of marrying the one I love. The one I want. Unfortunately, when I got her, I was rejected by her father. For no reason... just because I am a cripple... because of our culture and customs which empower the father to make the decision and make her father refuse me. What do we do? Nothing... nothing.”

Adam has known the woman for a long time and they have loved and understood each other. Her mother and siblings have encouraged him and the next step is to ask is her father. The mother tactfully conveys his marriage request to the father, gradually trying to show Adam’s good points by saying, according to Adam:

“There is a very good groom, respectable, from a good family, with good financial status, educated, has a car, and [is] hand-

some. The father was very obsessed with this while he was hearing. The mother continued by saying he has a tiny problem. He has a physical disability.”

Once the father heard that Adam is disabled, he “went crazy” and Adam recounts the father’s words:

“What is my daughter’s fault to marry a disabled man? How and what will I say to my family and my tribe? The people for sure will think that my daughter is a bitch, or people will think that she dishonored the family and we wanted her to marry a crippled man to conceal the scandal. Are not there any people on the earth, but a cripple? What did my daughter do to marry him?”

Adam continues, saying:

“The father was very, very angry and did not want anyone to discuss this matter with him. He was very stubborn and he wanted to know why I chose his daughter. He wanted to know if we had any relationship. The mother hid that we were in love with each other and said that is as a traditional marriage request. Since he strongly rejected me, the daughter was not able to open her mouth. She could not even say a word. If he asked her, she would not say that she wanted me. She was very scared and pretended that she never met me.”

Adam says that after the rejection he has been disheartened and has felt oppressed and frustrated. He expresses anger, saying that he is not guilty of any wrong.

“I feel frustrated and oppressed. I do not eat or drink and I smoke too much. I lived a beautiful dream, but it turned into a nightmare. I have lived all my life waiting for this moment. I grew up hoping that I will choose my wife. I have dreamt of having the life I want with

the one I want. After we agreed on every single detail of our lives and after we built our lives, the names of our children, the dream evaporates because of the beliefs, customs and traditions by a mere word of the father. *What is my fault? What is the guilt of my disability? What did I do to be refused?* We are now in the 21st century, and people still believe the same shit about disability. Anywhere I go I am rejected. I apply to work in the Gulf Countries and get the work and when they know that I am disabled they reject me. I asked God, *why to create me with disability? Why am I?* I start to blaspheme, while I am waiting for the patience. I start to convert to atheism. I am much oppressed. *What was I guilty of?* Nothing. How long do I have to wait... I am no longer able. I am no longer able. Sorry, I was a little nervous, but it is really annoying...”

It Is a Normal Contradiction

The participants report accusations of being contradictory or arrogant because they will not marry a disabled woman and the men do not disagree with this claim. Sami and Jamal say that their perspective is, indeed, a clear contradiction while Jamal considers it a “vague and understandable contradiction.” Sami divulges that this contradiction is normal and justified, while Adam believes this attitude is not contradictory. He attributes it to the need for balance.

Adam argues that balance allows the marriage partners to maintain their gender roles, a position well documented in the literature. He says:

“It is a balance. This is not because she does not enjoy mental abilities. It is a physical balance between people with disabilities and non-disabled people to achieve the integration and exchange of life’s roles. If we were both disabled, we would be a burden on our family.”

Adam finds that the inaccessibility of the environment constrains him so that out of necessity he *must* marry an able-bodied woman. He says he values disabled women and that he does not discriminate against disabled women or contradict himself. He believes disabled women are equal to other people and are able to marry either able-bodied or disabled men and have children.

In contrast, Sami considers his refusal to marry a disabled woman a contradiction but he sees it as normal and justified. According to Sami, his destiny as a man gives him the freedom to choose whomever he wants:

“But it is normal contradiction because I am not unjust. This is my and her fate. I am not responsible for this situation. It is our fate. I’m looking for the best, and women with disabilities are not better than non-disabled. Frankly, all normal people are better than disabled males or females. We are entirely different.”

Sami says he is not the oppressor and, therefore, he is not responsible for this contradiction:

“This is my fate to be a man and have the right to choose. If she had the choice, I do not think she would marry a disabled man. So are the things. I know I am oppressed like her, but her life is more unjust for her because she is female. So are the things.”

Jamal admitted to an inner contradiction yet he sees it as a contradiction that he does not understand:

“Is it ego? If it is ego then it will be my own decision. But, all individuals with disabilities do not want to marry disabled women. *Am I selfish?* Again everyone would be selfish, too. I do not think selfish is the reason. There is something inside me. I do not understand what it is and I would love to know what it is. I did not understand why I did not want to

have disabled woman even though I have been refused many times by non-disabled woman. There was something preventing me.”

Jamal never thought of a disabled woman as a wife and he refers to disabled women as “sinless and innocent.”

“I sympathize with all disabled women. I feel sorry for them. I feel sadness for the disabled women. Believe me or not when I hear about a disabled who will marry someone with or without disability, I feel very, very exultant. I often imagine myself a disabled woman and ask myself: *what is my fault that no one accepts to marry me?*”

Oppression Is Everywhere

Participants vividly describe their sense of hyper-visibility and stigmatization, both of which are related to tribal beliefs about normalcy, honor, and social standing (Gharibeh, 2009). Internalized oppression clearly is illustrated by what all three participants have to say about themselves and disabled women, and the decisions they have made about marriage. While they view themselves as oppressed and stigmatized and agree that disabled women share a similar social status, they realize that disabled Jordanian women experience stigma layered over stigma. The men seem to have fallen prey to what Charlton (2010) refers to as alienation, a form of disability oppression that divides people and isolates individuals, and which Foucault (1982) refers to as a dividing practice.

The participants’ “defensive othering” (Schwalbe, et al., 2000) reproduces the oppression they complain about yet they distance themselves from this, as does Sami below, by implicating society. Throughout the interviews, participants describe themselves as shameful and burdensome and they turn against disabled women by refusing to consider them marriageable. Sami vividly explains it similarly when he

absolves himself of the oppression of disabled women in the following excerpt:

“I don’t hurt the disabled woman’s feelings when I don’t marry her. I am not oppressive. I don’t hurt anyone. That is her fate and she must handle it. When I had disability, it was my fate, too and I adjusted with it. I will not blame anyone, if a woman or her family refuses me. So, nobody can blame me. Also, I want to say something, Where was the society when I was marginalized? Where was the society when I got fired from my work? I am not oppressive. Oppression is everywhere.”

Earlier we took a tentative stance on the social model and we recognized its problem in relation to impairment. Our participants’ lives serve as examples of the tensions inherent in the social model when it comes to impairment. They illustrate the importance of practical considerations when it comes to their physical functioning. It is essential to understand the participants as situated within broad cultural contexts as well as their own internalized oppression. They live in a conservative tribal society in a poor country in which the family is the central social structure responsible for providing care and support for its disabled members. Without parents, siblings, or a wife to provide necessary physical assistance, the men face significant barriers to fulfilling their traditional role as husband, father, and provider.

On the other hand, they consider disability a shameful burden that causes people to stare and intrude on their privacy. They long for “real women,” because beauty exists only in normality. They reject disabled women as marriage partners and absolve themselves of any guilt while blaming society, as does Sami when he asks, “Where was society when I was marginalized?”

Salam Jalal, EdD. recently finished his dissertation in the United States and is returning to Jordan to continue working to improve the lives of disabled people.

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Employment Outcomes for Young Adults With Autism Spectrum Disorders

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Abstract: This study investigated employment outcomes among young adults on the autism spectrum. Questionnaire responses indicated high job satisfaction and job retention. However, the majority were in low paid, part-time positions. Most found their job through a personal contact, and received a range of informal supports and accommodations on the job.

Keywords: autism, employment supports, adulthood

Literature Review

Autism Spectrum Disorders

Individuals with autism spectrum disorders (ASD: autism, Asperger's syndrome, pervasive developmental disorder – not otherwise specified: PDD-NOS) experience various challenges including difficulties with social interactions, impaired communication, and restricted activities and interests (American Psychiatric Association, 1995). Individuals can be affected mildly, as with high functioning autism and Asperger's syndrome, or more severely as with "classic autism". While symptoms tend to improve during childhood, adult outcome has been shown to be poor with regards to achieving independence in daily life, employment, and independent living (Billstedt, Gillberg & Gillberg, 2005). Rates of autism spectrum disorders continue to increase, and there is now a huge influx of individuals with ASD approaching their adult years (VanBergeijk, Klin, & Volkmar, 2008). This has recently led to increased attention being focused on the adult years, but there is still a dearth of information available to help understand how to support those with ASD in adulthood, and in particular how to ensure positive employment experiences.

The current study represents exploratory work to assess employment outcomes among those with ASD through questionnaires completed by individuals with ASD and questionnaires completed by parents/guardians of those with ASD. This work is unique in that few previous studies have directly questioned those with ASD and their families about their employment experiences. We were particularly interested in the earnings of those with ASD, whether they were more likely to work part-time or full-time, whether they received fringe benefits, how they found their jobs, what supports they received in the work place, their job satisfaction, and costs of family support such as lost parental income, time in helping with job applications, transporting their child to work, and providing emotional support.

Individuals with Disability and Employment

Research has shown that individuals with disabilities are frequently unemployed or underemployed (they want or are available to work full-time or longer hours than the ones they settle for). For example, The National Organization on Disability (2010) survey showed that 21% of Americans with disabilities were employed part-time or full-time compared to 59% of those without disabilities. People with disabilities make up only 3% of most companies' workforces, despite the fact that employers report that employees with disabilities are similar to those without disabilities in job skills and workplace behavior. Data collected from the Center of Disease Control and Prevention (CDC) show that among disabled men unemployment (defined in this data as not being employed for wages or not self-employed) was 45.3%, four times the rate for non-disabled male individuals. Unemployment was 55.1% for disabled women, twice the rate for non-disabled females (Smith, Ran-

dolph & Andresen, 2004). Those with disabilities are three times more likely to live in poverty and have an annual household income below \$15,000 (National Organization on Disability, 2004).

In the specific case of adults with ASD employment outcomes are disappointing and the majority of these individuals are unemployed (National Organization on Disability, 2004). Even those with qualifications are frequently underemployed (Taylor & Seltzer, 2011). Often, the job interview itself is a significant obstacle given the challenges experienced by those with ASD. Many potential employers are unfamiliar with terms such as Asperger's syndrome, or know very little about autism or Asperger's syndrome. The new version of the DSM-V will now merge the Asperger's Disorder category in to a broader "Autism Spectrum Disorder" category (American Psychiatric Association, 2013), which may reduce confusion among potential employers. Muller, Schuler, Burton & Yates (2003) interviewed 18 participants with ASD and found them employed in a broad range of occupations. However, most reported long periods of unemployment and / or underemployment and lack of opportunities for advancement. Several of the participants reported frustration at being placed in entry-level positions for which they were over-qualified. Many had patchy job histories with periods of unemployment and termination from positions making it more difficult for them to find new employment. Hurlbutt & Chalmers (2004) interviewed six adults with Asperger's syndrome regarding their employment experiences and also found dissatisfaction with finding work that matched their skills and abilities. Poor communication, social skills and sensory issues made job retention the biggest challenge for their participants. Howlin, Goode, Hutton, and Rutter (2004) showed that among adults with autism less than one-third were in some form of employment and this tended to be low paid leaving the individual unable to afford to live independently. Among their 68 participants the majority remained highly dependent on others

for support. Those with ASD have social and communication deficits that can make successful employment particularly challenging and result in a need for services and support, particularly for those without intellectual disability who often don't qualify for state and federally funded programs (Taylor & Seltzer, 2011).

Beneficial Effects of Employment

Employment provides important psychological, mental health, quality of life and financial benefits. Unemployed persons exhibit poorer mental health and well being outcomes. Garcia-Villamizar, Wehman and Navarro (2002) found that adults with autism in supported employment improved their quality of life, defined by categories of environmental control, community involvement, and perception of personal change. It is known that those with ASD can be successfully employed (e.g. Keel, Mesibov, & Woods, 1997). For example, those with autism have been found to outperform those without autism when engaged in non-verbal tasks that require visual-spatial abilities (Mottron, 2011), or in tasks that require them to process information in a short amount of time (Remington, Swettenham & Lavie, 2012). Employers can also benefit from hiring someone with ASD who are more likely to arrive to work on time, return from break on time, take few sick days, or waste time chatting with co-workers (Hurlbutt & Chalmers, 2004). Hillier et al. (2007) found that employers rated the performance of those with ASD very positively on a range of important job skills, including being punctual, knowing the job, being dependable, following directions, and beginning a task when requested to do so. Some challenges remained such as transitioning to a new task independently, asking for help when needed, and social integration in to the work place. However, if the work environment is supportive the chance of success is greatly improved for those with ASD.

Costs to Society of Unemployment Among Those With ASD

An increase in employment rates among those with ASD would result not only in individual benefits but also in decreased costs to society. The total annual cost to society of caring for someone with autism has been estimated at \$3.2 million per capita (Ganz, 2007). Jarbrink, McCrone, Fombonne, Zanden & Knapp (2007) evaluated the cost-impact to society of ASD by interviewing 19 young adults on the high functioning end of the autism spectrum. They found that half of the overall costs to society of supporting individuals with ASD were due to lost productivity. They also argued that if more individuals with ASD were employed it is possible that fewer would receive psychiatric care, there would be a reduced need for day programs and other community resources, and less burden on informal carers. There would also be a larger tax base and less financial dependence on the state and federal government. There are many costs to families themselves in raising a child with autism including costs of service provision, health care, as well as indirect costs. Often parents may have to work fewer hours, or not work at all in order to support their child (Jarbrink et al., 2007). School systems also carry the costs of supporting these individuals through special education and vocational programs. Given the need to reduce these combined individual and societal costs, more research is required on the employment experiences of those with ASD and what supports are necessary to ensure success. Success, as it pertains to this study, includes being employed, working the number of hours desired for the amount of pay desired, and experiencing high job satisfaction within a supportive work environment.

The goal of this study was to conduct an initial investigation of the employment outcomes and experiences of young adults on the autism spectrum. We particularly wanted to gain more detailed information than currently seen in the literature by gathering quantitative and quali-

tative information directly from young adults with ASD and their parents.

Method

Participants

Nineteen parents/guardians of adolescents and young adults on the autism spectrum completed a questionnaire reporting on their child's employment situation. Seventeen adolescents and young adults with ASD completed a questionnaire about their employment experiences. For 10 families both the parent and the young adult completed a questionnaire, but nine parents completed one without their child doing so, and seven young adults completed one without a parent doing so.

Among parents/guardians 17 mothers completed the questionnaire, one father and one grandmother. The majority of the parents ($n=13$) reported a mean total household income before taxes of \$100,000 or more with the rest responding in categories from \$50,000 up. Fourteen parents reported their child had a diagnosis of Asperger's syndrome, four autism, and one Pervasive Developmental Disorder – not otherwise specified (PDD-NOS). Seventeen parents were reporting on a son, and two on a daughter. The average age of their children was 21 years.

Among the adolescent and young adult respondents the average age was 23 years (range 19-28 years). There were 14 males and 3 females. Thirteen reported a diagnosis of Asperger's syndrome, two with autism and two with PDD-NOS. Eleven lived at home with their parents and six lived independently. Three had completed a high school education, 10 had some college but had not completed a degree, one had an associate's degree, and three had their bachelor's degree. Young adults were not eligible to participate in the study if they had not previously held a job.

Participants were recruited via flyers describing the study sent to targeted referral sources such as organizations providing services to those with ASD and their families. Most participants completed their questionnaire by mail but some who were taking part in various programs offered at the university (social skills, exercise, or music program), completed theirs in person. Each person who requested a questionnaire returned it, yielding a 100% response rate. Informed consent was obtained from all participants and parents/guardians. All aspects of the study were performed in accordance with the Institutional Review Board of the university.

Materials

The questionnaires (both the parent and the young adult versions) took around 30 minutes to complete. The parent/guardian questionnaire asked participants to respond to some demographic questions and then separated in to those whose son/daughter was employed, unemployed (jobless, but looking for jobs, and available for work), or out of the labor force (neither employed or looking for a job). Questions then focused on aspects of their job or previous job such as job title, salary, benefits, number of hours worked, size of company, and job search experiences. An additional section asked about the costs of family support in caring for a young adult on the autism spectrum. As those with ASD may need extra care, support and supervision, this section asked how many hours were parents, other relatives and friends providing this kind of help in an average week.

The questionnaire for the adolescents and young adults also began with some demographic questions and then focused on their employment experiences such as what their current (or previous) job entailed, their job satisfaction and attitudes towards co-workers using a Likert scale (please contact the corresponding author for a copy of the questionnaires).

Results

Parent/Guardian Questionnaire

Seven parents/guardians had a son or daughter who was currently employed, six a child unemployed, and six a child out of the labor force. Those who were employed had been in their current jobs for an average of 43 months (range 24 to 72), and worked for an average of 22 hours per week (range 6 to 40). Six were paid hourly and one was salaried. They worked in companies of varying sizes (three worked with 5-10 employees, two with 11-30 employees, and two with 100+ employees). They worked relatively close to home with an average length of commute of 15 minutes. Three worked in retail, three worked in administrative positions, and one was a software engineer. Only one of the seven employed participants found the job completely independently (he saw a sign on the door of a shop). Of the others, three were hired following a co-op opportunity, one was hired at a baseball club because the participant had previously attended camp there and was known to the employer, one worked for a friend of the family, and one worked at their parents' company. Participants took from one month to two years to find a job. Five of the seven employed participants received some sort of accommodations from the employer. These included increased flexibility with the job, flexibility with productivity, flexible scheduling, a place to go when feeling overwhelmed, job coaching, and additional general support including emotional support, and "extreme kindness and understanding". Five did not get any health care or dental benefits. Six of the seven were not offered any professional or on the job training. Regarding salary, in the twelve months prior to the study, before taxes two earned less than \$5,000, two earned between \$5,000-9,999, one earned between \$10,000-14,999, one between \$15,000-19,999, and one earned more than \$50,000. These results are summarized in Table 1.

Table 1
Summary of Employment Outcome Data from
Parents/Guardians whose child was
employed N=7

	Category	N
Paid	Hourly	6
	Salaried	1
Prior 12 mths earnings	<\$5,000	2
	\$5-9,999	2
	\$10-14,999	1
	\$15-19,999	1
	\$50,000+	1
Size of company	Small (5-10 employees)	3
	Medium (11-30 employees)	2
	Large (100+ employees)	2
Type of job	Retail	3
	Administrative	3
	Engineering	1
Found job	Independently	1
	Hired after a co-op	3
	Friend of family	3
Health benefits	Yes	2
	No	5
Professional training	Yes	1
	No	6
Accommodations	Yes	5
	No	2

Of the six parents whose child was unemployed, four reported that their child had previously been employed and two had not. Of those children who had previously been employed, the length of time since that previous employment ranged from 1-9 years. All four had been working part time, one in food service, two in office administrative jobs, and one in retail. Those in this category had been looking for a job from six months to two years. They had applied for an average of 17 jobs and had an average of five

interviews at the time of completing the questionnaire.

Of the six children who were reported to be out of the labor force, four were not seeking employment because they were attending school or training programs, one was waiting for a previous employer to rehire them, and one was in a psychiatric treatment program. Three had previously worked (all part-time) and three had never had a paid job. Of those who had previously worked, one did janitorial work, one worked at a school as an aide during recreation, and one helped with the kennels in a vet's office.

We were also interested in costs of family support in caring for a young adult on the autism spectrum. As those with ASD may need extra care, support and supervision, we asked how many hours were parents, other relatives and friends providing this kind of help in an average week.

Responses combined across the three groups (employed, unemployed, and out of the labor force) showed that the average number of hours per week spent in providing Personal Care to the individual with ASD in preparation for their work (e.g. dressing, taking care of their personal hygiene, etc.) was 7.2 hours. Families averaged 8.3 hours a week in providing transportation to their child's job, 4 hours a week in job interview preparation and completing resumes, and 11.1 hours a week in supervision/emotional support related to their child's job. Eight out of nineteen

parents (42%) reported that over the past six months they lost income (reduced number of paid working hours) because they provided care and support for the person with an autism spectrum disorder. Parents estimated that they lost an average of 23 working hours a week due to providing support to their child and estimated this to result in an average loss in gross income of \$600 a week. These results are summarized in Table 2.

Table 2
Costs of Family Support in Caring for a Young Adult on the Autism Spectrum
N=19

Category	Average
Average no. of hours spent per week providing personal care	7.2
Average no. of hours spent per week providing transportation to job	8.3
Average no. of hours spent per week helping with job interview preparation and resumes	4
Average no. of hours spent per week providing supervision / emotional support related to job	11.1
Average estimate of lost working hours per week	23
Average estimated lost gross income per week	\$600
Lost income over past 6 months	Yes: 8 No: 11

Young Adult Questionnaire

Adolescents and young adults with an autism spectrum disorder and with employment experience completed a separate questionnaire (available from corresponding author). Of the seventeen young adults who completed the questionnaire, eight had received general career guidance in high school, five had received training in job seeking, five in interviewing, six in resume preparation, and six had received training for a specific job/career. The remainder of the questionnaire asked participants to rate various aspects of their job. Two respondents did not

complete this portion of the questionnaire. Of the remaining 15 respondents, 10 either agreed or strongly agreed that their job was exciting and 11 reported being overall satisfied or very satisfied with their current job. However, 13 agreed or strongly agreed that their job involved a lot of repetitive work, 8 reported they were lacking opportunities for promotion and 10 said they would like more training in their job.

Twelve respondents either disagreed or strongly disagreed that their disability made it difficult for them to do their job, 10 reported that they were given freedom for making decisions in their jobs, and 14 either disagreed or strongly disagreed that they had been treated

unfairly or harassed at work because of their disability.

Respondents indicated their co-workers were friendly (n=15), helpful (n=14), respectful (n=15) and that their supervisors were concerned about the employees (n=13). The majority of respondents did not report fear of losing their job (n=12).

Two participants reported receiving “extra help” on the job – one had a job coach and the other reported having extra time to learn new tasks, extra coaching, and reminders to com-

plete things. Participants also rank ordered their priorities regarding employment from a list of 11 employment related factors. They assigned a number 1 to the factor they felt was most important through to 11 for the factor they felt was least important. These rankings were then averaged across participants (see Table 3).

Table 3
Average Rankings Given by Young Adults with ASD of Their Employment Priorities

Priority	Average Ranking
Income	3.43
Interesting job	3.5
Supportive environment	4.5
Opportunity for learning / skills	5.15
Interacting with others	5.2
Health benefits	5.62
Opportunity for promotion	5.9
Commuting time	6.21
Independence on the job	6.43
Involves challenging work	7.39
Vacation and sick pay	8.39

Note. Rankings are from 1-11 with 1 being most important.

Regarding overall job satisfaction, four participants reported being “very satisfied” with their job, seven reported being “satisfied”, two “unsatisfied”, and one “very unsatisfied”. Three participants did not answer this question. Eight said they would strongly recommend their job to a friend, five said they would have doubts recommending their job, and four participants did not answer this question.

Discussion

The results from our questionnaires looking at the employment outcomes of young adults with autism spectrum disorders (ASD) (aged between 19-28 years) indicated overall, a negative employment outcome among our sample. There was a clear pattern of those with ASD being in entry level, low paid positions. These findings support previous research showing poor employment outcomes for those with disabilities (e.g. Baldwin & Johnson, 1994, 1995; Carter, Austin, and Trainor, 2012; DeLeire, 2000; Kidd, Sloan & Ferko 2000; National Organization on Disability, 2004). While parents’ questionnaires permit us to cast light on the difficulty related to finding a “good” job, youth’s responses give us insights about the quality of their everyday working experience.

Responses From Parents of Children With ASD

Parents in this group reported that employment levels were low among their children. Only around a third of the children were employed, mostly in hourly, part-time positions rather than salaried, full-time positions. Only one of those employed was in a skilled job (software engineer) with the remaining in unskilled entry level positions with no fringe benefits. Salaries were low, with only one participant earning over \$19,999 in the previous twelve months. Among those who were currently unemployed but who had previously worked (n=7), the pattern was similar. All had previously only worked part-time in entry level positions.

Participants Currently Employed

Only one parent reported that their child found their job independently, the others all had prior connections to their employers either as a friend or member of the family, through a co-op experience, or previously attending a camp. Five out of the seven currently employed received some sort of accommodation including increased flexibility with the job, flexibility

with productivity, flexible scheduling, a place to go when feeling overwhelmed, job coaching, general additional support including emotional support, and “extreme kindness and understanding.” Quotes taken from parent questionnaires gave more insight in to the sorts of accommodations received which are often informal. For example, “He doesn't drive, so his supervisor and I work out schedules that accommodate mine/my spouse's needs as well” or, “They know [son] very well and build in support because they understand who he is and he understands the culture of the place.”

Participants Unemployed

Those who were currently seeking work appeared to have engaged in a relatively minimal job search process (e.g. they had applied for an average of 17 jobs and had an average of five interviews). Parents' open ended responses provided insight in to challenges with the job search, such as, “Rigidity in approaching the job search process and unwillingness to listen to advice from others; fear of making personal approaches; preference for solitary activities at home” or, “He has given up hope of finding employment and doesn't actively look unless we encourage him to apply for a particular position we find posted.”

Less than half of the participants received any vocational training in high school which may partly account for some of the challenges parents described above. This result is consistent with others studies that have also found an inadequate transition planning from high school to employment among those with ASD (Hetherington et al., 2010).

Participants Out of the Labor Force

The main reason for those who were not currently seeking employment (n=6) was that they were attending school or training programs. Three of these six had previously worked (all part-time), one in a janitorial position, one

as a school aide during recreation, and one in a vet's office.

Factors Which Influence the Employment Outcomes for Those with ASD

Parents also describe a range of additional factors which influence the employment outcomes for those with ASD. The levels of stress and anxiety experienced by those with ASD have a significant impact on their employment experiences, as indicated here, “This was her first part-time job and she quit after about a month. She was going through medication changes, and she was also highly anxious about the job - she was doing the work very well but couldn't see that. She had trouble feeling comfortable with the staff. The cleaning duties were hard for her - she worried about germs. We suggested she quit because she was just too stressed and anxious.”

Other parents reported problems with self-advocacy, motivation, and just a generally poor fit in terms of job match:

“The most repetitive and difficult times I have is trying to get him to understand how the ‘working world’ operates, and how his words and actions relate to that. Sometimes I feel unsure whether I'm dealing with Asperger's traits or just apathy/lack of motivation. He's basically high functioning but can't or won't self-advocate regarding issues at work. I explain steps he can take but he doesn't do it and then issues go unresolved.”

“He did work at a bagel shop washing dishes. He could not keep up with the time-frame that the bagel shop wanted him to so he was asked to quit. He returned with us full-time.”

“Left [food store] because he was tired of bagging and disliked fellow baggers. Not offered another position. Since graduating from college unable to find employment other than temp work.”

“If we didn’t own the company, I don’t think he would have been able to hold the job here. The staff here is understanding and helpful to him.....He has come a long way since he started working here in terms of work and his behavior, however, he still has moments of inappropriateness.”

Another parent described problems caused by her child working because of financial trade-offs:

“...As a result of his income he has lost his food stamp benefits. Because there is no public transportation to his job, however, a relative must drive him every day and a taxi picks him up at a cost of \$12 per day (\$240 per month). He lost about \$150 in food stamps because of his income and I was told that “everyone has transportation costs” – although I did point out that usually they do not amount to nearly 50% of net pay!”

Costs of Family Support

Data across the three groups (employed, unemployed, and out of the labor force) showed a variety of hidden costs families face when caring for young adults with ASD. The first cost component is in terms of time. Parents provide a high level of family support for the child with ASD in a range of areas including providing personal care in preparation for work, transporting their child to their job, helping with resumes and job interview preparation, and supervision / emotional support related to their child’s job. Clearly, supporting a child with ASD in employment and in seeking employment involves considerable sacrifice on the part of parents and caregivers. Quotes taken from the open ended questions on the parent questionnaire particularly highlight the support provided by families:

“One of parents must be available for transportation, meltdown periods, hygiene patrol, food prep and maid service.”

“The kind of support we provide to [son] isn't always quantifiable. It is incorporated into our daily routine. [Son] did lose a job he had as a store clerk – he was fired because he had made mistakes. We felt that people coming into the store had taken advantage of [him]. The baseball club job is not supported, but because they have known him since he was 4 years old, they understand how to work with him, what kinds of jobs to give him, and what not to ask him to do.”

The more hidden costs are associated with parents’ lost income, loss of career opportunities and depreciation of working skills. Nearly half our sample reported losing income and working hours due to providing care and support to their child.

“Pick [son] up in middle of day which splits the work day, can't work full time.”

“Accepted positions close to home which did not require a relocation (career advancement vs. stability); had a longer period where paid child care was needed; had no evening, travel or social events. I was able to balance for many years, but I did need to accept that top jobs in my field were out of the balance equation.”

“Mother left employment to provide care, support, and guidance when he was a child. Unable to return to field of training because credentials have expired and would need to return to school for re-training. My current income is therefore greatly reduced.”

This supports the findings of others who have also shown that employment is negatively impacted among parents of those on the autism spectrum (Baker & Drapela, 2010; Eskow, Pineles & Summers, 2011).

Responses From Adolescents and Young Adults With ASD

Adolescents and young adults on the autism spectrum responded to a separate questionnaire. After answering some demographic questions, participants were asked to rate various aspects of their job. Their answers give us unique insights about their perceptions of career opportunities, about the employment effects of their disability and about the work environments they face.

Job satisfaction was high among the respondents in this study. Most reported that overall they were satisfied or very satisfied with their current job and that their job was exciting. However, they also reported that their job involved a lot of repetitive work, that they were lacking opportunities for promotion and that they would like more training in their job. Given that 10 participants had some college experience and three had completed their Bachelor's degree, it was somewhat surprising that most of the participants were in entry level, low-paid positions. Migliore, Timmons, Butterworth and Lugas (2012) found that postsecondary education was a strong predictor of higher earnings among youth with autism. Some participants commented on the lack of challenges encountered on their jobs:

“As of now I am working part-time as a cashier at [large retail chain store]. I was laid off two years ago from my position as a job cost accountant for a construction company, and I have been looking for something in my field/equivalent to my capacity. [Large retail chain store] is a stopgap I tolerate (sometimes barely).”

“I enjoy it but I also find it monotonous at times.”

“It's a job, not a career.”

The majority of young adults did not report their disability to be an obstacle on their jobs or that they had been treated unfairly or harassed at work because of their disability. This is contradictory to some of the parent's comments,

suggesting a potential discrepancy between parents and children understanding of desirable performance or stigma:

“Over the past three years I've had over 10 jobs. The majority of which let me go due to my disabilities. I love the field I chose but there are too many schedule changes and transitions, and they always got mad because I took too much time. The field is very competitive and I prefer not to be in a job like that. The last job I had was the longest, and I gave them a disability letter near when I started, but it turned out they weren't willing to support me anymore.”

“I am making the best of a difficult situation. I do not see myself succeeding at any job without more support for my AS symptoms. Because I currently receive SSDI I have a small amount of flexibility pertaining to being forced into a job I would struggle with. I am working an unskilled job uncompensated on behalf of a charity.”

Most participants appeared to have been employed in environments that were supportive to them. They were happy with their co-workers and rated them as friendly, helpful, and respectful, and indicated that their supervisors were concerned about the employees. One participant comments:

“I thoroughly enjoy my job. Love talking to people, like doing the physical work cause I could never do a desk job, and I have a very supportive environment.”

These results contradict those found by Muller et al. (2003) whose participants expressed more negativity regarding their employment experiences, although did also report some isolated instances of vocational success, mostly in relation to finding the right job match or to having accommodating supervisors and co-workers. This discrepancy of results supports the idea that the relatively high job satisfaction

reported by participants in this study is likely to be closely related to the substantial support received in their workplace. Indeed both our young adult participants and their parents reported very high levels of support in the children's work environments.

Finally, in open ended responses, participants confirm what is already known about the beneficial effects of employment. They said:

"It's a simple and easy job but it gives me a paycheck and a schedule which has improved my self-esteem."

"My last job was enjoyable, as I was able to be productive with a number of tasks to perform."

In the future, a comparison group of typically developing adolescents and young adults would be useful especially to examine the question of whether the high number of job applications and interviews completed by those with ASD is related to their disability or the current economic situation. Across these two groups we could compare job search processes, job titles, status (full or part-time), salaries, benefits, training, career opportunities, and employment goals. This would permit us to identify factors that might be particularly unique among those with ASD.

Overall, these findings support other work in the disability studies field conducted with more varied populations including the work by The National Organization on Disability (2010) and the CDC both indicating disappointing employment outcomes for those with disabilities, particularly women and those in minority groups. When those with disabilities are employed they typically have fewer hours and are paid less, resulting in those with disabilities being significantly disadvantaged economically within our society (Shriner, 2001). Our results add to this literature and provide a unique focus on the rapidly growing population of those with ASDs. We hope this work will encourage further research focused on outcomes in adult-

hood such as transition and increasing financial independence. As more individuals benefit from early intervention and options for empirically validated service provision increase, more members of the disability community will be in a position to enter the competitive workforce. Greater understanding of the challenges faced, how to create successful placements, and improving employment outcomes will continue to be a significant concern within the disability studies field.

Conclusion

As a preliminary investigation our findings demonstrate that those with ASD have difficulty finding employment, typically find employment through people they know (perhaps more than would be expected in a typically developing population), are low paid workers, and are likely to work in part-time, entry level positions. Generally, however, they comment favorably about their work environment but also receive considerable support from their families who are subsequently impacted economically in terms of long term earning growth. Given the costs associated with caring and educating those with ASD (Ganz, 2007), as well as the proven abilities of those on the autism spectrum to be successful in the work place (Hurlbutt & Chalmers, 2004), our findings reflect the dire need for additional employment supports for those with ASD. It is clear that features of ASD can be highly desirable for employers such as reliability, attention to detail, preciseness, commitment, and honesty (Hillier et al., 2007). Given the right training both in school and on the job, and then supports in the workplace, the current employment situation for many individuals on the autism spectrum could be improved.

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Audio Description In Italy: An Anecdote Or A Social Integration Policy?

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Abstract: The European Community (EC) has issued several directives to promote social inclusion and media accessibility. In turn, countries within the European Union (EU) are implementing media access services for people with disabilities at different rates, speeds and styles. What may start in one country as a media access anecdote or sporadic event may develop into a service that aims to improve media accessibility for all. Media accessibility tends to begin as an isolated event, as in the case of the Cooperativa Sociale Scurelle (Scurelle Cooperative Association), the Cinema senza Barriere (Cinema without Barriers) or the Museo del Cinema in Torino (Turin Cinema Museum) events in Italy, but once the trend is underway, and the audience is aware of its availability, the next step would be to establish a standard quality service. This is the objective of this article. The first part aims to provide an overview of Media Access in Europe, paying special attention to Italy, where media access for the disabled is not widely available. While even a minimum cultural content could have maximum diffusion, the opposite is the case in Italy. Very few movies are accessible and sometimes, are duplicated. In other words, we found different audio descriptions of the same film. Media access duplication is a widespread trans-European phenomenon. The second part of the article examines the different approaches to audio description of the same film in Italy. The results go to show that, rather than opting for an access trend of isolated anecdotes, a widespread quality access content should be encouraged, taking into consideration the many and wide-ranging technical exploitation channels and formats.

Keywords: blindness, audiovisual translation, accessibility

Introduction

In the context of a society in which exchanges are becoming more and more facilitated due to new information technologies (ICT), it is becoming clearly evident that a certain sector of the population, namely the blind, have enormous difficulties in accessing information. Indeed, in this regard, the Italian Inter-ministerial Commission (2003) also considers that such access, besides influencing their *modus vivendi*, also represents an “opportunity for acquiring knowledge, education and work” (Italian Inter-ministerial Commission, 2003)¹ and, therefore, it is a right belonging to all citizens. In this context, it is necessary to clarify the meaning of the concept of “accessibility”. This term, which until recently referred to a physical reality, that is to say, architectural obstacles or barriers, were subsequently extended to indicate the “removal of [...] virtual barriers” (Italian Inter-ministerial Commission, 2003)² already specified by the United Nations (UN) in 1993 as follows: “Braille, tape services, large print and other appropriate technologies should be used to provide access to written information and documentation for persons with visual impairments.” (United Nations, 1993)³ This means that any user should be able to avail themselves of any audio or visual product, regardless of their physical or mental abilities.

In the same document, the UN also declared that “States should encourage the media, especially television, radio and newspapers, to make their services accessible.” Apart from the fact that the European Union (EU) has only recently taken the initiative of pushing for governments to become active on the legislative level - and despite the various documents which have seen the light in this regard - we must bear in mind the difficulties encountered by various

countries, such as broadband and broadcasting fees, to name but a few. In Italy, on 9th January 2004, the law known as the “Legge Stanca” (“Stanca Law”) was enforced - with the objective of eliminating “the digital barriers limiting or preventing access to information tools on the part of the disabled” (Legge Stanca, 2004).⁴ Moreover, a few years later, Article 26 of the Charter of Fundamental Rights of the European Union (2007/C 303/01), with reference to the integration of disabled people, continued in its efforts and insisted that “the Union recognize and respect the rights of disabled persons to benefit from measures to ensure their independence, social and occupational integration and participation in community life” (Charter of Fundamental Rights of the European Union, 2007).⁵

Let us consider how this applies to the Italian situation because there are fewer studies on this subject. In Section 3 of the “Contratto di Servizio RAI” (Service Contract of RAI, Italy’s national public broadcaster), the company guaranteed “access to its own multi-media and television production to people with sensory and cognitive disabilities, also by means of specific audio-described programs and telesoftware programs for the visually impaired, and programs subtitled with special pages from Televideo, recordable on VCR and DVD supports, and from their own Internet portal and through sign language translation” (ASL) (Contratto Servizio RAI, 2007).⁶ In particular, under Article 8, the company assumed responsibility for developing over the 2007-2009 biennium a series of programs in sign language to cover 60% of programming, as well as audio-description programs (without, however, specifying a percentage, probably lower in this case). The fact is that, despite these indications, to date RAI has failed to subtitle even 50% of the hours specified in the contract. The difference is minimal, however they do not explain if the percentage is calculated from 0-24 hours instead of from 6-24 hours, as it seems. Thus, “All the obligations relating to the accessibility on the part of the sensory dis-

abled to radio and TV programs, to information regarding social issues and human rights under the aforesaid Article 8 (written enquiry 4-03793 published 03/03/2010) need to be urgently fulfilled” (Contratto Servizio RAI, 2007).⁷

An Overview of Audio Description (AD) in Italy

The first audio descriptions in Italy were performed in 1992, thanks to a group of people with visual disabilities who decided to create a cooperative association (Cooperativa Sociale Onlus Senza Barriere, or Non-profit Without Barriers Cooperative Association) to “develop and produce multi-media editorial supports accessible to everyone” (Cooperativa Sociale Onlus Senza Barriere, 1992).⁸ It aims to promote ‘access to cultural heritage’ through audio descriptions and thus offer a variety of services.

Other associations have shown interest in these techniques, especially in the last five years, including the Cinema senza barriere or Cinema without Barriers,⁹ which began its activity in Milan in 2005 and later extended it to Rome and Bari, respectively the *Spazio Oberdan (Oberdan Cinema)* in Milan, the *Farnese Cinema* in Rome and the *Galleria multiplex cinema (Multiplex Gallery Cinema)* in Bari. Furthermore, the Museo del Cinema in Turin (Turin Cinema Museum) began in 2006; its first production cycle was presented this year and among its goals is to promote a “extended model of accessibility” (Museo del Cinema, 2006).¹⁰ The project called “Oltre la visione: il museo da toccare, il cinema da ascoltare” (Beyond Vision: a Museum to touch, a Cinema to listen to) (Museo del Cinema, 2006)¹¹ incorporates, among other things, AD for the cinema. Similarly, the “Blindsight project”¹² has been active in Rome since 2006 in collaboration with the associations that make audio descriptions: *Conseguenze* and *Subti*. The “Isiviù” association (2007 – Messina) also produces AD for the theatre. Moreover, the “Roma Fiction Fest” has been producing AD since 2009, in much the same way as “Film Voices” in

Bologna. Finally *CulturAbile*¹³ started its activity in 2010. To sum up, what we find is a trend that is gaining ground slowly but in a somewhat fragmentary way, whereby each group works in isolation. This situation leads to a dispersion of energy and higher costs because, instead of uniting efforts and working towards a single model with common guidelines for those who are involved in AD, each group works independently, following personal criteria. If we consider that the EU is aiming at accessibility for all people to any and every audiovisual product, it would be a major achievement if all of these could work in the same direction.

What follows is the audio description of the film *Charlie and the Chocolate Factory* performed by two Italian associations: the Scurelle Cooperative Association in Trent and Cinema without Barriers in Milan, where we propose to focus on a few similarities and differences.

Guidelines Provided by the Scurelle Cooperative Association in Trent and Cinema Without Barriers in Milan

The Trent Cooperative is concerned not only with AD but also with audio guides for museums, subtitling for the deaf, “accessible” websites and, among other services, they are also responsible for the first audio film library in Italy. However, as we have already clarified, I will focus on the AD of films that are not targeted to juvenile audiences.

Cinema without Barriers elaborates audio description, taking into account user needs from different perspectives, ranging from those who were born blind to those who have lost their sight at a later date, either in part or in full. Therefore, they enrich the colors, clothing, etc. with detail. In this sense the Scurelle Cooperative Association also operates along the same lines. In regards to the former, one of its primary objectives is to enable the viewer to “safeguard his own spaces of ‘imagination’”. To do so, it sets out a series of golden rules: “Describe what

exists; don’t give any personal interpretation of what you see, never talk above the dialogue or above any comments already present in the film; [indicate] when-where-who-what” (Cinema senza Barriere, 2005).¹⁴

On the subject of the information to which priority must be given, it is of paramount importance not to lose the thread, in rapidly-changing scenes and where there is very limited space, by describing these changes almost telegraphically, with indications such as “in the house” or “in the kitchen.” They also discourage use of expressions like “we see before us” and recommend use of the names of the characters (in order to avoid ambiguity in scenes where several characters are present). They stress the need not to give superfluous explanations, while stating that at times a few details are important. Regarding the audio descriptions provided by the Scurelle Cooperative Association, I lack the guidelines that have been used for their elaboration, but have been informed that they are preparing a publication to be released shortly. Both associations have a final phase in which the AD is assessed by a blind person. A fundamental difference between the two is that the Trent AD lacks images; it is an audio CD where “a voice describes scenes without dialogues” (Cooperativa Sociale Onlus Senza Barriere, 1992)¹⁵, which in some way entails isolation of the disabled person who cannot share this moment with other people with no problems of sight. In this connection, we must not forget the social function of AD, as explained by Jiménez for its “ability to activate in the receptors mental images that help them perceive the world [...] as perceived by people who see” (Jiménez, 2007, pg. 56).¹⁶

A Comparative Analysis of Charlie and the Chocolate Factory¹⁷

A comparative analysis has been carried out in order to evaluate the similarities and differences in the approaches towards AD production made by the Scurelle Cooperative Association (CSST) in Trent and Cinema without Barriers in

Milan (CSBM).¹⁸ Audio description it is a kind of translation, as the linguist and literary theorist Roman Jakobson (Jakobson, 1959) sustains. He distinguishes three types of translation: a) Intralingual translation, or rewording (an interpretation of verbal signs by means of other signs in the same language); b) Interlingual translation or translation proper (an interpretation of verbal signs by means of some other language), and c) Intersemiotic translation or transmutation (an interpretation of verbal signs by means of signs of nonverbal sign systems). According to Jakobson's terminology, AD is considered to be a type of intersemiotic translation, because it is "translated" from a visual code to another verbal code, that is to say, from an image into words. Indeed, in the same way that verbal language functions according to certain rules, we might also speak of a grammar of the image.

Technical Issues

Instructions for Audio Describers

CSST begins by providing information regarding the people who performed the AD, first of all by identifying those involved:

"The audio film library for the blind in Italy, a service provided by the Non-profit Without Barriers Cooperative Association, lends out audio films exclusively to blind people and people with impaired vision, who are members of the audio film library, in accordance with the rules and regulations they have signed in acceptance. Duplication and radio broadcasting of any of these films is forbidden. Person in charge of the audio film library: Eraldo Busarello; coordinator for the production of audio films for the blind: Anna Cassol; descriptive texts: Sabrina Rondinelli; audio technician: Alessandro Moranduzzo; audio tests: Nadia Costa and narrator: Claudio Quinzani" (CSST, 1992).¹⁹

The person drafting the AD and the person reading it are not the same. This happens in Spain, the US and in some cases in the UK

(Orero, 2007). The information provided by CSST contrasts with the lack of information on the part of CSBM.

General Recommendations for AD

In the AD, drafted by CSST, there is only one specification: "From now on, the names of the characters and places will be written exactly as they are pronounced by the dubbers" (CSST, 1992)²⁰ probably for the sake of coherence between what is being heard and what the voice artist is reading. By contrast, the AD by CSBM offers some basic recommendations to maintain the tempo in the development. In fact, in their guidelines it says: "Sometimes a touch of pathos is essential; if the film is a thriller the voice must reflect a certain degree of tension" (CSBM, 2005).²¹ Also it says: "Go on reading calmly beginning at 1.00.31," "Read quickly: 'In the factory, 20 years previously, everything is in order and very colorful,'" "Read very quickly, 'The prince is amusing himself with the princess,'" "Read quickly, 'They are clearing the table, which is, after all, their grandparent's bed!,'" "Read slowly with suspense 01.14.10 (by 15.08), 'In the icy-cold, snowy night [...],' "Read quickly: 'Dusseldorf,'" "Read telegraphically, very little space," "Read with suspense 02.11.23," "Say very quickly, after the ha, 'Ha,'" "Say the next bit in a slightly mysterious tone, 'Now, Wonka's secret ... is about to be unfolded.'"

A recommendation linked to time is also included: "after the crack of the torn tin-foil, go on to the next line."²²

Choice of Voice Artists

The guidelines relate to the film genre, tone, etc., but there are no specific comments regarding the voice artist. The voice artist is that of a female in CSBM and of a male in CSST.

Use of Film Language

The CSBM audio describers have adopted, albeit not frequently, a type of cinema language as can be seen in the following examples: "Im-

ages are rolling under the opening credits [...]”, “closing credits.”²³ The OfCom (2002)²⁴ (the acronym for Office of Communications- which substitutes the British Independent Television Commission [ITC]), suggests giving this type of information in the AD. In our case, we see that the CSST audio-description does not avail itself of such language.

However, the decoding of the image may not be all that evident at first glance, as different factors are involved in its construction (think of a static image), even less so if we consider a sequence of images on film. We have to reflect upon the communicative intentions of the director, as well as upon how he performs the task, and at the same time and as a result, whether the viewer is able to decode the information on the one hand and, on the other hand, whether the ideal recipient influences the AD configuration/construction. We have learnt how to write letters to make words and so to read and decode, now we are faced with an image. Reading an audio or visual text means recognizing - in the words of Bettetini (1984) – signs or clues “from the titles, angle shots, camera movements [...] and a distinctly expressive use of color [...]”²⁵ among other things.

When we say that we are conscious of the fact that AD should not include any personal interpretation, this must be as objective as possible. It is therefore even more necessary to learn to read the image, not only for its content but also for the way in which it is presented. Thus it can be vitally important to describe an action, a character or other elements highlighting the movements of the camera (the foreground, a detailed or general plan), or to indicate the narrative time (a flash back or forward). However, one important element that we must not lose sight of is the recipient, in the sense that the audience to whom an AD is directed is a generic audience, not a specialized one, therefore we should not adopt any specific language in this sector, because the message would reach only a privileged few.

CSBM employs expressions referring to the camera movements by means of widely accessible terminology: “*The camera lens*”²⁶ goes down the village streets, *frames* Charlie, [...]”, “the *movie camera goes back* out of the window, it’s snowing outside”²⁷ or “the father *is framed* from the inside of his mouth while his teeth are being explored [...]” (CSBM, 2005).²⁸ These references, as we have just seen, are used not only at the beginning or at the end of the film, but they are present – although they are few and far between – throughout the film. On the other hand, CSST avoids using this specialist type of language. In this regard, Gerzymisch Arbogast (2007) considers it important to audio-describe the “elements of how the camera is turned and positioned and how the pictures are arranged in a sequence of scenes, the recognition of a possible ‘leitmotiv’”. Indeed, from what we have been able to observe, CSBM states on its website that it has occasionally included “more specifically cinematographic data [...] because the description of how a movie camera is used can (if the character is in the foreground, for example) give some idea of the importance the director has decided to attribute to a scene” (CSBM, 2005)²⁹ and, in addition, it gives an idea of the director’s personal concept of film-making.

Beginning of the Film

Remael and Vercauteren (2007) mention the fact that the beginning of a film is where the most basic information is provided regarding the movie and its immediate development. Indeed, the AD produced by CSBM gives a detailed account of the origin of the film, the plot of the storybook from which the film has been adapted, the characters and other data:

“The film *Charlie and the Chocolate Factory* has been adapted from the book of the same title by Roald Dahl, where the author criticizes spoilt, greedy children, addicted to television, and rewards the modesty and benevolence of children who are used to doing without certain things, because they are more aware and respon-

sible. The director of the film is Tim Burton.

The book has already inspired a highly successful film in 1971, with Gene Wilder playing the role of the owner of the candy factory, Mr. Willy Wonka, now interpreted by Johnny Depp. This is the fourth time Depp has worked in collaboration with Tim Burton, after *Edward Scissorhands*, *Ed Wood*, and *The Mystery of Sleepy Hollow*. Playing the part of Charlie, the poor but sensitive child, is Freddie Highmore who has already worked with Depp, while David Kelly (who we remember in *Waking Ned*), plays Grandpa Joe. Other actors and actresses taking part in the film are Helena Bonham Carter (*Howards End*, *Big Fish*) and Christopher Lee, playing the part of Wonka's father. For the leading role, other actors, such as Robin Williams, Nicolas Cage and Michael Keaton had been taken into consideration, but Depp was the final choice... incidentally, he was allergic to chocolate as a child!!!!!!” (CSBM, 2005).³⁰

This information helps us contextualize the story and gain a little insight into the actors, by mentioning previous films interpreted by them, as well as other possible actors that could have played that role in place of Depp.

On the other hand, the AD produced by CSST gives the following description:

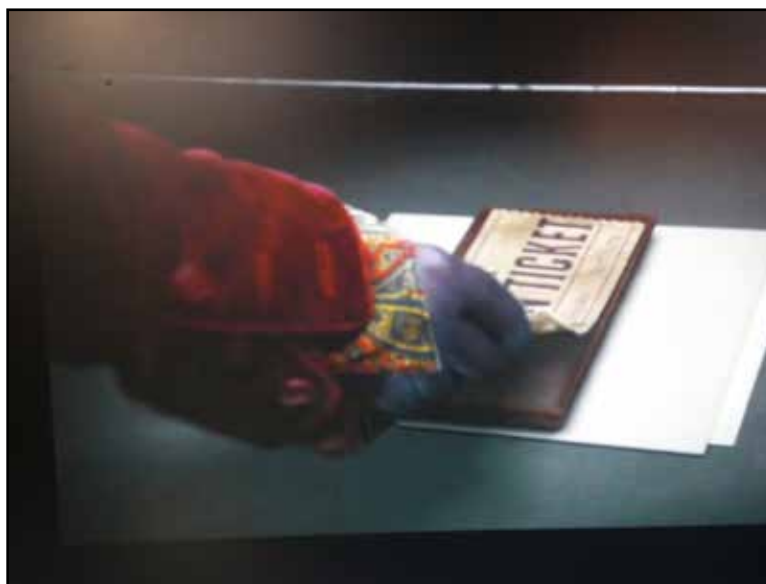
“Warner Bros Pictures presents *Charlie and the Chocolate Factory* starring Johnny Depp, Freddie Highmore, David Kelly, Helena Bonham Carter, Noah Taylor, Missi Pyle, James Fox, Deep Roy, and Christopher Lee. Directed by Tim Burton, Music by Danny Elfman, Produced by: Brad Grey.

Adapted from the novel: *Charlie and the Chocolate Factory* by Roald Dahl. Year of production is 2005” (CSST, 1992).³¹

The question is whether or not it is strictly essential to provide detailed information on the actors in the film.

Interpretative Level

The description of the images on the screen contains elements that are closely linked to the audio-describer's personal interpretation, as we shall see below. An example can be found in the description of the hand placing the golden ticket inside the bar of chocolate. CSST announces: “But before the wrapping paper is sealed, a mysterious purple-gloved hand lays a special golden ticket on 5 chocolate bars” (CSST, 1992)³²; whereas the description provided by CSBM runs as follows: “The tin foil is laid on the bars, in a whirl of flying lights and bars, until workers' hands place 5 golden tickets on 5 chocolate bars, before these are wrapped” (CSBM, 2005).³³



The CSST production, which describes this hand as “mysterious”, fires the listener's imagination, whereas that of CSBM speaks of “workers' hands”, thus offering an interpretation that does not correspond to the image on the screen, as can be seen in the photo.

Another example can be found in Wonka's childhood recollection of the night of Halloween: CSST states that: "He had gone to knock on the door of a nice lady," (CSST, 1992)³⁴ whereas for CSBM the lady is "fat." Both adjectives are applicable to the same person, but by using only one of them, instead of both, the information given is not objective. The first adjective refers to her character, whereas the second refers to her physical appearance.



Another instance of subjectivity is when Wonka "is applauded by his workers" (CSBM).³⁵ In actual fact, the spectator is unable to infer this from the images. CSST, on the other hand, states that "the crowd [...] had applauded him joyfully" (CSST, 1992),³⁶ given that we have no way of knowing whether these are his own workers.

There are many more examples, all of which would seem to confirm that both ADs present both subjective and objective elements in their description of certain images.



Conclusion

We are faced with two different products destined for the same audience. Taking into account that the *raison d'être* of any AD is to make a socio-cultural product accessible, if there is a common interest, this does not explain why the same film is duplicated, when there are so many products to be audio described (and here we refer not only to programs broadcast on television, but also cinema, theatre and museum products, as well as all the information available on the web). From a perspective of integration, AD still has a long way to go.

On the other hand, and with specific reference to the aspects analysed in both ADs, the AD produced by CSST appears to be more synthetic and synchronic in certain points, while the CSBM production is more closely packed and informative. This may at times have the effect of tiring the listener. Therefore greater care in the description of the images is of the essence. Furthermore, the provision of a document specifying the procedures employed would be invaluable.

In conclusion, my intent was to conduct a field study in order to open a perspective that

will lead us, with results from other studies, to the elaboration of guidelines that, at least in Italy, may be used throughout the country, at the same time creating uniform and consistent products. Given, as proposed by the EU and the UN, that media accessibility should always be a quality service, permanently available for all facilities, including the Internet, it would be recommended to avoid duplication.

The cost of accessibility is high, but minimal in comparison with the production of a film. If accessibility policies were adopted and perfected, the effect would be more impressive and the social impact more visible. We should learn from existing practices, in order to optimize and extend media accessibility to the category of public service. In this way, it would cease to be an anecdote relegated to small and closed circles. This is all the more surprising, given the many and wide-ranging possibilities of digital encoding, transmission and broadcasting.³⁶

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Endnotes

¹ Permanent Inter-ministerial Commission for the Use of ICT technologies for the Disadvantaged Social Categories (2003) *Tecnologie per la disabilità: una società senza esclusi*, [Technologies for the Disabled: a Society without Exclusions], http://www.cnipa.gov.it/site/_files/Libro_Bianco.pdf [Last access date: 15th September 2010]: “opportunità di conoscenza, istruzione e lavoro”. [The translations have been contributed by prof. M.C. Cignatta, Dept. of Foreign Languages, University of Parma.]

² *Ibidem*. Original text: “rimozione di [...] barriere virtuali”.

³ The Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993 (RUL 5 Accessibility) (<http://www.un.org/esa/socdev/enable/dissre00.htm>). [Last access date: 20th September 2010]

⁴ http://www.innovazione.gov.it/ita/documenti/socinfo11_06_02.pdf, p.28. Despite this, as is clearly explained on the website, if we consider that the Minister for Public Affairs pro tempore in 2001 had already despatched a communication on this issue, namely the “*Linee guida per l'organizzazione, l'usabilità e l'accessibilità dei siti web delle pubbliche amministrazioni*” [“Guidelines for the organisation, usability and accessibility of public administration websites”], the reason for the delay is incomprehensible. [Original text: “le barriere digitali che limitano o impediscono l'accesso agli strumenti della società dell'informazione da parte dei disabili”].

⁵ <http://eur-lex.europa.eu> [last access date: 2nd November 2010] [Translation: “la Unión reconoce y respeta el derecho de las personas discapacitadas a beneficiarse de medidas que garanticen su autonomía, su integración social y profesional y su participación en la vida de la comunidad”].

⁶ www.rai.it/.../5B1254996210634%5Dcontratto_servizio_5_aprile_2007.pdf and <http://banchedati.camera.it/> [Last access date: 22nd October 2010]. [Original text: “l'accesso alla propria offerta multimediale e televisiva alle persone con disabilità sensoriali o cognitive anche tramite specifiche programmazioni audiodescritte e trasmissioni in modalità telesoftware per le persone non vedenti, e sottotitolate con speciali pagine del Televideo in grado di essere registrate su supporti VCR e DVD e del proprio portale internet e mediante la

traduzione della lingua dei segni (LIS) ”]

⁷ *Ibidem*. [Original text: “obblighi relativi alla accessibilità dei disabili sensoriali alla programmazione radiotelevisiva, all'informazione sul sociale e i diritti umani di cui al citato articolo 8. (Interrogazione 4-03793 scritta pubblicata 3/3/2010) ”]

⁸ www.senzabarriere.org [Last access date: 20th September 2010]. [Original text: “sviluppare e produrre supporti editoriali multimediali accessibili a tutti”]

⁹ www.mostrainvideo.com subsidised by the Province of Milan and by a banking foundation [Last access date: 18th September 2010]

¹⁰ www.museonazionaledelcinema.it [Last access date: 15th September 2010]. Original text: “modello di accessibilità allargata”.

¹¹ Achieved with the help of the Piedmont Regional Authorities, the city of Turin and the CRT (Cassa di Risparmio di Torino) Foundation. Original text: “Beyond Vision: a Museum to touch, a Cinema to listen to”.

¹² <http://Blindsight.eu>, which also collaborates with other AD associations for the theatre and opera, like ‘ISIVIÙ’ in Messina and “Sferisterio opera festival” in Macerata (since 2009). [Last access date: 23rd September 2010]

¹³ <http://www.culturabile.com>. [Last access date: 23rd September 2010]

¹⁴ Original text: “mantenere propri spazi di ‘immaginazione’ [...] “descrivere quello che c'è; non dare una versione personale di quel che si vede; non parlare mai sopra il dialogo o il commento già esistente nel film; [indica] quando-dove-chi-cosa”.

¹⁵ Original text: “una voce descrive le scene prive di dialogo”.

¹⁶ Original text: “capacidad de activar en los receptores imágenes mentales que les ayuden a percibir el mundo [...] como lo perciben las personas que ven”.

¹⁷ We owe a debt of gratitude to the Scurelle Cooperative Association in Trent and to Cinema without Barriers in Milan for providing us with the AD script we have worked on for this research.

¹⁸ This research is limited to the analysis of a few aspects of one particular AD, for which reason the conclusions

drawn will not be applicable in general, but will be strictly relevant to this work.

¹⁹ Scurelle Cooperative Association, personal communication, 2010. Original text: “La Cineteca audio per i ciechi italiani, attività senza fini di lucro della Cooperativa Sociale Senza Barriere onlus è un servizio di prestito di audiofilms ad uso esclusivo dei ciechi e degli ipovedenti che hanno aderito alla Cineteca audio, nel rispetto del regolamento sottoscritto. Vietata la duplicazione e la radiodiffusione. responsabile della cineteca audio: Eraldo Busarello, coordinamento alla realizzazione audio per i ciechi: Anna Cassol, testi descrittivi: Sabrina Rondinelli, tecnico audio: Alessandro Moranduzzo, test audio: Nadia Costa e voce narrante: Claudio Quinzani”.

²⁰ Scurelle Cooperative Association, personal communication, 2010. Original text: “da questo momento in poi i nomi dei personaggi e dei luoghi vengono scritti come pronunciati dai doppiatori”.

²¹ Cinema without Barriers, personal communication, 2010. Original text: “a volte un po’ di pathos è necessario, se il film è un thriller la voce deve riflettere un certo livello di tensione”.

²² Cinema without Barriers, personal communication, 2010. Original text: “Leggere con calma costante iniziare a 1.00.31”, “leggerla veloce: Nella fabbrica, vent’anni prima, tutto è ordinato, coloratissimo”, “leggere molto veloce: il principe si intrattiene con la principessa”, “leggere veloce: Sparecchiano la tavola , che poi è il letto dei nonni!”, “leggere piano con Suspence 01.14.10 (entro il 15.08) Nella gelida notte nevosa[...]”, “leggere veloce: Dusseldorf”, “lettura telegrafica, pochissimo spazio”, “leggere con suspence 02.11.23”, “dirlo rapido dopo che si sentono gli ha/ha”. Il prossimo pezzetto dirlo con un po’ di mistero: Ecco, il segreto di Wonka...comincia a svelarsi”.

²³ Cinema without Barriers, personal communication, 2010. Original text: “Sotto i titoli di testa scorrono immagini [...]”, “titoli di coda”.

²⁴ www.ofcom.org.uk, the Code on Television Access Services (<http://www.ofcom.org.uk/tv/ifi/codes/ctas/#content>). That is government body regulating the telecommunications industries; a super-regulator merging the Radio Authority, Independent Television Commission, and OfTel.

²⁵ Original text: “dalle titolazioni, dalle angolazioni delle inquadrature, dai movimenti della camera [...] da un uso marcatamente espressivo del colore [...]”.

²⁶ The italics are our own.

²⁷ Cinema without Barriers, personal communication, 2010. Original text: “l’obiettivo della telecamera scende verso le strade del paese, inquadra Charlie [...]”, “La cinepresa indietreggia uscendo dalla finestra, fuori nevicata”.

²⁸ Cinema without Barriers, personal communication, 2010. Original text: “il padre è inquadrato dall’interno della bocca mentre esplora i denti [...]”.

²⁹ Cinema without Barriers, personal communication, 2010. Original text: “dati più squisitamente “cinematografici” [...] perché descrivere il tipo di uso della macchina da presa può (se il personaggio è in primo piano per esempio) dare un’idea dell’importanza che il regista ha voluto dare ad una scena”.

³⁰ Cinema without Barriers, personal communication, 2010. Original text: “Il film La fabbrica di cioccolato è tratto dall’omonimo libro di Roald Dahl, un libro in cui l’autore se la prende con i bambini viziati, ingordi, teledipendenti, e premia la modestia e la bontà di quelli che sono abituati alla rinuncia, perché più consapevoli. La regia è di Tim Burton. Dal libro era stato già tratto nel 1971 un film di successo, con Gene Wilder nei panni del padrone della favolosa fabbrica, il signor Willy Wonka, che qui è interpretato da Johnny Depp, alla quarta collaborazione con Burton, dopo “Edward mani di forbice”, “Ed Wood” e “Il mistero di Sleepy Hollow”. Nei panni di Charlie, il bambino povero e sensibile protagonista, troviamo Freddie Highmore che ha già lavorato con Depp, mentre in quelli di nonno Joe c’è David Kelly (lo ricordiamo in “Svegliati Ned”). Al film partecipano anche Helena Bonham Carter (che ha fatto Casa Howard, Big fish), Christopher Lee, che interpreta il papà di Wonka. Per il ruolo principale si era pensato ad altri attori, quali Robin Williams, Nicolas Cage, Michael Keaton, poi è stato scelto Depp, e pensare che da bambino era allergico alla cioccolata !!!!”.

³¹ Scurelle Cooperative Association, personal communication, 2010. Original text: “La warner bros pictures presenta la fabbrica di cioccolato con Johnny Depp, Freddie Highmore, David Kelly, Helena Bonham Carter, Noah Taylor, Missi Pyle, James Fox, Deep Roy, Christopher Lee. Regia di Tim Burton, Musiche di Danny Elfman, Produttore: Brad Grey. Tratto dal romanzo: “La fabbrica di cioccolato” di Roald Dahl. Anno di produzione 2005”.

³² Translation: “ma prima che l’involucro venga chiuso, una misteriosa mano inguantata di viola, adagia su

cinque tavolette uno speciale biglietto d'oro”

³³ Translation: “si mette la stagnola sulle tavolette, una fantasia di luci e tavolette che volano, fino a che delle mani di operai inseriscono 5 biglietti d'oro, su altrettante tavolette, prima che vengano chiuse”.

³⁴ Translation: “era andato a bussare alla porta di una simpatica signora”he had gone to knock on the door of a nice lady”.

³⁵ Translation: “viene applaudito dai suoi operai”.

³⁶ Translation: “la folla [...] l'aveva applaudito con gioia”.

Trends Toward the Integration and Inclusion of Students with Disabilities in Russia

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&

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Research Articles

Abstract: During the past 20 years, the Russian government and culture at large has increased its awareness of integrative and inclusive educational practices for children with disabilities. However, educational reformers cite the need for the implementation of these practices on public school campuses. In response to the dearth of legislative action in implementing integrative and inclusive practices, parents of children with disabilities, in conjunction with community organizations, have become strong advocates for the rights of their children to attend integrated and inclusive school settings. This paper presents the current changes in Russia's education system for students with disabilities as the country moves toward integrative and inclusive practices.

Keywords: inclusive education, international education, Russia

Across Russia, consensus exists that education should be available to all children, including students with disabilities (Malofeev, 1998). In many countries around the world, the term integration can be defined as (1) allowing a student to attend an educational institution or (2) removing a student from a segregated school site and educating that child in a general education school. Even more progressive is the term inclusion which means that students with disabilities are to be educated in the same classroom at the same school site as their peers without disabilities.

Law makers, educators, and families in Russia are grappling with the development of prac-

tices and policies that ensure children with disabilities have rich social experiences with peers while making sure their educational needs are met. In response to this concern, Russia instituted significant changes in educational programs in the past 20 years that include the following: (1) the development of opportunities for integration in the schools (students with disabilities can attend public schools in separate classrooms), (2) academic and instructional support for all students, and (3) research and experimentation regarding best practices in schools and universities to train teachers on how to improve educational opportunities for students with disabilities (Godvonikova, 2009; Morova, 2012).

A Review of Russian Special Education Practices

The current special education system in Russia can be defined as a large, overarching system and not specific, localized systems as present in US education. This lack of provincial input and control creates difficulties in implementing special education services. During the 1980s, this system undermined the creation of individualized supports for students with disabilities and underfunded special education services (Kordunov, Nigayev, Reynolds, & Lerner, 1988). Furthermore, children with special needs were traditionally placed in specialized, segregated settings, often in cities far away from family members. State budgets paid for these institutions which eliminated the financial stress for families (Kordunov et al., 1988). Into the 1990s and 21st Century, inclusive processes continued

to adhere to the rigid teaching conditions of Russian regular schools where the methodology of Soviet psychology and defectology (abnormal development) were followed (Nazarova, 2011).

Russian educators understand that some students with disabilities (e.g., speech disorders, hearing, vision, or musculoskeletal system disorders, intellectual disabilities) need differentiated instruction (Lesnevskiy & Miyakawa, 2009). However, there are varied opinions as to how services should be received. For example, Lesnevskiy and Miyakawa (2009) conceptualized educational placement as: (1) occurring in specialized and segregated settings, (2) in integrated settings where groups of children with disabilities learn in specialized classrooms that are placed on public school campuses (not in segregated school sites), or (3) individualized instruction that occurs at home and through distance technologies.

The segregation of students with disabilities is well documented throughout Russian history (Godovnikova, 2009; Iarskaia-Smirnova & Loshakova, 2004). Political directives indicate that as far back as 1806, the state supported a school for the deaf that existed in St. Petersburg. Due to public unrest in the early 1900s, the states could not provide the institutional financial support for students with special needs, resulting in hardships on families. By 1936, an escalating number of special schools were built to house children viewed as having special needs. Although a universal compulsory education edict was enacted in 1943 to service all students, students with special needs often did not attend school due to overcrowding (Malofeev, 1998).

Grigorenko (1998) highlighted the cultural shift of assisting students with disabilities that occurred in the 1930s. Pejorative terms such as “defectology” were coined to describe individuals with disabilities in Russia. *Hulfshules* or *help schools* were among the early attempts to educate children with disabilities. Originally, only children who were blind, deaf or had an intellectual

disability could attend segregated schools. In time, students with severe learning difficulties requiring specialized training were allowed to attend school. As a native Russian, and prominent psychologist, Lev Vygotsky established an institute to study the development of children with disabilities. Vygotsky along with his colleagues developed overarching theories guided by the following principles: a) a focus on prevention and rehabilitation, b) expansion of services for students with “mild” disabilities, c) the development of specific strategies for students with disabilities, and d) implementation of the zone of proximal development (i.e., difference between what a learner can do without help or what he/she can do with help). Vygotsky’s diagnostic and therapeutic efforts span 70 years of intervention and investigation (Grigorenko, 1998).

While Vygotsky contributed significantly to instructional practices for all learners, Russian educators and policy makers are still attempting to understand the best fit for these instructional theories. Russians who advocate for inclusive practices define them as the “process, result and condition when invalids [a term for individuals with severe disabilities] and other individuals with disabilities are not socially desegregated or isolated but participate in all spheres and forms of social life together (equally) with others” (Nazarova, 1984, as cited in Oreshkina, 2009, p. 262). Russian researchers Iarskai-Smirnova and Loshakova (2004) provide a broader definition of inclusive practices as educational strategies that meet the wants and needs of all children including those with disabilities. When compared to segregated school settings, they argue that inclusive schools foster children’s fullest participation in school and community life (Iarskai-Smirnova & Loshakova, 2004). Although the typical educational practice for students with disabilities in Russia is segregation (i.e., separate schools), several inclusive opportunities do exist for students to attend general education schools; however, they would be placed in separate classes. These opportunities are mainly found in primary educational settings. In fact, educators

in Russia created Project Inclusive Education Week in 2010, where they come together annually with the idea of incorporating inclusive practices throughout the country (Nazarova, 2011). Individuals with disabilities also participate in this event as advocates for changing policies and stigmas.

The emergence of these practices in education provides an opportunity for a major evolutionary leap in the development and understanding of inclusion as a real possibility for children with disabilities. However, researchers and educators express serious concerns about the validity of this trend (Zhavoronkov, 2011). For example, one concern is that Russia's move towards integrative approaches in special education is the result of Western influence and may not be applicable for Eastern European society (Alehina, 2012b). Furthermore, without the necessary legal, economic and social support, progressive inclusionary ideas and attempts may not procure the equality of educational rights and opportunities for students with disabilities.

Education for Children with Disabilities in Russia

Educational opportunities for Russian students with disabilities continue to evolve. In February of 2012, the Russian Federation adopted legislation to amend the Federal Law called *On Education* (2010). A student with a disability was now defined as a learner who had the physical characteristics and/or mental development that complicated or impeded the child's education (Alehina, 2012b). The federal education law included language that promoted inclusive education, where students with special education needs were taught in classrooms with children without disabilities. However, the current law failed to mandate teacher training to meet the needs of those children.

Although these amendments appear to indicate progression toward the full inclusion of students with disabilities being placed in general

education classrooms (not just schools), Russian proponents of inclusion continue to be discouraged by the lack of government support in providing resources for successful implementation. Furthermore, many Russian citizens do not feel the integration of students with disabilities with their non-disabled peers is appropriate (Iarskai-Smirnova & Loshakova, 2004). Although efforts to implement integration of students with disabilities on typical campuses occurred during the 1990s in Moscow and St. Petersburg (Alehina, 2012b), the systematic implementation of integrated education in Russia as mandated by legislation has yet to happen (Godovnikova, 2009; Korkunov, Nigayev, Reynolds, & Lerner, 1998; Nazarova, 2011). Parent and social organizations are most often responsible for promoting inclusionary initiatives and ideas in Russia, and as a result, most changes in educational policies have occurred in the last three years.

Beliefs on Inclusive Education

What are stakeholders' views on inclusion and integration and who has been involved in the education system reforms for the past 10 years in Russia? While stakeholders believe that inclusive education is the best way to educate children with disabilities, a broader viewpoint may have a greater impact on the implementation of inclusion (Iarskai-Smirnova & Loshakova, 2004). Examining the social relationships between traditional education and students with disabilities may provide a new lens in which to encourage active inclusion. By first changing the perceptions about children with disabilities, barriers to integration may be more easily overcome so that rich and diverse learning environments for all children can be created (Korkunov, Nigayev, Reynolds, & Lerner, 1998). Implementation of inclusive approaches must challenge the beliefs of general education teachers and address the issues of social justice for all children to fully participate in society.

Several trends are slowly developing as perceptions about disability are changing. The Rus-

sian people are slowly becoming more open in their beliefs of inclusive education and the number of segregated schools is declining as students with disabilities are starting to become “absorbed” into general education schools (Nazarova, 2011). In order for these changes to be successful and maintained, partnerships and support among all educational stakeholders need to be developed (Logomag, 2012).

Although Russian culture is making attitudinal gains towards inclusion, the cultural belief that people with disabilities are not equal creates extreme challenges for people with disabilities. Current debates in Russia surrounding inclusive education highlights the following issues: (a) Is inclusion necessary or even possible in Russia? (b) Will inclusion be beneficial for children and schools? (c) What new problems will inclusion create? Proponents of segregated schools fear that inclusion will destroy a system that is specialized, functional, and supported by educators familiar with disabilities. Some argue that this fear is a result of the emphasis on academic outcomes rather than valuing the development of academics combined with social and functional achievement that cannot be addressed as thoroughly as in a segregated setting (Alehina, 2012b).

One examination of inclusive practices in Russia surrounds a prolonged pilot project by Dr. Alehina (the fifth author) to assess the educational environment and its readiness in meeting the individual needs of students with disabilities. The investigation assessed the quality of inclusive practices and professional development for teachers with respect to all children with and without disabilities. The pilot project concluded that each school was in one of three stages: (1) beginning integrative practices (allowing students with disabilities to attend general education institutions in special classes), (2) preparation to begin to train the management of the school to consider adopting inclusive practices, or (3) unprepared to accept students with disabilities at this time.

Current Developments in Integration

As legislative practices and cultural practices changed, some progress toward integration of students with disabilities on general education campuses was made. One such example is the closure of approximately 50 segregated schools for students with disabilities in 2011 (Alehina, 2012a). It was expected that students who attended these segregated schools were to enroll in classes on a general education campus. While Russian policy makers focused on reducing the number of children in special education, it should be noted that they had conversely focused on preserving the system of separate educational institutions. With specialized segregated schools being closed and students with disabilities being absorbed into integrated settings, transformation of special education services is necessary. A new model requires collaboration and organization between general and specialized segregated institutions in order to ensure efficient and quality instruction for children with disabilities in integrated and inclusive settings.

In response to the growing integrative and inclusive philosophy spreading across Russia, a multilevel system of coordinated interdisciplinary institutions was created to support integrated services. In some regions of the Russian Federation such as the Chuvash Republic, Pskov, and Kaliningrad Oblast, these special education institutions known as resource centers aimed to develop inclusive processes and offer psychological and educational support for children with learning disabilities in secondary schools. The major purpose of a resource center was to create a common educational space where various types of educational institutions could network and provide additional remedial developmental assistance with a focus on students with hearing, vision, and intellectual disabilities.

The backbone of this multilevel resource center system was an inclusive education venue created in 1992. By 1998, 720 of these resource centers were developed to focus on the complex

psychological needs of students with disabilities, provide medical and social assistance, and assist in rehabilitation support for children with disabilities (Alehina, 2012a). The organizational model of the resource center is for the school psychologist, speech therapist, social workers and teachers to support students with disabilities using a consultative approach.

Another key component alongside the resource centers in fostering integrated education is the growing focus on early intervention. A structural unit was created that focused on Early Intervention Services for pre-school children ages 2 months to 4 years who were identified as at-risk for developmental disorders and in need of psychological, educational, medical and social assistance. The Early Intervention Services unit was created to teach young children compensatory strategies for coping with their disabilities (Alehina, 2012b).

There are currently over two million reported children with disabilities in Russia and the figure increases annually (Alehina, 2012a; Roza, 2005). Noteworthy, in 1995, there were 453,000 reported children with disabilities; in 2006, the number of reported children with disabilities was almost 700,000 children. However, disability related factors inhibit exact reporting of the incidence of disability. For example, about 90,000 children have physical disabilities, which limit their movement and potentially their access to educational services. As a result, this group may not be accurately represented in the statistics and one may surmise the incidence of physical impairments is higher than reported. In 2012, the Ministry of Education and Science of the Russian Federation developed a four-year plan that would allow 20% of children with disabilities to enroll in general education classroom. The goal is that by the year 2015, 10,000 educational institutions would allow unimpeded access to education services for children with disabilities (Alehina, 2012a).

Information on current inclusive practices reports that state educational institutions enroll more than 142,000 children with disabilities in regular education classes. Additionally, 132,000 children attend school in special classes for remediation in comprehensive schools. More than 44,000 children receive their education at home. Approximately 35,000 children receive no education, which includes 17,000 children who receive no education for health related reasons. Close to 29,000 children with intellectual disabilities remain virtually isolated from society residing in orphanages and boarding schools operated by the social system. In addition, 164,000 students in special schools are still forced to study in residential accommodations and they receive no training opportunities close to where they live (Alehina, 2012b). Thus, Russian education policymakers still have much work to be done regarding the inclusion of children and adolescents with disabilities.

Current Education Policy in Russia

Within the past decade, Russia has witnessed legislative gains on inclusive education practices, yet struggles with implementing policies. On September 24, 2008, Russia signed the Convention on the Rights of Persons with Disabilities and thus committed to the implementation of Article 24 Education. The article notes the right to education without discrimination on the basis of equal opportunity and states that all stakeholders shall ensure an inclusive education system at all levels (Alehina, 2012a). Duma Dmitry Medvedev made the ratification of the Convention on the Rights of Persons with Disabilities at the State level, and, following this ratification, inclusive education in the Russian Federation should be instituted in law to include all the necessary components needed to make inclusion of students with disabilities a reality. This includes determination of funding mechanisms, creation of the necessary conditions for successful special education services in general education classrooms and schools, and defined principles for adapting the educational

environments for children with special education needs. Although the educational policy of the state has focused on the development of inclusive processes since 2008, the widespread implementation of this policy is still undetermined (Godovnikova, 2009).

Another federal development is the 2011-2015 Federal Program of Education Development which focuses on the proportion of children with learning disabilities and other types of mild/moderate disabilities. It is important to note that the term learning disabled is not distinguishable as one of the eight unique classifications of disabilities. Students in this category may be considered “*temporary delayed in mental development*” as opposed to the term learning disability prominently used in the US (Orenskina, 2009). The aim of this program is to determine how high-quality general education practices will be obtained for this population. In response to the anticipated increase of children with disabilities from 30% to 71% by 2015 (<http://www.fcpro.ru/>), Russia has made a commitment of 287.7 million rubles in order to create successful socialization conditions for children with disabilities in educational institutions.

The 2011-2015 Accessible Environment report (<http://fcp.economy.gov.ru/cgi-bin/cis/fcp.cgi/Fcp/ViewFcp/View/2011/392>) predicts that by 2016, the proportion of educational institutions that have an inclusive environment for children with learning disabilities in Russia will be at least 20%. Federal funds for program activities and the development of integrated education for children with disabilities will be more than 9 billion rubles during 2011-2015. The new federal education standards of primary and elementary school students take into account the unique development of students with learning disabilities through the creation of individual training curriculum and programs that offer psycho-pedagogical support (http://www.educom.ru/en/The_Regulations).

Another legislative mandate, the National Educational Initiative called Our New School, created an expectation that each school must include all children (http://www.educom.ru/en/our_new_school_quot/). This mandate defined each school as providing opportunities for the successful socialization of children with disabilities. In accordance with the *Comprehensive Plan Development and Implementation of Modern Models of Education 2020*, the proportion of non-specialized educational institutions that create conditions for educating children with disabilities should reach 70% by 2016, and the proportion of children with learning disabilities who receive educational services in non-segregated institutions should also reach 70% by 2020.

In May 2012 the newly drafted law, *Education*, was presented to President Putin and the Russian Parliament. The intent was that this legal document would explicitly define the concept of inclusive education and help determine a list of special educational environments for teaching children with learning disabilities in the regular school. Furthermore, a unique piece of legislation was introduced in 2010 that addressed the actual training of children with disabilities. The Moscow *Law on Education of Persons with Disabilities* (2010) that established the *Inclusive Education, a Joint Educational Training* provided explicit training instructions for educating all children, including those with disabilities. The training targeted leisure activities, academic skills, and behavioral interventions.

While legislative progress toward integration is being made, the actual implementation may be extremely slow and dissimilar depending on the region of Russia (Korkunov, Nigayev, Reynolds, & Lerner, 1998; Godovnikova, 2009). In some regions such as Moscow, Samara, and Arkhangelsk, these processes are well advanced in their development and, in other regions, inclusive education practices are starting to emerge. In many Russian regions such as Karelia, Komi Republic, Perm, Arkhangelsk Oblast, Samara Oblast, and

Tomsk, veteran teachers continue to learn recommendations to make education more inclusive (Alehina, 2012a). Unfortunately, this practice was only developed as a pilot project without established regulatory and financial support. The state sponsored financing for inclusion has been sporadic and inconsistent. However, a new cultural perception is emerging that consists of viewing individuals with disabilities as acceptable members of society. Currently, 15 percent of adults with disabilities are employed. While most of these positions are menial jobs, they are typically permanent (Khudorendo, 2011). The Moscow N.E. Bauman State Technical University boasts a 100% job placement rate for graduates with hearing impairments. Education for students with disabilities is increasingly seen as a basic human right. Article 43 of the Constitution of Russian Federation mirrors the U.S. policy of a Free and Appropriate Education. While both initiatives are alike in language, they differ in implementation, teacher training and professional development (Khudorendo, 2011).

The Impact of Resources on Integration

The fiscal impact of inclusion is one of the most pressing issues impacting implementation of these practices. According to experts in the field of education and in light of Russia's current financial circumstances, it is premature to talk about the full implementation of inclusive education (Lesnevskiy & Miyakawa, 2009). The country's economic circumstances make the follow-through of legislative mandates difficult. The yearly per capita income of Russia's population is approximately \$16,700. The percentage of the population living below the poverty line, whose incomes do not reach the subsistence level has risen to 12.8% (according to preliminary estimates for 2011). At this low level of economic stability and security, some argue that focusing on European or American standards of social processes is extremely naive.

Moving Toward Implementation of Integrative and Inclusive Practices

The most important task in the development of integrative and inclusive education is to prepare the administrators and educators of traditional schooling institutions. It is imperative that teachers and education specialists receive training on research-based best practices in integrative and inclusive education. The Federal State Educational Standard of Higher Professional Education plans to address this need by training 50,400 teachers in psychological and pedagogical instruction to support children with disabilities in general education (Alehina, 2012b). This is the first time in the history of higher education that this will occur in Russia. Currently, teachers who want to teach with children with disabilities can obtain a bachelor's degree or receive specialty training followed by a master's degree that takes about two years. A team of universities that is working on this standard have developed a working session called "Psychology and Pedagogy of Special and Inclusive Education" as part of the training. The main objective is the development and review of basic educational programs, textbooks, and manuals for training in the field of inclusive education (Alehina, 2012a).

Given the fact that the preparation of students who wish to earn a bachelor's and/or master's degree in the field of inclusive education has just begun, Russia has embarked on a large scale task to not only prepare future teachers in inclusive practices, but also to reform the entire school system. The goal is to increase the number of training hours required to teach or be an administrator in an inclusive educational institution. The Moscow Pedagogical University offers licensed programs (e.g., school administrators, coordinators for the development of inclusive education, professional support and psycho-medical-pedagogical commissions and consultation) for the different disability categories of students.

As part of the State program *Accessible Environment* (2011-2015), the next three years will be used to plan and train more than 10,000 inclusive educational institution employees on theory and practice in educating children with disabilities. During the years prior to 2015, it is anticipated that 24,000 trained professionals will comprise 27% of the average annual number of teaching staff working in classrooms for children with disabilities (Alehina, 2012a).

Overall Concerns on Integration and Inclusion in Russia

There are many concerns and limitations regarding integrative and inclusive education in Russia (Alehina, 2012a):

1. Inclusive education is just beginning to be regulated by legal documentation. However, there is no mechanism for funding and implementing special education learning environments for children in general education schools. A working group of Russian educators prepared the *Inclusive Education* Project for the New Russian Law on Education. This project included a developed draft of federal and state educational standards for children with disabilities, and these standards are considered an integral part of the federal government standards for general education. From a regional perspective, the characteristics and traditions belong to Russia. The country as a whole holds the greater power to establish a systematic and comprehensive legal framework of inclusive education. However, in several regions of Russia, a number of localized laws, statutes, regulations, and instructions have been adopted that propose to define the procedures and mechanisms for the implementation of inclusive education.
2. There are insufficient materials and

technology to support inclusion in general education schools. Special equipment is extremely limited. The subsidies to schools for the development and support of the students with disabilities are not enough to support inclusive education. The preparation of educational institutions and the implementation of inclusive education for children with learning disabilities involve significant additional costs to improve the curriculum, increase teacher salaries, and support professional development opportunities for teachers and staff.

3. There is a lack of specialized expertise (e.g., speech therapists, psychologists, pathologists, physical therapy specialists) to support inclusive education.
4. General educators are professionally and psychologically unprepared to work with children with learning disabilities. Reasons for this include lack of knowledge of interventions and research-based teaching strategies, insufficient time for course preparation, professional insecurity, fear, and an overall lack of experience working with children with disabilities. Thus, professional development must be implemented for all teachers who will work with children and adolescents with disabilities.
5. There is an inadequate supply of textbooks, supplementary materials, and intervention programs for children with learning disabilities. Effective and adequate inclusion requires the development of individualized curriculum based on state standards that include organizational and methodological support.
6. In Russian society, there are socio-cultural and psychological constraints towards people with disabilities as held by the general population. Due to culture,

tradition, and an initial poor perception of people with disabilities, the common belief was that children with disabilities should be taught in segregated campuses separated from society (Godovnikova, 2009).

7. People with disabilities have fewer opportunities for professional education and the labor market; they have difficulty finding employment when they finish school.

Conclusion

Russian educators and families of children and adolescents with disabilities agree that integrating students with disabilities is the best method of educating children. Students with disabilities should be allowed to attend general education schools even if they are placed in special classrooms rather than being placed in segregated schools. It is hoped that the growing knowledge of research-based instructional strategies for children with disabilities, the recent wave of legislative support, the collaboration of experts in resource centers, and the increasing tolerance of Russian society for people with disabilities can contribute to sustained and successful implementation of integrated practices. Although there are many limitations and concerns, Russia has begun building the infrastructure for integrative and inclusive education for all learners.

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Lucky to Be Here

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Creative Works

Lucky to Be Here

My daughter tells me I am lucky to be here
instead of in her five-bedroom home,
with space for another child

but not a grandmother in a wheelchair.

I am lucky to be here.

My room yellow as the sun,

which warms my face.

On the porch I endure
people

age and abandonment.

I am lucky to be here,
the best nursing home,

instead of where I would be
if people knew
what killed my unfaithful husband.

Book Review

Title: *The Book of Goodbyes: Poems*

Author: Jillian Weise

Publication Date: Rochester, NY, BOA Editions, Ltd., 2013

Softcover: \$16.00

ISBN: 1938160142, 74 pages

Reviewer: Johnson Cheu, PhD, Michigan State University

Poetry, at least in terms of mainstream America, has continuously had one charge leveled against it: “it’s not accessible enough” – not plainspoken enough – hence, in part, the overwhelming popularity of former U.S. Poet Laureates Ted Kooser (*Delights and Shadows*, 2004) or Billy Collins (*Aimless Love*, 2013). Disability, too, has long heralded a rallying cry of accessibility, from the move toward universal design and still-fought battles over accessible public transportation and housing. It’s unfair, perhaps, to critique Jillian Weise’s new book *The Book of Goodbyes* in terms of such a mantra, for, as my students often ask, “Who reads poetry anyway?” Even my local bookstore (the non-corporate one) has given up (sadly) having a poetry section altogether, that one tiny stand-alone bookcase given away to “things people will actually buy.”

Still, the reality is that, for poetry, Weise has hit the (relative) big time: *The Book of Goodbyes* being published by the well-known small press BOA, and also having won the Isabella Gardner Award for Poetry for 2013, “given to a poet in mid-career with a new book of exceptional merit.” (74). Given those particulars, it is relatively safe to assume that people, both disabled, and nondisabled readers of poetry, will pick this book up. Whether they will be expecting something along the lines of Billy Collins or someone who is so-called “accessible,” or not, is anyone’s guess, but what they will not get is a poet or poetry that is easy.

What is wonderful about Weise’s new book is her undaunting fearlessness. In the poem “Café Loop” she takes on critics who discuss her work (and her) as, in essence, not being disabled enough. She writes, “She actually is very/dishonest...Limps a little. I mean not/really noticeable....How can she write/like she’s writing for the whole group? It’s kind of disgusting./It’s kind of offensive...I heard she’s not that smart.” (l. 13-20, 32 pp. 15-16). What is tough here is that she does not defend herself or directly admonish these speakers who question her, her commitment, her intelligence. She simply lets the criticisms “loop” about in a deft poem. It is an ingenious response really, to respond to her detractors who question her intelligence with a crafted piece of verbiage.

Likewise, her poem “The Ugly Law,” about The Ugly Laws that forbade disabled, disfigured, “grotesque” people from being in public, that were on the books of many towns throughout much of the nineteenth and twentieth centuries is (pardon the pun) a beautiful piece of work – a brilliant mix of the legal language and Weise’s own reflections. “I am not even unsightly. What a pretty face/I have I’ve been told....Is this all in the past?” (l. 65-67, p. 12). In this digital age, and beauty-obsessed, visual world we inhabit, an important question, not just for the status of disability, but for our media-driven and consumerist society at-large.

None of this may, in the end, be new to an audience familiar with disability and community history, issues, and politics, but it may be new to a wider poetry-reading audience. It is perhaps unfair that Weise, given the potential visibility of *The Book of Goodbyes*, will have to bear the burden of representation in this way. Many of the other poems in the volume are not quite as obvious in their disability-content (in poems about cut flowers, or the biting – in ways – “Poem for His Ex,” in which Weise asks, “Does it make you feel better/to know he cheated with a handicapped/girl?” (l. 25-27, p. 49). Some disability readers may want more overt disabil-

ity-themed poems. Love and sex and the visual still loom large in the book as in her prior one, **The Amputee's Guide To Sex** [Editor's note: reviewed in *RDS*, 4(2), 2008]. But Weise is a poet more assured of her voice, her sense of poetic line (her enjambment is skilled and a thing for poets to marvel at). She is tougher. Her work is tougher. People may debate over how accessible the poems are or ought to be. There ought to be no debate, however, over how unflinchingly good this book is.

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Johnson Cheu, Assistant Professor, is the editor of the scholarly collection: *Diversity in Disney Films* (McFarland, 2013) and served as the inaugural Fiction/Poetry editor for *Disability Studies Quarterly*. He has published poetry, essays, as well as scholarship in various journals and anthologies. He is on faculty in the Department of Writing, Rhetoric, and American Cultures at Michigan State University.

Book Review

Title: *Writing Disability: A Critical History*

Author: Sara Newman

Publisher: Boulder, CO: FirstForumPress, www.firstforumpress.com, 2013

Hardcover: ISBN: 978-1-935049-54-8

Cost: \$59.95, 203 pages

Reviewer: Dax Garcia

Sara Newman's *Writing Disability: A Critical History* begins with an explanation of the genesis of the project: Newman, a professor of English at Kent State University, was interested in the lack of awareness, both public and academic, of autobiographical works by writers with mental and physical disabilities, works Newman refers to as disability life writing. Newman found scant examples in Western literature, from ancient Greece until Helen Keller's fame in the early 1900s: "Thus, this study was born, a response to the following prompt: when, how, and under what circumstances have individuals with disabilities written from their own perspectives before 1900?" (p. 2). Newman presents disability across history as socio-historical, illustrating how individuals shift their representations of themselves and their disabilities based on societal standards. The book is an investigation of why and how members of different cultures have understood disability in different ways.

Writing Disability contains an introduction and eight chapters that represent different eras, illustrating major societal shifts in relation to disability: Ancient Greece and Rome, the Medieval period, the early modern era, the 18th century, the 19th century, two chapters on the 20th century, and a reflective final chapter. Each chapter examines from two to seven authors of an era, and explores society's changing relationship with disability, expectations of its members, and shifts in writing styles.

Newman assigns different models of disability through the eras. For example, in Ancient Greece and Rome, the writers examined adhered to a civic model of disability. Newman writes:

“According to this model, ancient societies evaluated disability against the ideal, balanced body and the participatory practices expected of the Athenian or Roman citizen; that civic, institutional model permeated their cultural understanding of who was a full-fledged citizen. To make decisions about particular disabilities, a person’s condition was evaluated on an individual basis against the group norm. In this way, an individual literally embodied his civic status (p. 22).”

Disability through the civic model was based upon the ability of citizens to perform their roles. A mother capable of raising her children and maintaining her home despite a missing limb may not have been considered disabled. However, a soldier with a missing limb that rendered him incapable of fighting certainly would have been.

Newman attributes changing models of disability to historical shifts in society, such as Church doctrine in the Middle Ages and the advancement of printing and adherence to the newly embraced Scientific Method of the Enlightened Age. The five high medieval women Newman examines wrote of their lives and disabilities in a religious context. During this period, many physical problems were commonplace and not considered disabilities. However, they were viewed as imperfections of both body and soul, and disability only “emerged when the individual recognized and discussed physical problems as barriers to achieving salvation and problems to be remedied” (p. 59). Disability for these medieval women existed as part of their relationship with God.

Newman’s chapter “The Long Eighteenth Century: Reason and Logic in an Enlightened Age” details two writers who lived between 1695 and 1830, during an era that saw disability move toward a secular model that favored objectivity and rational logic: “During this period, the presumably objective Scientific Method displaced earlier concepts of and practices in natural history... The resulting method and mentality sought to induce universal truths by objectively observing, measuring, and documenting the world’s myriad phenomenon” (p. 81). This shift represents the birth of the medical model of disability that treats disabilities as imperfections to be cured. The selected authors in this chapter, one blind and one born with a hunchback, write not of spirituality or a quest for perfection, but for cultural awareness and tolerance.

Writing Disability brings deserved attention and respect to disability life writing through Western history. Writing Disability is wonderful for anyone interested in disability life writing or the Western history of disability. It is an important text for the extensive historical knowledge it provides about how disabled persons and their disabilities have been recognized in societies. The book has applications for history, life writing, disability studies, sociology, and more, and will aid in the conceptualization of different social models of disability for both undergraduate and graduate students.

Dax Garcia, MA, is a doctoral student in English at the University of Hawai‘i and a graduate assistant at the Center on Disability Studies. He may be contacted at daxg@hawaii.edu.

Book Review

Title: *A Life Without Words*

Film/Video Producer: Documentary
Educational Resources, Director: Adam
Isenberg

Release Date: 2013

How to Obtain: <http://www.der.org/films/life-without-words.html>

Cost: \$24.95

Name of Reviewer: Amanda McLaughlin

This transporting film left me with one sobering thought, encompassed in the film's title, *A Life Without Words*. I realized all the thoughts in my mind were within the confines of language learned early in my life. What would it be like not to have this capability? What would thoughts look like without language? What would it mean not to use language to differentiate between everyday objects, colors, and feelings? What would it be to live a life without words?

A 2010 study led by Jennie Pyers from Wellesley College, tells us how language shapes our thought. She discovered, by studying Nicaraguan Sign Language (NSL), a language created in the 1970's, that, "The grand idea behind all of these singular observations is that as human language evolved, our mental abilities became increasingly entwined with linguistic devices. Those devices are part and parcel of modern language, and thus modern thought" (Yong, 2010). This research also indicates that as an adult it is nearly impossible to acquire some of the abilities that language provides a pathway for, such as spatial awareness. This interconnectedness that exists between language and learning about the world around us highlights the importance of *A Life without Words* and also shows the tragedy of it.

The film focuses on the eldest children in a family from the mountains of Nicaragua. Dulce Maria (28) and Francisco (22) were both born deaf. Until recently, neither had been educated

in any formal written, spoken, or signed language. Instead they had spent their days on their family's farm, with little connection to the outside world. They developed a basic way of communicating with their family, mostly through gestures and sounds, but their frustration was evident.

Dulce Maria's pain was more visible, her eyes filled with emotion and curiosity without the means of fully expressing it. It was like watching an artist try to create without the necessary tools. Francisco approached his circumstances differently, with a quiet stoicism, seemingly internalizing the difficulty he experienced. Had it not been for the scene where he cries as he watches his father emotionally discuss feeling powerless, one would think he was resigned to his life of limitation.

When a deaf sign language teacher named Tomasa visits the family, they seem mildly interested, a little confused, but also open. It is clear the parents know more could have been done for Dulce Maria and Francisco but were completely unaware of how to meet their needs. At one point the mother talks about trying to send them to school but with no accommodations for their deafness, they were bored and refused to go back.

When Tomasa begins working with them, they are at first reluctant and unsure. The teacher is kind and patient, attempting to win them over with jokes and cookies. Dulce Maria is harder to warm up to. Her family calls her rebellious and stubborn, two traits she readily displays. She watches Tomasa closely, intrigued but uncertain. Francisco is more open to learn and gives the teacher his full attention, enjoying the chance to be engaged.

We see that Tomasa is moved by her time with this family. She understands what it means to be deaf in rural Nicaragua, a part of the world that provides little to no resources for people with disabilities. She sees the potential of these two young people, how confined they have been,

and how devastating it is to not have access to something as basic as language.

The last scene of the movie is the teacher sitting with the family. She rests on a stool, camera directly on her. She begins to weep, to sob at the thought of living an entire life without the opportunity to communicate effectively, to develop relationships on a deep level, or to gain a true independence. She tells the mother how smart the kids are and how much they have to offer.

One is left thinking of the injustice revealed here, how these two people are so capable but wholly unassisted. What could they do with the proper tools? What would their lives look like had they learned sign language at a young age? This film not only explores the far reaching issue of a lack of education for those with disabilities in the developing world, but also puts you directly in the midst of its outcome. *A Life Without Words* is a beautiful, emotional, and informative documentary that offers many questions but does not lead the viewer, instead offering a meditative visual essay, where you can draw your own conclusions. It is suited for a wide audience, appealing to a disability studies as well as human rights interest. For more information, please visit <http://www.nicaraguansignlanguageprojects.org/>.

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Amanda McLaughlin is an editorial assistant at the Center on Disability Studies at the University of Hawaii, Manoa. She holds a Bachelor's Degree in Media Communications with an emphasis in Film. You may contact her at amandat2@hawaii.edu.

Book Review

Title: *Shakin' All Over: Popular Music and Disability*

Author: George McKay

Publisher: Ann Arbor: Michigan, 2013. In *Corporealities: Discourses of Disability* series. Editors, David T. Mitchell and Sharon L. Snyder.

Paperback: ISBN: 978-0-472-05209-7

Cost: Paperback: \$37.50, 230 pages (also available in hardback and e-book)

Reviewer: Steven E. Brown, PhD

When I opened *Shakin' All Over* I had no idea how much I would learn. Immersed in the book, I continually found myself looking up musicians I had not heard about, like Steve Harley and Cockney Rebel; Kevin Coyne and Kata Kolbert; Joy Division and the Epileptics; and ones I thought I knew a lot about, but did not realize they had a disability connection, such as Judy Collins, Donovan, and Dinah Shore.

McKay manages to discuss all of the above musicians and many more, while surprisingly (to him as much, or more, than to readers), disclosing his own disability and what he has learned about it in the process of writing this book. He deftly analyzes how disability fits in and influences popular music, such as the common shaking of many rock musicians; and how music has created disabilities, particularly, but not only, hearing impairments.

In the Introduction, McKay writes that purpose of this book is:

“to explore the common cultural and social territory of popular music and disability, which has been a hitherto neglected topic. It is situated at a nexus of disciplinary or sub-disciplinary concerns: disability studies, popular music studies, cultural studies, performance studies, gender studies, and theory. It is

intended as a timely musical contribution to the critical dialogue of recent years around disability culture, as one corrective to the relative silence of popular music studies here” (pp. 1-2).

This is an academic book about popular music and disability from a professor of cultural studies, who is also a musician and, as we find out throughout the book, a person recognizing his own disability and his personal and professional life are more intertwined than he realized. The author informs us early in the book his publisher has been reminded to focus on music that is popular and therefore does not focus much on musicians with disabilities, like Ian Stanton or Johnny Crescendo, writing and singing about disability issues--though they are mentioned.

The five chapters following McKay's introduction focus on particular aspects of his subject, including polio survivors and their influence on popular music, with a particular focus on Ian Dury, and discussions of many others, including Israel Vibrations, Gene Vincent, and Carl Perkins (the jazz musician, not the country singer), and Neil Young, who receives more focus in the second chapter on voicing the disabled body. That chapter also looks at Hank Williams and Mel Tillis, country singers with disabilities, and Curtis Mayfield, who became a quadriplegic during an accident while performing.

In the third chapter, focused on performing disability in pop and rock, McKay looks at unknowns, like Kata Kolbert, who is difficult even to find via search engines; and at Teddy Pendergrass and Robert Wyatt, performers who acquired a disability after becoming popular, like Mayfield. He also dissects epilepsy and its impact on performing and performers, with particular emphasis on Neil Young (whose epilepsy appeared when he was a young man; his polio as a child) and Ian Curtis of Joy Division.

The fourth chapter features Johnny Ray, an early pop star vocalist, pianist, and songwriter, who was deaf in one ear and wore a visible hearing aid, and seems to have been the only popular musician with deafness to this day. This chapter gives McKay a chance to integrate Deaf culture and studies into the book. This is also a chapter where McKay discusses music creating disabilities, particularly hearing impairments for both musicians and audience members exposed to loud music, and even to those of us listening at home, who might turn up the volume, especially with today's devices often in our ears for hours at a time.

McKay concludes with a chapter on “Crippin’ the Light Fandango: An Industry that Kills and Maddens *and* Campaigns,” with a look at Amy Winehouse who sang about rehab (or not) and committed suicide; Michael Jackson and Elvis Presley and their doctors; and a slew of others. It also includes activism, such as Neil Young's Bridge School, the origin of the March of Dimes, and continued efforts today to eradicate polio, with a poster featuring the Congolese band, Staff Benda Bilili, a group of street musicians who had polio and who have in recent years become popular.

McKay ends the book, surprised to be attending and enjoying a Stevie Wonder concert, since he is usually more interested in lesser known performers in smaller venues. But he finds Wonder to demand disability access and awareness, “delivered onstage by the disabled musician at the pop concert, and the way that that utterance had been so cheered by everyone that powerfully struck me. The shakin's not all over is it? The world still needs shaking up” (p. 194).

Throughout the book, McKay also incorporates many authors of disability studies into his analyses, including Rosemarie Garland Thomson, Petra Kupperts, Alex Lubet, Joseph Straus, David Mitchell, and Sharon Snyder, among many others. The integration of disability studies analysis with a cultural studies perspective is

one of the many gifts of this book, which I want in my own disability studies and culture library and which will hopefully be in many other libraries and used in many disability, cultural, and music studies courses.

Steven E. Brown, PhD is Professor of Disability Studies and *Review of Disability Studies* Media Reviews Editor at the Center on Disability Studies, University of Hawaii. He can be contacted at sebrown@hawaii.edu.

Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at: <http://www.hsls.pitt.edu/guides/histmed/dissertations/>

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