

Editorial

Editorial: Special Issue on Disability and Film and Media

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Abstract

This Editorial for v17i4, Special Issue of Disability and Film and Media, highlights the role film and media play in some work around creating more equity and inclusion. In addition to highlighting some examples from around the globe, it provides an overview of the contents of the issue.

Keywords: disability, film, media

Editor's note

We are delighted in this issue to feature as guest editors two of the nation's preeminent scholars on disability and film and media, Beth Haller and Lawrence Carter-Long. For years, they have helped shape our national (and global) conversation about the role film and media may play in our concepts of disability. We are grateful for their lending their voice to readers here in this issue. – RDS Editorial Team

So much mass media representation of disability for generations has reverberated with an ableist and inauthentic tone; many television shows and films still do. But authentic and empowering representations are beginning to take hold. Mass media reflecting empowering disability content can assist societies worldwide to better include and respect the disability community. People with disabilities are 15 percent of the world's population, 1 billion people, and fair and unbiased representation of disability in a country's news and entertainment media can help increase a disability justice perspective. The International Labour Organization (ILO) in Geneva, Switzerland says that "portraying women and men with disabilities with dignity and respect in the media can help promote more inclusive and tolerant societies" (ILO, 2015).

The world has seen more entertainment media created by the disability community in recent years. For example, the musical film "Best Summer Ever" (2020) features a fully integrated cast and crew of people with and without disabilities. *Variety* called it a "template for disability representation in Hollywood" (Ferme, 2021) because with its multiple stars with disabilities, it tells its story with disabled actors but is not focused on any kind of disability theme. "It's the first musical to star people with disabilities and the first SAG-registered movie in which more than half the cast and crew are disabled," according to the *Best Summer Ever* creative team (2020). Set to premiere at the SXSW Festival in 2020, which was derailed by the Covid-19 pandemic, it is now available on Hulu.

In 2021, the spinal muscular atrophy (SMA) community came together to create the "Spaces" music video. Directed by wheelchair-using filmmaker Dominick Evans and starring singer-songwriter James Ian, both of whom have SMA, it features adults and children with SMA and their families in pictures shown over lyrics that say, "I'm not invisible. I'm an original." and "If there is one thing to see, it's my humanity" (2021). It also shows the

wedding of well-known YouTuber couple Squirmy and Grubs (Shane Burcaw, who has SMA, and Hannah Aylward, who is nondisabled). The biotech company Genentech, which launched a new SMA treatment in 2020, sponsored the music video, and Evans directed the Los Angeles-based filming remotely with an iPad from his home in Michigan. Evans said that his work directing remotely illustrates that disabled people can be part of creating good representation in Hollywood, if they are given proper adaptations: He said, in the future, “I want to make a TV show that I direct from my home in Michigan so people can see that any disabled person that has the talent can do it. And I don’t want that to be seen as something inspirational but as something realistic. We can do these jobs if we’re given the right accommodations. I have chronic pain but I was able to direct the video ‘Spaces’ from my bed in the place I was most comfortable in” (Kinross, 2021).

In the United Kingdom, the British Film Institute (BFI) restarted an initiative in 2021, Press Reset, to get more disabled talent into equitable and inclusive spaces in the film and television industries. BFI is also educating these industries about the ableist structures within these fields. It wants film and television in the UK to be proactive in dismantling ableism. The steps the industries should take are: “recruit responsibly; engage with the Disabled community; set targets; equal pay; think about access; and be an ally” (BFI, 2021).

The articles included in this special issue delve into the current media issues about how disabled people and their issues are or are not presented equitably on screen, as well as considering problematic representations of the past. With their analyses, commentary, and reviews, the authors examine everything from disability metaphors in early 20th century Korea to temporal drag in the television show *American Horror Story* to how young disabled creators on Instagram are reinforcing their disability identity with their posts.

Two of the articles in this issue are creative works. Talia Steinmetz critiques the stigmatizing tropes of the 1996 Disney film, *The Hunchback of Notre Dame*, with a Disability Studies lens and then re-imagines the film, with an alternate script that centers Quasimodo as a hero. Quasimodo becomes a disabled human man with an excellent set of skills that will aid him on his Hero's Journey and in his pursuit of a fully realized romantic relationship with Esmeralda.

Director Cameron Mitchell provides a Director's Statement about his film, *The Co-Op*, which dismantles disability stereotypes by giving disabled characters, all played by disabled actors, the power in a robbery scenario. Mitchell wants his short film to prove that film can center disabled characters (and disabled actors) in any genre because people with disabilities are part of a strong community in society. Never again, he says, should Hollywood use the tired and stigmatizing disability stereotypes that so often have populated films.

Using the affirmation model of disability, Kristen Tollan investigated how eight young adults with disabilities used their Instagram photos and captions to express their identities as disabled people. She found that in addition to discussing their disabilities, chronic illnesses and/or mental health, the young adults reflected social media trends such as using existing hashtags, posting about family, friends and pets, and discussing gratitude and positivity about their lives. While reinforcing their disability identity through their Instagram posts, these young people are also showing nondisabled people that the disability experience is not a uniform one and that disabled people are happy and goal-oriented like many nondisabled people.

Alison Wilde analyzes disabled characters in the television series *American Horror Story (AHS)* to look at issues of narrative and representational in/equalities across seasons

with special attention paid to the “Freak Show” season. Even though the “Freak Show” season is lauded for the number of disabled actors employed, Wilde reminds us that the majority of disabled characters were played by nondisabled actors. Even though some argue that temporal drag queers the entire series, Wilde says that the disabled actors have been left out of this queering (with exception of Jamie Brewer, an actor with Down syndrome who is in multiple seasons of *AHS*.) Wilde explains that temporal drag in the series still favors whiteness and nondisabled actors.

John Ndavula and Jackline Lidubwi looked at vernacular radio in Kenya, stations that broadcast in local languages, to see how these radio stations’ content did or did not support inclusive education for disabled students in rural communities. They found that few vernacular radio stations aired information about inclusion in schools. Their interviews with key stakeholders in vernacular radio illustrated that even when a radio station discussed the topic of children with disabilities, inclusive education was not included. Their research showed that the radio stations rarely contacted disability activists or inclusive education experts on that topic. They recommend that vernacular radio producers broadcast more content about inclusive education and consult disability experts about that content.

Eunyoung Jung explores a print publication in the early 20th century in Korea to delineate how disability metaphors were used in content about the patriotic-enlightenment movement before Japan occupied Korea. The pro-independence, pro-modernization *Korea Daily News*, a voice of Korean elites, had a section called *pyunpyungidam*, filled with “strange stories,” some of which were populated by blind, deaf, and nonverbal archetypes of disabled people. Jung writes that these stories equated metaphorical blindness and deafness with “ignorant” Koreans, who the newspaper saw as clinging to outdated ways of being in the modern world. The metaphor of “muteness” was applied to other news media and Koreans

who surrendered to Japanese censorship. As in other cultures, Jung says that those in early 20th century Korea who were promoting Western enlightenment used the stigmatizing metaphors about disability that conveyed a message that people with disabilities are subaltern and deficient, further marginalizing an already oppressed group.

Jeff Preston reviews the new full-length version of *Code of the Freaks*, which he says presents academic theory and activism around Hollywood's representation of disability in an understandable and captivating way. It is filled with in-depth research and outstanding examples of the ableist structures surrounding the film industry's representation of disabled characters. Aman Misra and Kara Ayers review Dennis J. Frost's book, "More than Medals," which is a history of the Paralympics and disability sports in postwar Japan. Misra and Ayers say the book confronts wrong-headed notions that the Paralympics and disability sports in general are a product of the West. The book explores Japan's innovative approach to the Paralympics and delves into media coverage of and public attitudes toward disability, as they intersect with sports played by disabled people. Misra and Ayers hope this book will inspire much more research and analysis of disability sports in Asia. Finally, the essays also include an excerpt of an interview between Superfest co-director Emily Beitiks and Superfest founding member Peni Hall. The short conversation gives a glimpse into the origins of Superfest, the world's longest running disability film festival.

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Research Articles and Essays**Exploring the Development of Disability Identity by
Young Creators on Instagram**

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Abstract

This paper explores how disabled youth use social media to express their identity. Using Swain & French's (2000) affirmation model and methodological principles of photovoice, the study took Instagram photos from eight participants for analysis, with the results discussing trends in the disability experience in connection to personal expression.

Keywords: disability, social media, youth

Social media platforms like Facebook, Twitter, and Instagram have become a controversial yet undoubtedly popular use of technology. Baym (2010) explains that new developments of technology come with one of two common reactions: fear or enthusiasm. Fear emerges from the idea that communication has become shallower, threatening the quality of personal relationships. However, for others, excitement emerges. For these people, new means of communication offer opportunities for deeper, more diverse and more numerous connections across the globe (Baym, 2010). The latter reaction has inspired this research. This paper explores how these evolving methods of communication influence and are influenced by those in society who are often marginalized and overlooked: particularly, disabled youth. To fill the gap in this area of research, the present study examines trends in social media usage by disabled young adult participants in relation to the formation of their identity and self-expression.

Current Literature

Online access for disabled people

Communication technology is increasingly prevalent in the lives of young people ages 11-25, with youth representing the largest group of social media users in Western culture (Walker, King & Hartman, 2018; Park & Calamaro, 2013). Scholars began using social media more frequently as a tool for garnering knowledge about experiences of youth participants, explaining that “online data collection methods may be among the most effective methods for collecting data on adolescents and young adults (13-24 years old)” (Walker, King & Hartman, 2018, p. 45). They argue that using social media as a research tool may be more ecologically valid for specific populations, including vulnerable youth like those with disabilities. Disabled people are more vulnerable to social exclusion and isolation, along with associated psychological difficulties linked to these issues (Dobransky & Hargittai, 2016). However, Guo et al. (2005) found that internet use could significantly

reduce these social barriers to inclusion for disabled people by providing access to education, information, and social networks. Shaw and Gant (2002) also examined the impact of internet usage on the psychological health of its users. In their study of undergraduate students in a psychology class who chatted anonymously amongst each other online, Shaw and Gant (2002) found that internet usage is beneficial to users, associated with lower levels of depression and loneliness and higher levels of self-esteem and perceived social support. Obst and Stafurik (2010) discuss the internet in relation to disability by examining internet-based communication methods for people with physical disabilities. The authors propose the idea that communication over the internet can enhance the overall wellbeing of physically disabled users through opportunities for connection.

Identity development

Dunn and Burcaw (2013) state that identity refers to “conceptions of the self, expressions of individuality, and accounts of group affiliation. Identities define us because they contain traits, personal characteristics, roles, and our ties to social groups” (p. 149). In their article, Dunn and Burcaw (2013) conducted a literature review of various publications relating to disability identity. They found six key themes across six narrative articles that reflected ways in which disability identity is developed. The themes included communal attachment, affirmation of disability, self-worth, pride, discrimination and personal meaning. Dunn and Burcaw (2013) concluded that “disability identity entails a positive sense of self, feelings of connection to, or solidarity with, the disability community [... and that] a coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles” (p. 148). The authors believe that a coherent disability identity could serve as a tool to help one adapt to their disability and navigate the struggles associated with being a part of a marginalized group.

Cameron (2010) also examined, in his research aptly titled “Does Anybody Like Being Disabled?”, the idea of disability identity. One question addressed in his paper was “how useful of a concept is ‘disability identity’ as a tool to people with impairments in making sense of their own experience?” (p. 260). Cameron (2010) argued similarly to Dunn and Burcaw (2013) that disability identity allows people with impairments to directly address the personal tragedy ways of thinking that are consistently shown in society, particularly in the media. Belonging to a social group of disabled people allows one to make sense of the ideas of inadequacy and resist them.

Research Paradigm & Theoretical Position

Online platforms have been used as spaces for disability-related content more and more frequently, with opportunities for dialogue and collaboration making them increasingly popular. The present research takes on a novel approach to examining disability through these platforms. Being disabled is typically seen as negative; though it is important to recognize and articulate the struggles related to being disabled, it is also crucial to consider the idea that not all experiences of having a disability are negative ones. The social model has been recognized as allowing this positive paradigm shift.

The social model of disability views disability not as something that a person has (i.e., a physical or mental impairment), but as an oppressive societal relationship in which barriers and lack of access create disablement (Cameron, 2014). Furthermore, social modelists argue that to better the lives of disabled individuals, it is not always rehabilitation or treatment that is needed, but recognition and removal of physical and societal barriers (Cameron, 2014). Using Swain and French’s (2000) affirmation model as a theoretical foundation allows expansion on the social model’s discussion of disabled identity. Swain and French (2000) argue that the affirmation model is a “non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective” (p. 569). They

developed the affirmation model to directly contrast the personal tragedy model, a dominant view of disability often expressed by able-bodied and neurotypical people, and often internalized by disabled people themselves.

Research Questions

This paper was developed from a larger study, conducted by the author as a thesis study in 2020. The larger study explored the concepts of disability identity and building community. In this paper, the topic of disability identity is the focus. Thus, this paper is informed by one of the three original research questions:

1. How do disabled youth use Instagram to express their identity? What can be seen from both the images and captions they post about their evolving identity and self-concept as disabled, if anything?

Methodology

The purpose of this study was to examine usage patterns on social media by disabled youth. This topic is important to the field because the accounts analyzed in the study, along with the finding that the analysis elicited, can be used as a stepping stone for understanding the ways young people use some of their most favored spaces on the internet. The study shed light on the experiences of disabled youth from their own points of view, demonstrating them as valuable and important resources in academic research.

Research Framework

Deciding on Instagram

The first step was to select a platform that combines both text and image. Instagram, unlike other platforms, such as YouTube or Twitter, is distinct in that it requires the posting of an image or short video, as well as provides the opportunity to caption each post. Memes, images of text, screenshots, creative work, and photos taken by devices other than mobile

phones are all possibilities on Instagram (Laestadius, 2016). Furthermore, Instagram has a privacy feature allowing for accounts to become outright unavailable unless the user approves a follower request. All the accounts chosen for this study were public pages, making them both ethically and physically accessible.

Yi-Frazier et al. (2015) conducted a study using adapted methods of traditional photovoice on Instagram while working with youth with Type-1 diabetes. Drawing on their methods and early photovoice guidelines laid out by Wang and Burris (1997), a methodology was developed that suited the research goals of the present study.

Traditional photovoice methodology

Photovoice is a participatory action research technique in which participants are given a camera and asked to take photos of scenes around them related to a given topic or theme (Yi-Frazier et al., 2015). According to Wang and Burris (1997), photovoice is described as flexible and adaptable, able to meet the needs of a variety of communities and their goals. Yi-Frazier et al. (2015) elaborate further, explaining that photovoice usually involves a group discussion following the photography session(s) in which participants come together to discuss the photos and their experience. Furthermore, they state that using photography in youth populations has been shown to elicit unique and relevant perspectives relating to the young person's point of view, particularly in relation to experiences with play and school. However, it has also been noted that photovoice projects conducted with adolescents usually take more time and coordination than projects done with adult participants (Yi-Frazier et al., 2015). Therefore, Yi-Frazier et al. (2015) adapted this methodology to work best for their needs and involved Instagram as a tool in their photovoice methodology.

Adapting photovoice methodology

Once an understanding of photovoice methods was developed, the works of Yi-Frazier et al. (2015) as well as Gibney (2017) and Miller (2017) were drawn on with adjusted

methods to suit the present study's goals. Yi-Frazier et al. (2015) used Instagram as their primary method of photo collection; Gibney (2017) chose to use publicly accessible content on other social media sites including YouTube; and Miller (2017) used direct interviews with student participants about their social media usage in relation to queer and disability identity-making. Yi-Frazier et al. (2015) more closely followed photovoice methodology through an Instagram-based investigation with youth, which provided a resource for this study in relation to both data collection and analysis. Gibney (2017), in examining how "higher education students who identify as LGBTQ navigate their school and daily life experiences in relationship with their identity on web logs" (p. 2) provided another resource for shaping the analysis of the present study with her research analyzing YouTube and blog content. Miller's (2017) methodology used grounded theory for analyzing specific themes that emerged from their data. Together, these three studies aided in the development of a methodology that would be most effective and useful in the current research.

The Participants

To be considered as a participant, Instagram users had to meet a few specific criteria. Their profile had to be public. Their age had to be within the range of 18 to 25, therefore considered a young adult but not a minor. Participants who were under 18 were excluded, as this is still classified as a child by legal and ethical guidelines. Finally, the participants had to identify as having some sort of impairment or disability, though a specific diagnosis was not a requirement.

Eight participant accounts were chosen: four accounts selected were followed personally by the author and four were selected through searching the #disability hashtag on both Instagram and TikTok. While the original aim was to use Instagram as the primary source of both participant selection and gathering data, it proved difficult to find suitable accounts through exclusively browsing the #disability hashtag on Instagram. When browsing

on Instagram, the number of photos was overwhelming, with limited filtering options. The majority of popular posts within the Instagram #disability hashtag did not meet the inclusion criteria. Instead the author also searched #disability on TikTok, a more recently popular app, where 41% of the users are within the age range of youth (ages 16-24) (Beer, 2019). Once a participant was chosen from TikTok or Instagram, their content for analysis in the study was drawn exclusively from Instagram.

Data Collection

Laestadius (2016) describes three types of data collection methods for Instagram. The option chosen for this study involved viewing the participants' Instagram accounts on the app from a user's viewpoint, and then copying photos and captions into a database. To choose the photos and captions that were analyzed, the author went to each of the eight accounts and selected the 21 most recent photos, then downloaded the total of 168 photos (21 x 8 participants) to a computer for easier viewing. Choosing this specific number of photos created more validity, as a consistent amount of photos and captions from each account were examined without the inference of personal selection bias. Following that, all of the photos and their associated captions were collected into a spreadsheet to simplify and organize for analysis. Pseudonyms for participants were used at all times.

Data Analysis

In keeping with the adapted photovoice methodology used by Yi-Frazier et al. (2015), the photos of each participant were first grouped based on visual content. Seven types of photos were classified, including "selfies" (photos of the person, whether taken by others or on their own); old photos (including the person and/or family members/friends – typically scans or photographs of film photography); recent photos with friends, family and/or pets;

landscape photos; celebrity photos; internet memes (a humorous image, video, piece of text, etc., that is copied and spread rapidly by Internet users); and lastly, photos of objects, screenshots, or miscellaneous content.

Caption analysis followed and held the most detail about the participants and their experiences. The captions were analyzed in three stages. Firstly, the author read through the captions of each photo and classified the caption based on major themes that presented immediately. In the second stage, these themes were organized in a chart (seen in Table 1) which helped to see trends more clearly, both in the way they were presented across participants, and also how they connected to the concept of identity.

Results and Discussion

This study examined the content of eight Instagram accounts belonging to disabled youth between the ages of 19 and 24. After analyzing the photos and captions of 21 posts per account, there were trends in the types of images posted, as well as many themes that emerged from the captions. The first type of analysis includes a look the types of images posted. This was used as a way of noting whether there was a visual connection to the concept of disability identity at first glance. The themes observed in the captions are presented as well. Based on the research questions that inform the present research, it was expected that participants who posted more selfies would demonstrate a stronger connection to their identity as disabled, and that captions would reflect that.

Analysis of Image Trends

The results indicated a very diverse spread of image trends across the eight participants. Some posted nearly all selfies (Austin, Ashley) while others favored landscapes (Zoe) or photos with friends and family (Zane). The one type of content that was not posted by any of the participants was memes. These image trends were notable as they indicated

preliminary insight into the caption themes that later emerged from the participants' posts. It was more common for the participants who posted selfies to also share details about their disability and their identity as disabled. However, the image trends did not exclusively predict who would discuss their disability on their Instagram profile. In other cases, such as Zoe, Payton, Ashley and Brittany's profiles, the types of images they posted (landscapes, selfies, writing, etc.) indicated the elements of their lives that were important to them, outside of their disability (e.g., friendships, creativity, travel, etc.). Although the participants never explicitly discussed identity formation in their captions, it became apparent that identity as a concept, particularly in relation to their disability, was pertinent to the participants.

Analysis of Caption Themes

A number of themes were found across the photo captions of the eight participants (seven across multiple accounts and some that were unique to one or two participants). Some themes were grouped into smaller classifications, such as merging the themes of disability and chronic illness as well as mental health, to reflect the interconnected nature of disabling physical and mental symptoms. In doing this, the study ended with four themes for discussion.

The four themes for discussion from the photo captions are visualized in Table 1 below, as well as a list of other less commonly seen themes that were mentioned, organized by individual. The author's first impression was that the disability theme and the social media trends theme would connect more closely to the concept of identity.

Table 1. *Thematic comparison of participant captions*

Four Discussion Themes

	Disability, chronic illness, and mental health	Family, friends, pets	Positivity, gratitude and giving back	Social media trends
Chelsea W.	x	x	x	
Brittany A.	x	x	x	x
Zoe W.		x		
Zane V.	x	x	x	x
Alexis S.	x	x	x	x
Payton L.	x	x	x	x
Austin G.	x	x	x	x
Ashley M.	x	x	x	x

Other Themes

- Chelsea W. — living life to the fullest; growing up; home
- Brittany A. — living an ordinary/normal life; writing/work/school; home
- Zoe W. — living and ordinary/normal life; writing/work/school; home; LGBTQ; travel
- Zane V. — none
- Alexis S. — school/work; sports; religion/church
- Payton L. — school; uniqueness; resiliency
- Austin G. — none
- Ashley M. — ballet

Discussion of Themes

Social Media Trends

“Social media trends” as a theme encompasses the use of hashtags in captions, as well as posting content relating to popular, often viral, trends. Zane, Payton and Austin most commonly followed trends with their content, which reflects the fact that these three participants, along with Ashley, were found on TikTok, a platform that thrives on viral content. Furthermore, the use of hashtags and creating “viral” content allows Instagram users to be found by others outside of their immediate or “real life” circle and expand the reach of their content.

One participant, Austin, is a rising TikTok star, with 12 million likes and nearly 500 thousand followers. Living in the United States, he has cerebral palsy (CP) and is also hard of hearing. Much of his popular content deals with having CP and his experience as

disabled. Something unique about Austin's account is that some of his more viral videos show him using American Sign Language to perform popular songs. He also often performs trends like TikTok dance routines while discussing disability at the same time, usually through the use of captions. On Instagram, his first 21 photos contained 20 selfies and a photo with his mom. Austin's account featured disability as a theme on occasion, but most commonly focused on social media trends and overall positivity.

Zane's profile included hashtags in every post, including ones relating to his disability (#downsyndrome, #dslove, #worlddownsyndromeday, #321). Zane was found on TikTok. Zane has Down Syndrome and is 19 years old, residing in the United States. On TikTok, he creates popular videos with his older brother. At the time of this research, Zane and Peter had 3 million followers on their TikTok account, and nearly 72 million likes. Their joint Instagram profile has 71,000 followers. On Zane's individual account, his bio has the phrase "Changing Perspectives One Heart at a Time | Down Syndrome." It is important to note that Zane and Peter share the Instagram account that was analyzed in this study. Therefore, it is Peter who typically writes the captions seen on the account. Understanding the concept of identity in relation to Zane and his disability is thus mediated through Peter's voice and his conceptualization of his brother's disability as an ally to the community, rather than a disabled person himself.

Payton included the hashtag #actuallyautistic on one Instagram post, but the majority of her hashtags were related to increasing her visibility on social media, including ones like: #followme, #photooftheday, #fashion #self and others. Payton was also found on TikTok, where she has a significant following of 540,000 people and 8 million likes. Since the original research was conducted, her TikTok following has grown to over 2 million users. While some of her content is following TikTok trends, her most "viral" content talks about her living with autism and what autism is like for a young person, especially a girl. Her

Instagram account has over 40 thousand followers, most of whom likely found her from TikTok, as is indicated by her bio (“ya i’m that autistic girl”). Payton is 20 years old and Canadian. The make-up of her first 21 photos was almost entirely selfies, with 81% or 17 photos being of her and the remaining 4 including Payton and friends. Payton did mention disability in her posts on occasion, but more commonly, her friends and family, as well as some social media trends were themes seen in her captions.

Two other participants also had unique patterns of hashtag use in their posts. Chelsea included no hashtags in her posts, perhaps indicative of the fact that she did not profit off her social media posts and already had a rather large following from her public speaking and advocacy work. Brittany, a twenty-four-year-old resident of the United States and the oldest participant, lives with a diagnosis of Spinal Muscular Atrophy Type 2 (SMA 2). Brittany and the author are personal friends who rather found each other on a blogging site. Brittany is also close friends with another participant, Zoe, who she has known for 11 years. Zoe is the single participant from outside of North America, residing in the United Kingdom. She is diagnosed as having autism and mental illness and identifies as disabled. Zoe and Brittany met online through a fan-fiction website, and the author met Zoe through Brittany.

Zoe had a more unusual selection of content in this study, with her Instagram photos displaying a majority of landscape photos (48%). Selfies were only 14% of her first 21 photos. Her Instagram bio described her pronouns (she/they) and also stated that she identifies as a “queer poet & storyteller based in [location].” Zoe’s themes did not discuss disability at all, focusing rather on her work as a writer, her travel experiences, her friends and family and LGBTQ+ issues.

Brittany used hashtags frequently in similar ways to Zane and Payton; however, there was a notable difference in that many of Brittany’s posts included her own writing, and even the posts that were not related to her advocacy work showed the prevalence of disability

awareness and activism in her life. Hashtags related to her writing included:

#authorsofinstagram #authorlife #writersofinstagram #ownvoices #criplit #sciencefiction

#fantasybooks. Further, Brittany posted selfies including hashtags like #livemoremagic

#myeverydaymagic #spinalmuscularatrophy #spinalmuscularatrophytype2 #disability #dis

abilityawareness #disabledandcute #disabledpeoplearehot #disabledfashion. The hashtag

#myeverydaymagic is popular among people of all abilities, with photos posted sharing a

similar aesthetic of light colors, flowers and other visually pleasing content. However, in the

context of a person with a disability using this hashtag for her selfie, something more could

be indicated which connects to the idea of disability identity. Brittany lives with SMA Type

2, a severe disability that is also a visible disability. Brittany strives to make disability a more

prevalent part of the literary landscape and also non-fiction spaces, as evident by her use of

the #ownvoices hashtag. Perhaps by using hashtags like #myeverydaymagic, Brittany is

attempting to normalize the everyday activities of disabled bodies and their own existence in

social media spaces, which are often filled with glamourized, able-bodied celebrities and

influencers. Brittany's attempts at normalizing disability also speak to the first research

question of this study— how disabled youth express their identity through photos and captions

on Instagram. In viewing Brittany's photos and captions, it is clear that she views her

disability as a prominent part of her identity. However, she also recognizes the normalcy of

being disabled, no different than her identifying as a “storyteller, space babe [or] fairytale

enthusiast” (taken from Brittany's Instagram bio). It could also be said that Brittany's

Instagram patterns show an owning of her disability, something that is in keeping with the

social model and the affirmation model of disability. The affirmation model (Swain &

French, 2000) provides the opportunity for disabled people to choose how they identify.

Here, Brittany demonstrates an interchangeable identity that reflects her unique

characteristics and the freedom to be who she wants to be on any given day.

These ideas coincide with a point drawn in Cameron's (2007) article on disability narratives, in which he states that there is a "normality genre" in popular media (specifically films, but arguably, it can be seen in writing and television as well), in which disabled people perform the "alien" role, as if in a science fiction story— "representing a threat to the fabric of normal decency, which has to be resolved... in order that normality can be preserved or restored" (p. 502). He then goes on to state that this resolution typically happens by means of death or curing the character's disability. However, writers like Brittany include characters with disabilities who are the protagonists, yet do not face untimely deaths or overcome their impairments. She further emphasizes this in her own life through the reclaiming of her identity as the protagonist of her story with her own "everyday magic."

Payton and Ashley's accounts provided interesting results in this area as well, as both posted almost entirely selfies, and had very limited content associated with their disability (Payton has Autism and mental health issues, while Ashley deals with Anorexia Nervosa and undiagnosed physical issues). Instead, their themes focused much more heavily on the things that interested them, such as fashion, makeup, dance and other "typical" hobbies for girls. This aligns with Hill's (2017) study on disabled girls' self-representation practices online, in which she states that "disability is often framed as a problem or lack, and that experiences of disability for girls appear to trump or silence other experiences, such as those of sex and gender, and the intersections that exist between these" (p. 114). It is highly likely that these girls, whose content on other social media platforms focuses heavily on their disability, curate their Instagram accounts more carefully as a way of normalizing *other* aspects of their life, outside of their disabilities.

Ashley, found on TikTok, is currently undiagnosed but deals with chronic illness. Currently using a NG tube for feeding, she speculates that she has Ehlers-Danlos Syndrome as well as some type of gastrointestinal illness. Ashley is 24 years old and lives in Canada.

Her TikTok is popular for her content relating to disability, but also for her dances and other on-trend videos. On TikTok, Ashley has over 70,000 followers and nearly 800,000 likes. Her Instagram focuses on a different part of her life – her experience as a ballerina. Her Instagram bio reads: “Ballerina; Documenting my journey through the ups and downs of my personal struggles mentally and physically through dance.” As would be expected, dance was the most common theme across her captions and photos, although disability, friends and family, positivity and giving back were evident as well.

Payton is also known on TikTok for posting content dispelling myths about girls with autism. On Instagram, however, Payton and Ashley post pictures with their friends and other “ordinary” activities that are outside of the realm of frequent doctor’s visits and psychiatric diagnoses. Payton and Ashley’s accounts connect with the discussion of identity, particularly in relation to the choice of identifying as disabled (or not). As described in Dunn and Burcaw’s (2013) work, there are key aspects of disability identity, such as pride, self-worth and personal meaning. However, some people with impairments don’t develop their self-worth from their impairments, like Payton (Watson, 2002). It is also important to note that Payton identifies as autistic, a group whose members often title themselves as neurodivergent rather than disabled. In this case, her identity is fluid, and at times may be represented or referred to as neurodivergence or disability, while at other times, she chooses to identify based on other important aspects of her life.

Disability, Chronic Illness and Mental Health

Across the captions analyzed from all of the participants, disability showed up frequently, but was also often separate from chronic illness and mental health. For instance, Brittany commonly discussed her diagnosis of Spinal Muscular Atrophy as her disability, but never mentioned any mental health diagnoses as a disability. She still discussed mental health in her posts, focusing on it more as a common aspect of human nature rather than a disability.

Payton, in contrast, has diagnosed mental health issues and talks about them alongside her discussions surrounding autism. Disability was discussed at times purposefully with a clear intent to demonstrate a point, whereas other phrases about disability were said in a more casual, commonplace way. For example, in her April 9, 2020 post, Alexis wrote about her service dog assisting her in dealing with her high heart rate (due to Postural Orthostatic Tachycardia Syndrome or POTS). She then easily segued into talking about her homework and basketball activities.

Alexis, who has a fairly large social media following, with 7600 followers on her account at the time of the study, was found through her work as a disabled model for a popular clothing line. The make-up of her Instagram account included 17 selfies out of the first 21 photos, 3 miscellaneous and one with a friend. Her bio read “chronically ill semi-functional human; owner of [company]; crushing stereotypes, kissing fish, cutting down on waste; service dog [name].” Alexis’s profile paid frequent attention to disability related topics, including her diagnosis of Ehlers-Danlos Syndrome among other unknown conditions, as well as her work and school life, sports, and religion.

In contrast to Alexis, Brittany typically wrote captions centered around one main topic, often disability-related but not always. Her post on March 8, 2020 read: “We have the first presumptive coronavirus case in Minnesota. Which is something. I'm officially on lockdown, which means I'm wearing nothing but pajamas and listening to my embarrassing playlist of bubblegum pop to keep my spirits up. It's not fun being immunocompromised in a world full of germs. I'm fighting tooth and nail to keep from falling into a depressive episode, so naturally, I'm writing a blog post about it.”

Outside of the disability-related hashtags, three participants posted about disability most frequently and in-depth – Chelsea, Alexis and Brittany. Chelsea is the only participant who is no longer living. She had a very large online following at the time of her death;

however, this study has upheld her anonymity in keeping with the protocols of the research. Chelsea was a 21-year-old living in the United States at the time of her death. She died from complications associated with a lung transplant. She was living with cystic fibrosis and was undergoing a double-lung transplant surgery in 2018 when she passed away. Therefore, her data is the oldest, chronologically, covering the timeframe of January to September 2018. Chelsea's profile was the most diverse in terms of types of photos and all four of the common themes were evident on her profile, with a particularly high amount of posts talking about disability.

For Chelsea, it was impossible to post photos of herself on Instagram without her disability being apparent, as she wore a nasal canula at all times to deliver oxygen support to her lungs. However, it was entirely her choice to become an activist in the disability community. Her Instagram account, nearly 2 years after her death, still has 162 thousand followers. Many of her longer post captions were filled with her opinions about living life as a "sick person," but also a young person, and trying to reconcile the two into a high quality of living. Of the 21 posts that were analyzed from her account, four stood out as the most important. In one from June 21, 2018 she discussed losing her apartment to mold toxicity, which is dangerous for anyone, but especially someone with cystic fibrosis. She wrote not only about the struggle of having to find a new apartment in California, but also the "spectacular" way in which her life "fell apart," and the emotions that came from living with a chronic illness whilst trying to live a life she was proud of. Chelsea shared in a June 21, 2018 post that she

spent the past year just barely holding myself above ground- juggling being sick with the deep incessant need in me to do something of value with my time. I've been exhausted just keeping myself alive and have nothing left to give to the world around me. That has always been my biggest fear in life, that I would spend everything I had "fighting" my illness and have nothing to offer- and for me, living without being able to give something of yourself to the world, living without adding value to the world, is not a life I want... You

can't put your life on hold until your "better" life begins. You have to fight like hell to make sure that the life reflected back at you right now is one you want to be living. I'm not going to let myself live a life I'm resentful of. Not if I live for another three months and not if I live for another 30 years.

The quote emphasizes a few different things about Chelsea's life with a chronic illness, the main one being just how much it shaped her short life and the identity she had. Chelsea often referred to herself as "sick" in her posts, but she also frequently mentioned the life she wanted to lead and how important it was to her to be proud of the legacy she left behind. Instagram provided a platform for Chelsea to express these thoughts and have them received by other youth who felt the same, either with a disability or without. For Chelsea, it was impossible to share parts of herself without also sharing that she was disabled, due to the visible nature of her oxygen support. However, Miller (2017) discusses the contextual management of one's identities. He describes the participants in his study as carefully considering how they would represent themselves in particular online spaces. For Chelsea, perhaps the curation of her Instagram account allowed her to compartmentalize her disability in ways that she could not do in real life. Chelsea's Instagram photos were the most thematically diverse. Furthermore, a lot of her captions discussed her disability, but on her terms. The captions contained Chelsea's own words and thoughts about her disability, rather than perceptions that other people might carry with them when they passed her on the street (such as those attached to idea of personal tragedy). Some of Miller's (2017) participants also discussed the idea of facing judgement on an online platform – either as something they experienced, were actively trying to avoid, or no longer were concerned about, in relation to their queer and/or disabled identities. Chelsea shows a lack of fear in her posts– not fear of death, or judgment, although perhaps an unfulfilled life was one thing she did fear.

Summary of Results

The results indicated that identity was expressed in a variety of ways across the participant profiles. Identity was shown most clearly through the frequency of the participants posting selfies, but also through specific identifying labels used in bio sections, repeatedly included hashtags and the thematic concepts that emerged from each unique photo caption. Each participant demonstrated more than one of the four themes in their posts, as well as other themes that were not addressed by all participants, but rather that were specific to their own individual experiences. Identity was shown through not only the sharing of one's experiences with disability, but also the other elements that made up their life. Normalizing disability as an everyday occurrence and also living life to the fullest were two concepts that, when juxtaposed, actually went hand in hand, as they provided opportunities for the disabled participants to achieve goals and find happiness, whilst also indicating to able-bodied people that the disability experience cannot be generalized.

Conclusions

Technology is advancing rapidly, providing unprecedented opportunities for research and exploration. However, disabled people are often left behind in this modern technological age, included as an afterthought rather than a part of the process from the beginning. Social media and other online spaces provide a unique tool for researching the youth demographic, particularly those with disabilities and severe mental health issues. Instagram presents an opportunity for disabled youth to explore their identity.

This research, shaped by the affirmation model of disability (Swain & French, 2000) examined the profiles of eight young adults with various disabilities. The aim of the paper was to explore the ways that Instagram was used as a platform for self-expression in relation to developing one's identity as disabled. The study's primary strength was the exploration of

the disabled experience through the viewpoint of disability insiders, rather than family members or medical professionals. The study also relied on the affirmation model as a theoretical foundation. In using the affirmation model, the study brings awareness to a model which prioritizes positive identity, encompassing both impairment *and* disability (Swain & French, 2000). The study presented an insider view of disability as experienced by young people, on a platform that is underrepresented in academic research, yet extremely popular and influential in the lives of youth.

Limitations

A limitation of this study is the lack of diversity across the participants. While the diagnoses of the participants were different across each person, other elements of diversity were not as well-represented in the sample. For example, the study participants came from North America and the UK, which are predominantly white countries, and all of the participants in the study were white or white-passing. Furthermore, there were only two male participants, and LGBTQ+ status was disclosed by only one of the participants (Zoe). While these participants met the inclusion criteria of the study, it would certainly improve future studies in this area to include a more diverse sample of participants.

Implications for Future Research

Future research could immensely benefit from a larger, more diverse sample in which race, gender, sexual orientation and country of residence and other characteristics were more varied across participants. Intersectionality is a major part of disability studies as a field, considering the ways in which disability interacts with other areas of societal marginalization such as race and sexual orientation. To further examine how these different identities impacted one's portrayal of their disability identity would certainly improve the impact of the research. Identifying as only disabled or only Black or only a woman would lessen the impact of the struggles that are faced when all of these identities meet. Thus, the results of the

present study could vary greatly based on the unique combinations and interactions of social identities.

Furthermore, it would be very interesting to see how the results of the present study translates across platforms other than Instagram. Although this study only examined Instagram as a platform, it was noted that different content could be explored on platforms like TikTok or Facebook. For instance, Payton is known on TikTok for her autism-focused content, and exploring the area of disability-related videos on that platform alone would provide novel and interesting insights into the topics at hand. For instance, looking at commentary on a platform like TikTok could show how the disability-related content is perceived by viewers.


Final Thoughts

The main concept in this study, the development of identity, served as the vessel through which to research the disabled population, the only socially oppressed group which any person can find themselves in at any time. Identity was demonstrated both through expression of being disabled and what that means for a young person, but also through the exploration of other unique traits, qualities and events that make up the life experience of a youth. This was influenced by their online activity on such a novel platform. Through the activism of these participants, living their day-to-day lives as disabled youth, their followers are presented with plentiful opportunities for exploration into what it really means to be disabled and given a reminder of both the diversity and common ground found in the human condition.

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Research & Essays**Vernacular Radio Stations and Inclusive Education in Marginalized Communities in Kenya**John Ndavula¹ and Jackline Lidubwi²¹ Murang'a University of Technology² Inclusive Media Project in Sub-Saharan Africa at Internews**Abstract**

This paper addresses a qualitative research project concerning the role of vernacular radio in promoting inclusive education among rural communities in Kenya. It suggests that the media plays a crucial role in highlighting inclusive education as an educational approach and philosophy that provides all students with community membership and greater opportunity for academic and social achievement. The study involved interviews with 20 key informants who included radio presenters, producers, and stakeholders in inclusive education in Kenya. Findings indicate that few vernacular radio stations aired disability specific content despite the fact that existing broadcasting laws provide a framework for broadcasters to include disability specific content in their programming. Some radio stations aired a wide array of topics on disability but failed to capture specific issues relating to inclusive education for children with disabilities. Radio packaged disability content into a variety of program formats providing multiple angles for stories on children with disabilities. The use of inclusive language in reporting was more likely to influence societal perceptions towards education for children with disabilities. Few inclusive education stakeholders were involved in generating content on inclusive education for radio, and even fewer disability activists used vernacular radio to champion the rights of children with disabilities. The study recommends that vernacular radio stations should broadcast more disability specific information on inclusive education. Furthermore, disability stakeholders should engage with producers in radio stations to do this accurately.

Keywords: inclusive education, vernacular radio, marginalized communities

How can access to the unique powers of local, vernacular media empower marginalized populations? How may this potential power benefit those most marginalized, especially students with disabilities? And how may considering these questions fit into Kenya's larger goals of universal access to education? This paper addresses a qualitative research study exploring the role of media in promoting inclusive education in Kenya. The focus will be on how vernacular radio stations are setting the agenda of inclusive education in the country. It is well recognized that media plays an enormously influential role in public responses to emergent issues in society (Leask, Hooker & King, 2010). Radio has an unparalleled reach as a communication mechanism (Gunther, 1998). It has substantial power in setting agendas, that is, what we should be concerned about and take action on, and in framing issues, that is, how we should think about those issues (McCombs & Shaw, 1972). Radio continues to be a vibrant, multi-vocal, persistent, and mobile feature of daily life (Battles & Patterson, 2018). As a platform, it remains a vital cultural force for various social groups to advocate for change (Starkey, 2017). This essay considers how this influence may be leveraged towards supporting inclusive education.

Inclusive education for children with disabilities has been a major focus for disability activists and parents of children with disabilities since laws on universal access to education were passed in Kenya. It is estimated that only one in six disabled children attend school in Kenya (National Coordinating Agency for Population and Development & Kenya National Bureau of Statistics, 2008). Those few who do face the familiar problems of exclusion, stigmatization, inappropriate curricula, poorly equipped schools, and insufficiently trained teachers (Global Education for All, 2016). There are currently 1.3 million people in Kenya living with a disability. Of these, only 39% have attended a mainstream primary school, and only 9% have attended high school (National Coordinating Agency for Population and Development & Kenya National Bureau of Statistics, 2008).

Addressing this disparity, and with a focus on leaving no one behind (as articulated in the Agenda 2030 for sustainable development), the Kenyan government generally increased the primary net enrollment from 75% in 2006 to 83% in 2012 (World Bank Group, 2012). However, the statistics for the most marginalized groups are not as impressive. The enrollment of learners in schools that cater for special needs currently stand at 102,749 students, of which 21,050 are in special schools and 81,649 are enrolled in integrated special units at both primary and secondary schools (Republic of Kenya, 2015). According to

estimates, these enrollment figures represent about one-third of the expected number of learners with special needs. According to Gebrekidan (2012), Africans with disabilities are among the poorest of the world's poor, and such exclusion from education further perpetuates the cycle of disability and poverty (Bii & Taylor, 2013).

At the same time, enrollment is no guarantee of success. In fact, those enrolled are far more likely than their nondisabled peers to drop out. For example, in the District of Nyando, the dropout rate amongst disabled children is estimated at 75%, compared to 40% amongst their nondisabled peers (Global Education for All, 2016). This difference can largely be attributed to the fact that disabled children do not receive the amount and type of attention needed to successfully complete their education. With no assessment at enrollment, or any other stage, the teacher is left unsure as to how to teach the child and what to expect.

Given these challenges, students require inclusive education. This means placing students with disabilities of all ranges and types in general education classrooms with appropriate services, care, and support (Lipsky & Gartner, 2006). It is important to notice that inclusion contains a very radical idea of diversity that is not found in the idea of integration. While integration has principally to do with proximity and opportunities for social interaction, inclusive education advocates for full membership and conjoint participation with peers at all levels of education. Inclusive education not only involves fundamentally re-thinking the meaning and purpose of education for all children and young people, but it also refers to the restructuring of ordinary schools as well as being pro-active. The principle of inclusion raises fundamental questions about the nature and purpose of our education system and the part schools play in the life of the community. Schools do not exist in a vacuum; they are part of the wider community, and community life does not stop at the school gates (Johnsen & Skjørten, 2001).

This interconnected nature of school and community has been supported by a number of international conventions on education. Documents emerging from these include international and national legal frameworks and policies that bind the government of Kenya in recognizing the rights of persons with disability. A case in point, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is an international convention aimed at protecting the rights of persons with disabilities (United Nations Convention on the Rights of Persons with Disabilities, 2007). It promotes and protects the rights of every

Kenyan living with a disability thanks to its ratification on 19 May 2008 by the government of Kenya.

Article 24 of the CRPD requires state parties to recognize the right to education for children with disabilities and education free from discrimination [sic]. It states that “state parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, state parties shall ensure an inclusive education system at all levels and lifelong learning.” The article further states that children or adults with disability cannot be excluded from the education system on the basis of disability, and people with disabilities must be given the opportunity to learn the life and social development skills they need. To ensure this education is free from discrimination and offers equal opportunity, state parties are required to provide an inclusive education system.

Similarly, the United Nations Convention on the Rights of the Child (1989) is the first legally binding international instrument to incorporate the full range of human rights—civil, cultural, economic, political and social rights. The four core principles of the Convention are (1) non-discrimination; (2) devotion to the best interests of the child; (3) the right to life, survival, and development; and (4) respect for the views of the child. The Convention protects children’s rights by setting standards in health care, education, and legal, civil, and social services. By agreeing to undertake the obligations of the convention, the Kenyan government committed to being held accountable for this before the international community.

In a similar commitment, Kenya adopted a new constitution in August 2010 that contains a substantially improved bill of rights and represents a real change in the protection of the right to equality and non-discrimination in Kenya. The constitution lists equality as one of six essential values upon which governance should be based. These expressions of principle are given legal force in article 10, which prohibits discrimination on grounds of disability. The constitution provides for children with disabilities’ right to free and compulsory basic education, as well as access to quality services, and to educational institutions and facilities. Various other legal provisions and policies in Kenya advocate for the provision of education for children with disabilities. The Basic Education Act (2013), Special Needs Education Policy Framework (2009), and Persons with Disabilities Act (2003) all address critical issues related to education for learners with disabilities. Indeed, Kenya has

a rich legal landscape that can guarantee the safeguarding of the needs of children with disabilities. Greater awareness of these legal frameworks, though, is crucial.

Mass media in general, and radio in particular, can help provide greater awareness of the fundamental rights to education for children with special needs. A report by the Rockefeller Foundation asserts that community radio is one of the best ways to reach excluded or marginalized communities in targeted, useful ways (Dagron, 2001). As far back as the mid-1940s, community radio has demonstrated its potential for social change (Pavarala, 2003). In rural areas, 95% of Kenyans regularly listen to the radio (BBC Media Action, 2018). The Communications Authority of Kenya (CA) puts the number of radio stations broadcasting in local vernacular at over 30. Vernacular stations command 38 percent of the total radio market share (Media Council Annual Report, 2019). The majority of these stations are privately owned while others are either state-run or community based local language stations. Vernacular radios are especially popular in rural areas, with a majority of listeners being older than 30 years (Media Council of Kenya, 2012). These statistics suggest that vernacular radio can potentially and effectively reach rural communities with targeted information regarding education inclusion for children with disabilities.

Theoretical Framework

The study was guided by the agenda-setting theory of media. This theory lays emphasis on the ability of media to influence the importance placed on a topic of public agenda (McCombs, Shaw & Weaver, 2014). The theory posits that when a news item is covered frequently and prominently, the audience will regard the issue as more important. Repeated news coverage of an issue appears to have an influence on the public perception of the importance of issues (Happer & Philo, 2013). In essence then, issues highlighted by the media become issues that the society accepts as important for attention and discussion (Dragu & Fan, 2016). Consequently, the media can be used to influence policies and the way people think.

In outlining this process of agenda setting, Folarin (2005) describes the elements involved in agenda setting to include the quantity or frequency of reporting by the media, prominence given to the reporting, the degree of the conflict generated in the reports, and cumulative media-specific effects over time. On the other hand, Lang and Lang (1983) outline six key factors in agenda setting as:

1. highlighting some events or activities and making them stand out,

2. determining the required amounts of news coverage to gain attention, framing of events and activities in the focus of attention,
3. selecting the language used by the media to affect perception of the importance of an issue,
4. linking the activities or events that have become the focus of attention to secondary symbols whose location is easily recognized, and finally,
5. accelerating the agenda through well-known and credible individuals to speak out on an issue.

A critical issue in this process of agenda setting is that the media person setting the agenda must be conversant with the topic about which the agenda is being set. Additionally, the journalist should be prepared to implement the issue in stages as the concept of agenda building seems to suggest. Media framing of an issue and the role of well-known individuals commenting on the issue should be considered equally important (Oyero, 2010). The labels that journalists (especially well-known ones) apply to events can have an important influence on whether the public pays attention to the issues connected with the event. Agenda setting theory is relevant because it provides the basis for examining how vernacular radio stations in Kenya are promoting inclusive education especially for the most marginalized students with disabilities.

Methodology

This study used a qualitative research design for data collection and analysis to establish the role of the vernacular radio stations in promoting inclusive education in rural communities in Kenya. A purposeful sample of 20 key informants (presenters, producers and stakeholders in inclusive education) were interviewed to provide in-depth information. We drew a purposeful sample which implies intentionally selecting “information-rich” individuals who would help in understanding the central phenomenon and best answer the research questions. A purposive sample of disabled people’s organizations (DPOs), county education officers, parents, caregivers, head teachers, teachers in public primary schools and media producers, reporters, and presenters were selected. Two participants from each stratum were selected for interviewing.

We developed two structured interview guides which ensured that we asked each respondent the same questions in the same way. We used the first interview guide to gather

data from radio producers, reporters and presenters. We used the second interview guide to get information from stakeholders in inclusive education in Kenya. We selected individual participants who were most likely to contribute appropriate data, both in terms of relevance and depth. For example, we identified radio presenters dealing with reporting disability stories in vernacular radio, and also staff members from the Department of Special Needs Education in the Ministry of Education. We explained interview confidentiality to each participant as well as described how their quotations would be attributed in reports.

We analyzed the qualitative data thematically. Coding was done according to the principles of thematic coding (Miles & Huberman, 1994). Preliminary codes were identified and then categorized and developed into more abstracted themes that captured participants' contextual responses to the coverage of inclusive education in vernacular media. The themes were discussed and revised. Each theme was then reviewed to discuss general findings.

Results

The study findings indicate that few vernacular radio stations in Kenya cover inclusive education in their programming. Out of the thirteen radio stations we sampled, only one station, Ingo FM, had a disability specific program. The program was titled *Obulamu shibuli okhukhaywa tawe* (loosely translated 'Disability is not inability') and aired on Wednesdays at 8:45 pm. Two radio stations aired stories on inclusive education: Emoo FM (which broadcasts in the Kalenjin language), and Ingo FM (which broadcasts in the Luhya language). One radio news reporter stated that his radio station does not allocate time for inclusive education content, but news items on inclusive education are given prominence depending on how they are packaged and their news value. Radio news reporters from other stations noted that content on inclusive education is aired depending on the availability of such stories. This implies that vernacular radio stations do not prioritize inclusive education content in their programming.

Language Use

Language used in the media to describe disability both shapes public attitudes and reflects prevailing assumptions about disability (Jones & Harwood, 2008). Our findings indicate that when vernacular radio stations in Kenya use inclusive language it is likely to influence societal perceptions towards education for children with disabilities. One radio reporter we interviewed stated that his station had trained reporters on using inclusive language when writing disability stories, they avoid using 'disabling' language labels in

vernacular and instead use ‘enabling’ language. Given that vernacular radio stations use language that is the first language of the community, the community is thus likely to comprehend inclusive education messages more clearly.

Feedback from Community

Moreover, vernacular radio plays an important role in setting the agenda of inclusive education in the society. Findings indicate that whenever radio aired content on inclusive education, there was a spike in feedback from the community. A news presenter stated that his audience appreciated content on inclusive education and requested more. A radio producer noted that most community feedback indicated a desire for more information on inclusive education. The radio producer further indicated that listeners yearned for more information on disability because in some communities disability was considered a curse. Radio presenters who reported on disability stories had a high following and listenership due to the unique stories they told. Presenters reported receiving numerous calls and text messages from listeners who testified how the stories changed their perceptions about inclusive education.

Accuracy of News Stories

As we have previously established, there is a need for accurate information on inclusive education to be aired on radio. For this to happen, there needs to be active collaboration between radio producers and stakeholders in inclusive education. These may include the Department of Special Education in the Ministry of Education, DPOs, inclusive education learning institutions, parents, and caregivers. However, the stakeholders in inclusive education hardly engage radio producers to produce content on inclusive education. An official from the National Council of Persons with Disabilities admitted to not working with radio stations but stated plans were underway to partner with radio stations to provide content on inclusive education. The involvement of stakeholders in generating content on inclusive education will help ensure that radio will provide accurate content.

Coverage of Inclusive Education in Vernacular Radio Stations

Packaging of Content

The way a news story is packaged, or framed, can affect how audiences understand it. Media frames are considered as central organizing ideas that provide meaning to events (Scheufele, 1999; Gamson & Modigliani, 1989). Media frames serve as guidelines to journalists who recognize and categorize information before relaying it to the masses. Radio producers stated that they used interviews, discussions and talk shows for the packaging of radio programs related to inclusive education. In addition, news and program correspondents packaged inclusive education content as features, news stories and shows. One radio producer noted that interviews were carried out involving stakeholders both in government and private sector. Packaging inclusive education content into a variety of program formats helps to capture the complexity of the issue and can help influence society's understanding of the importance of education for children with disabilities.

Selecting News Sources

Media coverage of disability stories can potentially contribute to mainstreaming inclusive education. Most radio producers indicated that they sourced their news stories on inclusive education through media briefs and releases from relevant institutions as well as from investigations by reporters. On the other hand, stakeholders in inclusive education observed that the level of awareness of inclusive education by production teams at vernacular radio stations is insufficient. This has led to the prioritization of sensational news at the expense of content on inclusive education, despite its importance and the need for it. As one disability rights activist put it, "society needs a lot of sensitization on inclusive education since many children with disabilities are still hidden in homes with no access to education" (S. Odawa, personal communication, July 10, 2019).

Topics Covered

The number of topics on inclusive education aired on radio may affect the knowledge levels of the audience. Radio producers we interviewed indicated that the range of stories on inclusive education they covered included the right to education, contribution of children with disabilities to the development of society, and the right to life for children with disabilities. Other topics included public awareness of children with disabilities, origin of disabilities, and forms of disabilities. Radio content also included challenges faced by children with disabilities and the role of individuals, communities and the government in supporting people with disabilities. Although a wide array of topics on disability are aired by

vernacular radio, specific issues on inclusive education are not well articulated.

Media Advocacy Strategies to Promote Inclusive Education

Radio remains likely to be the most powerful, most accessible, and most affordable medium for reaching large numbers of people in isolated areas. Even the remotest villages have access to vernacular radio, which builds on the oral tradition of rural populations. Despite vernacular stations now commanding 38% of the total radio market share (GeoPoll, 2019), few disability activists utilize vernacular radio to champion the rights for children with disabilities. Instead, disability rights activists interviewed indicated a preference to engage with television rather than radio when creating awareness on inclusive education. Some stated that they lacked the vernacular language proficiency to engage with vernacular radio stations. Most disability rights activists reported conducting advocacy campaigns through television, print media, social media and conferences. With print media requiring literacy and television being quite expensive to broadcast in, it would appear that vernacular radio would be better suited to reach rural, marginalized communities. Indeed, O'rao (2009) states that largely rural and less formally educated communities lend themselves well to the radio medium in terms of access to information. Radio stations are therefore better placed to communicate the importance of inclusive education to create awareness that can lead to much needed attitude change in the community.

Discussion and Recommendations

Our study found that few vernacular radio stations in Kenya cover inclusive education in programming, and only one among the thirteen stations sampled had a disability specific program. This is true even though existing broadcasting laws provide a framework to include disability specific content: the 2016 Programming Code for free-to-air radio and television issued by the Communication Authority of Kenya (a media regulatory body) calls for broadcasters to promote disability specific content (Communications Authority of Kenya, 2016). Furthermore, section 4.1 of the Code provides for airing of content specific to children to promote their physical, mental, and social potential.

Moreover, our findings indicate that vernacular radio stations in Kenya use inclusive language which is likely to influence societal perceptions towards education for children with disabilities. Language provides a forum to both construct and understand reality and current power structures. Unfortunately, the language used to refer to people with disabilities has historically marginalized them, portraying them in a derogatory way (Hadley & Brodwin,

1988). By defining individuals on the basis of disability, they may be reduced to their disability and thereby dehumanized (Back, Keys, McMahon & O'Neill, 2016). This highlights the importance of vernacular radio stations employing inclusive language, as doing so is likely to influence community attitudes towards inclusive education. Indeed, the UN (2020) asserts that images and stories in the media can deeply influence public opinion and establish societal norms.

Another finding from our study was that content aired on inclusive education directly correlated with a spike in feedback from the community. This is important as feedback provides a way to measure the audience's reception of a message and its effectiveness (Sambe, 2008). Thus, content aired by vernacular radio on inclusive education generates more interest among the community members and is likely to influence their perceptions on inclusive education.

Similarly, the involvement of inclusive education stakeholders in generating content on inclusive education will potentially improve the accuracy of this content. Despite this, few disability activists utilize vernacular radio to champion the rights of children with disabilities. The Kenya National Survey for Persons with Disabilities Report (2008) notes that when information is made about people with disabilities, there is a need to involve stakeholders who can ensure accuracy of information. By ensuring that stakeholders in inclusive education participate in creating content for radio, they will feel better represented and can ensure greater accuracy of information. An insider is viewed as better able to promote and protect the interests of individual communities and groups (Hyden, 1996).

In addition, packaging inclusive education content into a variety of program formats helps capture the complexity of the issue and can help generate audience interest. We can conclude that a sustained effort in providing a variety of programming content on inclusive education could possibly help counter existing stereotypes about education for children with disabilities.

Our study found that while vernacular radio covered a wide range of topics regarding disability, specific issues relating to inclusive education for children with disabilities were not well articulated. As Krosnick & Kinder (1990) have argued, media coverage of a topic serves as a prime influence on public opinion about that topic and their perception of its importance. Consequently, vernacular radio's coverage of topics on inclusive education can influence the public's perception regarding the importance of education for children with disabilities.

Recommendations

Our study recommends that vernacular radio stations should broadcast disability specific content in line with the Programming Code. Most particularly, radio stations can privilege information on inclusive education for children with disabilities. We further recommend that disability rights activists should engage more with vernacular radio stations to generate content to support inclusive education. In cases where they lacked vernacular language proficiency, they can sponsor programs on inclusive education, bring in experts who are well versed with vernacular language, or engage translators when providing content. By so doing, the potential of this powerful local media to help change for the better the lives of many of the most vulnerable members of its communities may yet be realized.

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Research Articles and Essays

Disability Metaphors and Patriotic-Enlightenment Movement in

The Korea Daily News, 1907-1910

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Abstract

This article explores how disability metaphors were used in *the Korea Daily News* from 1907 to 1910, particularly in the section titled *pyunpyungidam*, meaning strange stories. The author argues that this early modern Korean newspaper used blindness to portray its antagonists and to construct “illegitimate” citizens in the context of the patriotic enlightenment movement against colonialism. This article also shows how language disabilities were used as a metaphor to express despair because of Japanese colonial media censorship.

Keywords: disability, metaphors, *the Korea Daily News*

Disability has been overlooked in both enlightenment studies and postcolonial studies, despite the use of the idea and image of disabilities to shape and symbolize the ideas of enlightenment and colonialism. As Cleall and Gust (2021) put it, it has been assumed that “all histories of the enlightenment can be written without consideration of disability, or the marginalization of disability as an insignificant side-issue.” The age of enlightenment was the time when the disability was constructed as something abnormal that must not be tolerated in society (Thomson, 1997). This idea of “abnormality” not only oppressively impacts people with disabilities but also works as part of the reasoning of enlightenment philosophy. For instance, western enlightenment philosophers used disabilities as an experimental object to examine humanness, the link of mind and the body, and the condition of a civilized individual (Cleall & Gust, 2021; Wright, 2010).

In a similar vein to studies of enlightenment, postcolonial studies also lack investigation into questions of disability in their work, with the exception of a few scholars (Barker, 2014; Barker & Murray, 2010; Erevelles & Minear, 2010; Grech & Soldatic, 2015; Sherry, 2007) who explored the intersections of disability studies and postcolonial studies. While postcolonial studies actively engage with race, gender, and ethnicity to analyze colonial and postcolonial texts, they have almost entirely neglected disability (Grech and Soldatic, 2015). In addition, Grech and Soldatic (2015) also mention how “there are few references to processes of disablement for disabled people in [postcolonial] scholarship,” even while they use disablement as a metaphor to describe the colonized condition.

Considering the Korean context, there is almost no study of disabilities in enlightenment and postcolonial studies published in English or Korean. While symbolic meanings of disabilities in Korean literature during colonization have been explored (Han, 1991; Kim, 2016), the idea of disability as a part of the mechanism of enlightenment and

colonial frameworks is rarely examined. In this vein, this study aims to explore how disability was constructed in newspaper articles in early 20th century Korea, in which several social ideas were rigorously introduced, contested, and implemented, including enlightenment, colonial imperialism, western ideas of modernization, patriotism, etc. This study approaches the Korean news discourse on disability as a way to critically review Korean patriotic enlightenment thoughts in the colonial context, as well as their process of disablement in the context of colonization and the enlightenment movement in Korea. Toward this research goal, this study analyzed *The Korea Daily News*, specifically the *pyunpyungdam* column from 1907 to 1910.

The Korea Daily News and Pyunpyungdam Section

Most modern newspapers in Korea emerged around the turn of the 19th and 20th centuries, amid the situation of invasion by western and Japanese imperial powers with a view toward accomplishing the independence of Korea and “enlightening” Koreans with a new wave of western ideas of modernization. In particular, the era between 1895 (Gabo Reformation) and 1910 (The colonization of Korea by Japan) in Korea is usually called the patriotic enlightenment period. During this period, the concept of modernity was introduced to Korean intellectuals, and they sought to implement this new concept as a tool not only to reform the Korean society but also to defend the country from imperial nations, particularly Japan. In this process, “print capitalism” played a major role in shaping Korean modernity to become more like western countries. The modern print media, such as newspaper, journals, textbooks, literature collections, and modern novels provided a place for the production of discourse in which various new modern concepts competed with each other (Jin, 2004; Kim, 2007), in particular in order to overcome this national crisis in Korea. In particular, *Korea Daily News*, which is under the scope of this article, is considered the center of rigorous

patriotic enlightenment discourse (Jung, 2003).

The Korea Daily News was first published on July 18, 1904, by Ernest Thomas Bethell, a British Journalist, and ran the Strange Stories section beginning on May 23, 1907, until the newspaper's final publishing date on August 28, 1910. At that time, Japan was already exercising strong censorship of the newspapers, and suppressing Korean newspapers and journalists. However, because the publisher was British – whereas main editor (Gi-tak Yang) and most journalists were Koreans – *the Korea Daily News* was able partially to avoid that type of censorship until 1907. *The Korea Daily News* was the most influential and popular media outlet on behalf of the Korean People. The main themes of *the Korea Daily News* were the independence of Korea, modernization and enlightenment, and these themes appeared frequently with the intersection of disability in its articles.

The Korea Daily News regularly featured a section of unusual fictional stories involving people with disabilities from 1907 to 1910. The name of that section was *pyunpyungidam*, meaning a kind of curious, strange, interesting, or weird story. While *the Korea Daily News* mostly delivered facts and actual events, it compiled this particular section from reader contributions. Readers sent their fictional stories to *the Korea Daily News* to express their desire to become writers or storytellers (Jeon, 2010). While many of them focused on sensational or fun stories, this section also published satire stories and social criticisms (Jeon, 2010). It is noteworthy that editors of *the Korea Daily News* also emphasized that modern fictional stories should be enlightening and didactic (Koo, 209) in their editorials.

According to Jeon (2010), 746 stories in total were published in the *pyunpyungidam* section. I found 328 articles from the *pyunpyungidam* section in the Korean newspaper archive database (<http://kinds.or.kr>). As seen in Table 1, sixteen stories relating to disabilities

were found among them. In total, forty-five articles from the *pyunpyungidam* section, as well as editorial and general news sections in *the Korea Daily News* were analyzed to understand those sixteen stories. The topic of disabilities in the *pyunpyungidam* section has been rarely recognized among scholars in Korean literatures. For example, Jeon (2010) classifies 126 *pyunpyungidam* articles thematically and finds thirteen themes, including general funny stories, gender issues, family relationships, criticism on Korean society in general, or other empires, except the topic of disabilities. Disability is so invisible that its stories are classified as “general” funny stories. Table 1 shows a summary of *pyunpyungidam* stories relating to disabilities. All disability-related terms were directly translated from the stories, even though most of them are not acceptable or appropriate in present Korea and they are considered derogatory language. But in the early 1900s, they were common words to describe people with deafness or language disability. They include *jangnim* or *sokkyung* (literally person with a cane and indicating people with blindness), *beongeori* or *banbeongeori* (literally meaning mute or half-mute, indicating people with hearing disabilities and/or language disabilities). *Byungsin* was translated as “cripple,” which literally means defective body, and described people with physical disabilities.

	Date	Subject
1	12/18/1907	a ‘half-mute’ family (parents, a daughter, and a son-in-law)
2	6/23/1908	a ‘mute’ son of ‘mute’ parents, who became a scholar
3	7/3/1908	a daughter-in-law who killed a chicken to prevent the sunrise
4	12/5/1908	communication of a deaf/‘mute’ woman with an officer by means of gestures
5	12/6/1908	a father and a bad son with disabilities
6	12/24/1908	three men pretending to be ‘mutes’ for begging
7	1/6/1909	one blind man imagining future prosperity based on one found coin
8	1/14/1909	officer Min's impropriety of speech
9	1/29/1909	Impressions of a deaf man, a blind man, and a ‘crippled’ man, about a temple
10	3/24/1909	misunderstanding of “teeth” (sounds like “stupid mute,” taken to mean vulva)

11	6/15/1909	two blind men discussing the colors and patterns of a temple
12	8/12/1909	the inability of three 'half-mute' daughters to disguise their disability
13	8/18/1909	two officers insulting each other ("son of a monk" and "son of a shaman")
14	11/14/1909	a person pretending to be a 'mute' for begging
15	8/7/1910	a 'half-mute' family (parents, their daughter, and their son-in-law)
16	8/23/1910	low-level officers drive away a bad superior officer

Table 1 Summary of Pyunpyungidam stories relating to disabilities

To explore how the newspaper media used the disability metaphor, I incorporated the methods of critical discourse analysis (CDA) (Gee, 1999; Wodak & Meyer, 2009). This article first examines what people with disabilities in pyunpyungidam represent, and then situates these disabilities metaphors in the context of patriotic enlightenment movement in colonial time in Korea.

Disability Metaphors in *The Korea Daily News*

This article focuses on two disability metaphors – blind and 'mute'/'half-mute'. Rather than using these words to describe individuals with disabilities from that period, the pyunpyungidam section stories constructed social meanings around these labels and conveyed other metaphorical meanings through the stories. In the pyunpyungidam section, the metaphor of blindness was used to refer to any Koreans who lacked awareness of historical change. They were also constructed as a non-legitimate Korean citizen. The mute / half-mute metaphor was used to describe the tragedy of the absence of media freedom under Japanese censorship, including the loss of Korean "voices" in the newspapers.

Blind Metaphor

“Blindness” as lack of awareness. The main characteristic of persons who are blind in *pyunpyungidam* is not simply presented as a physical condition of vision, but also as a sort of absence of awareness. In other words, the blind in these stories are unable to see something, and furthermore they cannot “see” that very fact of what they cannot see. One story from 1909 presents this kind of characteristic of blindness:

One blind man, one deaf man and one cripple went to see a temple. They sat on the rock to rest their tired legs when they reached a place after crossing over big mountains and rugged passes. Then, the blind man pointed toward the mountain with his cane far away and said, “How great it is! The various colors of the temple building are so clear and bright that I cannot forget it. How poor is the person who cannot see that scene!” (Jang, 1909)

The motive of this story can be found from the story itself. A man who is blind went to see a temple and was quite impressed with the colors of the temple building. There is a common Korean saying related to this scene and this image of the blind. That proverb, which might apply in this context to the blind man’s way of seeing the patterns and colors of temple building, is “*sogyong dancheonggugyeong*,” which means a wasted or unappreciated sight, or seeing things without discerning their contents. When the man in the first story speaks of how great the temple building was with its beautiful colors, this newspaper’s readers would likely laugh at his exclamation and think that he was silly and ignorant, since it is assumed that he could not really see the temple but is only pretending to be able to see it.

Regardless of their prior experiences of vision or lack thereof, their present inability to see is not their most important characteristic in these stories, but rather, what is most

significant is that they are pretending to know something that they cannot possibly know. Why does the story talk about blindness in this way? The limitation referred to here is not especially related to literal, disability, but is rather connected to particular characteristics of ignorant and pretentious people in general. This can be one indication that the focus of these stories is not to discuss particular or even typical real-life blind people, but rather to covertly discuss and criticize a target, as a concealed subtext of the narrative.

An important clue is found in one editorial in the same newspaper, which is useful in explaining the usage of blind metaphor in the *pyunpyungidam* stories.

Though Sakwang has good ears, he will not be able to hear as a representative of the obscure deaf. And though Iru has good eyes, he will not be able to see as a representative of millions of blind people. ... Some people say that the sky is round and earth is square; the sun has the appearance of a king and the moon the appearance of a subject. Nonsensical ideas are often stated. ... People talk about the countries of the world, and believe in ridiculous things like Kwanhung-kuk (“Stitched-chest-land,” a country where people sew their own chests closed) and Ilmok-kuk (“Cyclops-land”). Because they have become blind and deaf citizens: they cannot see or hear, even though they see with their eyes and hear with their ears. (continuation omitted) (“Botonggyoyugui pillyo,” July 7, 1908)

Unlike the *pyunpyungidam* section, the identity of the blind and the deaf is clearly explained in this editorial. While the editorial was explicitly intended to “educate” readers, the *pyunpyungidam* as a fictional story sought to “entertain” readers, with the message of enlightenment and modernization remaining implicit (Jeon, 2010). People who are blind in the *pyunpyungidam* stories are Korean citizens who still hold nonsensical ideas and ridiculous beliefs, and who fail to recognize that a nasty wind and horrible rain invade the

front yard and door [of Korea] (“Botonggyoyugui pillyo,” July 7, 1908). In this vein, people with disabilities in the pyunpyungdam section represented analogously as “disabled” with respect to their time and culture. According to Ryu (2005), the early Korean newspapers criticized Koreans’ lack of awareness or “wisdom” because its editors thought that Koreans were too ignorant to realize that injustice of the present situation and they did not even have a sense of shame or anger

Blindness for what? At this point, one question arises: What are people who are blind- metaphorically Koreans – “supposed” to see, that they are blamed for failing to see? One story (“Dorosogyeong,” 1909) of a man’s being made able to see, seems to offer a very interesting response to this question. In this story, there is a man who used to be blind, but whose eyes have suddenly been opened, and now he is sitting in the street crying. He says that the sky, earth, sun, moon, mountain, and river are so radiant and so charming that he cannot walk. A teacher in the country gives him the advice that he should become blind again and the man agrees with the advice. The meaning of the sky, earth, sun, moon, mountain and river in this story is not clear. Fortunately, though, the newspaper added commentary to the story, at the end of the section. They edited the paragraph of commentary in a way different to the story itself, in order to mark that this commentary is not part of the story.

Currently, there are many persons who are sitting in the street crying because they are too surprised with the new culture of the world to have a sense of direction. No one leads them to progress, and stubborn scholars mislead them back to their former behaviors and pleasures. It is miserable! How many have become blind again! (“Dorosogyeong,” 1909)

In this story, what the metaphorically blind are supposed to see comes to the front. They ought to see and learn the “new culture of the world.” The teacher in the country may

be depicting a Confucian who wishes to preserve his traditional philosophy and culture in Korea, and is opposed to accepting modern, western culture and values. In addition, as claimed in the previous editorial (“Botonggyoyugui pillyo,” 1908), some Koreans were still “blind” in that they believed in the existence of strange and barbarous countries in the world outside of Korea, not seeing the civilization and modernization of western countries. In fact, this newspaper continually delivered news from western countries including the U.S., with great interest and full of positive reports about western civilization and culture. *The Korea Daily News* introduces special education for students who are deaf and blind in America with a special interest in the idea of public education even extending to students with disabilities. In another editorial (“Gungminui oeyanggwa,” 1910), the newspaper describes western countries as thriving nations and Asian countries in contrast as declining nations. To overcome their national crisis – namely, that Korea was on the verge of being colonized by Japan – Koreans were being called on to “open” their eyes and “see” the modernized western societies, and to accept and learn from it without embarrassment and surprise: in short, not to be like the man who wanted to become blind again in the previous story.

Not legitimate Korean citizens. The newspaper’s warning against being blind is more than simply advice. The writers’ voices become more urgent and more angered against such “blind” Koreans in other articles. They describe some Koreans not only as failing to see changes in the world, but as floating on clouds (“Gungminui oeyanggwa,” 1910). They are criticized as not physically laboring yet wanting to be rich. This image of a person is a little different from previous characters who do not see and are “ignorant.” He is described more negatively, as a non-productive person. Other editorials in this newspaper have a similar description for a certain “class” of people: those who are clothed and eating, even though they play rather than work. In one such editorial (“Yuiyusikaneunjaneun,” 1909), the writer

defines group as those who eat someone else's profit without using their arms and legs. In this category are Korean classical scholars, monks, prostitutes, exorcists (fortune tellers), petty town officials and their servants, *and the blind*. They are seen as thieves and not legitimate Korean citizens. The different groups that make up this class seem to be very different from one another, and it is rather difficult to determine what they have in common that this editorial treats as a reason for judging them so harshly. In the general news column of this newspaper, there appears a similar categorization of "undesirables" ("Dangyeonhigeumharil," 1908). The report – which is in fact not really a news fact, but another editorial – advocates a policy of prohibition toward exorcists (fortune tellers), magicians, *and the blind*, arguing that they are thieves, cheating people and taking their property. The newspaper features continuous reporting of this type of "theft," by the blind and fortune-tellers, who seem to be presented here as a singular category of people. For centuries, fortune-telling had been a typical occupation of the blind in Korea, but at the beginning of the 20th century, such work came to be considered a form of theft, and came under strong criticism. In addition to fortune-telling, which this newspaper essentially treated as a crime in its reporting, the newspaper would also be sure to report any actual crimes committed by people with disabilities.

It is necessary to consider the context of the social development of Korea in the beginning of the 20th century in order to understand why they are considered thieves. The Korean enlightenment thinkers including intellectuals who published the early modern newspapers editors of *the Korea Daily News* thought that those able to work physically on farms and in markets and factories, etc., were vitally necessary in the establishment of an emerging "new Korea." Those whose livelihood was perceived as absorbing the profits of those productive classes, on the other hand, did not measure up to the same standard of

importance, and were considered “drains on society,” or simply, “thieves.” This newspaper took on the responsibility of breaking through conventionalities in the interest of promoting modernization in Korea, and classical scholars, prostitutes, monks, exorcists (fortune-tellers), petty town officials and their servants, as well as the blind, were significant targets of this iconoclasm. In their discourse, the blind fortune-teller would not be unnecessary in a modernized Korean society, but would in fact act as a barrier to new and rational ideas in the new century.

“Mute” and “Half-Mute” Metaphor

The tragedy of family fate. Another group of persons with disabilities that appear as frequently in the *pyunpyungidam* section of *the Korea Daily News* are people called “mutes,” or “half-mutes.” The words “mute” and “dumb” are no longer used in Korean public media, but they were used in the 20th century to refer to certain people with disabilities. It is not necessarily easy to determine the identity of the mute in these stories, because the description of mutes differs significantly from that of the deaf or of language disabilities. Taking into account the characteristics of individual described in this section, the mute cannot speak at all, and communicate by means of gestures, which is hard to be considered as Korean sign language because it is described as a funny and ridiculous way instead of a communicative way. Of these, some seem to be deaf, because others who are able to speak nevertheless use gestures to communicate with them. In the other category are the half-mute. They are described to be able to hear and speak in these stories, but have difficulty articulating and pronouncing words correctly. They are clearly not deaf, as they do not use gestures at all and have no trouble hearing what others say. It is difficult to determine which factors may have contributed to their unclear and incorrect pronunciation. Half-mutes appear more often in this newspaper than do mutes, not only as characters and symbolic figures. In comparison to the

stories about blind people, the stories featuring mute and half-mute people much more frequently involve family relationships.

In the *pyunpyungidam* stories, half-mutes are usually described as members of half-mute families, for instance being half-mute parents or half-mute sons or daughters. In several stories (“*hanjibe se sikgu*,” 1907; Kim, 1908), it is portrayed that (half-) muteness “runs in the family:” that they marry other (half-) mute persons, as well as that their children are also (half-) mute. In another story, a woman has three daughters who have not yet gotten married, and all three of her daughters are half-mutes (Kim, 1908). However, there is one story that depicts a man’s status change after leaving his parents:

One mute man made his living farming in a ravine. He married a mute woman, and they lived in the mountains, and they had a son. When their son was three years old, he began to eat rice, but he ate with his hands like his parents; and in everything else he did, he imitated his parents. And so, he became mute. ... (continuation omitted). (Kim, 1908)

This story describes the son as having *become* mute after a process of imitating his parents. Later on in the same story, the son is said to have become a scholar, but only after leaving his parents and obtaining his education formally in a school. Unlike this “success” story, there is another one that shows how hard it was to escape the status of being half-mute, and this story was shown two times in this newspaper.

There was a family made up of a husband, a wife, and one daughter. All three were born half-mute. Their daughter had reached the proper age to get married. So they chose a very handsome man, but didn’t realize that their future son-in-law was also half-mute. On the wedding night, the man wanted to hear the way his bride spoke, but he could not initiate the conversation, because his speech was not smart. Finally, he had the idea to get his hat dangerously close to the fire while pretending not to notice. As his wife watched him sitting still apparently unaware that his hat was about to burn, she

grew nervous and said "Lok at the fai (Look at the fire)." When he heard the way she spoke, he knew that she too was half-mute like him. He made fun of her and said "Loga she tong (Look how she talks)." As her mother peeked at them through the door, in order to see if her son-in-law's speech was smart, she was astounded to discover that he was also mute. She said, "Bo o de a mus (Both of them are mutes!)." Her husband said, "Hepis! Ma fei (Helpless! My fate!)" ("Bonsasawon," 1910; "Hanjibe se sikgu," 1907)

The parents in the story sought to have a son-in-law with a "smart" way of speaking. The mother of three daughters tried to help them get married by hiding the fact that they were half-mute, but they ultimately fail to conceal it. Moreover, they are also terribly disappointed to learn that their son-in-law is a mute just like them and their daughter, and they lament their fate as a "mute family," having not one family member in two generations who can speak very well.

The fact that this story of the "fateful" half-mute son-in-law was printed two different times in this newspaper tells the urgency of this story's message. The final words of that story may be particularly helpful in interpreting what is being represented in this newspaper by means of the metaphor of the half-mute or mute. The father of a half-mute daughter exclaims, "Helpless! My fate!" He and his wife were desperate to gain a new family member who could speak out in their place, as they were half-mute. But now they resign themselves to their fate, and the father's words clearly reflect the intensity of their frustration. He cries out his recognition that they are cursed to remain a half-mute family.

Different disabilities portrayed in this section of the newspaper represent different voices, situations or perspectives, and they are presented in very different tones, particularly between the stories of blind people and those of deaf or mute people. While the newspaper seeks to instruct people who are blind and command them to open their eyes, the stories of

mute and half-mute persons typically illustrate a family's situation, focusing on the perceived tragedy of it. Thus, it seems that the newspaper presents the stories of mute and half-mute persons in a much more empathetic tone than that of the stories of blind persons. One editorial in this newspaper speaks with a similar empathetic tone.

In the sick Korea, people lack knowledge; there is corruption of morals; manners are wild and an unfortunate fate emerges. The only one teaching and leading them is the Newspaper (...) Newspapers, who today carry such a great duty and responsibility on their shoulders, are not free at all. They've become half-blind and half-mute, because their eyes of spirit and truth have been pulled out by a sword, and their mouths of love and goodness are burned inside with flames. How can they fulfill their duties and responsibilities? (Gak singmun wihyeopaneun, 1909)

The newspapers in the early 1900s were explicitly used as tools not only to teach, enlighten, and change Korea, but also to resist the Japanese domination of Korea. The belief that the only way to rescue Korea and its citizens besides military resistance was the voice of the newspaper led to the establishment of many new newspapers around 1883. Both inside and outside of Korea, many efforts were made to speak out through the medium of newspapers, analogous to the families of half-mutes seeking to have a new member who could speak well. However, it seemed that these efforts failed, as Korea was unable thereby to escape the situation in which they could not speak out clearly; their mouths of love and goodness are burned with flame; and they become half-mute. The significance of half-muteness as a metaphor for the condition of the newspapers can be seen in another news article in the same issue of this newspaper, about the discontinuance of other newspapers:

Do you like being a mute?

The sale and distribution of the 144th issue of Sin-han-min-bo [a name of other newspaper] and the 61st issue of Dae-dong-gong-bo [a name of other

newspaper] are prohibited for breach of public order. (“Beongeoriga jonnya,” 1909)

As seen in this news brief, the condition of being mute is used to refer to the state of newspapers without freedom of speech. In this vein, the “flame” can be thought of as the censorship which was imposed by Japan. On July 24, 1907, the Korean government, in forced submission to Japan, enacted the Law of the Newspaper, which aimed to suppress and control Korean newspapers that had been active in speaking on behalf of Korean Patriots. Under this law, even Korea Daily News – which was published by a British man (though the contributors and almost all administrative staff were Koreans) – could not evade the Japanese censorship. It rendered nearly all the newspapers’ condition one of “silence” and “darkness” in the years leading up to 1910, when Japan took away the national sovereignty of Korea. To many Koreans, the loss they had suffered was unbearable.

The (half-) mute can be understood as symbolizing Koreans themselves being enervated by its loss of voice. The voice of despair expressed by the father (“Helpless! My fate!”) was first published after the enactment of the censorship law in the year 1907, and echoed again (when the story was reprinted) just prior to the forced discontinuance of Korean national sovereignty in the year 1910. In addition, it cannot be a coincidence that the *pyunpyungidam* section first appeared in 1907, and featured stories relating to disabilities increasingly year by year until 1910. The empire of Japan prohibited Koreans to talk about its colonization of Korea, and this prohibition applied especially to newspapers. It was a terrible suffering for Koreans to become “a mute,” being unable to say even one word, even though they discern what is wrong or right (“Pirichunchu,” 1910).

Disability Metaphor in Patriotic-Enlightenment Project in Korea

A metaphor is an analogy comparing two objects or ideas, conveyed by the use of one word or phrase in the place of another. Metaphors rely on, and in turn reinforce, the supposition

that the two concepts involved are equivalent, even though they are usually entirely different in reality. *The Korea Daily News* – a patriotic enlightenment-oriented publication – applied this metaphor to “ignorant” Koreans who persisted in tradition, and to citizens whose way of life made them “illegitimate” participants in the new, modern Korea, equating their condition with that of blindness. While this metaphor of blindness was used for Others, the mute and half-mute metaphor was also used for the media itself, to express their despair and helplessness at their inability to resist colonial oppression. Similar metaphoric usage of disability increased conspicuously during the Japanese colonial time (1910-1945), especially in modern Korean literature. Characters with disabilities in Korean modern literature during this time often represented Koreans who were unable to protect themselves against Japan and could not speak freely under Japanese censorship (Choi, 2001; Han, 1991, 2005.); this trend closely resembles the mute/half-mute metaphors examined in the present study. According to Choi (2001, p.434), impairment and disability in such Korean literature during colonial times were “phenomena that are *socially* produced, maintained, and enforced” through “the physically impaired and disabled figures' struggles to become socially able beings” with an “anti-colonial message.” This practice of using disabilities as a metaphor in literature continued even after liberation from Japan, although less literature of the kind was produced, and with some different traits, such as the change of main characteristics from physical disabilities to psychological or mental illness, or newly coined terms referring to people with disabilities (Choi, 2001).

This usage of disability metaphors was not coincidental but resulted inevitably from the interaction between colonialism and the new ideas of western modernization and enlightenment during the 19th and 20th centuries. In particular, the otherizing process of individuals with disabilities in *the Korea Daily News* is also reflected in the discourse of civilization, which was another dominant cultural discourse created and enforced by western and Japanese imperialism. The western idea of civilization has been used as a justification for colonizing

non-western and “uncivilized” countries (Hall, 2007). Japan, the first country in East Asia to contemplate and adopt western ideas of modernization, used the same dichotomy of civilized vs. uncivilized (i.e. barbarian) as a rationale for its invasion of other Asian countries including Korea (Ham, 2004). Japanese imperial invasions were framed as providing the benefit of civilizing other Asian countries, and Japanese colonialism was credited as the catalyst for the modernization of Korea. Ironically, this imperial discourse of civilization was also used by Korean intellectuals to achieve national independence against imperialism.

Freedom and independence are key concepts in the early modern newspapers in Korea and were most frequently mentioned in *the Korea Daily News*. According to Ryu (2005), they have a dual meaning: one is the condition on the national level, of not being subordinate to other countries, and the other meaning is the independence of the people as individuals. Most Korean elites believed these could be only achieved by actively adopting a western idea of modernization and changing Koreans into “enlightened” citizens. Moreover, national and individual independence were strongly connected in early modern Korean thought. An individual’s independence – meaning their ability to work for their own living in the newly modernized society – was considered a prerequisite condition for the national independence of Korea. In this vein, any presumed dependence became a target to be rejected, and *Korea Daily News* used a mechanism of exclusion to bring about their desired change in society. Park’s explanation (2004) about excluding “Others” during the Korean enlightenment period is useful in explaining otherizing process including individuals with disabilities in the newspaper. Park (2004) argues that the common contempt for exclusion of Others helped people who produced and maintained ideas of enlightenment and national discourse to bind together. Additionally, during the 19th and 20th centuries, the idea of “new” and “modernized” nations was being invoked around the world, including exclusionary discourses and practices toward presumed

non-citizens. Korea in the 1900s was not exceptional in this regard (Park, 2004). Cleall & Gust (2021)'s explanation sheds light on this history:

In questioning the boundaries of humanity, however, they constructed a hierarchy of embodiment, with the able-bodied, white, and elite man at the pinnacle, leading the path of “civilization” and “progress.” The consolidation of this paradigm during the course of the nineteenth century led to disabled people being increasingly understood as defective and aberrant, in need either of curing and assimilating to fit the norms of society, or of eradicating entirely (Cleall & Gust, 2021)

As the nineteenth century in western history shaped the repugnant image of people with disabilities, the early twentieth century in the wave of modernization in the Korean colonial context “led to disabled people being increasingly understood as defective and aberrant, in need either of curing and assimilating to fit the norms of society, or of eradicating entirely” (Cleall & Gust, 2021).

One circumstance that deserves attention is the way exclusion was used both by colonial oppressors and by patriotic movement leaders during this period. Although Korean intellectuals wanted to resist Japanese oppression, they went about this, ironically, by means of their own exclusion strategy, resulting in oppressing other marginalized groups and projecting them as barriers to the achievement of a new modern independent nation, as this research has examined. Similar otherizing/exclusion processes were also carried out within Japan and Western countries against members of their own societies as well. In particular, otherizing by use of a dichotomy was a universal strategy in the colonial period. The British empire used the civilizing mission concept, which included enlightenment ideals as a justification for its imperialism in colonizing other countries (Ham, 2004; Schmid, 2002). Japan used the same dichotomy of civilized vs. uncivilized to justify its political interference in Korea as well as its colonization (Ham, 2004; Schmid, 2002).

Ghandi (2019) pointed out the problem of anti-colonial nationalism, which paradoxically learned key lessons from the oppressors it opposed. Korean intellectuals, especially invested in enlightenment patriotic newspaper production, used the same dichotomy framework of new Korean new citizens vs. Others in their criteria for meeting a western standard of modernization. Any group of people who deviated from the image of newly modernized (i.e., westernized), enlightened, productive, educated, and independent citizens were regarded as others. This list included metaphorically blind people, those unable to “see” this social change, those who maintained a traditional fortune telling profession which was an object of iconoclasm, those who may live as beggars, again entirely out of step with the idea of a modernized society, even though certain forms of poverty are also results of modernization.

One may argue that there is a logical leap in reasoning that these disability metaphors in *the Korea Daily News* created actual exclusion of contemporary people with disabilities. It is worth noting that enlightenment discourse did not exist only on a symbolic level, but was strategically aimed at disturbing Korean individuals’ desire to be transformed into enlightened citizens (Jung, 2003). People with disabilities who were considered abnormal or had already been marginalized (therefore categorized as Others) could only be accepted by demonstrating their transformation into faithful subjects of the patriotic enlightenment movement (Jung, 2003). The ideas of individual’s differences, rights, needs, and desires were not yet considered relevant, and even current “postmodern” societies still struggle to escape the discourse of independence, productivity, and contribution as requisite conditions for legitimate citizenship. In addition, the cultural discourse as social praxis soon become the reality (Hall, 2007).

The concept of subaltern (Guha & Spivak, 1988) may be useful in explaining this relationship between the patriotic Korean enlightenment intellectuals activists who produced and circulated this otherizing discourse and people with disabilities who were constructed as Others by this media discourse. The subaltern studies, particularly in the context of India, explain how subaltern groups actively resisted both colonial power and domestic oppression, unlike the dominant historical explanations that emphasize the influence and leadership of middle class educated elite groups. Similarly, it is critical to recognize that *the Koran Daily News* was the dominant voice of Korean elites during that time, while the voice and the silence of contemporary subaltern groups, such as people with disabilities, still needs to be explored through different historical sources and methods.

Starting with several “strange” stories relating to disabilities in *the Korea Daily News*, I encountered a wave of modernization and enlightenment influences during the colonial period in Korea, which had a critical role in creating the disablement practice especially by using negative metaphorical images of people with disabilities in the media. Korean early 20th century intellectuals conveyed their voices in this newspaper, producing and circulating the disability stories. In these stories, people with disabilities are subject to deficiency as a metaphorical tool to convey the idea of western enlightenment and modernization and the suffering of ongoing Japanese censorship. Even though their intention was to suggest how Koreans could overcome this colonial situation and proceed to become a modernized and enlightened society, in the process they stigmatized and marginalized people with disabilities in their discourses. In addition, simply, *the Korea Daily News*’ use of disability metaphors transforms something natural into something ugly (Sontag, 2002). While we cannot live without metaphors, the words we use expose our attitudes toward others, and so we ought to be careful about the metaphors we choose to use (Sontag, 2002). This type of discourse that blames others using the metaphor of disabilities seems particularly dangerous. It is reminiscent

of the discourse of the social burden, which has continued to promote the underlying concept of eugenics since the beginning of the 20th century. Since we still live in the time or the result of modernization and colonization, more research would be necessary to examine how the metaphor of disabilities in media has been constructed in the linear and superficial approach of modern and colonial knowledge in the world.

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Disability Metaphors and Patriotic-Enlightenment Movement in *the Korea Daily News*, 1907-1910 <https://rdsjournal.org/index.php/journal/article/view/1126> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

Research Articles and Essays

Temporal drag, Radical Negativity and the Re-articulation of

Disabled Identities in American Horror Story

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Abstract

American Horror Story (AHS), a US anthology horror series created for cable network FX by Ryan Murphy and Brad Falchuk, broke new ground in its capacity for presenting disabled bodies in most of its interconnected miniseries. In an (almost) ensemble cast throughout, disabled characters were most in evidence in series four, 'Freak Show', with several parts played by disabled actors, e.g., Mat Fraser (Paul), Jyoti Amge (Ma Petite) and Rose Siggins (Legless Suzi). Additionally, Jamie Brewer, an actor with Down Syndrome, was featured in several of the series (as Addie, Nan, Hedda. Marjorie, before reprising Nan, allowing her to run the gauntlet of character types). AHS has been seen to offer much potential in 'queering' representations on many axes, especially, sexuality and gender; Geller and Banker (2017), for example, have argued that the show creates 'temporal drag' through its rejection of 'historical verisimilitude'. Women, particularly female 'stars' also played significant central and recurring roles, once again challenging the conventional positioning of women within the horror genre, whilst simultaneously troubling, repeating and neglecting some familiar tropes, e.g., the excision of the monstrous woman and the whiteness of history (King, 2016). Taking forward the idea that the show queers the normativities of reproductive futurism (argued by Geller and Banker) this paper considers the value of the show for the

depiction and rethinking of disabled people's subjectivities, particularly in terms of use of 'temporal drag', and 'radical negativity', e.g., embracing sex, death and violence. The paper concludes that progress in disability representation has been made, but that significant narrative and representation inequalities remain within AHS.

Keywords: American Horror Story, narrative inequality, temporal drag

Understandably, there was much excitementⁱ about the inclusion of disabled actors in American Horror Story (AHS), an anthology horror series (FX) featuring an (almost) ensemble cast of well-known actors throughout, including Jessica Lange, Angela Bassett, Sarah Paulson and Kathy Bates. Whilst these and other high-profile actors perhaps added to the marketing, appeal, and success of the show, it is of some significance that it also took ‘risks’ⁱⁱ with the employment of disabled actors, introducing the audience to Jamie Brewer, an actor with Down Syndrome, as a regular player throughout the anthology series. Moreover, alongside the roles played by Brewer, there were several significant parts played by other disabled actors, e.g. Mat Fraser (Paul), Jyoti Amge (Ma Petite) and Rose Siggins (Legless Suzi).

Not only did this mean that ‘real’ disabled people gained much higher visibility, and were able to showcase their talents, the potential for groundbreaking portrayals of disability was high, especially as AHS has been seen to offer much potential in ‘queering’ normative representations along several axes, especially sexuality and gender (see Geller and Banker, 2017). Indeed, AHS can be seen to tick several diversity boxes in its presentation of disability and impairment. This is most notable in terms of greater equity in the employment of disabled actors – across impairment groups— and can also be seen on content, especially in the agency of disabled characters, and the disabled people’s activism which ensues. Season Four, *Freak Show* (henceforth *FS* when referring only to AHS’s *Freak Show*), in particular, provides themes which echo some of the earlier radical content of Tod Browning’s 1932 ‘horror’ film *Freaks*, which was arguably the most political representation of disabled people in the history of cinema (see Markotic, 2001 for an analysis). One of its greatest similarities was that they both portrayed a range of disabled characters whose guiding principle is that of solidarity to other disabled people. As Nussbaum argues, *FS* ‘replicates’ the focus on

‘horizontal identities’, the driving force of *Freaks*, where people defined by their bodily difference from accredited norms take this identity as core, as a point of pride. Importantly, in both cases it is clear to the viewer that these horizontal identities are a matter of survival against disabling norms, with only those who are trusted as non-oppressors accepted into the group of disabled people as ‘one of us’ⁱⁱⁱ.

For these reasons alone, *FS* can be judged favorably, taken on a standalone basis, especially in terms of its inclusion of disabled people and its rights-based content. However, we cannot assume that the inclusion of disabled actors or such political content is sufficient; the way a story is told is fundamental to what meanings we take from it. This is a lesson we have learned from the restructuring of potentially valuable stories of disabled people’s lives being used to promote inspiration porn (see Mureda, 2020). Instead, we need to consider the complexities of cultural representation and viewer interpretation, the wishes of the marginalized disabled audience, and the obduracy of media stereotypes in production contexts which are governed by commercial interests. Specifically, we need deeper analysis to gain better understanding of how AHS, as a whole, has contributed to the evolution of disability representation, and whether or how it has moved beyond the narrative and representation inequalities which dominate the mediascape. Further, given the re-articulations of disabled identity, and the fluidity of portrayals therein, there are other novel aspects of disability representation in AHS which may serve to persuade us to rethink some of the criteria on the disability movement’s recommendations for improving media portrayals. Arguably (perhaps), one of the progressive qualities in disability representation within the whole show lies in terms of including disabled people in its ‘radical negativity’^{iv}, something which may be seen as antithetical to disabled people’s media agendas, especially to appeals for ‘positive’ imagery, an approach which will be considered further.

I am arguing that *FS* needs to be contextualized within the entire anthology to be able to give it the scrutiny it deserves. As enjoyable as *FS* was, the presence of disabled actors, or indeed of actors from Black and other marginalized groups, is no guarantor of representational change, of narrative equality, or of meaningful impacts on re-articulations of disabled identity in the wider world, as I have argued elsewhere (Wilde, 2018).

Fundamentally, then, I start this analysis by raising key issues of narrative and representational in/equalities, across all series.

Disability, multiplicity and AHS

As suggested, the majority of the disabled actors in AHS were in S4, *FS*, the only season which was overtly associated with disability. In addition to the actors already mentioned (Fraser, Siggins and Amge) there were other disabled actors in *FS* in more minor roles, including Benjamin Eric Woolf and Drew Rin Varic^v. I believe it to be important to mention them in this paper, especially as their presence lent added authenticity to the ensemble in the context of the freak show, serving to make the whole cast of ‘freaks’ feel more genuine, despite the casting of several non-disabled actors. Other actors who tend to be marginalized in the screen professions were also cast as freaks, people who lived their embodied status in their real lives – Erika Ervin, also known as Amazon Eve (a woman who is six feet and eight inches tall), and Chrissy Metz (a woman who is much larger/heavier than average).

Notably, Woolf’s appearances in two series placed him in sharply contrasting roles. In S1 he was cast as Infantata (a dismembered baby brought back to life as a bloodthirsty ‘monster’), and in S4 he played the character of Meep, a mild-mannered ‘geek’, who only speaks his own name. Historically, those employed as geeks were there to instill fear in the audience through the performance of ‘disgusting feats and tricks’ (Germann, 2002, para 1),

often biting the heads of chickens in the original freak shows. The ‘geek show’, warm-up element of the freak show placed ‘geeks’ as the lowest of the low within the cast, and they were treated as such (Germann, 2006). Although Meep’s portrayal retains historical verisimilitude in the latter sense, both characters could be criticized for their resemblance to dominant tropes of dwarfs. Woolf had pituitary dwarfism^{vi}, and his portrayal of Meep can be interpreted as falling into the categories of ‘comic sidekicks or magical freaks’ especially as he is in a freak show (Martin, cited in Benedictus, 2010, para 2). Similarly, his Infantata character could be seen to echo conventional portrayals of dwarfs as evil (Barnes, 1992). But Woolf’s placement in two completely different roles refuses a straightforward stereotyping of his impairment, as an individual actor or as a representative of the dwarf community. Moreover, these characterizations should be placed within the context of the whole show, where many non-disabled actors also play freaks of one sort or another, with many exhibiting traits of evil, and few being presented as ‘positive’. Together, this spread of roles and personality attributes indicate a considerable degree of narrative and representational equality within *FS*. However, as Brewer and Woolf were the only disabled actors to appear in more than one series, this made for a sharp contrast with many of the non-disabled cast; leading roles, across the whole anthology, including some disabled characters, were played by actors such as Frances Conroy, Lily Rabe, Kathy Bates, Lange, Evan Peters, Sarah Paulson, and Angela Bassett.

Jamie Brewer: The destabilization of Down Syndrome and disabled womanhood

As suggested, Jamie Brewer was the other actor who was given an opportunity to show an impressive range of acting skills. Indeed, her inclusion as a recurring member of the cast, in a number of different roles, is perhaps the most radical re-presentation of impairment, or disability that we might find in recent years, especially as she was allowed the freedom to

challenge conventional portrayals of Down Syndrome without recreating new stereotypes. Although I have argued that the creation of stereotypes is largely unavoidable (Wilde, 2004; 2018), this form of horror fantasy enables a strategy of ‘radical excess’, i.e., ‘difference – radicalised difference, or very briefly, difference that cannot be contained by any unifying system’ (Ang and Stratton, 1995, 124). Such features are evident throughout AHS – whereby there are few norms to deviate from and there is a continuous ‘destabilisation of the natural’ (Kuppers, 2002, 191), which tends to deconstruct conventional abnormality/normality dualisms, exposing ‘common-sense’ understandings of impairment and disability. Other dimensions associated with more realist fare are also thwarted, even our expectations of life and death; some of Brewer’s characters, like others, continue to exist in different guises after they die. Nowhere is this strategy of radical excess more apparent than in the characters played by Brewer. Moreover, her shifting roles created additional fluidity, defying any urge to stereotype.

Jamie Brewer was introduced to us from the start as a key (if not leading) member of the cast in Season One as Adelaide ‘Addie’ Langdon, daughter of Constance Langdon, played by Jessica Lange (a leading actor in the first four series), then went on to feature in several later seasons (as Nan, Hedda, Marjorie, then Nan again). The first of these roles cast Brewer as an abused dependent of her mother, but she was also a threatening character who was defiant at times. It could easily be argued that this first role drew on previous cultural understandings of victim status and Down Syndrome, learning difficulties, and disabled womanhood, but the complexity of Addie’s character skewed this considerably. As Brewer then went on to occupy a multiplicity of roles in AHS, this disruption of stereotyping much went further. Disturbing such tropes even further, subsequent roles she played included the promiscuous, clairvoyant witch Nan in Season Three, *Coven*. Nan’s occult powers and sexual

appeal are underestimated by all those in the coven with Nan going onto a relationship with her new neighbor, Luke Ramsey, perhaps reminding the audience not to make assumptions about her desirability. Nan is eventually killed as a sacrifice to Papa Legba (the gatekeeper of the spirit world), ending up in 'hell' as his sidekick, a position which she prefers to her previous life in the coven (she returns with him, much later, in Season Eight, *Apocalypse*). Having established herself in a range of roles, Brewer then goes on to play a ventriloquist's dummy, Marjorie, in Season Four, *FS*. This was a notable casting decision given that this series presented all its other disabled cast members as acts within the freak show. To complicate her parts even further she is not just cast as the doll – the puppet's master Chester believes her to be a real person, thus her primary role is to act in Chester's hallucinations, often in a cruel and manipulative ways, driving him to acts of violence. By her third role then, the audience have seen her shift through a wide range of personalities, and a key development in this role lies in Chester's utter dependence on her, including her opinions of his attitudes to women, and love and sexual relationships. This, and her capacity to initiate violent acts, progressively take her further away from our expectations of cute and cuddly, innocent, helpless depictions of Down Syndrome.

Forcing these re-articulations of disabled women's subjectivity further – having firmly established that people with Down Syndrome are sexual subjects, have strong identifications with other women (including those who are non-disabled, especially in *Coven* and *Cult*), hold capacities to control others, and are as capable of evil and violence as anyone else – she goes on to play the part of a member of the feminist, anti-patriarchal group SCUM, in Season Seven, *Cult*. The SCUM cult, like many other aspects of the show, refers to, or is based loosely on, historical events, in this case the publishing of Valerie Solanas's S.C.U.M. Manifesto (see Solanos, 1967). The changing form, and semi-ensemble cast, and a time-

hopping structure across all the series, allowed her to present a range of character types, something which seems unprecedented, especially for someone with her impairment. Although people with Down Syndrome, and people with intellectual impairments generally, have been afforded a larger range of roles^{vii} over recent years, many of which have included radical departures from old tropes^{viii} (e.g., dependency and infantilization (Arnold, 2018, Mathews, 2018)), such fluidity of personality and character is maximized in media which offers a range of characters, offering a more diverse range of portrayals and personality types. Old stereotypes also tend to unravel when a greater number of disabled characters are shown, with the frequent exception of dwarfs (Wilde, 2018); this occurred, for example, when a range of different actors/characters with Down Syndrome were cast in *No Offence* (2015-2018), encouraging us to acknowledge the heterogeneity of the community of people with Down Syndrome (Jones, 2015).

Brewer's occupation of a multiplicity of roles in AHS, spread over different time periods – including resurrections of individual characters throughout different seasons – can be theorized as a form of 'temporal drag' (Geller and Banker, 2017, explained further in the next section). As such it has taken the deconstruction of stereotypes much further, shattering ideas of fixed identities. Significantly, her inclusion in the temporal drag of the show puts her on a par with the non-disabled characters of the main ensemble cast. I have argued elsewhere (Wilde, 2004; 2018) many of the problems with stereotyping lie in relationships of narrative and representational in/equality. That is, it is usual to see multi-dimensionality in non-disabled characters, whose personalities are often allowed to evolve, though we can see them conform to stereotypes in phases of their evolution. Conversely, stereotypes of marginalized groups are rarely afforded such fluidity, and often denied 'the full range of humanity' (Bowdre, 2009,107), largely dependent on the positioning of non-disabled bodies (like white

and/or and middle-class bodies) as ‘coterminous with the endless plenitude of human diversity’ (Dyer, 1988, 47, cited in Bowdre, 2009, 109).

Apart from the roles played by Brewer and Woolf, all the remaining disabled actors are to be found in S4 as suggested. As good as this was in presenting new, or revised versions of disabled personhood (albeit many ideas borrowed from in *Freaks*, 1932), closer analysis of S4 will be valuable in investigating the re-presentation of both impairment and disability. Comparison of other disabled characters and actors’ roles, and the ways in which these relate to the whole anthology will be especially useful in investigating rearticulations of impairment tropes and politicized portrayals of disability.

Themes of disability and disabled characters in *Freak Show*, and *Asylum*

Freak Show

As suggested, *FS* carries most of the burden for disability representation across the entire AHS series, especially as that it where we meet most of the disabled actors. Many disabled people welcomed the visibility of disabled actors in FS, despite some concerns about the exploitative potential of this season (Nussbaum, 2014). However, disabled people are undoubtedly underemployed in the show as a whole. In FS, a minority of non-normative bodies are played by disabled people, an estimated six/seven amongst a cast of forty-four, with a further eight/nine disabled/freak roles played by non-disabled actors (see below for examples). The predominance of non-disabled actors seems especially problematic in a genre which relies heavily on the depiction of abject and non-normative bodies and minds. Nonetheless, with the emphasis of this series placed firmly on disability and explorations of ideas of freakdom, it echoed and developed many of the themes Browning’s *Freaks*. Clear

similarities can be seen in expressions of group solidarity and the reversal of the insider/outsider hierarchies which position disabled people as abnormal, even as ‘bare life’, a state conceptualized by Agamben as a state of exception from social/human life structured through biopower (discussed in relation to disability, in Reeve,2009). Like *Freaks*, FS often works to show disabled people in situations which challenge audience expectations of disabled people, position them as important and valuable human beings, whilst retaining elements of spectacle, refusing a simple reversal of moral protagonism, and rejecting the safety of happy endings.

Despite the disabled actors being comparatively few, most of these had significant and multidimensional roles, most of which transcended conventional portrayals, e.g., in the depiction of disabled bodies as sexual agents, as desirous, and desirable. The inclusion of several disabled actors also allowed for a more diverse range of disability representation, including various impairments as well as Black disabled women, or disabled women ‘of colour’^{ix}, who are rarely employed in film and television (Wilde, 2020). Furthermore, whereas the context of the freak show immediately positions the disabled actors (as well as the non-disabled actors playing ‘freaks’) as a spectacle, often based on historical figures^x or trends (Lewis, 2020), the showcasing of disabled people performing extraordinary or spectacular feats was kept to a minimum, focusing more on their lives within the freak show/world. Mat Fraser for example had previously used Sealo’s original freak show act as the basis for one of his own, amalgamated in his portrayal of Paul as the ‘Illustrated Seal’,^{xi} but FS focused on his life narrative rather than these acts.

Like most of the other series, the plots are complex and intertwining, with a large cast, far too intricate to do them justice within one article. However, taken as a whole, it seems accurate to say that, as integral as the disabled actors are to the story telling, none of them are

amongst the main protagonists. In addition to viewing the series, a cursory glance at cast lists of main, recurring and guest characters^{xii} shows this to be the case, with all main parts being played by members of the main AHS ensemble. Whilst most of the disabled characters show a great deal of capacity for self-determination and resistance to the oppressive and evil forces surrounding them, invariably non-disabled aggressors, it is often the disabled characters who become the victims of cruelty and violence. There is certainly a strong case to show the barbaric treatment of disabled people given the history of freak shows, especially as few characters escape the violence or supernatural forces which are a hallmark of whole show. Stories such as the capture, killing and subsequent exhibition of Ma Petite at the Museum of Morbid Curiosities, are often portrayed as a necessary form of magical realism which fits with the show's broader commentary on many aspects of society, historical and contemporary e.g., cults and forms of neoliberal governance in Series 7. This is offset well with the magical realism within the rebellion of the 'freaks' in the penultimate episode. At this point, they attack Stanley, who has come to the community to recruit 'freaks' to the Museum of Morbid Curiosities and make him look like Meep - a homage to the finale of *Freaks*, where the freaks reshape their adversary Cleopatra into a human duck.

Despite their casting outside the core groups of the 'main cast', it is also true to say that the disabled characters (played by both disabled and non-disabled actors) were endowed with many personality traits, and significant back stories, enabling them to thwart what the audience comes to expect of supporting disabled actors; they are certainly not treated as ciphers for the journeys of the non-disabled leads (Darke, 1998; Shakespeare, 1997, 23). Most characters tend to be multi-dimensional in their own right, and the presence of multiple disabled actors, with varying impairments, and diverse personality traits added to this.

Paul's character, for example, shows him as an ambitious person (having tried to seek

Hollywood fame through his move to the US), who is unashamedly vain, e.g.; “I have the face of a pretty lad. A handsome face. Could you imagine this mug on a normal body? I could have ruled the world” (also quoted in Oswell, 2014). His beauty and sexual status also play out in his appeal as a lover, (particularly to Elsa Mars), within orgies, and eventually in his love for Penny, initially a hospital volunteer who has inherited a disablist attitude from her father, who he eventually turns into a freak as punishment for her relationship with Paul. But Paul has many other significant traits: he is also angry at his ‘monster’ status, as his comments on his pretty face imply, but shows a great deal of compassion towards Penny’s eventual ‘disfigurement’, blaming himself. He is also one of the leading protagonists of the community of freaks, opposing the mistreatment inflicted by the new owner Dandy Mott, actions which lead eventually to his death. Similarly, Legless Suzi’s character, while more peripheral than Paul, shows variation across the FS season; although she is eventually killed with her fellow freaks, she is an important member of the disabled community, demonstrating along the way a significant capacity for violence. The only characters played by disabled actors who are cast in roles which are close to stereotypes of their impairments, are Woolf’s roles as Meep (as discussed earlier), and Jyoti Amge’s role as Ma Petite (she is the smallest woman in the world, according to Guinness World Records, 2021), notwithstanding a similar stereotype in the character of Pepper (see Asylum section). Ma Petite’s child-like, innocent traits and eventual kidnapping and murder are quite typical of the stereotyping of people with dwarfism (Wilde, 2018), especially the infantilization which they are made to endure in their everyday lives (Shakespeare, 2010).

These complex personality traits lead us away from fixity to more dynamic, open-ended expectations of what disabled people are or what they might be, what they do or may do. A key component within this is their participation in ‘negative’ portrayals; as such they

have an equal stake in the ‘radical negativity’ of the whole show. Geller and Banker demonstrate the radical potential of this negativity, where negative states of being (including violence, sex, extreme ‘carnal aesthetics’, witches, asylum inmates, and monsters) are seen as central for the production of meaning and being. Indeed the ‘freaks’ are one of the many aspects of the whole show which carry the radical negativity ‘opposed to every form of social viability’ as theorized by Geller and Banker (2017, 43). As can be seen, in most of the examples above, all of the disabled actors, and indeed the disabled characters, are placed in storylines which demonstrate ‘negative’ dimensions of personality, and some of the destructive forces which ruin their lives. Whilst such portrayals may have been met with disapproval from disability scholars, and the disabled people’s community, over the last few decades (e.g., Barnes, 1992), especially as common victims of violence, there is no doubting that these social dynamics exist and are a part of our history, and of contemporary life. Indeed, some authors have written on the virtues of similar portrayals as forms of ‘radical negativity. Halberstam (2011) has written that ‘queer negativity’ and ‘radical passivity’ position the work of artists such as Yoko Ono and Marina Abramovic – emphasizing masochism, submission, fragmentation, and sacrifice^{xiii}, as statements of radical passivity, ‘of pure opposition that does not rely on the liberal gesture of defiance but access another lexicon of power and speaks another language of refusal’ (139). He goes on to say that art such as this

binds the perpetrator to the criminal, the torturer to his victim, the corporate raider to the site of pillaging; collage shows the open mouth, the figure in distress, the scream and its cause; it glues effect to cause and queers the relations between the two (144), and suggests work such as Ono’s ‘inhabits a form of unacting, unbeing, unbecoming’ (145).

This queering of subjectivities, being, and normativity, and the power of radical negativity also lies at the center of Geller and Banker's (2017) analysis of *AHS*, as a show with radical antisocial queerness at its core. They also suggest that its disruptive capacities are driven by the creation of 'temporal drag'. They argue that the show contrasts sharply with the usual serial televisual structures, by the 'narrative momentums' (29) offered by temporal drag. Put as simply as possible, combined with the role of the death drive, as a key part of the radical negativity of the show, the use of temporal drag rejects historical verisimilitude, and a linear 'chain of events' (40), even refusing death as the end of life (several characters come back to life within and across the series^{xiv}). Together these are theorized to pose a challenge to the real world 'politics [] propped on the fantasy of the (reproductive) future' (36).

It is even true to say that disabled characters are included in this temporal drag *within FS*, as they exist in the afterlife, where Penny and Paul are now married and all the freaks perform as before. However, this is a very limited form of inclusion. Unlike many of the other characters, and actors, the temporal drag afforded to the freaks is contained within the bounds of *FS*. We do not meet them in other seasons. Given the radical excess and key mechanisms of radical storytelling this is a significant form of inequality, which I will briefly return to in the final sections.

Asylum

Despite the association of *S4* with disability, impairment and disability were present, if less explicit, throughout most seasons, most notably in season 2, *Asylum*, set in Briarcliff Manor in the 1960s. Themes of madness and oppressive power relations between inmates and their caretakers are writ large within this series. Of particular note are the links made between institutionalization, mental illness, disabled people, cruelty, and religion, with many of the evil acts committed by nuns and clergy, especially Monsignor Timothy Howard, Sister Jude

(Jessica Lange), and Sister Mary Eunice (Lily Rabe, possessed by The Devil in the course of the story). There is also a potent theme established between the disablement of those who have labels of madness imposed upon them by medical professionals, and their ultimate demise. This is embodied in the character of Oliver Threadson, at first portrayed as a benign and kind-hearted psychiatrist, who sets out to rescue Lana Winter from her wrongful confinement, before the show exposes him as the serial killer 'Bloody Face'. Indeed, *Asylum* covers many of the bases of disablist oppression. It is eventually revealed that Dr Arthur Arden, the asylum's Administrator, was former Nazi doctor and scientist Hans Grüper, who is using the inmates to continue his experimentation; this commonly involved severe mutilations to, and mutations of, the inmates' bodies. As such, the disciplinary regimes or ideologies of religion, medicine, and politics can all be seen to contribute to the horrors of the asylum and the oppression of those locked within it.

Not only does present set clear themes of disablement, focused on the evil power relations of those who wield it, it also introduces us to more characters we will meet in later series, including Lana Winters, played by Sarah Paulson. Another of these was Pepper, an inmate of the Asylum. Pepper was played by a non-disabled actor, Naomi Grossman. Born with microcephaly, her back story is that her family abandoned her to an orphanage and Elsa Mars (as played by Jessica Lange) rescued/ recruited her for her Cabinet of Curiosities, i.e., the freak show. Like many others in the asylum, she was put in the asylum against her will after being framed for a crime she didn't commit; indeed, she played a comparatively innocent, playful, friendly, yet timid person in both series (see the AHS wiki for examples), closely emulating the personalities of those with similar conditions in *Freaks*^{xv}. One might argue that Pepper's character is a little more retrogressive than her predecessor 'pinheads' in *Freaks*. In both cases, the show is owned by a woman who shows some degree of

benevolence towards those she recruits. Elsa Mars employs Pepper as her personal assistant, a choice which is akin to the expectations placed on those in by Madame Tetralini in *Freaks*. However, as Hawkins (1997, 268) has argued, the depiction of the original ‘pinheads’ emphasized their childlike traits – often playing, singing, dancing, and giggling – and show how they look to Tetralini as a protector/mother figure, but that the narrative works to tell the audience that ‘physical difference is an accident of birth’ (ibid), and that we should all be treated as ‘God’s children’. Although Pepper’s trajectory through the freak show often emphasizes her humanity, and her life beyond the show (with her cruel family and then in the asylum), demonstrates how society metes out barbaric treatment to many or those deemed different, the moral message to the audience is less direct.

Although *Asylum* was the second season, Pepper’s life in the freak show (S4) came first, quite typical of the time-hopping of the anthology. Unlike Brewer’s character, or that of most of the other ‘freaks, Pepper’s personality is rather stereotypical, resembling many other figures with intellectual impairments across the contemporary mediascape (see Hawkins, 1997, and Mathews, 2018, for example). Indeed, it is impossible to separate the seasons, one from another, by design, as they all have linkages which play out in other seasons, e.g., Gruper’s responsibility for the amputation of Elsa Mars’ (Jessica Lange) legs in S4, set a decade earlier than her roles as Sister Jude in *Asylum* (S2).

Such flipping back and forth between time periods is a key feature of the show. Similarly, the continued/recurring appearances of some characters across seasons, alongside the changing use of an ensemble cast, usually in a time-defying manner (e.g., Grossman’s Pepper back story emerging in S4 after her first appearance in S2), adds to this drag. Hence some non-disabled actors play different characters in various series, while some reprise original roles, with most doing both. But, as suggested, the ongoing inclusion of disabled

actors was less in evidence, with the exception of Brewer, in five of the eight series, and the more minor roles of Woolf (in S1 and S4). The only other forms of temporal drag afforded to the disabled actors' characters were those contained *within FS*, the 'family together'^{xvi} featured in the after-life after they were killed by Dandy Mott. Underlining the temporal drag and radical negativity of the whole show Ethel asks the (afterlife's) freak show audience, and, by implication, us, whether stars shine more brightly in life or death, presenting the newly resurrected Elsa Mars as proof of the latter.

As radical as these strategies have proved to be (Gellner and Banker, 2014), paradoxically, this issue of shining stars is part of the problem of the show – the non-disabled actors (or less visibly disabled) are allowed far more opportunities to sparkle brightly throughout all series, perhaps dimming the gleaming talents of the disabled actors. Indeed, Randle and Hardy (2017) have provided evidence that there is an industry perception that disabled actors are always at 'entry level' effectively preventing their ascension to the heights of stardom.

Further, the show has a greater linearity than some of the other series (e.g., *Murder House*, and *Coven*) with only Pepper appearing as the same character in an earlier series/later time period. Although *FS* is clearly based in a period which marked the end of the original freak shows, whilst indicating that the new age of television and Hollywood will continue the legacy of en-freakment, the end of the freak shows can also be read as implying moves towards a post-disablist society, in much the same ways that *Coven* suggests a post-racial one. King, for example, has argued that while *AHS* has provided an 'uncharacteristic visibility' to women in the genre, as both 'monsters and victims' (557), the narratives in *Coven* serve to both analyse and criticize racial oppression, 'reversing some racists tropes' and presenting racism as 'truly abject', they also reinforce some sexist imagery, and support

the ‘cultural amnesia’ of a ‘post-racial utopia’ (571); she theorizes that this is brought about by the portrayal of the monstrosity of white racism, embodied in the figure of LaLaurie (Kathy Bates). The same seems to be true of aspects of *FS*, with several leading figures, such as Stanley and Dandy Mott marked as non-disabled, treating disabled characters as far less than human in their quest to use them for their own sadistic ends.

So far, I have argued that disabled actors have been offered several opportunities to forge new understandings of disability, and that this is also true of the reformulation of racial and gender relationships within this show. But these portrayals of disability are not in conditions of disabled people’s own making, despite some negotiations (Oswell, 2014). That is, disabled people are rarely in the position of writing or directing the stories (see Wilde, 2018). But I have also suggested that their narrative inclusion is partial and unequal. So, how radical is *AHS* in its re-articulation of disabled identity?

‘Ego loves identity - Drag mocks identity - Ego hates drag’ (Paul, 2013)

AHS has been seen to offer much potential in ‘queering’ representations on several axes, especially sexuality and gender, and in so doing it puts many aspects of contemporary identity in doubt. Geller and Banker (2017) have argued that one of the most significant ways in which the show confounds our expectations of social identities is through its use of ‘temporal drag’ and its rejection of ‘historical verisimilitude’. They argued that the show queers the ‘normativities of reproductive futurism’, which perhaps questions ideas of normality across the board. The interconnectedness of the stories between series and the time-hopping, plus the additional of supernatural, science fiction and occult features is seen to destabilize the ‘formal structures on which reality is propped’ (37), queering linear narratives and creating ‘new expectations of temporality and death’ with characters often returning to life within and across series. This is especially true of depictions of women, with female stars

playing significant central and recurring roles, serving to challenge or trouble the conventional positioning of women within the horror genre, e.g., through a re-imagining of the monstrous feminine, though it has been argued that they repeat some familiar tropes and perpetuate the cultural amnesia of a ‘post-racial society’ (King, 2017).

I have argued that these features of temporal drag are less true of *FS*; like other seasons it has a narrative arc, but it also has a greater sense of closure, despite minor linkages to some of the characters played by non-disabled actors, e.g., Elsa Mars. The vast scope of the show, and its creative attempts to queer time and audience expectations whilst subverting oppressive imagery seem to get in the way of its capacity to hit its representational targets, especially in terms of race and disability. Although we get a glimpse of its potential to disruptive dominant ideologies and to contest utopian visions of the future they are bound up with, e.g. eugenic betterment, the rethinking of disabled people’s subjectivities is less apparent beyond the limits of *FS*. Certainly, *S4* allows just as much opportunity for the disabled characters and the audience to find ‘senseless enjoyment’ in the ‘radical negativity’ of ‘meaningless sex’ and ‘irrational violence’ (Geller and Banker, 2017, 43) which characterize expectations of the whole show, offering a diversity of disabled roles which might otherwise be refused in the name of ‘positive imagery’. This seems to be a step forward. But it is significant that the temporal drag is not afforded to them. As Murphy himself has said, ‘This season, once you die, you’re dead’ (Stack, 2014, para 24).

Thus, temporal drag has been theorized as the primary queering mechanism of the whole show but denied to almost all the disabled actors. The characters played by Jamie Brewer are notable exceptions, although she never returns as her *FS* character Marjorie (a ventriloquist’s dummy). Hence disabled people are still located just outside the boundaries of ‘queer time’ in the Horror Story’ universe, unable to fully harness ‘the powers of horror’ to

‘refute the norms of straight television’. Further, the fact that non-disabled actors cast in leading disabled roles (e.g., Lange, Paulson and Peters) are major players in the ensemble cast serves to exacerbate these considerable narrative inequalities. In terms of representational and narrative equality, it seems fair to say that (a diversity of) disabled actors and stories were integrated well, but that they are not yet included. This suggests that the radical status of AHS, and the progressive affordances of temporal drag continue to privilege whiteness and non-disabled identities.

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Footnotes

ⁱ See Mipuri (2014) and Nussbaum (2014) for example, and their anticipation of a reformulation of disabled identities.

ⁱⁱ As I argued in 2018, the inclusion and exclusion of disabled actors is usually woven into the ‘unconscious bias’ against disabled people as a commercial risk, and assumptions about the safety of casting people with star status.

ⁱⁱⁱ This idea of ‘one of us’ is pivotal to the film *Freaks*, with ‘We accept her, we accept her, one of us’, chanted by all the disabled characters in a key scene, a wedding banquet; this scene is cited frequently in popular culture, references in shows such as *The Simpsons*, and *South Park*, and in popular film and music (the Ramones ‘Pinhead’), and as an influence on Christine and the Queens.

^{iv} Here I am following the work of scholars such as Sedgwick (2003), Halberstam (2011), and Žižek (1993), in (briefly) conceptualizing radical negativity as ways in which cultural representations can ‘valorise negative states of being as key conditions both for the production of meaning and being and as organizing principles of identity’ (Goldsmiths, 2014, para 4).

^v I have only discussed actors where there a public record of their impairment; it is possible that other actors categorized as/assumed to be non-disabled may have a disabled identity. Jessica Lange, for example, has spoken publicly about her depression (McKenna, 1995).

^{vi} I have used past tense as he died in 2015.

^{vii} See footnote ii.

^{viii} This would include the wide range of people with Down Syndrome cast in *No Offence* (2015-18), Zachary Robin Gottsagen playing a starring role as Zak in *Peanut Butter Falcon* (2019), Steven Brandon playing the central protagonist, Luke, in *My Feral Heart* (2016), and the casting of Connor Long (Tommy) Bridget Brown (April) as a married couple in *Wiener Dog*.

^{ix} Whilst I have reservations about using these terms, there are currently none which are universally accepted as best terminology.

^x Mat Fraser’s character Paul, billed as ‘the illustrated seal’ for example, is an updated version of Stanley “Sealo” Berent. See Lewis (2020) for further discussion of this and other characters, and Ogidi at the BFI (2003-14): <http://www.screenonline.org.uk/people/id/932307/index.html>

^{xi} The character Paul as the illustrated seal, appears to have been a compromised rearticulation of the writer’s

original character - a lizard man, renegotiated by Fraser, as he has pointed out (Oswell, 2019, para 9); probably bringing knowledge which as a greater verisimilitude to real freak shows, whilst putting Fraser's acting talents in clearer view.

^{xii} Several of these can be found, with little difference amongst them, i.e. the American Horror Story Wiki

[https://americanhorrorstory.fandom.com/wiki/Category:Freak_Show_\(story\)](https://americanhorrorstory.fandom.com/wiki/Category:Freak_Show_(story)); American Horror Story on IMDB

(https://www.imdb.com/title/tt1844624/?ref=tttop_ep_tt), and also on Wikipedia

https://en.wikipedia.org/wiki/American_Horror_Story:_Freak_Show.

^{xiii} Halberstam discusses Yoko Ono's 'Cut piece' in particular. See:

https://www.moma.org/learn/moma_learning/yoko-ono-cut-piece-1964/

^{xiv} This is a pattern set right at the start in S1 with the 'entropic Gothic' of Murder House, featuring a 'claustrophobic sense of enclosure in space and repetition in time' (Keetley, 2013, 89)

^{xv} This includes Schlitzie Surtees; see Alverman (2019) for example, retrieved 2nd August, 2021 from

<https://www.publishersweekly.com/pw/by-topic/industry-news/comics/article/79587-nobody-s-fool-the-story-behind-zippy-the-pinhead.html>

^{xvi} This was a phrase used by Ethel Darling - the 'bearded woman' when she welcomes Elsa Mars to the afterlife

– this can be seen at: <https://www.youtube.com/watch?v=VhOKKeEvIPU> (Retrieved 4th August, 2021).



Temporal drag, Radical Negativity and the Re-articulation of Disabled Identities in American Horror Story

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Multimedia**Review: *Code of the Freaks* (2020)**

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Abstract

The documentary film *Code of the Freaks* explores representations of disability in American film. Designed to be enjoyed by academic and non-academic communities alike, the ultimate objective of the film is “to capture the conversations that we and those within our communities were so desperate to have, hoping that these conversations could also have a wider audience and reach” (Chasnoff et al., n.d.). This brief review outlines some of the key arguments of the film and connects the work to research happening in the field of media and disability studies.

Keywords: film studies, disability studies, narrative prosthesis

An important dichotomy lies at the heart of the documentary *Code of the Freaks* (Chasnoff et al., 2020): the ways we mediate disability and the actual lived experiences of disabled people. Representation of disability in film appears ensnared in Deleuzian rhizomatic simulacra (1994), doomed to perpetually repeat, expand and naturalize several key tropes or “codes” of disability despite the apparent disconnection from lived experience. Written by Chicago-area academics and artists Susan Nussbaum, Alyson Patsavas and Carrie Sandahl and directed by Salome Chasnoff, *Code of the Freaks* picks up the mantle from works like Norden’s *Cinema of Isolation* (1994) or Chivers’ *The Problem Body* (2010), seeking to identify and chronicle the (mis)representation of disability in over a century of American film, with Nussbaum et al. explaining,

With few exceptions, disability still functions as a storytelling device, an inspirational trope, and a vehicle for a non-disabled character development. These images, in turn, continue to perpetuate disability oppression in their erasure of the full lives disabled people live and their propagation of harmful stereotypes that disabled lives are less valuable and/or less worthy of living. (Chasnoff et al., n.d.)

The prostheticizing of disability for narrative benefit, popularly explored by Mitchell & Snyder (2001), is unpacked throughout this feature-length documentary in a series of interviews with academics, activists and artists and accompanied by clips and exemplars from recent and historic film. Designed to be enjoyed by academic and non-academic communities alike, the ultimate objective of the film is “to capture the conversations that we and those within our communities were so desperate to have, hoping that these conversations could also have a wider audience and reach” (Chasnoff et al., n.d.).

Straddling the delicate balance between inquiry and critique, *Code of the Freaks* begins with a radical proposition: perhaps the film *Freaks* (Browning, 1932) is one of the truest representations of disability in film. Despite critiques of a film that leverages disability to induce fear or anxiety in nondisabled audiences, *Code of the Freaks* notes that *Freaks* features one of the biggest casts of disabled actors and that within the “freak” community we see a type of solidarity and internal support networks that exemplify the best of the modern disability community. In fact, the film argues, *Freaks* does well when compared to the current incarnation of representations of disability in popular culture. *Code of the Freaks* focuses the rest of the film on identifying, exploring and critiquing typical tropes found in Hollywood films “about” disability. To begin, the film explores the modern obsession with inspirational stories about disability, in which cure or superpower is deployed to sanitize or “fix” disability to the joy of nondisabled audiences. When disabled characters are not uplifting or teaching nondisabled characters valuable lessons, they are instead presented as monsters or villains, not unlike the findings of Paul K. Longmore’s work on facial deformity as symbolic of villainous intent (2003, p. 133) or Angela Smith’s exploration of monsters in *Hideous Progeny* (2012). While hero and villain stereotypes of disability in film have been amply explored in the academy, the film also considers the ways disabled characters are (de)sexualized, presented as either incapable of sexual performance or elevated to fetishized object of exotic vulnerability in the case of d/Deaf women (Wilson, 2013). The film also notes, quite uniquely, that when disabled characters are sexualized it is usually with nondisabled characters. Finally, the film considers the pitfalls of using nondisabled actors to “play” disability and the ways the demand to be “cured” is satisfied when the nondisabled actor, now restored and out of character, walk to the podium to accept an Oscar.

The truth strength of *Code of the Freaks* is its ability to translate years of academic

theory and activist discussion into a compelling and easy to follow documentary. Well researched with excellent exemplars, the film manages to condense a ton of ideas into a tight, digestible package that makes good on answering the documentary's central thesis. This is perhaps no surprise, given the years of experience in the production team along with the wonderful cast of interviewees. Of note is the exceptional editing, which helps make the film feel more like dynamic conversation than droning lecture. The film also opts to spend ample time "showing" rather than just telling, splicing together commentary with clips from over a century of film to great result.

Although there are few criticisms to be made of the film, there were two things that have stuck with me after watching the documentary several times. One critique of the film is the limited time spent delving deeper into the political economy of Hollywood films. The film does mention some of the business factors driving representation, gesturing to some of the systemic explanations as to why we represent disability the way we typically do, but there was some fertile ground here that was unfortunately not fully cultivated. Another limitation of the film is the almost exclusive focus on representations of disability from the United States, both in interviewee and exemplar used. This heavy focus on American thinkers and texts leaves the film as exploration of (mostly) *American* discourses of disability that may not feel as grounded for viewers in other regions. Less focus on American examples could have added nuance to the existing investigation, especially in a streaming era that has brought significant access to foreign content that may be starting to "flip the script" on American disability hegemony.

Ultimately, *Code of the Freaks* offers a compelling and engaging overview of representations of disability in film. The documentary expertly explains the common mistakes made in films about disability and suggests succinctly why we must tell better

stories about disability. As educational as it is entertaining, this film is great for both novice and advanced educational settings, being just as comfortable in a film production classroom as in a disability studies graduate seminar.

The film is available for educational and personal use from Kino Lorber.

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Multimedia

“More than Medals” Sets the Stage for Tokyo Paralympics First-of-its-Kind Historical Analysis

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Abstract

This book review of “More than Medals” by Dennis J. Frost highlights the numerous strengths of this text’s coverage of the Paralympic movement in Japan. The first of such historical accounts written in English, Frost describes the progression to current day through analysis of five disabled sports events from the post-World War II era to the upcoming Paralympic Games in Tokyo. This text initiates an important call to action in ending the Eurocentric portrayal of the Paralympic movement with greater inclusion of Eastern perspectives.

Keywords: Paralympics, Japan, identity

As the world prepares for the Tokyo 2020 Paralympics, it is an ideal time to consider a new publication focused on the Paralympic movement in Japan, “More than Medals” by Dennis J. Frost. Much of the current and past coverage of adapted sport has been limited to a European or American context. “More than Medals” belies that notion. It is a deep dive in the history of a relatively unknown sports movement in the East. Author Dennis J. Frost (2020) attributes the restricted coverage of the Paralympic movement in the East to language barriers but cultural differences related to the perception of disability also seem to be at play. Frost deftly navigates historical storytelling to a cohesive timeline of both individuals and the Paralympic movement in the East.

The research for this book entailed translation from Japanese to English, and the author acknowledges this at the very beginning. Having said that, it is worth mentioning that there is a rich body of para-sport research written in Japanese. Sport scholars have spent years studying the system leading to literature both discussed in this book, and other work yet to be uncovered to a global audience. “More than Medals” focuses on five sports events in Japan: the 1964 Paralympics, the FESPIC Games, the OITA International Wheelchair Marathon, the 1998 Nagano Winter Paralympics, and the 2020 Summer Games. Until now, this coverage was limited due to a combination of language and access barriers.

Frost begins with Japan’s storied history of persons with disabilities with formal programming dating back to the World War II era. Post War rehabilitation centers for veterans also hosted sport events for persons with disabilities. The 1960 Rome Olympics was the inception of the Stock Mandeville Games. A predecessor to the modern Paralympics, many para-athletes used the same facilities used by non-disabled athletes in the weeks prior to these Games. In 1963, Japan announced its intent to host the Paralympics. Despite assumptions that the Japanese had no prior experience with adapted sport, the wheels were

set in motion for an international event.

Frost's book describes the inception and progress of the adapted sport movement in Japan. From its beginning as a public health rehabilitation measure to now hosting two Paralympic Games, amongst other sport events of repute. The examination of Japan's history, its people, and success in hosting these sports events provides perspective on the meaning of disability and sport in the East.

Central to the success of sporting events and their potential impact on society is media coverage of the events. Frost dedicates an entire chapter on the media coverage of persons with disabilities in Japan. Para-sport was initially advertised for rehabilitation. This was how promoters of sport events advertised competition, and this frame was further reinforced by the media. Frost traces the evolution of media portrayals of athletes with disabilities across time.

Howe (2008) has said that media research in, and coverage of Paralympic Sport has increased considerably in recent years to the point where, in the twenty-first century, the Paralympic Games are "a relatively high profile mediated event." In a comparison between the coverage of the 2004 Athens Paralympic and Olympic Games, Chang and Crossman (2009) add that media representations of sport events perform a wider hegemonic function of normalizing what society perceives about "body, gender, class and ethnicity. This has the effect of reinforcing ideologies.

Members of the Royal Family in Japan, and later politicians who would attend these events would be given central attention in said press coverage. The chapter on the media is well portrayed and raises questions of the real purpose for hosting adapted sport events.

However, the vivid description of visual and film could have been complemented with some images in the book.

Considering the intersection of culture and disability, Frost describes the portrayal of western athletes versus that of the local Japanese Paralympic team members. The Japanese media referred to the foreign visitors as “bright” and successful. On the other hand, Japanese athletes were demeaned to highlight flaws, often related to their disabilities. European models were praised as countries which helped “disabled people feel very bright.” Frost (2013).

These comparative portrayals should be further examined by scholars of decolonization and critical race theory. As one looks at sport through the lens of sociology, humanities, and other related disciplines, one understands the links between sport and society. Frost provides a useful roadmap for future research, including the role of disability studies in understanding Paralympic sports, their media coverage, and its impact on society.

If you track the progress in the growth of adapted sport in Japan, over time one can see the introduction of professionalism which made the games more recognizable to an international audience. It also speaks of the impact Japan had on neighboring nations who were being introduced to adapted sport either by attending these events, or by interacting with the media.

A potential weakness of this analysis may be the missing measurable impact of the Games on the East. What has been the impact of the Paralympic movement on the people of Japan? Have legislative changes concerning the human rights of persons with disabilities been aligned with the growth of the Paralympic movement in the East? If the media perception of adapted sport sets the tone for everyday conversation, it would be worthwhile to measure its impact on Japanese society at large. Has accessibility in Japan improved in

response to hosting these five historical events?

According to van der Veere (2020), organizing committees for the 2020 Games “are duplicating common misrepresentations that already exist within Paralympic discourses.” The Supercrip and Superhero tags, commonly used to market the Games, set impractical expectations for the larger population of persons with disabilities. In other words, there seems to be this disparity in how Paralympians are portrayed in the media when compared to the everyday lived experiences of persons with disabilities. Van der Veere refers to this as a “visual dominance of persons who can take advantage of technology.”

This book was published prior to the second COVID-19 wave, and the hosting of the Tokyo Games, postponed from 2020 to 2021. As subsequent waves of COVID-19 variants rage across the East of the world, questions on the viability of the Games have been raised. While athletes with disabilities may disproportionately be at a greater risk of contracting COVID-19 infections, this discussion should not be restricted to the Paralympics alone. Yamaguchi (2021) reports that as of June 2021, less than 10% of the country’s population is vaccinated. Citizens of Japan are calling for the Games to be canceled in fear of rising cases (Turner (2021)). A subsequent edition of this book could explore the impact of the pandemic on the adapted sports movement globally.

“More than Medals” upends the assumption that the Paralympic movement has been led exclusively by the West. While largely a historical account, Frost’s book also highlights the role of innovation in the advancement of the Games. Readers with a disability studies background will appreciate his nuanced analysis of the shift of disability coverage and perceptions across the timeline. “More than Medals” is a historic first with its English language coverage of the Paralympics in the East. It should be widely read for this reason and

the strong foundation it builds for future literature to come.

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Creative Works

“The Co-Op”: Director’s Statement

Cameron S. Mitchell,

CSM Productions

Abstract

Cameron Mitchell (CSM Productions) is a film director, cinematographer, and son of Disability Studies professors David T. Mitchell and Sharon L. Snyder. In this article, Cameron discusses the making of his short film “The Co-Op” and how it deals with themes of disability in film portrayal, independence, and interdependence as well as its autobiographical content.

Keywords: film, disability, filmmaking

“The Co-Op”

“A robber’s plan goes horribly awry when he realizes that the store he has targeted is full of disabled people.”

Link to Film: “The Co-Op”

<https://youtu.be/96HYQ-wV46g>

It’s been a long path to the current state of affairs for Cameron and his directorial short film debut “The Co-Op.” What initially started as an entry in the 2017 Easterseals Disability Film Challenge 72-hour film festival has since gone on to feature in more than 20 film festivals all over the world including Over The Rhine, Osaka Bright, Holly Shorts, Festival Inclus Barcelona, and Slamdance 2021, to name a few. Beneath the wry wit and satire of the film, the director hopes that the festival platform can provide viewers with an entertaining and brief exposure to the vastly untapped world of real disabilities portrayed on screen: the film’s cast is made up almost entirely of disabled people.

Hollywood has long ventriloquized disability for its means throughout its history; an actual disabled person rarely is offered the roles that are meant to portray them in an already scarce market where said roles are determined by screenwriters, directors, and producers who are themselves able-bodied or don’t have real lived experience with disability. As the robber comments “you folks should seriously consider adding some stairs...it is certainly attracting

some undesirable clientele,” “The Co-Op” looks to point at and dismantle these attitudes in the cinematic universe and in the world around us.

“The Co-Op” is meant to mess with your notion of what “cinema” is and play with all the poignant examples in your mind that might pop up in the Western dialogue that has primarily excluded disability as an outlier rather than included it. I wanted to take this very familiar movie trope that we know from cinema history and flip it on its head. Why don’t we ever see any disabled people in these scenes? Is it because action films are inherently linked to the energy/entropy of an able-bodied person, perhaps? Do we not believe a disabled person could participate in a robbery as a perpetrator or bystander?

The concept for “The Co-Op” came about as a thought experiment. I wanted my first narrative film to be about disability and have a majority of the cast that was actually disabled. I cast all of the main disabled characters before their parts were even written and then brainstormed a way that they would all be in the same place at the same time. An accessible grocery store. Since many of the spaces we frequent even today hinge on inaccessible or barely pass as accessible, it was important that the scene take place in a plausible reality: we really have yet to fully integrate access in real life and on set so I think it is only fair that a situation with primarily disabled people could occur in an accessible community store such as a co-op. Finally, in writing the dialogue, I drew heavily from my history of experience with disability with my family. The scene where the robber picks my father out of the chair is a scene I have relived personally in my life thousands of times as I have literally had to pick my father up and hoist him into inaccessible trains, busses, buildings, and the like (the Parthenon is among other notable highlights belong in this list). So, primarily the experience of interdependence (a family of varying capabilities relying on each other to survive in the day to day world) as well as my own experience as a person with an invisible disability (sleep

apnea) and someone who has experienced the big d word “Diagnosis” serve as the primary background that informs this short.

Jasmine is played by my sister, Emma Mitchell who has cerebral palsy and is blind. My father, David Mitchell, plays David—in real life he is a professor of disability studies as well as an individual with Spinal Motor Atrophy, a form of muscular dystrophy. Ricky is played by my friend James Curran, who also has a type of SMA. And Barb is played by my friend Brittany Blythe, who is an amputee. I cast and wrote all of these roles with the firm belief in mind that “...people can give Oscar-winning performances of themselves if you simply do not tell them to act” (Gareth Edwards said some iteration of this in an interview in *American Cinematographer* regarding his film *Monsters*). “The Co-Op” is essentially a raw test of this idea but applied to disabled people...and the desire to watch them kick ass!

It’s time we let real authentic disabled people into that world and prove that they are capable of being in every film, from a blockbuster to an indie, in every genre and concept—not just poorly type cast roles where they play outsider villains or their bodies are used as some form of narrative prosthesis (a term coined by my folks David Mitchell and Sharon L. Snyder) (See Mitchell & Snyder, 2001). “The Co-Op” is a litmus test for this in the case of the genre film. It purposefully blurs the line between dark comedy, sci-fi, horror, and drama to demonstrate how all of these genres can become so much further enriched when we enter the world of disability openly and knowingly rather than just letting it be a byproduct of the idea or the film itself.

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Review: “The Co-Op”: Director’s Statement

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Creative Works

Heroic Justice for Quasimodo Through Re-creation: Examining Disney's Denial of Romance and the Hero's Journey

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Abstract

By analyzing disability stereotypes and story structure, this paper critiques how Disney's *The Hunchback of Notre Dame* denies Quasimodo romantic opportunity because he does not fit the heteronormative abled model of a Hero. Based on these intersectional issues, this paper ends with an alternative script to give Quasimodo heroic justice.

Keywords: Hunchback of Notre Dame, Hero's Journey, ableism

The following essay and creative rendition of Disney's *The Hunchback of Notre Dame* began as a final project for an undergraduate course about disability in U.S. pop culture. The assignment was to analyze a negative representation of disability in entertainment and to "fix it" through re-creating it in a less ableist manner. In what follows, I present my initial critique of Disney's adaptation and assess the existing disability studies scholarship that has already analyzed Quasimodo. I take these arguments further by showing how Disney's denial of romantic opportunity reinforces stereotypes of disability and asexuality and by analyzing these themes in the context of intersectionality. Lastly, I end with a re-creation of key scenes from the film which demonstrate an alternative, more realistic disability story.

The Hunchback of Notre Dame as Current Media

I chose to analyze Disney's 1996 film *The Hunchback of Notre Dame* because of its continued contemporary importance. In 2019, Disney announced that a live-action remake of *The Hunchback of Notre Dame* was in development with well-known creatives such as Alan Menken, Steven Schwartz, and Josh Gad already committed to the project (Fleming, 2019). Fans of the original movie have already been asking about casting on social media and suggesting dream casts (Gad, 2021; Hammer, 2021; Pádraig, 2020; Suhas, 2019). But while there has been concern about the racial/ethnic problems of the animated film in regards to the portrayal of Romani people, or Roma, (referred to as "gypsies" in the film, a word considered a slur today), there have been only a few articles discussing the portrayal of Quasimodo as disabled (Gardner, 2019; Lopez & Panchanathan, 2019; Second Nexus Editorial, 2019; Suhas, 2019).

Representation of disabled people is lacking in mainstream media, especially positive intersectional portrayals. Intersectionality in *The Hunchback of Notre Dame* exists between

disability, gender and sexuality, and racial/ethnic oppression. As an influential producer of media, Disney has the opportunity and the means to represent multiple oppressed groups through intersectionality, and, if done well with positive representation, they could alter perspectives of viewers. Disney's films are repeatedly at the top of the box office and remain in the public consciousness with the additional marketing and merchandise of each film (Clark, 2019). Disney continues to be influential in setting an example of what is accepted and "normal" in society. Their films uniquely appeal to all ages, seemingly targeted at children while including storylines and humor that adults enjoy as well (Resene, 2017).

I argue that one of the reasons that Disney's films are repeatedly successful is due to their use of story structure. By using this structure, Disney's films are familiar, easy to follow, and satisfying. This allows films to be successful while still creating strong, interesting plots for the audience. However, I argue that due to Quasimodo's disability, Disney broke away from their foundational rules of storytelling in *The Hunchback of Notre Dame*, thus denying him a true role as Hero.

By analyzing Disney's *The Hunchback of Notre Dame* from an intersectional lens combined with the lens of film critique and then using that analysis to rewrite sections of the script, I offer a solution to the ableism and representational issues that occur repeatedly in Hollywood. Films can be made to be entertaining while still having intersectional representation and addressing social justice issues.

Disney's Adaptation of *The Hunchback of Notre Dame* (1996)

The Hunchback of Notre Dame (Trousdale & Wise, 1996) is one of Disney's darkest animated films, including themes of ethnic oppression, sexism, sexual harassment, ableism, and abuse, to name only a few. *The Hunchback of Notre Dame* did eventually achieve a G

rating after some edits, though it was not these adult themes, the violence, the death or “the use of the word ‘hell’ or ‘damnation’ that the [ratings] board took issue with” (Bahr, 2021, para. 32) but small details instead, such as needing to muffle the word “sin” in the song “Hellfire.” Adapted from Victor Hugo’s novel published in 1831, the Disney version differs greatly, diluting the plot to focus on the character known as the Hunchback, or Quasimodo. In the original novel, Quasimodo is the bell ringer of Notre Dame after being abandoned there as a baby (Hugo, 1831/2009). He is born with what is described as a “hunchback” (medically known as kyphosis), and he is also described as having a large wart covering most of his right eye (Mayo Clinic, 2020). Quasimodo also becomes deaf as he lives and works in the bell tower. When translated into the Disney film, Quasimodo’s character still has a “hunchback”, but his eye is no longer covered by a wart (though it does appear as if he’s squinting at times), and he is no longer deaf. Quasimodo falls in love with a Romani woman, Esmeralda, whom he tries to protect from his racist guardian, Judge Frollo. Captain Phoebus works for Frollo before falling in love with Esmeralda, becoming her and Quasimodo’s ally against Frollo.

Literature Review

The Hunchback of Notre Dame & Disability

A wide range of academic work has been written about *The Hunchback of Notre Dame* since the original novel by Victor Hugo was first released in 1831 (Horowitz, 2014; Joshua, 2011; Ledder & Münte, 2019). As the famous story has been adapted many times since its original publication, some articles solely focus on theater or older film/TV adaptations (Avery, 2004; Horowitz, 2014; Nyman, 2010; Szwydky, 2010; Whittington-Walsh, 2002).

The Disney version directed by Gary Trousdale and Kirk Wise (1996) has been

analyzed as well with scholars mainly focusing on variations from the book, racial/ethnic representation, religious allusions, or gender presentation (Al-Othmani, 2014; Artman, 2016; Fadner, 2016; Hancock, 2008; Johnson, 2019). And while some works have examined the Disney version in regards to disability studies, most have used Quasimodo as a brief example of a disabled character within a larger critique on disability tropes (Longmore, 2003; Norden, 2013; Purcell, 2020), such as the “Obsessive Avenger” (Norden, 2007, p. 128) and the “Innocent Fool” (Hess, 2019, p. 4). I expand on these analyses by considering how disability stereotypes intersect with film theory, specifically how the tropes affect the Hero’s Journey.

Film Theory

The Hero’s Journey, or monomyth, was coined by Joseph Campbell, and is one of the most well-known structure for storytelling. It models a pattern seen in myths across cultures that supports a “shared unconsciousness and reflect[s] universal concerns” (Vogler, 2007, p. 4-5). Campbell’s Hero’s Journey begins with the Hero’s Call to Adventure. The Hero must have a want or need that they pursue or confront on the Journey. The Hero encounters several archetypal characters, such as Allies, Mentors, and Shadows, or characters who challenge the Hero, such as the antagonist. The Hero goes through a series trials before the Hero rises again for the Climax, the final confrontation against the antagonist. Hollywood films typically end happily with a successful Hero who obtains their want as a reward, often a female “love object” for cis male Heroes (fulfilling society’s heteronormative expectations). This story structure creates a familiar plot path that is satisfying and is almost expected now in Hollywood films due to its consistent use in film and other media.

Other works in disability studies have discussed the Hero’s Journey in relation to disability, but none have focused on Disney’s *The Hunchback of Notre Dame*. One work explored the Hero’s Journey in regards to Hugo’s original book, but Hugo’s text varies

greatly from the Disney film so the analysis is largely inapplicable (Wildgen, 1976). Other works examined disability representation in films, such as *Percy Jackson: The Lightning Thief* or *Frozen*, but they only briefly discussed the Hero's Journey (Natalia & Djundjung, 2015; Resene, 2017). My work here attempts to integrate both disability studies and film theory to examine disability representation in *The Hunchback of Notre Dame*.

Gender & Sexuality

While some scholarship mentions Quasimodo's unrequited love towards Esmeralda, only a few examine it from a disability studies perspective (Avery, 2004; Norden, 2013). Some works even defend why Quasimodo's love was unrequited (Lorenz & Panchanathan, 2009), such as a review that claimed Disney had made a "very wise choice in keeping Quasimodo 'single'" and deviating from the repetitive "'happily-ever-after'" (McCord, 1998, p. 93). However, I argue that making Quasimodo's affections unrequited is harmful. As Kathi Wolfe remarked, "What does this movie say about those of us with disabilities? It says...that no matter how heroic we are, we will never have a loving romantic relationship" (1996, p. 32).

This harmful assumption has been noted in previous disability scholarship: that all disabled people are asexual *because* they are disabled (Lund & Johnson, 2015). In addition, in media, asexuality is mostly represented in disabled characters, resulting in the belief that "'people' are assumed to be sexual while 'people with disabilities' are assumed to be asexual" (Lund & Johnson, 2015, p. 129). This not only reinforces the stigma that disabled people are inherently asexual, but it also reinforces the belief that asexuality is something to "cure" or "treat" under the Medical Model of disability rather than being understood as a legitimate sexuality (Haller & Zhang, 2014). Asexuality *is* a sexual identity, independent of any other factors, defined as "someone who does not experience sexual attraction or an

intrinsic desire to have sexual relationships” (Asexual Visibility and Education Network, 2021), but they may still experience romantic attraction. Romantic and sexual attraction are often incorrectly conflated in society, thus the belief that if disabled people are asexual, then they also are aromantic (lack romantic attraction) and therefore are not potential partners. Disney’s adaptation reinforces these stigmas through Quasimodo’s unrequited love for Esmeralda.

Previous works examining gender focused mostly on Esmeralda’s representation in the Disney film (Hancock, 2008; Johnson, 2019). One briefly examined Quasimodo’s role as a masculine hero but only in terms of morals and ethics. (Artman, 2016). None examined the film in terms of how gender is performed and “effects a false stabilization of gender in the interests of heterosexual construction” (Butler, 2004, p. 110) – in other words, how society’s mandatory heteronormative structure demands gender be performed in specific ways, including, as McRuer explains, being *abled* (Ledder & Münte, 2019). Previous scholarship also did not address Quasimodo’s romantic arc through connections between disability, gender, sexuality, and the Hero’s Journey as I do below.

Quasimodo’s Hero Denial

First, Quasimodo is introduced as the protagonist in the prologue’s musical number. As the Hero, according to the Hero’s Journey, Quasimodo must be relatable, learn or grow the most out of all other characters, and be active and drive the story forward (Vogler, 2007). But sacrifice is “the true mark of a Hero... [his] willingness to give up something of value, perhaps even [his] own life” (Vogler, 2007, p. 31). Quasimodo, therefore, does meet the requirements of a Hero. He is relatable; he grows in his character arc over the film; his actions move the narrative forward; and, he is willing to risk his own life to save Esmeralda.

However, the most important part of being the Hero is the “Elixir” that the successful Hero gets at the end of their journey (Vogler, 2007). This can be in the form of new knowledge, an object, or love — “one of the most powerful and popular Elixirs” (Vogler, 2007, p. 221). This is where the Disney film fails Quasimodo. Plot points are set up in the film early on to be paid off later. Esmeralda is introduced and set up as a love interest for Quasimodo. When Quasimodo is humiliated and abused at the Festival of Fools, Esmeralda steps forward to help him. Later, Esmeralda finds Quasimodo in Notre Dame, and they get to know each other. When she leaves, Esmeralda kisses him on the forehead, promising to visit. Quasimodo also has two songs about his feelings for her, furthering this set up.

Therefore, following the Hero’s Journey, Quasimodo’s Elixir would be a romantic relationship with Esmeralda. However, this never happens. Instead, Esmeralda starts a relationship with Phoebus. In the middle of the film, Esmeralda rescues Phoebus from a river after he is injured by Frollo's guards, and she brings him to Quasimodo to keep him safe. There, Esmeralda and Phoebus kiss in front of Quasimodo, who looks away, crushed. He later states to one of his gargoyles friends:

What am I supposed to do? Go out there and rescue the girl from the jaws of death, and the whole town will cheer like I'm some sort of hero? She already has her knight in shining armor, and it's not me. (Trousdale & Wise, 1996)

This variation from the Hero's Journey is not a coincidence. If Quasimodo were not disabled, he would never have been denied the romantic relationship with Esmeralda. But because of Quasimodo’s disabilities, he is portrayed as Other in the film - he is not “male” enough. Phoebus, though, is exaggerated into the ideal heteronormative male - tall, muscled, and confident (Avery, 2004). While Quasimodo does save Esmeralda, he does not fit the heteronormative abled binary, so he is not allowed to be a suitable partner for Esmeralda.

Instead, Phoebus fills this last part of the Hero's role, succeeding in a romantic relationship with Esmeralda.

Furthermore, once Phoebus steps in as a substitute Hero with Esmeralda, Quasimodo is no longer even associated with sexuality. At the end, Esmeralda and Phoebus go to the steps of Notre Dame, greeting the crowd. Esmeralda returns for Quasimodo, who is still inside. It then cuts to his point-of-view, looking up at Esmeralda as she offers him her hand, like a mother might offer her hand to a child.

This moment with Esmeralda precedes another childlike connotation as the first character to greet Quasimodo on the steps is a young girl. However, even this girl treats Quasimodo like a mother as she touches his face and then pets his hair — almost like a mother might soothe a child. This infantilization is further emphasized as Phoebus and Esmeralda watch in the background like proud parents (Byrne & McQuillan, 1999). Thus, Quasimodo's returned qualities as the Innocent Fool complete Disney's ableist denial of the Hero's Journey to him.

Author Notes on Rewriting Excerpts of the Script

To allow Quasimodo a full Hero identity, I rewrote the script with the aim of presenting him as a complex adult with a successful romantic relationship. I could have made it more intersectional with the inclusion of LGBTQIA+ characters or writing Quasimodo as D/deaf as he is in the original Victor Hugo novel. However, I wanted to focus on rewriting the story with the characters as they exist in the Disney film so as to focus on correcting the intersectional issues already present and allowing Quasimodo his complete Hero's Journey.

I did not remove how Quasimodo was treated by Frollo or all ableism for two reasons: first, unfortunately, the oppression and discrimination has historical background. So, there is

some accuracy to how Quasimodo was treated and to disregard history, I believe, would be to ignore the struggle of disabled people throughout history. Second, this abuse is something that disabled people still encounter today. For instance, Frolo could represent an exaggeration of an overprotective parent of a disabled child who prevents them from being independent. Of course, Frolo's reasons for isolating Quasimodo are not out of overprotectiveness or love, but the effect is similar. Quasimodo is isolated, has very little comprehension of the real world, feels frustrated with his situation, has low self-esteem, etc.

I also humanized Quasimodo's actions and movements. In the Disney film, Quasimodo can break through chains, move heavy objects, scale buildings, etc. Some of this strength may be realistic as he does work in the bell tower. However, the imagery also has bestial associations. For instance, when Quasimodo encounters Phoebus looking for Esmeralda, Quasimodo reacts violently, swinging a torch towards him and yelling. He is not speaking in full sentences though, just grunts and phrases. Next, there is the image of Quasimodo breaking through the thick chains on top of the roof before rescuing Esmeralda, looking almost like a bear breaking free. To address these issues, I gave Quasimodo full sentences in the scene with Phoebus. I also replaced the scene where he breaks out of the chains with him escaping past guards by using his familiarity with the bell tower.

Most importantly to the Hero's Journey, I developed Quasimodo's romantic chemistry with Esmeralda and gave them a happy ending together. I kept lines about Quasimodo's insecurities though, as those anxieties are plausible for anyone to have, regardless of disability. Even the line in the song "Heaven's Light" ("Though I might wish with all my might / No face as hideous as my face / Was ever meant for heaven's light") (Trousdale & Wise, 1996) could work for anyone's anxieties about their appearance, such as acne scarring or a birthmark. In addition, even if Quasimodo was referring to his disabilities,

this song comes soon after the Festival of Fools, and the harassment would certainly have renewed any insecurities he had.

My aim was to make Quasimodo's story more realistic in its portrayal of disability. His disability is still noticed and marks him as different, but I also aimed to recognize how that affected him over time instead of ignoring it. Quasimodo is also recognized as equal a suitor to Esmeralda as Phoebus is, granting Quasimodo the full role of the Hero that Disney had denied him.

Quasimodo's Heroic Justice: Excerpts of a Re-created Script

Excerpt One^{1,2}

(Quasimodo and Esmeralda proceed onto the balcony to a beautiful view of Paris.)

Esmeralda: I bet the king himself doesn't have a view like this! I could stay up here forever.

Quasimodo: You could, you know.

Esmeralda: No, I couldn't.

Quasimodo: Oh, yes, you have sanctuary!

Esmeralda: But not freedom.

Quasimodo: I don't have freedom either. But the view is beautiful at least.

Esmeralda: Who keeps you here?

Quasimodo: Judge Claude Frollo. I was abandoned as a baby, so he took me in.

Esmeralda: Frollo raised you?

Quasimodo: Well, technically? He gave me food and had the cathedral give me shelter. But he also tells me I'm a monster, so...

Esmeralda: He tells you that?

Quasimodo: All the time. But it doesn't make sense.

Esmeralda: Give me your hand.

(She takes his hand and looks at his palm.)

Quasimodo: Why?

Esmeralda: Just let me see. (*Tracing his palm lines with her finger*) Hmm, a long lifeline... Oh, and you'll have a long and happy romantic relationship with someone. But... Hmm... I don't see any.

Quasimodo: Any what?

Esmeralda: Monster lines. Not a single one.

(*Quasimodo takes his hand back, examining it himself.*)

Quasimodo: It never made sense when Frollo called me that... I can't read all that well, but I overhear mass all the time. And the archdeacon always says that Jesus loves all people. But Frollo says—

Esmeralda: Frollo also says that Roma, “gypsies”³ are evil. Now you look at me. Do you think I'm evil?

Quasimodo: No, no! You are kind, and good, and—

Esmeralda: And Roma. So maybe Frollo's wrong about the both of us.

(*Quasimodo stares at her thoughtfully, looking at his hand again.*)

Quasimodo: I have an idea to get you free.

Esmeralda: But there's no way out. There's soldiers at every door.

Quasimodo: We won't use a door.

Esmeralda: You mean... climb down?

Quasimodo: Sure. You carry him (*motions to Djali, Esmeralda's goat*), you climb on my back.

Esmeralda: Are you sure that's safe?

Quasimodo: I climb around the bell tower all the time to get to all the bells — just hold onto me. I'll be careful.

Esmeralda: Okay. Come on, Djali.

(*Djali hops into her arms.*)

Quasimodo: Ready?

Esmeralda: Yes.

Quasimodo: Don't be afraid.

Esmeralda: I'm not afraid.

(Quasimodo leaps over the edge and holds on to a gargoyle head.)

Esmeralda: Now I'm afraid.

Quasimodo: The trick is not to look down.

(Quasimodo begins swinging down the exterior of the cathedral.)

Esmeralda: You've done this before?

Quasimodo: No.

(Quasimodo finally stops on a slanted roof.)

Esmeralda: Wow. You're quite an acrobat.

Quasimodo: Thank you—

(His words are cut short as the tile they're on breaks free and they begin to slide down the roof as if they were on a sled. They're able to jump off their sled just before it goes sailing off into the air. It lands a few blocks away. The guards on the ground hear the crash and go off to investigate.)

Guard 4: Check the alley!

Guard 5: This way!

(As guards pass, Quasimodo, Esmeralda and Djali hide as part of a statue. When the coast is clear, they speak again.)

Quasimodo: That was close... Is Djali okay?

Esmeralda: *(catching her breath)* Yeah, just a little startled.

Quasimodo: You should get going before the guards come back.

Esmeralda: Come with me. To the Court of Miracles. Leave this place.

Quasimodo: I don't know... You saw what happened to me today. *(He rubs his shoulder where the skin is still raw under his shirt from the ropes earlier that day at the Festival of Fools.)* What if that happens again?

Esmeralda: All right, then I'll come to see you.

Quasimodo: What? Here? But, the soldiers, and Frolo, and...

Esmeralda: I'll come after sunset.

Quasimodo: At sunset, I ring the evening mass, and after that, I clean the cloisters, and then I ring the vespers, and—

Esmeralda: Quasimodo?

Quasimodo: And then I have to— yes?

(Esmeralda gives Quasimodo a little peck on the cheek.)

Esmeralda: We can do those things together. Can I come visit?

Quasimodo: *(blushing red as he raises a hand to feel the spot on his cheek where she kissed him. He nods.)* We can even watch the sunrise together sometime. Just be careful.

Esmeralda: I'd like that. And if you ever need your own sanctuary and freedom—

(Esmeralda pulls a talisman off her neck and hands it to Quasimodo.)

Esmeralda: —this will show you the way.

Quasimodo: But how?

Esmeralda: Just remember: When you wear this woven band, you hold the city in your hand.

(Djali bleats as the guards are returning.)

Quasimodo: Hurry! You must go!

(Quasimodo puts the necklace around his neck, squeezing Esmeralda's hand in goodbye. Esmeralda swings down a rope to the ground and runs off into the dark. Quasimodo climbs back up to his tower. As soon as he reaches the door to the steps down, Phoebus appears.)

Phoebus: Hi there. I'm looking for the gypsy³ girl. Have you seen her?

(Quasimodo takes a step back, suspicious.)

Quasimodo: No. Get out.

Phoebus: Hey, man. I'm just—

Quasimodo: You're just leaving. Get out!

Phoebus: Wait! All I wanted was to—

Quasimodo: Go!

Phoebus: I mean her no harm!

Quasimodo: Liar. You work for Frolo. Now, get out!

(Quasimodo tries to move past Phoebus. Phoebus follows him down the stairs, reaching for his arm as they reach the bottom. Quasimodo flinches, shoving Phoebus away and moving back.)

Quasimodo: Don't touch me!

Phoebus: Okay, okay. I'm sorry. Just— You tell her from me, I didn't mean to trap her here, but it was the only way to save her life. Will you tell her that? *(No response.)* Will you?

Quasimodo: If you go. Now!

Phoebus: I'm going, okay?

(Phoebus starts to leave, then turns to say something.)

Phoebus: Oh. And one more thing. I'm sorry about what happened at the festival today.

Quasimodo: Why didn't you do something— *(he eyes Phoebus's uniform)* — Captain?

Phoebus: I wasn't free to—

Quasimodo: No! You are free! You could have done something, but you did nothing! You just stood and watched as I was tied up and beaten! Harassed!

Phoebus: Frolo would have—

Quasimodo: Don't tell me what Frolo would have done to you! *I know!* I've dealt with it for 20 years! So don't say that you're sorry or that you pity me when you would never have done anything differently.

Phoebus: ... I would've— I'll just go then... I'm still sorry.

(Exit Phoebus. Quasimodo returns to his room and the gargoyles.)

Hugo: Hey, hey! There he is! Yeah! Ooh-hoo!

Victor: You ejected that tin-plated baboon with great panache!

Hugo: The nerve of him! Trying to give some weak apology! And then snooping around here trying to steal your girl.

Quasimodo: My girl?

Laverne: Esmeralda. Dark hair, works with a goat. Remember?

Hugo: Boy, I do! Way to go, loverboy!

Quasimodo: Loverboy!?! Oh, no, no...

Laverne: Oh, don't be so modest.

Quasimodo: Look. I appreciate what you're all trying to do, but let's not fool ourselves. Ugliest face in all Paris, remember? I'm not exactly handsome, human or monster. Anyway, she deserves someone who is free to explore everything out there with her. *(The gargoyles slowly melt into the background as Quasimodo begins to sing, "Heaven's Light".)*

SO MANY TIMES OUT THERE
I'VE WATCHED A HAPPY PAIR
OF LOVERS WALKING IN THE NIGHT.
THEY HAD A KIND OF GLOW AROUND THEM
IT ALMOST LOOKED LIKE HEAVEN'S LIGHT.
I KNEW I'D NEVER KNOW
THAT WARM AND LOVING GLOW
THOUGH I MIGHT WISH WITH ALL MY MIGHT
NO FACE AS HIDEOUS AS MY FACE
WAS EVER MEANT FOR HEAVEN'S LIGHT

BUT SUDDENLY AN ANGEL HAS SMILED AT ME
AND KISSED MY CHEEK WITHOUT A TRACE OF FRIGHT

I DARE TO DREAM THAT SHE
MIGHT EVEN CARE FOR ME
AND AS I RING THESE BELLS TONIGHT
MY COLD DARK TOWER SEEMS SO BRIGHT
I SWEAR IT MUST BE HEAVEN'S LIGHT!

Excerpt Two

(A huge crowd has gathered to watch the burning of Esmeralda, who is on a pyre. Frollo stands next to her. Roma and Phoebus watch from barred wagons. As the archdeacon comes out to see what is happening, guards block him off.)

Frollo: The prisoner Esmeralda has been found guilty of the crime of witchcraft. The sentence: death!

(Cheers go up from the crowd.)

Frollo: *(Leans close to Esmeralda)* The time has come, gypsy. You stand upon the brink of the abyss. Yet even now, it is not too late. I can save you from the flames of this world, and the next. Choose me, or the fire.

(She spits in his face. The crowd gasps in horror.)

Frollo: The gypsy Esmeralda has refused to recant. This evil witch has put the soul of every citizen of Paris in mortal danger...

(His voice trails off as we fly up to Quasimodo in the bell tower. Two guards stand watch — one at the door to the stairs down and one at the balcony. The gargoyles come back to life as Quasimodo moves towards the newly barred window for some privacy.)

Hugo: Come on, Quasimodo! Snap out of it!

Victor: Your friends are down there!

Quasimodo: It's all my fault. I led Frollo to the Romani hideout.

Laverne: How could you have known Frollo was following you? Come on, Esmeralda needs your help!

Quasimodo: Yeah, but I'm up here! And she — *(he looks out the bars on his window to the pyre in the middle of the square)* she's down there.

Victor: But you can't let Frollo win!

Quasimodo: *(angrily)* How can I stop him?! I'm stuck up here.

Hugo: So, you're giving up? That's it?

Quasimodo: No! I just—

(Quasimodo sees Esmeralda below, about to be burned at the stake. He presses his hand to his cheek where she had kissed him before.)

Frollo: ...for justice, for Paris, and for her own salvation! It is my shameful duty to send this unholy demon back where she belongs!

Quasimodo: NO!!

(At his shout, the guards draw their swords. Quasimodo moves towards the balcony door.)

Guard 1: Turn back around.

(Quasimodo hesitates before dodging and running to the left, towards the beams underneath the bells. The guards shout at him, chasing after him to catch him. Quasimodo nimbly leaps from beam to beam, comfortable balancing after having done it his whole life. One guard trips, letting out a yell and falling. Quasimodo grimaces at the yell, but he keeps moving, heading back to the balcony. He looks down at the square as—

Frollo touches the torch to the pyre, starting the fire.)

Quasimodo: Esmeralda!

(He looks around, spotting a rope left behind from recent roof repairs. He loops an end of the rope around a gargoyle, rappelling down the side of the cathedral. He jumps off, landing on

the platform and knocking into a guard. The guard falls to the floor, dazed. Quasimodo grabs the guard's sword, holding it in front of himself defensively before using it to cut through Esmeralda's ropes.)

Frollo: Guards! Seize him!

(Phoebus, tied in the wagon from the jail, realizes what is happening and quickly picks a fight with a guard, creating a distraction. Split into groups, the guards hesitate where to go, allowing Quasimodo to carefully pick up Esmeralda in a fireman's hold as he grabs the rope, swinging back to a low ledge on the second floor of the cathedral. He climbs through the open window, holding Esmeralda as he looks up at the sky desperately.)

Quasimodo: Sanctuary! Sanctuary! God, if you can hear me, if you're there, I beg for sanctuary for her!

(All is silent in the courtyard as everyone stares up at the window with Quasimodo. Frollo sneers, stalking towards the cathedral doors with a group of guards.)

Quasimodo: SANCTUARY!! SANCTUARY!! SANCTUARY!!

(Fighting breaks out between Frollo, Phoebus, Quasimodo, the guards, Roma, and the citizens of Paris. Quasimodo brings Esmeralda to a room in the cathedral as she is still unconscious from smoke inhalation before going to help defend the cathedral from inside.)

Excerpt Three

(Quasimodo returns to Esmeralda's side as the fighting slows, not knowing that Frollo made his way inside.)

Quasimodo: We've done it, Esmeralda! We've beaten them back! Come and see!

(She doesn't move.)

Quasimodo: Esmeralda? Wake up! You're safe now.

(He squeezes her hand gently, but still nothing.)

Quasimodo: Esmeralda? Oh, no!

(He tries again, tapping her cheek lightly. She doesn't respond.)

Quasimodo: No, no. Esmeralda? But... you're free now.

(He begins to cry. Frollo enters and touches Quasimodo on his shoulder. Quasimodo flinches, pulling away, but Frollo grips his shoulder tighter as if it's comforting.)

Frollo: Exactly. She is free. Her soul will be judged, and justice will be served.

Quasimodo: No. You— You *killed* her.

Frollo: It was my duty, horrible as it was.

Quasimodo: Then your duty is wrong!

(He wrenches free of Frollo's grip, still facing away from him though, kneeling next to Esmeralda's still body protectively.)

Quasimodo: What did she ever do that was wrong?

Frollo: Her? Quasimodo, she's a gypsy. She commits witchcraft. Her people are sinners.

Quasimodo: But she harmed *no one*!

(Frollo pauses, looking at Quasimodo thoughtfully. A small laugh escapes him.)

Frollo: Oh, you poor, sweet boy. Have you fallen in love with her? Do you think she could really ever love you? She's all witchcraft and trickery. Lust. A deadly sin, my boy.

Quasimodo: No— no. She is kind and warm, gentle.

Frollo: All lies. She played you like she played Captain Phoebus.

Quasimodo: Phoebus...?

Frollo: And you, you're so naïve, Quasimodo, that you fell for it. She would have sold your soul to the devil. There, there, Quasimodo, I know it hurts. But now, the time has come to end your suffering, forever. Heartbreak is painful, but I promise— it won't hurt much longer.

(We see that Frollo has a dagger. As Frollo raises it to stab him, Quasimodo sees the shadow of the dagger. He turns and struggles with Frollo before taking the dagger from Frollo's hands. Nervously, Frollo backs away, his hands up.)

Frollo: *(nervously)* Now, now, listen to me, Quasimodo.

Quasimodo: *(angrily)* No, you listen! All my life you have told me the world is a dark, cruel place. That people will hate me! That I'm a monster! And— and some people are mean, but—

(Quasimodo glances back at Esmeralda for a moment before turning to glare at Frollo.)

Quasimodo: That's not always true! People can be truly kind and the brightest of bright stars. And some — *(thinking back to Phoebus — ignorant but well-meaning towards him)* some might not do everything the best way, but they mean no harm by it.

(Quasimodo looks at the dagger in his hand, his reflection appearing distorted in the bevels of the blade.)

Quasimodo: You told me I was a monster, a hideous creature that people would fear and hate. But now, I see that the monster is you! Full of hatred and cruel thoughts, seeking out violence. I won't be like you. *(He throws away the dagger.)*

Esmeralda: *(weakly)* Quasimodo?

(Quasimodo turns and sees Esmeralda sitting on the bed.)

Quasimodo: Esmeralda!

Frollo: She lives! *(he grabs a sword.)*

Quasimodo: No!

(He picks Esmeralda up and runs out onto the balcony. Frollo follows, but when he gets outside, he sees nothing but gargoyles. After looking left and right, he looks out over the edge and finds Quasimodo hanging there with Esmeralda.)

Frollo: Leaving so soon?

(He swings his sword, but Quasimodo dodges the blow by swinging onto scaffolding from the roof repairs. Frollo goes to swing again.)

Quasimodo: In here!

(Quasimodo helps Esmeralda inside through a broken window. Frollo jumps down, blocking him.)

Frollo: I should have known you'd risk your life to save that gypsy witch. Just as your own mother died trying to save you.

Quasimodo: What!?

Frollo: Your filthy gypsy mother resisted arrest. She ran, holding you, and she fell. Against my better judgement, I let you live, thinking you would be of use to me one day. But now I'm going to do what I should have done twenty years ago!

(He lunges with his sword. Quasimodo hurries backwards, yelling as he stumbles and grabbing the edge of the scaffolding. Frollo grins, stepping on Quasimodo's hand. He cries out in pain, moving his other hand to grab onto the window frame. The scaffolding creaks as Frollo leans over, his sword at the ready.)

Frollo: And he shall smite the wicked and plunge them into the fiery pit! Both of you!

(The scaffolding, however, sways as the pole comes loose, falling with a clang. Frollo reaches forward, trying to grab onto Quasimodo's torso as the scaffolding falls from under him. Esmeralda tries to reach out for him, but he's too far.)

Esmeralda: Quasimodo!

(Frollo's grip on Quasimodo slips, and he falls with a scream. Quasimodo's arms shake from the exhaustion of holding on, but he falls with a shout.)

Esmeralda: NO!!

(Quasimodo falls right along the building, close enough for Phoebus and another man to catch him a floor below and pull him back inside. Phoebus waves the other man off to help

others before checking on *Quasimodo*.)

Phoebus: Got you! Are you alright?

(Quasimodo nods, shaken from falling and watching Frolo fall to his death. He may not have loved or even liked the man, but he was the only person he even knew for 20 years of his life until now. Phoebus helps Quasimodo lean against the wall.)

Esmeralda, coughing a little from the smoke inhalation from before, appears in the hallway. She rushes to Quasimodo and Phoebus, looking at them worriedly.)

Esmeralda: Quasimodo?

Phoebus: He's okay. Just a little shaken, I think.

(Quasimodo looks up sharply at Esmeralda's voice, reaching for her hand and holding it in his.)

Quasimodo: Are you alright? I— I thought you were dead...

(His voice cracks on the last few words. Phoebus glances at the two of them before stepping back to give them some privacy. Esmeralda smiles sadly, moving to lean on the wall next to Quasimodo, still holding his hand.)

Esmeralda: I'll be okay. Should probably rest for a few days, but I'll live. What about you?

(She leans over, stroking his cheek gently just above a small cut and examining his injured fingers. He shrugs — he's had worse before.)

Esmeralda: Well, I think you could do with some first aid and rest as well. Do you have anything for cuts in your room?

(She turns to leave, but Quasimodo hasn't moved, her hand still in his.)

Esmeralda: What?

(Quasimodo hesitates nervously, looking away as he pulls himself together. Phoebus grins at him from the end of the hall, giving him a thumbs up. The gargoyles outside the window next to him wink and do the same.)

Quasimodo: I— I love you, Esmeralda.

Esmeralda: I love you too, Quasimodo.

(Quasimodo looks up at her brightly, grinning. He steps closer to her, leaning in a little as he's seen the couples do in the streets below him. But he pauses, checking to make sure it's okay.)

Quasimodo: Can I—?

(Esmeralda grins, nodding as she leans in, threading her fingers through his hair.)

Quasimodo wraps an arm around her waist, kissing her gently.

A moment then—)

Phoebus: *(teasingly)* Alright, alright!

(Quasimodo and Esmeralda step back, though Quasimodo's arm is still around her. His face is slightly pink. Phoebus steps over, congratulating them.)

(Cut to the next morning — The citizens of Paris and Roma alike bustle around the square, running errands and cleaning up after yesterday. Esmeralda and Quasimodo stand in the doorway of the cathedral. He looks a little nervous, but he kisses Esmeralda, holding her hand as they step outside together. As they leave the building, people stop, staring at Quasimodo. He notices, tensing a little. Esmeralda squeezes his hand, getting his attention as they walk.)

Esmeralda: Where do you want to eat? Quasimodo?

(Quasimodo glances around thoughtfully, trying to ignore the stares.)

Quasimodo: The baker's? I've always wanted a fresh croissant.

(Phoebus moves through the crowd, joining them.)

Phoebus: Hey, lovebirds! Mind if I join you for breakfast together? What are you eating?

Esmeralda: *(teasingly)* Morning, "sun god". We're getting croissants.

Phoebus: *(groans in delight)* Yes! Warm croissants for breakfast — definitely worth the wait. And don't think I didn't catch that jibe at my name. I didn't choose it.

Quasimodo: *(relaxing, laughing a little and joining in the teasing)* But you didn't change it either.

(Phoebus laughs, nodding as he leads the way, chattering on and on with them. The crowd loses interest slowly, resuming their daily activities.)

Clopin: SO...

HERE IS A RIDDLE YOU NEVER CAN GUESS

SING THE BELLS OF NOTRE DAME!

WHAT MAKES A MONSTER, AND WHAT MAKES A MAN?

SING THE BELLS, BELLS, BELLS, BELLS...

WHATEVER THEIR PITCH, YOU CAN HEAR THEM BEWITCH YOU,

THE RICH AND THE RITUAL KNELLS,

OF THE BELLS OF NOTRE DAME!

(A long pullout, as we see Quasimodo, Esmeralda, and Phoebus step inside the bakery. We continue to pull out, until the entire city is in view. Fade to black. The end.)

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Footnotes

¹ For the purpose of rewriting the script, I referenced a transcript found online (Transcripts Wiki, 2021).

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³ "Gypsy" is only used in the context of the time period's ethnic oppression.



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Notes from the Field

Conference Announcement:

37th Annual Pacific Rim Conference on Disability & Diversity To Be Held Virtually February 28 & March 1, 2022 HST

Pac Rim Team 2022,

Center on Disability Studies, University of Hawai'i at Mānoa

Abstract

An overview of the 37th Annual Pacific Rim International Conference on Disability and Diversity hosted by the Center on Disability Studies, College of Education, University of Hawai'i at Mānoa. The event takes place (virtually this year) February 28th & March 1st, 2022 HST (with a Pre-conference Celebration Day February 26, 2022 HST).

Keywords: conference, disability, diversity

37th Annual Pacific Rim Conference on Disability & Diversity

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<https://pacrim.coe.hawaii.edu>

February 28th & March 1st, 2022 HST
(+Pre-conference Celebration Day February 26, 2022 HST)

Registration Link: <https://pacrim.coe.hawaii.edu/registration>

For 37 Years, The Center on Disability Studies (CDS) at University of Hawai‘i at Mānoa has hosted the Pacific Rim Conference, inviting people from around the world to Hawaii for the premier gathering on disability. This year, due to the pandemic, CDS (lead by Interim Director Dr. Kiriko Takahashi) will host the annual conference virtually. This year’s theme *Mobilize for Action!* invites attendees from around the world to come together as a global community and share strategies for affecting positive change for those with disabilities.

Events

- There are over **100 live events** from presenters from over 14 countries and most US states, including paper and poster presentations.
- Additionally, there will be several **Capacity Building Institutes, free to attendees**. These are pre-event workshops February 26 HST, free for registrants (a fee applies to others). Most are 90 minutes to 2-hours long. From an International Forum on regional and international concerns, to dialogues on housing, storytelling, promotion, and legislation, the sessions offer strategies to expand your knowledge and skill sets.
- In Partnership with the Paul K. Longmore Institute on Disability, the conference also features a line up of films from **Superfest**, the world’s oldest disability film festival.

Speakers


This year's speakers include a woman whose life has embodied this year's theme (*Mobilize for Action!*), the disability rights activist **Judy Heumann**; she will serve as opening keynote speaker. Heumann is joined by noted poet and climate change activist from the Marshall Islands **Kathy Jetñil-Kijiner**, who will serve as closing keynote speaker.

Other nationally and internationally renowned speakers at the event will include President Biden's recent Department of State appointment, Special Advisor on International Disability Rights **Sara Minkara**. Also appearing will be the distinguished community performance artist and a disability culture activist **Petra Koppers**, who will be debuting work from her latest work, the open access *Eco Soma*. This year's conference will also feature renowned disability scholar and activist **Dr. Kara Ayers**.

37th Annual Pacific Rim Conference on Disability & Diversity
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 Conference Announcement: 37th Annual Pacific Rim Conference on Disability & Diversity To Be Held Virtually February 28 & March 1, 2022 HST
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