The Impacts of Disability Representation in Media on Disabled People in Society

by

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DISSERTATION ABSTRACT

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Title: The Impacts of Disability Representation in Media on Disabled People in Society

A large amount of research in media has focused on examining the disability representations that had been found in media, while the effects of these representations on disabled people had been scarce. This research explored how disabled people of various intersecting identities felt about disability representations found in media. In using intersectionality, controlling images, and representation theory as frameworks, the research questions examined how disabled people experienced representations they saw in media, the impacts that these representations had on disabled people, and their reflection regarding the representations of disability in media. Through five virtual focus groups from June to September 2024, eighteen diverse disabled participants discussed topics of disability in media. Through inductive reflexive thematic analysis, three main themes were identified: 1) disability representation experiences; 2) disability representation requests; and 3) fighting for inclusion and support.

The first theme was broken up into five subthemes that included the consequences of no representation; growing up and disability representation; intersectionality; love and disability; the treatment of disabled people; and impacts of positive disability representation. The second theme had these four subthemes: favorite disability representation; authentic representation; eliminating certain disability stereotypes; and disability representation recommendation reactions. The final theme included the following five subthemes: family and disability; being disabled is advocacy; the fight to be included; disability community support; and hope for the future.

When answering the first research question on disability media experiences, participants were divided into either the impact in self or the influence on society. Stereotypical representation that disabled people did or did not see negatively impacted how they felt about themselves and wanting to be as normal as possible to fit into society, and oftentimes yearning for relatability and guidance from authentic characters to be validated. Additionally, stereotypical representations bled into discrimination, often seeing disabled people as child-like, helpless, and unable to work, which impacted how relationships formed around and about disabled people, oftentimes needing them to educate society regarding the misrepresentations of media disability.

In examining the impacts on participants based on the disability seen in media, disability was framed to be taken as a bad thing, which led to participants needing to fight the stereotypes. Stereotypes inform everyone that being disabled is a bad thing and it means that there something is "wrong" with you because you do not align with the "norm." This in term forced disabled people to hide and reject their identities, which nondisabled people normalize and justify the accepted actions against disabled people by showing their need to be cured, their need to choose death as a happy-ending, and overall fearing disability. Stereotypical representations force disabled people to counteract the stereotypes by overcompensating by taking on risky behaviors or being blunt since controlling images made disabled people devalue themselves. In the loneliness they feel due to the lack of relatable media representation, community builds when they meet other disabled people who give them disability pride and to advocate for authentic representation.

In exploring how representations have or could evolve, participants praised certain stories and championed for the importance of authentic and diverse representations. Some favorites

examples included the documentary, *CripCamp* and the TV sitcom, *Speechless*. Disabled people want to see uncontrolled images of disabled characters that make mistakes, are funny, loud, imperfect, sexy, and have big personalities. It is equally important to see characters with similar identities and disabilities as well as explore a range of disability experiences.

By examining the negative and positive impacts of disability representation on disabled people shows the importance of representation not for the audience but society as a whole—it's not just about making disabled people feel seen but also be accepted in society as whole, loud personality individuals and not as tokenized characters only present for the benefit of nondisabled people and systems. A limited sample size and lack in gender diversity were some of the limitations for the study and cannot be generalized to the broader disabled population. Further research can expand on various diverse identities, propose an updated list of disability representation in modern times, and explore the development of "disabnormativity."

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TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION	11
II. CONTEXT OF THE RESEARCH	17
Common Disability Models	17
The Disability Community	21
III. LITERATURE REVIEW	26
Disability Stereotypes in Media	26
Entertainment for the Dominant Groups	32
Disability Representation in Children's Media	34
Media Effects on Audiences	37
Where Are We Now	41
IV. THEORETICAL FRAMEWORKS	44
Representation Theory	44
Controlling Images	46
Intersectionality	51
V. METHOD	55
Research Design	56
Thematic Analysis	57
Researcher and Participants	59
Sampling and Recruitment	61
VI. FINDINGS	62
Demographics	62

Theme #1: Disability Representation Experiences 65
The Consequences of No Representation 67
Growing Up and Disability Representation 69
Intersectionality 75
Love and Disability 78
The Treatment of Disabled People 82
Impacts of Positive Disability Representation 88
Theme #2: Disability Representation Requests 93
Favorite Disability Representation 94
Authentic Representation 103
Eliminating Certain Disability Stereotypes 106
Disability Representation Recommendation Reactions 111
Theme #3: Fighting for Inclusion and Support 115
Family and Disability 116
Being Disabled is Advocacy 119
The Fight to be Included 123
Disability Community Support 126
Hope for the Future 129
VII. DISCUSSION 134
RQ1: Disability Representation and Disabled People 134
Impact on Self 135
Influence of Society 142
RQ2: Impacts of Disability Representation 146

Disability Is a Bad Thing 146
Fighting Against the Stereotypes 151
RQ3: Disability Representation Ideals 156
Praised Disabled Stories 157
The Importance of Authentic and Diverse Representation 159
Concluding Thoughts 162
IV. CONCLUSION 165
Future Research 167
Limitations 169
Recommendations 170
APPENDICES 172
A. APPENDIX A RECRUITMENT SURVEY 172
B. APPENDIX B FOCUS GROUP QUESTIONS 182
REFERENCES CITED 184

LIST OF TABLES

Table Page

1. Common Disability Stereotypes in Media List Table 1 28

2. Demographics Table 2 64

CHAPTER 1

INTRODUCTION

When I was nine years old, I saw my first film with disability representation. Nine years old was also when I received my first manual wheelchair. Being born with muscular dystrophy, a progressive disease that affects the muscles, I eventually needed a mobility device to help me navigate the world. As a child in the 1990s, I did not see any modern kid-friendly shows or films featuring disabled characters. I did have a relative who would have me watch black and white films with disability representation. These were traumatizing to me, to say the least, as many depicted disabled children being abused and segregated.

The movie, *The Miracle Worker* (1962), told the story of Helen Keller. The narrative followed Annie, Helen's aide, who was tasked with teaching Helen, who was deafblind, how to communicate through hands-on and sign language practices. Although my physical disability was not the same as Helen's deafblindness, the movie's portrayal of isolation, cleverness, and being pushed past your breaking points resonated with me. Having been sent to many doctor's appointments and put into different physical therapy sessions, my family did the best that they could. They did not know much about disability until I got officially diagnosed at age seven. Even after this diagnosis, doctors did not say anything other than "there is no cure." Living with a disability requires disabled people to adapt to a nondisabled world. The only way I knew how to do that was through the disability representation I saw in media.

Helen was kept away from society and often confined to a small space often. A prominent scene in *The Miracle Worker* included Helen locking her aide, Annie, in a room and escaping into the backyard. This was a funny, relatable, and smart scene to me, and has stayed with me all of these years. Helen's wealthy family treated her as worthless due to her inability to communicate with and understand them. Helen was portrayed as a "problem child," someone

with unpredictable actions and who was incapable of intelligence, forcing Annie to be physically harsh with her. At the same time, that scene of tricking Annie showed Helen as someone clever and smart, worthy in her resourcefulness. It was as if I saw Helen as a friend, telling me that even if I was made to be around many medical professionals and not other children, I could be clever and resourceful. Even if my physical disability was treated as a "problem" and a burden in social settings, I still had my own mind that was under my control.

The Miracle Worker demonstrates many examples of how representation in media creates the catalyst for "controlling images." For example, it includes the stereotypes of disabled people as sinister (when Helen shows frustration for not being understood or has a meltdown when she does not use utensils for food), as having to be locked up and not be part of society, and as being helpless and unable to do simple life tasks. These paint ableist perspectives of how disabled people may act and why they should be kept away from society. However, at the end of the film, Helen "overcomes her disabilities" through supercrip abilities and accomplishes things no one thought she could, which saw a pushback from disability activists (Kunze, 2013). By making the ending inspirational, the film suggests that the harsh treatment of a deafblind child was worth it, and that all disabled people could be successful in society once they overcome all of their obstacles, which are caused by their disability and not by social structures. This could be harmful messaging for disabled children and their parents. Socially, when nondisabled parents are told of their child having "special needs," they may struggle with the obstacles they believe they and the child may experience, making the child feel the need to prove their worth by accomplishing "normal" milestones like gaining employment (Apgar, 2023). Apgar (2023) discussed how many memoirs of parents with disabled children were from White perspectives, using "burden" stereotypes and overcoming narratives to showcase how their child achieved social acceptance and belonging.

Hill Collins (2000) developed the term, *controlling images*, to describe stereotypes placed on nondominant groups that create oppression. This is accomplished when oppressive structures, from white supremacy to patriarchy, control certain frames that force expectations and social norms upon each group. This explanation was first developed in discussing how Black women were placed into frames of images such as "the mammy" (a concept emerged from enslaving Black women) and "the strong Black woman" (a role tied to matriarchy) (Hill Collins, 2000). The mammy was positioned as an image of the faithful, obedient, Black female servant meant to be seen as an asexual surrogate mother who was caring and nurturing toward a white family's children. The strong Black woman was positioned as the superwoman myth of a working-class, single-parent Black mother incapable of fulfilling society's traditional gender roles as the caretakers of the home and family. Controlling images push stereotypes further into the livelihoods of real people, normalizing their treatment and punishment if they fall outside of those frames.

Controlling images form due to a collection of stereotypes. The first person to coin the term "stereotype" was Walter Lippman (1922). He was mostly interested in the public opinion and media, and how "manufactured content" was used by mass media structures to sway the audiences to have certain opinions in favorability towards elected officials. He introduced the concept of "pictures in our heads" in relation to how audiences visualize the world around them, and how their emotional imaginations were formed by their own beliefs and experiences (Lippman, 1922). Essentially, stereotypes are the widely held, one-dimensional perceptions about certain types of people. The framing of disability was centered on imagined beliefs based on the imagery that was accepted in mass media including news, movies, articles, and more. (Ellis et al., 2020). Thus, the image of disability has run on "imagined" stereotypes, such as the

reoccurring usage of a wheelchair as a blanket disability to represent all disabilities (Ellis & Goggin, 2015) instead of realistic, multi-faceted representations. Controlling images of disability supported narratives that chained disabled characters to their disability or illness, creating one-dimensional perceptions of disabled people (Norden, 1994; Shakespeare, 1999).

Several studies have discussed disability stereotypes found in media (Abbas et al., 2004, Barnes & Mercer, 2001; Black & Pretes, 2007; Bond, 2013; Gulya & Fehérvári, 2021; Holcomb & Latham-Mintus, 2022; Shakespeare, 1999). Hunt (1966) and Longmore (1985) were some of the first to discuss disability stereotypes in media and their negative consequences in places such as advertisements, television programs, and films. The most common ten disability stereotypes were labeled as such: pitiable, pathetic, and child-like; an object of violence; sinister, evil, and punishment for being criminal; the person with disability as atmosphere or feeds curiosity; a supercrip with super qualities who overcomes disability; something to laugh at; one's own worst-and-only enemy; a burden to others and society; asexual and undesirable; and incapable of fully participating in everyday life or happiness (Biklen & Bogdan, 1977).

Disability's misrepresentations are "often used to symbolically represent 'criminality, tragedy, pity, fear, charity, and ridicule'" (Abbas et al., 2004, p. 1). These frames fuel stereotypical treatment of disabled people that can lead to potential dangers within structural systems: for example, forcing disabled people to be sterilized so they could never have children, or justifying the act of "mercy killings" (Oregon Public Broadcasting, 2020). The disability representations being created can dictate how disabled people should be seen, treated, and oppressed, yet research rarely examines how these representations impact actual disabled lives or why disability narratives need to change.

For this dissertation, it was important to listen to disabled voices regarding the representation of their own disabilities that they had witnessed being portrayed—or not being portrayed—and to understand how these representations create internalized ableism. Internalized ableism, or internalized oppression, is how disabled people accept and act within the stereotypes and social treatments they believed to be accurate, usually in self-sabotaging or self-segregating ways (Jeffress et al., 2023; Shakespeare, 1996), such as if the common stereotype of disabled people not being able to love made them feel that they were not worthy of dating anyone.

For the purposes of this study, the term "disability" was used as a broad term that encompassed: physical disabilities (e.g., muscular dystrophy, cerebral palsy), visual disabilities (e.g., blindness, color blindness), neurodivergence (e.g., autism, ADHD), mental illness (e.g., social anxiety, schizophrenia), chronic illness (e.g., lupus, cancer), and deaf representation. It was important to have conversations about the past, present, and future of disability representation, and how disability representation in media has impacted disabled peoples' relationship with their own disability/ies.

Through the use of small focus groups, this study investigated how disabled people reflected upon and interpreted disability representation throughout their lives. The intimacy of having delicate, personal conversations about experiences living as a disabled person in a society that operates through an ableist lens allowed participants to discuss how certain representations have impacted them in a shared and safe space. Collectively, disabled movements were started by disabled people fighting the ableist frames and harsh treatments they faced together (Oregon Public Broadcasting, 2020). When studying disability representation from the lens of disabled audiences, media professionals, researchers, and educators should integrate disabled people and

invite them to reshape the controlling images to be in line with and authentic to actual disabled experiences and desired representations.

The successive section of this dissertation outlines the "context of research," and discusses different disability models and the disability community. The "literature review" section introduces topics on disability stereotypes in films and television, entertainment for the dominant groups, disability representation in children's media, media effects on audiences, and where we are now. The "theory" chapter centers on representation theory, controlling images, and intersectionality. The "method" chapter explores topics of focus group participation, inductive thematic analysis, design, sampling, and recruitment. The "findings" section includes a detailed summary of the demographics and discusses three main themes: disabled people's relationships to and experiences with disability in media; disability representation requests for better representation; and fighting for inclusion and support. The "discussion" section circles back to the research questions—labeling each one as: RQ1: Disability Representation and Disabled People, RQ2: Impacts of Disability Representation, and RQ3: Disability Representation Ideals—explores limitations and adds future research proposals. The final section is a conclusion of the research, along with recommendations for future action. The document ends with two appendices—Appendix A includes a recruitment survey and Appendix B includes focus group questions—and a references list.

CHAPTER 2

CONTEXT OF RESEARCH

Garcia-Iriarte, McConkey, and Gilligan (2016) introduce ten models of disability, four of which will be addressed in this dissertation: medical, economic, charity, and social. Many media representations stem from the medical model, meaning that disability is framed as an illness rather than an identity (von Krogh, 2010); thus, the idea of "curing" disability controls many of the disability narratives in media as well as greater society (Haller, 2010; Jeffress et al., 2023; Nelson, 1994). In setting up this foundation, it was important to identify how disabled people discuss these representations and advocate against many stereotypical representations (as described below), and why many prefer the social model of disability. Friction between medical model–based media representation and the disability community is present because disabled people are excluded from decision-making opportunities (Barnes, 1991), due to the predominant hiring of writers and producers who tend to be nondisabled yet "are in control of the media industry and use disability as a hook to draw the attention of the audience" (Grech, 2018, p. 3).

Common Disability Models

The medical model is one of the oldest models of disability (Garcia-Iriarte, McConkey, & Gilligan, 2016). This model centers on the framework that a person's illness or condition takes away from their life and that they need to be fixed in order to be accepted—the ideology of being labeled as a tragedy (Reynolds, 2017). In other words, disabled people are meant to be "medically" treated in order to fit into society's standards of living and be accepted in a nondisabled world (von Krogh, 2010). Medical model media images can include showing disabled people needing to be separated and treated in isolation, as seen in *The Miracle Worker* where Helen was kept away from everyone, or in the story arc of a male character becoming

paralyzed and reclusive after an accident, as seen in the film, *Me Before You* (2016), culminating in him choosing assistive suicide rather than the burden of being disabled.

This ties into the ideology that disabled people are not capable of contributing to the financial health of society and should be confined to a place where their life goals could include working towards becoming as nondisabled as possible. Finkelstein (1993) explained how the "economic model" is tied to individual abilities and wealth generation that supports currency production for society, and that only "normal" people could and should be employed. Those deemed not "normal" (e.g., wheelchair user, blind), as decided by a medical professional, would automatically be labeled as someone who is not capable of working due to their disability (Finkelstein, 1993).

This aligns with the medical model of an unhealthy body and mind seen as a problem that cannot be part of society's systemic operations in favorable ways, and thus must be stripped of all rights and autonomy. For example, when disabled people are denied access in casting calls for disabled characters—whether that is the performance practice or the production practice (Brown, 2021)—different avenues of media misrepresent disabled people (e.g., anxieties about their deformed bodies, authority figures making decisions for the "sick") compared to how they actually live their lives (Darke, 2003). This is parallel to the real-life decisions that are made for disabled people by nondisabled people. When they are deprived of agency, control over their bodies, or any human rights (Oregon Public Broadcasting, 2020), disabled people can either become silent in isolation or fight in unity, which is why many disability advocacy groups formed. Garland-Thomson (1997) discussed how the outlook of medical disability needed to be moved to the realm of "political minorities" in order to consider disability as a "context of social

power relations . . . a representation, a cultural interpretation of physical transformation or configuration" (p. 6).

When a disabled person is depicted as "less than" a nondisabled person. This includes when nondisabled people put a distance between themselves and disabled people based on how controlling images have normalized the perception and treatment of disability. When dictating how disability should appear in media, anything outside the societal "normal" tends to not be socially accepted, creating any "differences" such as a wheelchair-user to be pitied or feared (Garland-Thomson, 2002). This can even be seen in public places, such as bathrooms and parking spots that constantly reinforce the normalization of segregating disability—and usually an afterthought in design. If there is no access, there is no opportunity; therefore, there is separation, which is seen as the disabled person's problem rather than a social issue.

Thus, disabled people are not seen as those who could be successful, let alone provide for a family or raise one, and are therefore expected to live on welfare. This can create the need for nondisabled people to treat disability as "charity." Through the charity model, disability is painted as something pathetic and pitiful, and "helping the poor, the sick, and the disabled is a rewarding deed" for nondisabled people (Ellis & et al., 2019, p. 189). These acts, such as MDA Telethons that raise funds to "help" disabled individuals (usually children) MDA Telethons (Haller, 2010), are often portrayed through inspirational frames, requiring the aid of nondisabled people who may then feel good about giving funds to help "cure" a sick child (Rimmerman, 2013), and feed back into the medical model. This ties in with the constant cycle of controlling images seen not just in fictional media, but real-world narratives and social structures.

Part of the fight for better inclusion involves the disability community voicing their experiences. This is seen through the social model of disability which focuses on "the

experiences of disabled people, challenging the dominant individual models espoused by non-disabled people" (Swain & French, 2000, p. 570): for example, having only stairs to a restaurant makes it less accessible to someone who needs a wheelchair to move their body. The models discussed above largely shape how disabled people are treated in society, yet many disabled activists view disability from a social model (Shew, 2023). This ideology sees disability through a socially oppressed view due to the lack of access and inclusion in society (Mul, 2018), as well as the oppression and disadvantages placed on disabled people (Thomas, 2004). It supports the idea that disabled people are whole people, not simply humans with impaired body parts who are unable to work and support others, and understands that disabled people possess the full range of human experiences (Conroy, 2008). In other words, the medical model looked at the "disease/cure-needed" angle of a person whereas the social model looks at how the social stigmas of disability are culturally constructed.

It was important to note that sometimes the medical model and the social model exist cohesively (Ladau, 2021). Additionally, the seismic shift between the medical model of the issue of an impairment versus the social model of having nothing to do with an impairment dismissed the realities that removing all barriers for all disabled people would be impossible as some need accommodations that hinder other disabled people's impairments (Shakespeare, 2013). As Crow expressed, "Most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives" (1992, p. 7). As much as the social model has helped start social movements and saved disabled lives (Crow, 1996), it would not be the catch-all model of disability.

The social model was fueled by activists in the disability community to combat the medical model (Thorneycroft, 2024). They turned the tables and illustrated how the struggles

that disabled people face were socially constructed. Moreover, experiences and voices of disabled people should hold priority over those of nondisabled people when it comes to making decisions for themselves. The power structure was rooted in nondisabled people oppressing and exploiting disabled people both on- and off-screen for the benefit of nondisabled people, whether that was capital gain, entertainment, or career accomplishments (Moyer, 2015). This was one reason disability advocacy pushes for its own representation, particularly for its human and civil rights. This study advocates alongside disabled people by bringing forward their voices and experiences with how the representation of disability has impacted and influenced their lives.

The Disability Community

Disabled people have a long history of organizing protests and advocacy efforts, such as the Rehabilitation Act of 1964 and the Americans with Disabilities Act (ADA) of 1990 (Public Broadcasting Service, 2011). The ADA was intended to end disability discrimination in public entities such as transportation, education, and employment (ADL Education, 2017). This was no easy feat, and disabled people protested through acts such as climbing the steps of the Capitol and chaining their wheelchairs together to prevent being arrested in Washington, D.C. (Public Broadcasting Service, 2011). This legal landmark was the first step in getting disabled people to be integrated into society. However, the ADA did not instantly transform deep-rooted societal biases and stereotypes. More than thirty-five years later, disability discrimination and bias still exist in stereotypical media representations and public places, including lack of accessibility to schools, housing, voting stations, and health care (ADL Education, 2017).

Many disability stereotypes (e.g., pity, evil, helpless, burden) tie into the cultural concepts of disability inherited from the medical model, and shape discourse around how disability is perceived (Cunningham, 2016). Jenni Gold, a wheelchair user who produced the

documentary *CinemAbility* (2012), which investigated disability representation in media, questioned why disability was always portrayed in the worst of ways (Sun, 2016), questioned why disability was always portrayed in the worst of ways (Sun, 2016). She said:

> In *Million Dollar Baby*, you had a character who is a boxer, who fights and overcomes her lack of money and her awful family, but the one thing that is insurmountable is a physical disability to the point that she is helped to kill herself (Sun, 2016).

Part of the social battle is the power struggle with nondisabled people about disabled people in media, including the practice of praising nondisabled actors and writers for creating disabled characters (Nelson, 1994; Pulrang, 2020). *CinemAbility* discussed the topic of how nondisabled actors can play disabled characters, yet many disabled actors cannot even obtain access to auditions.

Continuous barriers of inaccessibility exist for disabled performers, filmmakers, and writers trying to find entry into the entertainment industry, which is why grassroot organizations are created to help combat issues of inequality (Brown, 2021). In this sense, it is disabled people who are burdened by the ableism of the industry. Disabled people are influenced by media they consume, just like nondisabled audiences, and their ideologies about disabilities can be a place where, from a young age, internalized ableism starts to form. Internalized ableism creates a cycle where the disabled person accepts and adopts ableist ideologies because society pushes that narrative forward (Shew, 2023). In turn, this project aims to understand if, how, and when controlling images birth internalized ableism within disabled people.

Disabled actors want opportunities to "act" past the role of the "disabled" character that is only hired to portray some disability element beneficial to the story—something that is called typecasting (Zuckerman et al., 2003). Typecasting refers to casting certain types of people for

particular roles on repeat based on a single type or genre of work, such as a character with dwarfism playing an elf. In this light, authenticity is important, but this ideology limits disabled performers to essentially play "themselves" or stereotypical versions of disability. The limits placed on them prevent them from advancing into other roles beyond the representation of disability, while nondisabled performers can play both nondisabled and disabled character, and be praised for depicting the latter. Pulrang (2020), a disabled columnist, argued that acclaimed films from the 1980s to the mid-2000s included disabled characters and themes that were created by nondisabled people. He said:

> During this time, writing or playing a disabled character was one of the surest paths to both popular and critical regard, as well as Oscars and other film awards. A *Washington Post* article in 2015 noted that a third of the Best Actor Oscars since 1988 went to actors playing characters with disabilities. And in 2017, IndieWire listed no less than 59 actors nominated for playing disabled characters.

This in turn fuels images of disability that disabled people may not be able to escape because their access to media representation was denied. In the battle for equality and the shattering of stereotypical images that shape how disabled people were supposed to live based on the nondisabled lens, the only way to be heard is to have a unified voice.

The representation of disability does not go unnoticed by disabled people. As with the fight for their human rights with the ADA, which aimed to end discrimination (Public Broadcasting Service, 2011), many advocates have used grassroots (Ladau, 2021) and media activism to protest against oppressive practices, such as the #SayTheWord (e.g., "disability") campaign (Shew, 2023) and #TheBarriersWeFace to resist the medical model (Mulderink, 2020). This can be called hashtag activism as way to filter topics and conversation to reach certain kinds

of communities and experiences and engage with activism, oftentimes amplifying underrepresented voices, like the trans community (Jackson et al., 2018). This can shape how people talk about social issues, build awareness, or call attention to a problem and generate a conversation.

Additionally, in 2019 a disabled writer designed the Disability Pride flag—which has been adopted by the disability community—to represent: physical disabilities (red stripe), neurodiversity (gold stripe), nonapparent and those not yet diagnosed (white stripe), emotional and psychiatric disabilities and mental illness (blue), sensory disabilities including deafness and blindness (green), and disabled lives lost to ableist violence and abuse (black) (Columbia University Irving Medical Center, 2023). The disability community's voice amplifies these issues with the aid of social media, as "Stories told from a victim's standpoint" have the ability to create empowerment and awareness, which can be done through "social media platforms [that] enable disability advocates to set up spaces where disabled Internet users can tell their own stories directly, presenting their experiences as 'expert' views on disability in contrast with dominant narratives and media stereotypes" (Ellis et al., 2020, p. 383).

The "nothing about us without us" online movement spans across the disability community (Iezzoni & Long-Bellil, 2012) and education (Craig & Piskur, 2012). The slogan argued that disabled people should control disability representations and be able to move toward a power discourse where disabled people took their power back to make their own decisions versus one that was riddled with stigma (Wolffs & Hums, 2017). With the aid of social media, the disability community's voice amplifies these issues. Thus, understanding how representations in media impact and influence disabled people, and how they live in society, is important in order to make positive change for disabled people. Additionally, listening and including disabled

people normalizes their experiences, validates their feelings and expertise, and introduces the importance of giving disabled people back their power and control (Brune & Wilson, 2013). In sharing similar discrimination experiences, people's intersections of oppression became a fuel for finding solutions that promote equality. As marginalized individuals build their own communities in response to being "othered," they are able to advocate together and empower change for themselves and other marginalized communities (Crenshaw, 1991). Thus, disabled people have grown to lean on each other and unite together.

Within the disability community, some people prefer to have society see them as a person first and reject their disability just to fit into the world, while others want to choose their disabled identity pride and embrace it (Ladau, 2022; Shew, 2023). In other instances, identity-first or person-first language can differ based on a person's disability type and acceptance (Bogart & Dunn, 2019; Grech et al., 2023). It is important to note that disability as an impairment that ties to the medical model of needing a cure, and is seen as something wrong with a body, while disability as an identity embraces the experiences of having a disability while being a person in an ableist society (Shakespeare, 2013). How disability is represented in media aligns with not only social structures—possibly based on the stereotypes they see in media—but how disabled people see themselves. Some disabled people may identify with the stereotypes and prefer to be treated as inspiration or as helpless, while others do not. It is important to examine how disabled people prefer to live in accordance with the controlling images placed onto them.

CHAPTER 3

LITERATURE REVIEW

Media was intended to tell stories by creating certain narratives. When it came to disability representation, much of its portrayal included negative images, catapulting several harmful stereotypes outlined in the first section to popularity. Many of these were built on society's belief that disabled people, who were oftentimes hidden from society, did not fit the norms required to be included in society. Myth-filled disability stories were created by nondisabled people as a way to rationalize disabled people, who were seen as something foreign due to their segregation in society (Baskin & Harris, 1977). Most of these stories were intended to be forms of entertainment for dominant groups (as discussed in the second section), catering to nondisabled curiosities about disability, which had been structured to be separated from society. People had a desire to look and stare at those "freaks," which solidified what would and would not be considered a beauty standard in media (Garland-Thomson, 2002).

Often, disabled characters were present simply to act as atmospheres to a storyline or be the moral of the story for nondisabled people (Nelson, 1994). These images of disability had an effect on disabled audiences, regarding their opinions of the representation and how people treated them out in public (as detailed in the third section). This thread was explored through researching how disability was portrayed in children's media, as well as children's understanding of disability in literature. To wrap up the chapter, it was important to investigate the present and future of disability representation according to different reports conducted by disabled activists and nonprofit.

Disability Stereotypes in Media

Traditional disability stereotypes have existed for decades, with depictions of disability as something to cure being traced back to the Bible (Norden, 1994). Disability representation has been examined in movies (Darke, 2003; Haller & Larsen, 2002; Hayes & Black, 2003; Safran, 1998; Whittington-Walsh, 2002), television shows (Foss, 2014; Kolotouchkina, Llorente-Barroso, García-Guardia, & Pavón, 2020; Kraayenoord, 2011; Longmore, 2003; Montgomerie, 2010), and books (Aho & Alter, 2018; Brenna, 2009; Dowker, 2004; McGrail, 2016; Rubin, 1987). Many of these text-based studies focus on content related to physical or developmental disabilities. The mediums proved to showcase common negative stereotypes of disability such as a burden, helpless, evil, or incapable of living in society (Barnes, 1992).

Following Biklen and Bogdan's (1977) original list of disability stereotypes (disability as pitiful or pathetic, object of violence, evil, prop to a storyline, super abilities, laughing matter, one's worst-and-only enemy, a burden, asexual, can't participate in everyday life) found in children's literature, films, television programming, newspapers, and advertisements (see Table 1), Rubin and Watson (1987) conducted similar research by studying juvenile fiction literature, and added the stereotype of "disability as something in isolation." The most popular list of stereotypes cited was circulated by Barnes (1992), which built off of the existing Biklen and Bogdan (1977) list but conducted a meta-analysis of stereotypical examples found in media (such as television shows, films, newspapers, and advertisements) and added a "disability as normal" category, which Clogston (1994) refers to as "ordinary." In another study, Barnes (1991) discussed how stereotypical assumptions arise from social norms, folklore, myths, and beliefs about disabled people within cultures.

In 1994, Nelson focused on Biklen and Bogdan's (1977) list, adding the category of "better off dead" trope; Longmore (1985) also discussed how disabled people were portrayed as

not worthy of living a happy life, and that their only point of release from the challenges of disability was death. The ten common media representations are further explained with examples in Table 1, including the other two categories of isolation (Rubin & Watson, 1987) and better-off dead (Nelson, 1994).

COMMON DISABILITY STEREOTYPES IN MEDIA LIST

Stereotype	Explanation
1. The disabled person as pitiable and pathetic	Portrays disability as a tragedy to pity, pulling at the hearts of viewers; oftentimes being moral lessons for nondisabled characters (Biklen & Bogdan, 1977). To further these plot devices, the disabled character is usually portrayed in childlike and incompetent ways, lacking superiority (Black & Pretes, 2007). Examples of films that portray disability as pathetic to evoke emotion: *A Christmas Carol* (1938, 1951, 1984, 1999, 2009), *Moby Dick* (1956), *Winnie the Pooh* (2011), *Wonder* (2017).
2. The disabled person as an object of violence	Portrays disabled characters as victims to abusive behaviors due to their helpless nature and dependency on others (Biklen & Bogdan, 1977). These further bleed into normalizing killing disabled people (including unborn babies), abandoning disabled children, and using crime as a natural solution to problems seen caused by a disability (Barnes, 1992). Examples of films that portray violence is justified towards with disabled characters: *Whatever Happened to Baby Jane* (1962), *Lady in a Cage* (1964), *Diary of a Mad Black Woman* (2005), *Music* (2021).
3. The disabled person as sinister and evil	Portrays disability as a form of punishment for bad behavior. Characters are seen doing something malicious or evoking terror, and are usually villains (Biklen & Bogdan, 1977). Another layer deals with disabled characters as creatures where "ugliness" equates to being a criminal or an evil-doer who wishes to destroy nondisabled people, causing society to fear disabled people (Black & Pretes, 2007). Examples of films that represent disability as punishment or evil: *Hook*, (1991), *Star Wars Episode III: Revenge of the Sith* (2005), *Joker* (2019), *The Witches* (2020).

4. The disabled person as atmosphere or curio	Portrays disabled characters just for the atmosphere of a storyline; usually as "curious objects" or "freaks" that makes looking at disabilities fascinating (Biklen & Bogdan, 1977, p. 7). This narrative device adds to the visual impact that exploits the appearance of disabled bodies to the level of being exotic or feared (Barnes, 1992). Examples of films that use disability as a visual emphasis: *Frankenstein* (1931, 1970, 1994, 2004, 2025), *The Good, The Bad and The Ugly* (1966), *The Phantom of the Opera* (2004), *Nightmare Alley* (2021).
5. The disabled person as super cripple	Portrays disabled characters with super or magical abilities as a way to prove their worth for acceptance into society, oftentimes offsetting or overcoming their disabilities through adversity (Biklen & Bogdan, 1977). These narratives serve as inspirational frames wherein courage helps accomplish greatness (Black & Pretes, 2007). Examples of films that portray disability with special powers or overcoming disability: *Forrest Gump* (1994), *Daredevil* (2003), *Temple Grandin* (2010), *The Theory of Everything* (2014).
6. The disabled person as laughable	Portrays disability as something humorous, where the disabled person is a dumb, accident-prone fool who gets into unfortunate situations and survives by sheer luck, oftentimes ridiculed for jokes or mocked (Barnes, 1992; Biklen & Bogdan, 1977). Examples of films that portray disability as something to laugh at: *Mr. Magoo* (1997), *The Waterboy* (1998), *The Ringer* (2005), *Finding Dory* (2016).
7. The disabled person as his/her own worst and only enemy	Portrays disabled characters who "could 'make it' in society" once they stopped self-pitying and being bitter about being disabled, rising to the challenge and having a positive attitude (Biklen & Bogdan, 1977, p. 8). These narratives usually include anger at one's disability, and society blaming them for not having the determination or self-acceptance to deal or cope with their condition for a happier life (Black & Pretes, 2007; Nelson, 1994). Examples of films that portray disability without a positive attitude: *Born on the Fourth of July* (1989), *My Left Foot* (1989), *What's Eating Gilbert Grape* (1993), *The Upside* (2017).
8. The disabled person as burden	Portrays disabled characters as too helpless to care for themselves, dehumanizing and objectifying them as requiring nondisabled people and society to take on the difficulties of caring for those with "special needs" (Biklen & Bogdan, 1977). This narrative

	device also uses disabled people as props to paint their families and/or caregivers as saints/saviors and generous people for taking on the burden of caring for a disabled person (Black & Pretes, 2007). Examples of films that illustrate disability as a burden on loved ones: *Heidi* (1937; 1968; 2005; 2017), *Love and Other Drugs* (2010), *Me Before You* (2016), *Breathe* (2017).
9. The disabled person as non-sexual	Portrays disabled people as asexual and incapable of intimacy and love, oftentimes rationalizing partners having affairs and not being attracted to their partner anymore (Barnes, 1992; Biklen & Bogdan, 1977). On the flip side: disabled characters (usually men) as having sexual desires they are usually not able to achieve or fearful of fulfilling sexual pleasure (Barnes, 1992; Biklen & Bogdan, 1977). Examples of films that portray asexual narratives or unattainable sexual desires: *The Elephant Man* (1980), *Lady Chatterley's Lover* (1981; 2022); *The Sessions* (2012), *You're Not You* (2014).
10. The disabled person as incapable of participating fully in community life	Portrays disabled characters as ones who cannot be integrated into society or participate in life events like working, raising a family, or enjoying leisure activities, causing them need to be segregated into institutions until they can "act nondisabled" and make contributions to society, because disabled people are "hopeless dependents" (Biklen & Bogdan, 1977, p. 9; Black & Pretes, 2007). Examples of films that portray disabled people who are not able to be members of the community: *The Miracle Worker* (1962; 2000), *Rain Man* (1990), *I Am Sam* (1991), *The Sea Inside* (2004).
11. The disabled person as normal	Portrays disabled characters as those without "impairments" in a sense where their disability-identity and personalities were not present and experiences of discrimination were erased (Barnes, 1992). In other words, able-bodied attributes or imagery were "emphasized while impairments are played down or ignored," especially in minimal or background roles (p. 15). This dictated that there was no need for change regarding "policies to bring about a society free from disablism" (p. 14) and the change of normalcy was "squarely on individual disabled people rather than on the disabling society in which we all live" (p. 15). Examples of media that portray disability without disability identity or personal experiences: *X-Men* (2000), *Brave* (2012), *The Grand Hotel* (2019).

12. Disabled person isolated from others	Portrays disabled characters as separate and hidden from others, oftentimes depicted as loners or being alone (Rubin & Watson, 1987). Examples of films that portray disability in isolation: *The Hunchback of Norte Dame* (1939; 1996), *Edward Scissorhands* (1990), *The Secret Garden* (1993), *Frozen* (2012).
13. Better off dead than disabled	Portrays disability as something unbearable to live with, making death is the desired release for disability's struggles (Nelson, 1994). Examples that include killing off a disabled character: *Gattaca* (1997), *A Walk to Remember* (2002), *Million Dollar Baby* (2004), *The Fault in Our Stars* (2014).

Table 1. Two columns listing the thirteen common disability stereotype and their relevant definitions as described by different scholars, along with examples of films.

To further break down some of the stereotypes, historically, disabled people in media have served to amuse, concern, or inspire nondisabled people. Safran (1998) discussed how in the early 1910s and '20s, films focused on caring about disabled people through medicine or creating a cure that would "fix them." Later representation focused on using disabled people as forms of entertainment for nondisabled audiences. In this post–World War II era—the late 1940s—movie framing focused on disabled veterans. The 1950s portrayal of disabilities focused on supporting the idea of overcoming a disability with the help and assistance of family and friends. In the 1960s and '70s, the focus shifted to portraying physical disabilities as something inspirational, through disabled characters either becoming supercrip (Black & Pretes, 2007), or being awarded for overcoming struggles or being pitied, or being shown as needing a cure in order to live independent and happy lives (Hayes & Black, 2003).

The common representation of deafness portrayed deaf people as "deaf and dumb" (Foss, 2014). Although most deaf people identify deafness as deafhood, which is a culture and a language, most of society and studies treat being deaf/hard-of-hearing (DHH) as a disability.

Foss (2014) analyzed over 250 episodes of television, airing over a span of 26 years (1987-2013), that featured a deaf character and found that shows portrayed deaf people as helpless for not being able to save someone when a robbery occurred or hear a fire alarm in a burning kitchen. Another discovery was how deaf people were "savage" or criminal because they couldn't hear a police officer telling them to stop. What people see in media about disabled people gets translated into how disabled people are treated in society. Mediums such as films and television assist in forming "the public's beliefs and dispositions about people with disabilities" (Schwartz et al. 2010, p. 841), and these problematic storylines push their stereotypical messages onto real-life disabled people (Calder-Dawe et al., 2020). This project examines how disabled people feel about the representations they saw—or did not see—in media and how disabled audiences interpreted these representations.

Entertainment for the Dominant Groups

For decades, disabled people have been portrayed as freaks—an early depiction was in a 1932 film simply titled Freaks—a label that can be dated back to disabled people being used in circuses as attractions for nondisabled people to stare at (Haller & Larsen, 2002; Whittington-Walsh, 2002). The pity label, as experienced via the charity model, was developed to attract audiences to see these "freaks" and teach nondisabled people to have pity for those who were different and "less fortunate" than them (Hayes & Black, 2003). Another example of a "freak" character was *The Elephant Man* (1980) where the main character was confined to a dark cellar or put in an isolated hospital due to his abnormally sized head.

In a similar sense, *Mask* (1985) portrayed a mother confining her disabled son to the house not because he is incapable of going out in public, but solely because his face is deformed. Such confinement shrinks a disabled person's social circle, taking away their ability to understand and be understood by others, thus fueling images of depression, sorrow, and anger in

disabled characters. In a final example, the main character in *The Phantom of the Opera* (2000) hid from everyone and wore a mask in order to not make nondisabled people uncomfortable (Nelson, 1994). Many of these associate disabled characters with monsters that were meant to be feared by others or looked at with curiosity (Schatz & George, 2018).

In a nonfictional sense, disabled "freaks" fueled the curious stare for nondisabled people that can be seen as unwelcomed, invasive glares to fuel visual curiosities about the rarity of disability in public places (Garland-Thompson, 2009). Prior to the 1970s, "many US states had on their books 'ugly laws': restrictions placed on individuals with visible physical impairments, preventing them from being seen in public places" (McCarthy, 2021, p. 23). There seems to be a thread where some deemed a "freak" was allowed to be on display for amusement and entertainment purposes, but was too terrifying to be seen in public otherwise. Fiction and reality may be one in the same, paralleling what it meant to show disability in media.

Media narratives exploited the way "disabled people have variously been objects of awe, scorn, terror, delight, inspiration, pity, laughter, or fascination—but they have always been stared at" (Garland-Thomson, 2002, p. 56). Rosemarie Garland-Thomson (2002) discussed the visual aspects of disability and what it meant to "see" disability in art, film, books, etc. The "abnormal" body was stared at not through a look of desire, but of sheer curiosity. This may explain why nondisabled people would not want to see disability on the screen the way they want to see conventionally attractive people on the screen, since disability was considered unattractive and undesirable. Disability is not seen as "attractive" unless it was used to make the target audience want to watch the representation, whether to feel "inspired," "good," or "curious."

Most disabled people were portrayed as passive characters and were oftentimes in the background (Longmore et al., 2016); narratives had no use for them beyond one-dimensional objects for audiences to stare at (Nelson, 1994). Disabled people had a tendency to exist solely to

help the storylines of nondisabled people and entertain audiences—since television aimed to reach a broad audience—they were used to evoke pity and emotion, and to be plot devices for nondisabled character's arcs of growing and becoming better people (Biklen & Bogdan, 1977; Black & Pretes, 2007). Many films use disabled stories (e.g., Helen Keller, Stephen Hawking, Kim Peek) without supporting disabled actors or creators, instead setting up nondisabled people to win awards and be praised for their hard work (Pulrang, 2020). Disabled people were not only told how they should be represented on television but were also never part of the representation-writing process (Barnes, 1991; Ellis, 2019). Blogger Harris (2014) discussed how nondisabled actors may be able to engage and understand a disabled person in order to play their disability and create a believable performance, but the issue remains with the way disability is treated as a tool for the storyline.

Disability images of disabled people crafted by nondisabled people create very narrow, if not one-dimensional stereotypical representations of disabled people (Norden, 1994). If disabled people are rendered voiceless and isolated and are not given the opportunity to make decisions for themselves, then the only way for society to understand them is to create stories about them for the nondisabled audience, played by nondisabled actors. Society may accept this norm, abiding to the economic benefits of using disabled people's stories and struggles to further nondisabled careers and normalize stereotypical treatment of disabled people. The similarities of fiction and fact seem interchangeable in how disabled people are seen and treated.

Disability Representation in Children's Media

Many children and disabled children grow up learning about the world around them and their identity through media (Anderson, 1983), so how children learn about disabilities, either their own or others', can impact their disability beliefs for the rest of their lives. Eder et al.

(2010) provided insight into the importance of diverse fictional characters for children's development, discussing how fictional characters shape audiences' understanding of the world and help navigate complex issues, such as identity, morality, and social norms. The actions of fictional characters are viewed as models for behavior, promoting empathy between the viewers and the characters, influencing how audiences can react to characters, developing emotional triggers, and building relationships based on an imaginary world.

There had been some research on children's literature and disability representation (Rubin & Watson, 1987; Dowker, 2004; Brenna, 2015; McGrail, 2016; Aho & Alter, 2018) as well as mental illness (Walh, 2003; Wilson et al., 2000) and Down Syndrome (Dağlı et al., 2021; Lloyd & Brodie, 2000) in children's media. Throughout literature and its history, much of disability narratives have been medically and socially constructed to be fixed rather than fluid (Lane, 2005). As nondisabled children learn about disabled people as being different from them and not having any similarities with them, these beliefs tend to result in segregating and isolating anyone that would be considered as different (Solis, 2004). In this stance, the focus on "difference" is seen as something to fear, ridicule, and stigmatize, and "normal" aligns with good appearance, physical "wholeness," and high intelligence full of successful stories (Adomat, 2014).

Research of Disney content found negative disability stereotypes portrayed in stories such as *The Hunchback of Notre Dame* (Norden, 2013), *Snow White and the Seven Dwarfs*, *Cinderella*, and *Beauty and the Beast* (Schwartz et al, 2013). In the original *Hunchback of Notre Dame* (1939), the disabled character was seen as a savant—a disabled person who is only viewed as successful because they are courageous or brilliant—and reinforced "their 'difference' against the 'normalness' of the other characters" (Whittington-Walsh, 2002, p. 699). More recently,

Holcomb and Latham-Mintus (2022) conducted a content analysis of disability representation in Disney and Pixar films, using pre-identified and emergent (progressive) disability and illness-related stereotypes to analyze 20 films from 2008-2018. Their findings showed existing traditional stereotypes (e.g., disability as humor/joke, pity or helplessness, evil), though as there were some progressive representations (e.g., disability seen as a systemic issue in accessible spaces, disability as an ordinary part of life), results were ultimately mixed. However, overall conclusions pointed to the fact that much of disability representation was still rooted in traditional stereotypes within children's media. In such, research from academics is needed—specifically, research on an array of disabilities within the children's sector—including content to research from the entertainment industry.

On the flip side, Pirofski (2002) had found models of socially active, equal, and independent representations in a study of contemporary children's novels. Prater and Dyches (2008) seemed optimistic about the early 2000s where children's literature have positive attitudes towards disabled people. This is important because having empowering and positive representations can teach readers not only empathy and finding similarities will all kinds of people (Gervay, 2004) but also about certain human differences (Salend, 2001). *Sesame Street*—a puppet show for children—gained traction in research over a decade ago of how children interpret disabilities (Cole, 2008; Dyson, 2005; Sell, 1995; Dickter et al, 2021). Diamond and Kensinger (2002) noted how preschool children understood the idea of adaptive equipment that aided someone's disability, but lacked the understanding of why someone with Down Syndrome could not do a task.

Even if there has been some movement toward improving the representations of disability in children's media, many historically rooted stereotypes persist. Many children's books still give

"subliminal or frankly negative messages" regarding disabled lives (Saunders, 2000, p. 1). Disability representation lacks positive, authentic messages, whether it's in movies, television shows, or books. All in all, there needs to be a conversation about disability in real-life children's shows. The slow or nonexistent progression of disability representation means that disabled people have to fight for their own representation and inclusion. From character creation to the selecting actors, most stories with disability representation are controlled by nondisabled people. This study explored how participants felt about disability representation and how that impacted them, along with hopes for the future regarding disability representation.

Media Effects on Audiences

Cultures in society form and shift, as do meanings and words. The influences of media messages discussed by Gray and Lotz (2019) illustrate the effects of television on people such as how much World War II propaganda "worked when it reached its targets" (p. 153). The *Television Studies* (Gray & Lotz, 2019) discussed some concepts around the paradigms of mass communication, anti-feminist genres depicted gender, media habits and rituals in family dynamics and attitudes, and cultures that arise from popular culture. Using certain discourse stereotypes situated power dynamics and put disabled people in an oppressed environment. On the extreme end, the force of these controlling images led disabled people to internalize and oppress themselves. In this view, the important focus was not on the disabled person but rather on the power relations of the discourses surrounding the disabled person. Media does have effects on audiences to some degree as explored below.

As mentioned previously, there was a loop of how images and messages about disability shape society's perceptions of disability (Nelson, 1994; Susman, 1994). In a study examining how nondisabled audiences thought about disability prior to versus after viewing a film about

disability, there was a significant increase in audiences having positive beliefs about disability afterwards (Schwartz et al., 2010). Other studies focus on the pre- and post- effect on how people see disability after viewing a film (Kubrak, 2020), the perceived realism regarding disabled individuals' thoughts on how mass media represented disability (Zhang & Haller, 2013), or how nondisabled children understand disability in the television series *Sesame Street* (Diamond & Kensinger, 2002).

When asking disabled young people (whose disabilities included physical disability, sensory disability, and deafness) from New Zealand about their experiences with ableism (Calder-Dawe et al., 2020), the collective responses spoke of continuous staring, questions about disability, and uncalled assistance from strangers when in public spaces. The participants spoke of how stereotypes shaped nondisabled people's interactions and behaviors with disabled people, at times including the participants' parents. In this study, major focus was on nondisabled people knowing what disability "should look like" (Calder-Dawe et al., 2020). Furthermore, the medical model enabled intrusive interactions with strangers who offered pity, "cures" or "remedies," and inquiry into confirmation of disability diagnosis. This was an example of how disability stereotypes in media control people's interactions with and beliefs about disabled people, as well as what disability "should look like." Additionally, Samsel and Perepa (2013) found that disability in films and televisions influenced teachers' understandings of disability, including how they understood and approached disabled students. There needs to be a call to action that further pushes how disabled people are treated because of how stereotypes in media shape audiences understanding about disability and how disability should behave or not behave in society.

Young television viewers—children and teenagers alike—could become accustomed to certain moral and ideological frameworks that would not encourage them to adopt new ideas (Buckingham, 1987). More importantly, media could promote certain messaging that has "a substantial impact on public attitudes toward individuals with disabilities" (Safran, 1998, p. 467). A study on a superhero with disability analyzed autism representation (Chow & Hayawaka, 2022). Over a hundred children were asked about their thoughts on autism, with most having no knowledge of or having negative ideologies about it. After viewing television episodes of the show *Hero Elementary*, children showed favorability toward and positive understandings of autism. The kinds of media that children watch and read impacts them, and if there is no positive disability representation, both disabled and nondisabled children may grow up having poor or negative understandings of disability. This study explored participants' experiences with disability representation as children, much of which had negative effects as explained in a later chapter.

The effects of disability representation in children's media have been studied primarily in the literature space, exploring how it changes children's attitude toward disability (Adomat, 2014; Wilkins et al., 2016). Gulya and Fehérvári (2023) found that second- and third-graders had negative attitudes toward disabled people after reading textbooks featuring stereotypical disabled characters. A study by Cameron and Rutland (2006) revealed that reading stories with characters with disability and discussing the story over several weeks lowered biases of nondisabled children against disability. In another study, Cameron et al. (2011) found that nondisabled children who pretend-played with children with disability showed lowered intergroup bias. Furthermore, American children who pretended to live as a child with disability (Langer et al., 1985) showed a better understanding about those "different than them." When such stories and

imagined interactions are facilitated, positive effects prevail (Vezzali et al., 2015), because, according to the social cognitive theory, children's development is diversified by what they observe.

Research has showed how disabled children and adolescents oftentimes face poor treatment and bullying, resulting in poor mental health (Baams, Talmage, & Russell, 2017; Blake et al., 2012; Carter & Spencer, 2006; Lindsay & McPherson, 2012). However, positive representations of disability in children's media could promote more positive beliefs in disabled youth (Holcomb & Latham-Mintus, 2022). Upon examining studies conducted on audiences regarding disability and representation, as well as disabled children and audiences, most research centered on studying disability as a "difference," such as how nondisabled audiences understood those with "special needs," rather than a named disability, as a natural part of society. There has been a limited amount of focus on incorporating disabled voices in relation to the content being produced in media, which this study examined.

Overall, society's lack of exposure to disability narratives can impact how they understand or misunderstand different disabilities and interact with disabled people in real life (Longmore, 1985; Nelson 1994). Fiction mirrors reality but often touches on social concerns and issues without fully exploring them (Wood, 1975), allowing traditional stereotypes to oppress and segregate disabled people from living equal lives parallel to those in power. Dominant groups can only benefit by exploiting others (e.g., through using disabled stories for films, winning acting awards for a performance of disability) (Hall, 1997). This project turned to disabled people to examine how they were impacted by media narratives that shaped presentations of disability. Disabled people remain left out of many conversations regarding social norms, media, and research. More research on how disability representation influences

disabled people is needed; there must be a call to action in having disabled voices and narratives portray progressive representations of disability, to reduce the oppression of disabled people and the resulting internalized ableism and social isolation.

Where We Are Now

In the last few decades, not much has changed regarding positive disability representation in media, although there has been some traction in the right direction. Shows like *Game of Thrones* (2011-2019) and *Speechless* (2016-2019) included both a disabled actor as well as disabled consulters on the show. However, in the latter instance, a nondisabled creator was awarded all recognition for the show's creation, which had been inspired by his disabled brother (Martin, 2020). In more detail, Martin (2020) conducted a discourse analysis of disabilities represented in live-action television shows: *Speechless* (2016-2019) and cerebral palsy; *Atypica*l (2017-2021) and autism; and *Breaking Bad* (2008-2013), featuring multiple disabilities. The analysis drew conclusions between the shows' representation of "classic" disability stereotypes in media (e.g., defective, supercrip, helpless) and the social and medical models of disability.

The analysis of representation found a mix of outcomes. For example, *Speechless* dove into the background of the show's creation and the main character's disabled actor, as well as the themes of independence, inspiration, and dating; its biggest issue was that because the main character was nonverbal, everyone talked for him, propelling the stereotype that disabled cannot speak for themselves. *Atypical* focused on the autistic main character doing things to fit into a "normal" life in order to have society accept him by changing his atypical behaviors. Stereotypes of pity, fear, ridicule, and burden were also explored, especially in the themes of dating. *Breaking Bad* explored several disabilities within its side characters, including positive and

negative depictions of representation, which included temporarily disabled characters. Martin (2020) discussed how he was only able to locate four shows with leads that were disabled.

Along the lines of representation, some progress can be identified. The popular franchise of *Game of Thrones* (2011-2019), which featured a character with dwarfism and humanized the representation, which could influence future projects through the framework of collective intelligence meaning-making (Ellcessor, 2016). The 2021 film *CODA* (an acronym meaning "child of deaf adult") (Heder, 2021) centered on deaf subculture and music, and was highly acclaimed by disabled audiences (Beck, 2022). The film followed the main character as she struggled to get support from her deaf family, played by three deaf actors, on her journey to become a singer, creating an "internal conflict arising between hearing and hearing impaired" (Singh, 2023, p. 101). This film was compared to the deaf representation in *Sound of Metal*, which included Deaf consultants to make sure the deaf and disability representations would prevent criticism regarding nondisabled actors playing disabled roles (Singh, 2023). It may have been possible the industry was listening and possibly starting to turn the pages toward an authentic, powerful, fierce representation of disability (Foster & Pettinicchio, 2021).

As the disability and Deaf communities advocated for authentic representation, there had been strives in creating better representation (Singh, 2023), even if at minimal levels. Organizations had given some attention to disability representation in media. The Ruderman Foundation conducted a report of 2015-2016 television shows with disabled actors and found that five percent of disabled actors were playing disabled characters (Woodburn & Kopić, 2016). Reports from the Geena Davis Institute showed that between 2018-2021, the number of disability representations in children's television, films, and television movies had declined compared to previous years (SeeJane, 2022), with less than four percent of characters across the three

mediums having a disability. Disability had the most negative stereotypes traits (e.g., unintelligent, unattractive, undesirable) and the least lead time compared to other identity categories such as body type, age, gender, and queerness.

In collaboration with the Ruderman Foundation, SeeJane (2025) conducted a content analysis of 350 scripted television shows from 2016-2023, and found that less than 4% had disabled characters, 21% of disabled characters were authentically cast, and the majority of disabled characters were White and LGBTQIA+. There was a call to action for more and better representation, including the fight for disability inclusion and understanding starting to take root. In 2025, USC Annenberg published a report: "Inequality in 1,800 Popular Films: Examining Portrayals of Gender, Race/Ethnicity, LGBTQ+ & Characters with Disabilities from 2007 to 2024" (Smith, 2025). The report indicated that less than 2.5% of speaking characters in top 2024 films were disabled; 68% of the depictions of disability were for physical disabilities (n=105); most of the disabled characters were male (61%), white (71%), and heterosexual (almost 100%); and 41.5% of disabled included having caregivers assisting them.

Examining the state of disability representation sets a foundation to what audiences have access to. By connecting the dots to historical narratives of disability lets the research explain where representations are coming from, where they are now, and where they may be going forward. In this sense, this sets up the participants to reflect on their own childhood memories of disability representation, how they engage with disability media currently, and what they hope to see in the future.

CHAPTER 4

THEORETICAL FRAMEWORKS

Films normally looked at a disabled character through their disability first, rather than their personality, their independence, or their economic success. As mentioned before, disability was presented and imagined from a nondisabled lens. Hayes and Black (2003) examined disability stereotypes in films of the 1980s and found that movies tend to illustrate disabled characters as being confined to an isolated place not because of their disability per se, but rather for the comfort of nondisabled people (Nelson, 1994). The main characters in films like Rain Man (1988) and Forrest Gump (1994) propelled the idea that disability was only one way of existing because media "serves a critical educational function" where on-screen representations construct our view of society (Safran, 1998, p. 468). This cemented media as a tool to educate and inform audiences about disability (Nelson, 1994). This concept treated disabled audiences as though they did not exist, as nondisabled audiences were the ones being entertained. Thus, this study aimed to examine how media representations created controlling images that impacted how disabled lived their lives and interacted in society.

Representation theory

Media is carefully crafted by dominant groups. Hall (1997) discussed the stereotypes constructed by media and how they impacted people's lives are elements of symbolic power. Hall introduced ideas of how media presented real-life images through the use of imitation, meaning however people presented themselves in real life was altered, forcing them to re-represent them to fit a certain narrative. Moreover, the representation agenda was usually set by those in power who saw nondominant groups as "less than" or in unfavorable or undesirable ways. This controlled messaging was constructed through language that shaped certain beliefs

and codes about nondominant groups, such as stereotyping Black people as violent. Stereotypes exist in the spaces where there are inequalities of power, where power marks, assigns, classifies, and ritually excludes others based on dominant ideals (Hall, 1997). Media, therefore, became a tool for representation to influence society's opinions and the process of meaning-making regarding people in society.

As representation shaped societal thought, stereotypes became constructed in order to understand someone or their behaviors through reducing people to cliché and often negative traits, such as "Black criminals" or a "Mothering woman." This frame of stereotyping normally targeted marginalized groups, popularizing flat and hollow understandings of marginalized identities. As media was created for and by people from dominant groups, creating recurring stereotypes about nondominant groups reinforced a hegemonic hierarchy to allow those in power to maintain control. Changing traditional stereotypes into progressive ones can happen over time through the process of transcoding, which is why disabled people being involved in media infrastructures matters (Hall, 1997). As example could be a counter-stereotype of a sophisticated disabled Black CEO of a company balancing taking care of their family and running a business.

Hall's (1997) understanding of representation as a cultural phenomenon used a wide range of different representations to foster certain understandings of people as portrayed in media. This included the media spaces of disability, which was often associated with stereotypes such as evil, helpless, and supercrip (Barnes, 1992). A stereotype was carefully crafted by those in power to allow disability representation in films, shows, news, and more to "entertain" nondisabled audiences at the expense, discrimination, and segregation of real disabled people. This abuse and mistreatment has been further normalized because disabled voices were not only silenced, but denied access to dominant positions of power and opportunity (Durham & Keller,

2012; Swain & French, 2000). This created flawed systems of how audiences thought about fictionalized, stripped-down traits of disability as "preferred meanings" through fixed points of understanding (Hall, 1997). These notions of understanding usually came from the media that audiences consumed, and the more audiences viewed repeated stereotypes, the more they would be cultivated to believe these messages, accepting stereotypes as the truth (Browne Graves, 1999). In terms of disability representation, traditional stereotypes of meaning-made representation, which were rooted in oppressive and discriminatory aspects, would be placed onto real people (Nelson, 1994). The cycle of disability stereotypes has unfortunately continued, as current research has found no or little change in how disability was progressively represented (Holcomb & Latham-Mintus, 2022).

Controlling Images

Media was created to be entertainment for the dominant culture (Durham & Keller, 2012). This included tailoring attention and interests to the White, able-bodied, male gaze, normalizing the use of disability as entertainment and the view of disabled people as "less than" human. Our social construction of the representation presented was something society accepted and normalized. This could further be explained in Hill Collin's work talking about "controlling images" where collections of stereotypes work together to construct perceptions of people in their expected status roles (2000). Hill Collins (2000) also discussed how "certain assumed qualities that are attached to Black women [and other nondominant groups] are used to justify oppression" (p. 5). There are essentially images created to normalize specifically targeted ideologies and discourses about specific minority groups to solidify certain imagery and control over these groups.

In its theoretical development, the oppression that Black women faced placed certain expectations on them to the point that these ideologies got propagated in media through various stereotypes, which became everyday treatments in society (Hill Collins, 2000). For example, how the "mammy" was expected to work for White families for less pay, as if she had no family of her own. The hours were long and the work was hard, and due to this, the mammy was seen as a "bad mother" for her family. While the Black mother was exploited to work in order to support her own family, she could not care for her own children, yet the oppositional image of a White mother was seen as a "good mother" who was present for her children. This was what oppression looked like because society used both mothers to justify and structure hierarchy that normalized these images into continuous discrimination as seen in history (Hill Collins, 2000).

If the "mammy" was just there to *serve*, then the possibility of job advancement for Black women denied them the ability to climb the corporate ladder. In comparison, a similar comparison could be said of how disabled were there to *inspire* others by accomplishing simple tasks and were not seen as leaders who had the intellect to make authoritative decisions in the corporate world. When these two images were added to a stylish White nondisabled man in a position of power, the perceptions of who got advancement opportunities turned into realistic expectations. He was given the opportunities to succeed because he was seen capable of the job as presented in media, expecting to be treated in that way. The collection of stereotypes, whether in relation to other people or historical stereotypes merged for one person and controlled their image to society's power structures. Without a hierarchical structure, there would be no one in the dominant role.

These power models of oppression were there to keep certain groups of people in a box that was "designed to make racism, sexism, poverty, and other forms of social injustice appear to

be natural, normal, and inevitable parts of everyday life" (Hill Collins, 2000, p. 61). This can be traced to the image of the "strong Black woman," which means that Black women could be worked to death without speaking out, and if they would, they would them be seen as Black criminals. In the example of the "helpless" disabled person who could not do anything and therefore paid below minimum wage to do simple, copious tasks normalized disabled to live in poverty, making them be treated as charity cases (Ladau, 2021; Nelson, 1994). In catering to many injustices without many repercussions, dominant groups socially created stereotypes of the "angry/assertive Black person" where "each [controlling image] reflecting the dominant group's interest in maintaining Black women's subordination" (Hill Collins, p. 72). Adapting this theoretical framework for the dissertation, it offered the opportunity to examine how disabled people feel controlled by certain images found in media about disability.

These frames came from the history of how each marginalized group had been treated due to a colonized capitalistic culture (e.g., Black people enslaved to do labor for White people or disabled people being isolated without the opportunity to work) that created certain images for the White masses where any markers for difference would be "othered" (Lerner, 1997). Behaviors or representations outside the "norm" were oppressed, such as with the placement of disabled people in institutions where they were trained to be "normal" enough to be put back into society, involuntarily sterilized, or killed to "better society" (Oregon Public Broadcasting, 2020). Disabled people had their independence taken away and were treated as though they were in prison, being told what to do and when to do it, and anyone who broke the rules or directions were punished (Oregon Public Broadcasting, 2020).

The system of eugenics and mercy killings to "improve society" claimed that those people, if even considered as human beings, were not important, because disability was thought

to be biologically connected to inferiority in poverty, gender, and race (Pernick, 1996; Stubblefield, 2007). Moreover, during the Holocaust, disabled people were considered unproductive, unworthy, and too defective to be living, justifying their killings (Friedlander, 1995). Norden (2006) discussed how disabled characters sacrificed themselves to save nondisabled people as a way to unburden society, arguing that disabled peoples' "disempowerment lies within the nature of their disabilities and therefore they are incapable of being rescued" (Whittington-Walsh, 2002, p. 702).

The decreased power and financial status that disabled people experience came from crafted prejudices placed on disabled people by society seen in certain controlling images, while at the same time society responded to disability needs as "inappropriate and disempowering" (Abberly, 1993, p. 111). Disabled children who needed classroom accommodations may have not been able to attend school due to accessibility barriers (San Francisco State University Students and Faculty, 2017), depriving them of the chance for an education or job advancement. This played into the idea that media was being created by ones who were trustworthy, educated, and "the best for the job," allowing them to craft inaccurate, one-dimensional stereotypes of nondominant groups and hiding the problem of inequality instead of fixing it.

The impacts of disability stereotypes were crude and simplistic representations, saturated with inaccurate images of disabled people (Shakespeare, 1999). Further, Shakespeare stated:

> The use of disability as character trait, plot device, or as atmosphere is a lazy short-cut. These representations are not accurate or fair reflections of the actual experience of disabled people. Such stereotypes reinforce negative attitudes towards disabled people, and ignorance about the nature of disability (p. 164).

Fictional characters catered to and fit into our cultures and social knowledge, all while promoting

stereotypical traits and ideologies to the viewer (Eder et al., 2010). This led to the notion that not seeing a positive or a diverse pool of disability representation as a regular part of stories equated to disabled people being something "different" and "othered." As a consequence, they were meant to be excluded or treated unequally in society.

Being silenced and seen as a "problem" prevented disabled people from having basic human rights such as control over finances, health, social life, and education. The disabled people held in the institutions that used these inhumane practices formed an advocacy group to fight for their human rights as people; they were able to get these institutions shut down and changed into more community-based support systems (Oregon Public Broadcasting, 2020). However, mental institutions, along with places for "invalids," still exist. Because controlling images led to oppression of and real-world dangers for marginalized groups, Hill Collins (2000) argued for resistant measures, such as not accepting negative stereotypes and creating better representation of nondominant groups.

The United Nations discussed how media could influence society's values and attitudes, with the need to fight against negative stereotypes (Secretary General, 1994). As dominant groups further develop structures in their ideals, the inequalities that put disabled people as an afterthought, if at all considered, continue to spread (Ellcessor, 2015). Those in power needed to keep promoting the narrative that disabled people could not be productive in order to supply a nondisabled person's ego (Garland-Thomson, 2011). There is more to be done than solely seeing a film about a disabled person. Current social structures depict how disabled people are supposed to be controlled in society through education, employment, health, or abuse. More importantly, how disabled people could be socially included and create relationships that curated cultures, versus being hidden away to please nondisabled people's comfort levels (Nelson, 1994).

Intersectionality

Controlling images can be paired with intersectionality, a term coined by Crenshaw (1991). As a definition, intersectionality referred to the ways in which the interactions of how social identities situated people's experiences in society. More specifically, intersectionality identified how the intersections of identity created unique forms of inequality that were distinct and prone to higher levels of oppression. This prism examined how society cannot always see the injustices done by someone with multiple identities, such as a Black disabled woman. Divided, these identities, for example, a Black man fighting for his rights or a white woman testifying for fair wages, introduced two separate oppressed groups could stand a chance in justice. However, the combination of a Black person who was a woman was where the recognition for justice became invisible. As a result, multiple groups of people could experience oppression, discrimination, and othering based on experiences within disability, gender, and race, among other demographics; some individuals could experience ableism, sexism, and racism all together (Jordan-Zachary, 2007).

Intersectionality centers on social categorizes that deal with the multiple ways that people from different identities structure experiences of disadvantages within the realms of oppression (e.g., ableism, racism, sexism) as they relate to systems of power. Tying in with Hall's representation theory, Crenshaw pushed the idea further regarding how when dominant groups think about disability from controlling vantage points, it could result in a range of varying oppression, such as a disabled Black mother experience a higher level of discrimination than a white disabled mother (Jeffress et al., 2023). This can create power systems in how audiences think about stereotypes, representations, or equality of "preferred meaning" through fixed and stoic points of understanding.

In a narrower focus, *representational intersectionality* refers to how stereotypes based on several identity categories are combined within media representations that create narratives about people who occupy multiple marginalized identities (Crenshaw, 1991). Intersectionality could bring media a malleable understanding of how various combinations of identity shape social norms and experiences due to "social, cultural, political, and economic processes" (Naples et al., 2019, p. 5). As noted previously, markers of difference such as skin color or mobility devices as justification for oppressive actions and systemic discrimination against those who lack traits such as whiteness and able-bodiedness (Jeffress et al., 2023; Lerner, 1997). More specifically, these actions within disability target bodies and minds outside the norm.

Dominant identities hold all the power in creating the representations of nondominant groups, pushing stereotypical imagery onto marginalized identities instead of exploring diverse characters' identities. Dominate groups use stereotypes "to attempt to fashion the whole of society according to their own worldview, value-system, sensibility and ideology" (Dyer, 2012, p. 277). To this, Hill-Collins (2000) explored the *matrix of domination*, which is a framework that explores how multiple systems of power are interwoven and mutually reinforcing. These multiple interconnected systems of power create a matrix which is a complex structure where people's position in society is shaped by their multiple intersecting identities where intersectionality is focused on identities that are interwoven. This can be identified through three levels of domination: The first relates to interpersonal and individual dynamics in terms of attitudes, beliefs and everyday interactions; the second level is at the community or group level relating to norms, customs, and shared cultural narratives; third, the institutional systems relate to laws, policies, social structures including education, healthcare, criminal justice, media, etc. (Hill-Collins, 2000). From a social location and power stance, people occupy different positions

within the matrix—where intersectionality aligns with—is a mix of privilege and disadvantage. In media, there is a structure where race, gender, class, shapes who creates certain narratives, character experiences, and messaging that aligns with social norms, including who is represented and how they are represented, oftentimes reinforced oppression at multiple levels.

In turn, controlling images are stereotyped representations designed to shape public perception and justify the domination of marginalized groups on the basis of disability, gender, race, and any other form of social identity. Media images can objectify marginalized group by establishing certain archetypes, stereotypes, and tropes that normalize and fix those differences to align with dominant ideals. Controlling images, intersectionality, and representation theory is more than certain misrepresentations of nondominant identities. The system of representation operates through social control as a way to justify oppression and discrimination such eugenics, institutionalization, policing and incarceration, surveillance, reinforcing certain gendered expectations, limit economic and social mobility.

Research has vastly explored the topics of disability discrimination in society regarding the topics of gender as well as race (Bailey & Mobley, 2019; Brown & Moloney, 2019; Naples et al., 2019; Pickens, 2019). Disability as an identity could be seen as a way to challenge the preexisting notions of being disabled equating being an invalid, since disability pride was born as a stance on the importance of disabled people in an oppressed society. However, the identity of disability usually does not stand on its own, considering it does not solely isolate and target White men, the group normally chosen to represent disability in media depictions (Barnes, 1992; Bond, 2013). A woman, a queer person, a Latino person, and members of any other nondominant groups can be or become disabled. Thus, the collection of identities “interlock in ways that make them inseparable, especially given how ableism, ageism, racism, and other forms of oppression

and marginalization are jointly constructed" (Guidry-Grimes et al., 2020, p. 28). This dissertation explored many oppressive systems when it came to media's influence on disabled people, and ways disabled people combatted or lived within controlling images.

In the quest to examine disabled audiences' thoughts and reactions to different disability representations present in their lifetimes, the following research questions were split into three main areas of focus.

RQ1: How have disabled people experienced disability representations in media throughout their lives?

RQ2: What kind of impacts have different disability representations had or may have on disabled people?

RQ3: In what ways do disabled people believe disability representations have evolved or may evolve?

CHAPTER 5

METHOD

The overall methods for this research included snowball sampling participants through inviting them to complete a survey about themselves and a favorite disability media example. Next, participants were selected into specific focus groups based on similar disabilities that included five virtual focus groups. After the focus groups were transcribed and coded, certain themes emerged that answered the research questions. Qualitative research, such as interviews and focus groups, allows the researcher to examine different worldviews and experiences of participants (Brinkmann & Kvale, 2009). In particular, focus groups—which were used to answer all three research questions—are meant to gather information to "better understand how people feel or think about an issue, product, or service" (Krueger & Casey, 2000, p. 4), including observing interactions between people in a self-contained environment where discussions are moderated (Morgan, 1997). This lets a researcher collect insights on similar or polarizing views, observe the social dynamics between different groups of people and identities, and understand group narratives and norms, which can be determined from the shared views within the studied social dynamics (Morgan, 1997). The benefits of focus groups allow the researcher to "fill in the gaps" regarding people's beliefs or experiences through methods such as observations, interviews, or surveys (Dimitriadis & Kamberelis, 2013, p. 48).

For this dissertation, focus groups were used to understand how disabled adults view disability representation and how such representations had impacted how they lived their lives in society. In this sense, the authority of the researcher shifted to the participants, allowing them "to 'take over' or 'own' the interview space, which can result in richer, deeper understandings of whatever is being studied" (Kamberelis & Dimitriadis, 2013, p. 41). Additionally, giving the

space for participants to share their beliefs and experiences allowed them to show how they may agree or disagree about a topic, as well as respond to various opinions and questions brought up by the group (Morgan, 1997). Although focus groups offer results that gather a broad range of insights in a shorter time and among more people than in-depth interviews, the researcher should aim to allow all participants to contribute, rather than have the group influenced or dominated by a single person (Morgan, 1997). In employing this method, the collection of ideas give almost free range for the discussion to be guided in a way to uncover common as well as uncommon perspectives about the topics of disability representation in media.

Research Design

A recruitment and eligibility survey (Appendix A) allowed participants to share their media use, an example of disability representation in media, demographics, and availability. The online survey was managed by Qualtrics and did not take more than 10 minutes to fill out. In adapting the ideology of grouping similar disabilities together, the survey helped create groups of those who had visual disabilities, physical disabilities, or multiple disabilities. Once focus groups were scheduled, each including about four or five people, reminders were emailed to participants. The goal of each focus group was to keep the discussion open and inclusive of all participants. Many participants fed off each other's examples of disability in media, with some remembering old examples they had not thought of previously.

The focus group questions listed in Appendix B were intended to create a 90–120 minute discussion. The main questions included a breakdown of three sections: focus of disability representation in media, impact of disability representation in media, and desired disability representation in media. These included probing or additional questions to prepare for different directions the focus group could take. These prepared prompts and follow-up questions were

available to guide the focus group participation in moments where discussion seemed to flourish in a particular topic.

The focus groups were recorded on Zoom. Participants were requested to have their camera and microphone on when speaking. Video and audio requirements made it easier to understand people and be able to see their reactions to a topic, and when a participant's voice was hard to hear or understand, visual communication helped understand them better. I had full access to the recording via the UO Zoom cloud software protected by a password in order to view the recording. The Zoom transcripts were downloaded, listened to, and cleaned up after each session in a Word document, where the data was color-coded for responses, themes, and quotes.

The transcription included the timestamps of each speaker and a label of "Speaker 1," "Speaker 2," etc., to indicate each person's response. Main themes aligning with the research questions (representation, impact, desired representation) were color-coded. Comments were added into the document to indicate agreement or disagreement as well as different levels of emotion (e.g., negative and positive responses about disability representation) and common responses between various focus groups. Codes were double-checked, including any grammar issues, which included listening to the transcription for accuracy. An example of codes included "favorite or ideal representation"; "peer support and connecting with other disabled people"; "feeling alone or isolated"; "feelings of alone or isolated"; "internalized ableism"; "need to hide disability"; and "representations seen in media." The next section discusses the thematic analysis of the study.

Thematic Analysis

Thematic analysis offers the researcher a flexible tool to analyze a complex and large sum of data. The benefit of not being able to predict the outcome is allowing the research to pull on participants' personal experiences and perceptions. Building on themes provides the opportunity to draw conclusions, like which stereotypes impacted disabled people the most or which ones came up the most across focus groups. Thus, allowing the research to offer multiple ways to construct findings (Scharp, & Sanders, 2019). When collecting data via focus groups, it is important to understand what the participants are saying and what is important to them. Each focus group offered its own unique set of data, which was thematically evaluated through inductive orientation—themes that emerge once the data is collected. Thematic analysis (TA) identifies, analyzes, and illustrates themes and patterns of a collected data set (Braun & Clarke, 2006). This can include discovering recurrent "themes" (Scharp & Sanders, 2019); for example, some participants discussed similar disability stereotypes in the same media examples across multiple focus groups.

This advantage gave voice to disabled participants, demonstrated how they created meaning-making through discussion, and evoked experiences (Scharp & Sanders, 2019). This can be completed via Braun and Clarke's (2006) six steps: data familiarity (being emerged in the data set and gathering insights), coding for categories (developing codes for groupings based on the data collected), generating themes (analyzing the different types of themes that are prominent for the project), reviewing (revisiting the coded themes with the data to justify a certain grouping), definitions (using language such a "positive disability representation" to label a data set), and locating exemplars (discussing what the themes and data mean in the context of this research). An example of coding the data content was using color to code similar experiences, ideas, and beliefs that arose across groups. The data collected through the use of focus groups

aimed to answer the research questions, in which the themes that were found told a story shared by the disability community.

Due to their group-based nature, focus groups serve as the best approach to discuss the collective approach to understanding how the disabled community feels about current disability representation and to "generate ideas" about how those representations have influenced them throughout their lives. Recurring themes were identified along with insights from participants' responses that answered the research questions. Four overarching themes were identified that included subthemes and quotes. Each subtheme and quote were carefully examined multiple times to assure they were appropriate for the main theme, research question, and understanding of the relationship between each set of data and goal of the research.

Participants and Researcher

Each focus group housed people with similar disabilities to encourage a higher chance of shared experiences, since when the same disabled identities are in a single group, it often gives "participants a common background that" encourages discussion (Mack et al., 2024). Disabled people have had to unite to fight for their rights, build community, and combat ableism through activism (Iezzoni & Long-Bellil, 2012; Ladau, 2022; Shew, 2023). This discussion, held with a diverse pool of participants, was intended to share similar experiences with disability representations portrayed in media, which is a topic actively discussed by the disability community online (Shew, 2023), and make participants feel less alone.

The target participants were disabled individuals over the age of 18, who consumed media to some level and were able to discuss at least one example of disability in media. Disability of participants was identified through the recruitment survey in three ways: by self-identifying their disability (e.g., blind or physical disability), the offset of their disability, and

which devices help support a participant (e.g., wheelchair). The three items were not mutually exclusive, but did give an idea of how participants were connected to their disability.

Some of the goals included examining participants' experience growing up with and without disability in media, how certain disability representations or stereotypes had impacted how they navigated social spaces, and the current and future ideas about disability in media. Focus groups allowed participants to ponder and talk through their ideas and think about new interpretations of disability representation. Some topics of discussion included how disabled images take shape for disabled people through examples of internalized ableism, resistant practices to combat stereotypes that shape controlling images, and the treatment from nondisabled people.

In being a disabled researcher, I did not fully separate myself from the research, as this aided me in guiding a deeper discussion. In this sense, it is important to address reflexibility, which allows for the researcher to not just collect data but be critical about executing and evaluating the data (Kajornboon, 2005). Through reflexibility, the researcher acknowledges one's self in relation to the research at hand, giving attention to one's own experiences and personal insights—including uncomfortable moments—that may arise (Pillow, 2003). As such, the interpretation of themes, patterns, and even the coding process is at the discretion and experience of the researcher. It is important for self-reflexibility to acknowledge how each researcher can actively produce knowledge based on how they experience (or don't experience) realities that connect to the participants (Kim, 2001; Markham 2009).

Thus, my positionality centers on being a white heterosexual wheelchair-user female pursuing a PhD degree in America. This was taken to identity personal markers of how I understand and interpret the data that honors the depth of participants' experiences. The

intertwined relationship between the researcher, participants, and data offers a one-of-a-kind qualitative analysis that is unique and complex.

Recruitment

Recruitment relied on close connections to the disability community, thus allowing for a natural non-probability snowball sampling option through email. A non-probability snowball sampling method asks participants to share the study with other people or organizations that may be interested in participating. I identified myself as having a disability as well as posting about research in disability-specific Facebook groups. Disability advocates and influencers were asked to participate and spread the word about the study. It was important to recruit a diverse pool of participants because traditionally, White participants have been the main audiences who produce the results. Through email and Facebook posts, the initial outreach included 32 disabled adults who filled out the eligibility survey. From there, 18 individuals were able to participate in the focus groups based on responsiveness and availability. Having 18 participants seemed to be enough, because saturation was reached, meaning that the same themes and discussions were being shared among participants (Hancock et al., 2016).

An indirect benefit included helping this study discover insights about disabled people's feelings and thoughts about disability representation in media. These insights can potentially help media professionals, story and character developers, scholars, and others form more effective messages and understand what the current generation think about seeing physical disabilities in media. Participants got to discuss experiences and feel good about having their voice be heard, many indicating afterward that they enjoyed the conversations. Many seemed happy to positively impact disability representation for the future. These voluntary participants were also offered a $50 gift card.

CHAPTER 6

FINDINGS

Among the 18 participants across the five focus groups, three overarching themes regarding the lack of, stereotypical, or authentic disability representation in media emerged. The first theme was related to disability representation experiences, which included the consequences of having no disability representation, disability and media effects while growing up, intersectionality, romantic relationships, how disabled people were treated in public spaces, and the impacts of positive disability representations. The second theme centered around disabled people's requests regarding disability representation that included favorite representations, authentic representations, suggestions for eliminating certain disability stereotypes, and thoughts on recommended disability representations. The third theme discussed how disabled people fight for their inclusion and support relating to family dynamics, advocacy of just living, fighting for belonging in public spaces, the importance of disability community spaces, and their hope for the future. All three themes had strong agreement between participants and focus groups, who shared a variety of personal stories on how media representation had affected how they lived.

Demographics

There were 29 participants who filled out the eligibility survey, but only 18 participated in the focus groups. The 11 participants who were not selected either did not respond to email communication, had conflicting schedules, or gave one-word or brief answers in the eligibility survey. The 18 disabled participants took part in 85–110-minute virtual focus groups that occurred from July to September 2024. The participants represented a diverse range of identities and backgrounds, media consumption, and types of disability. Although participants were not directly asked about their disability, many discussed in detail the kind(s) of disability they had

(e.g., spinal muscular dystrophy, depression). The majority of participants had an income level below $30,000 and had at least a high school diploma. Some of the participants were students, unemployed, or had a career job.

There were six participants from Texas, four participants from California, two from New Jersey and Kentucky, and one from New York, North Carolina, Oregon, and Washington. There were 14 female, two male, and two non-binary participants, with their ages mainly falling into the young adult category as follows: five participants indicated ages 18–22, three indicated ages 23–27, six indicated ages 28–35, one participant indicated ages 36–44 years old, and three indicated ages 56–67 years old. Slightly more than half of the participants indicated having more than one disability (n = 10), which included combinations from a list of options including physical disability or limited mobility, neurodivergence, mental illness/psychiatric disability, chronic illness, learning disability, hard-of-hearing/deafness, and visual impairment or blindness. Five participants had solely a physical disability and three identified a visual disability. Disability onset ages ranged from birth to two years old (n = 10), childhood (n = 6), teenager (n = 1), or late adulthood (n = 1).

All participants indicated using mobility or support devices that ranged from glasses or contact lenses, wheelchairs, shower or commode chairs, robotic arms, BiPAP breathing masks, walkers or leg braces, service animals, walking or white canes, or fidget toys. Glasses and/or contacts were indicated to be used the most by participants (n = 13), with wheelchairs coming in at a close second (n = 11) and a reliance on a white or walking cane being indicated by four participants. Racially, the majority of participants were White/European (n = 11), followed by Hispanic or Latino or Spanish Origin (n = 5); the smallest categories were Black or African American (n =1) and Asian or Asian American (n = 1). When indicating sexual identity, a

majority of participants identified as heterosexual (n = 10), followed by queer (n = 4), bisexual (n = 3), and unsure (n =1). The participant demographics and their focus group numbers are indicated in Table 2 below, including their pseudonyms.

DEMOGRAPHICS

State	Pseudonym	Gender	Age	Disability Type	Disability Onset	Devices	Race	Sexuality
OR	Sally 1	Woman	18–22 yrs old	Epilepsy, Chronic illness, Mental illness/ psychiatric disability,	10 years old	Glasses/ contacts	White/ European	Heterosexual
WA	Chloe 1	Woman	18–22 yrs old	Chronic illness, Neurodivergence, Mental illness/psychiatric disability	11 years old	Glasses/ contacts	White/ European	Unspecified
CA	Kristy 1	Woman	23–27 yrs old	Hard-of-hearing/deafness, Neurodivergence, Mental illness/psychiatric disability	3 years old	Service animal	Multi-racial	Queer
CA	Jazmyn 1	Woman	28–35 yrs old	Physical disability/limited mobility, Neurodivergence, Mental illness/ psychiatric disability	Since birth	Glasses/ contacts, Walking/white cane, Mobility scooter, Walker or leg braces	White/ European	Heterosexual
TX	Keisha 2	Woman	23–27 yrs old	Physical disability/limited mobility, Chronic illness	Since birth	Wheelchair, Glasses contacts	Black or African American	Heterosexual
TX	Josie 2	Woman	18-22 yrs old	Physical disability/limited mobility, Chronic illness, Mental illness/psychiatric disability,	5 years old	Wheelchair, Glasses/ contacts,	Hispanic or Latino or Spanish Origin	Queer
CA	Lonni 2	Woman	28–35 yrs old	Chronic illness, Physical disability/limited mobility	A few weeks old	Wheelchair, Glasses/ contacts, Other (BiPAP)	Hispanic or Latino or Spanish Origin	Bisexual
CA	Fera 2	Woman	23–27 yrs old	Physical disability/limited mobility	9 months old	Glasses/ contacts, Wheelchair	White/ European	Bisexual
TX	Daisy 3	Woman	56–67 yrs old	Physical disability/limited mobility, Chronic illness	Since birth	Walker or leg braces, Glasses/ contacts, Other (shower chair, BiPAP)	White/ European	Heterosexual

TX	Opal 3	Non-binary	18–22 yrs old	Physical disability/limited mobility	Since birth	Wheelchair, Walker or leg Braces, Glasses contacts	Hispanic or Latino or Spanish Origin	Bisexual
TX	Axel 3	Non-binary	18–22 yrs old	Physical disability/limited mobility, Neurodivergence, Mental illness/ psychiatric disability	4 years old	Wheelchair	White/ European	Queer
KY	Tammy 4	Woman	56–67 yrs old	Visual impairment/ blindness	50 years old	White/walking cane	White/ European	Heterosexual
TX	Ahmed 4	Man	28–35 yrs old	Visual impairment/ blindness	8 years old	Glasses contacts, White/walking cane	Asian/ American	Heterosexual
NC	James 4	Man	28–35 yrs old	Physical disability/limited mobility, Chronic illness, Visual impairment/blindness	18 months old	Wheelchair, Glasses contacts	White/ European	Heterosexual
KY	Polly 4	Woman	56–67 yrs old	Visual impairment/blindness	14 years old	White/walking cane	White/ European	Heterosexual
NJ	Stacey 5	Woman	36–44 yrs old	Physical disability/limited mobility	Since birth	Wheelchair, Service animal, Glasses contacts	White/European	Heterosexual
NY	Claudia 5	Woman	28–35 yrs old	Physical disability/limited mobility	6 months old	Wheelchair	Hispanic or Latino or Spanish Origin	Heterosexual
NJ	Nelly 5	Woman	28–30 yrs old	Physical disability/limited mobility	Since birth	Glasses/contacts, Wheelchair, Other (shower/ commode chair, robotic arm)	White/ European	Queer

Table 2. A table detailing demographic information such as participant location, fake name gender, age range, disability, onset of disability, support devices for disability, ethnicity, and sexual identity. The numbers next to each name in column 2 indicate the participant's focus group number.

None of the participants asked for any accommodations other than captioning and planned 5–10-minute breaks. Participants were asked to keep cameras on during the focus groups while speaking. Only one participant did not show their face.

Theme #1: Disability and Media Effects

This section addresses the overarching theme of what kind of relationships disabled people had with the disability representation found in media, or lack of it, through six sub-themes. These include diving into participants' experiences regarding: 1) the consequences of no representation; 2) growing up and disability representation; 3) intersectionality; 4) love and disability; 5) the treatment of disabled people; and 6) the impacts of positive representation. Within the first sub-theme, for example, when participants saw stereotypical or negative disability representation as children or teenagers, they felt shame about being disabled and wanted to hide their disability. Many did not recall any representations at all, as discussed in the second sub-theme, making them feel like they were alone and unseen, without any characters they could connect to or learn from.

The third sub-theme centered on how participants' lives could be harder if they were from certain religions, ethnicities, or gender identities that may have increased the guilt, punishment, or silencing of disabled individuals. Participants voiced their desire to see more diversity and intersectional experiences of disability, not only to be seen themselves but to learn about others' experiences. In the fourth sub-theme, participants wished love and romance were not stigmatized and that society saw them as people who could be good partners who were not inherently asexual, which disabled social media influencers have worked to showcase. The fifth sub-theme investigated how nondisabled people believe disabled should behave in public based on media stereotypes, such as "angelic and pure," "inspirational," "childlike," and "praying for a cure." Many participants recalled how nondisabled people either labeled disabled students as "strong" and "inspirational" or treated them as though they had no intelligence or potential to have a career.

The sixth and final sub-theme emphasized how participants would have felt seen, gained confidence, or had resources for navigating the world if they had witnessed certain types of positive disability representation. These sub-theme discussions ranged from negative reactions to disability representation to the positive examples of representation that made them feel connected to the characters. These discussions included stereotypes such as "inspirational" and "infantilization," and centered around how good representations can make significant changes for disabled people.

The Consequences of No Representation

Many participants brought up how there was no disability representation in media for them while growing up, and that not being "seen" negatively affected them. They shared how this made them feel "lonely in my disability," "isolated," and "self-conscious," with an overall discussion about how growing up with no or solely stereotypical disability representation made it difficult for them to understand or navigate society with their disability. Nelly, a wheelchair user, would have accepted her disability and tried "reaching out to other disabled people my age sooner [if I'd seen more representation in media]." Opal, another wheelchair user, expressed how the absence of disability representation meant more than just never seeing a wheelchair user in any media. They said:

> Not seeing that in the media as a child, I just felt like a lot of the things that made me uncomfortable…It took me a lot of processing and unpacking on my own that I think maybe would have been easier if I had the community like even just online, like influencers or just having seen realistic representation in the media. I think that would have been very helpful.

Josie, a wheelchair user, did not see disability representation until she was 16 years old; reflecting five years later, she remembers how she "craved it so much, like I wanted to have that character, [who] could relate to you or who I, like, saw myself in [as a child]." Regarding negative disability representation, Josie shared that when she first heard of the film *Music* (2021), which featured an autistic character who was not played by a disabled actor. She thought "'that's so cool'...I was excited." As a fan of Sia, the film's director and writer, Josie was disappointed to see the controversy regarding the film's ableism and Sia arguing with disabled people in response to their criticism online. This "stained how I approach disability presentation…growing up and seeing the different forms of disability representation, [I realized] how a lot of them were negative." Josie added that seeing better representation would have been a positive thing for her disability pride. She said:

> [It would have] helped my disability pride journey, accelerated it and [been] there when I needed it the most my teenage years…It would have helped me with small things, like asking for help: I never saw a disabled person openly asking for help, whether it's to open a door, to open something…It brought shame to myself, because you see all these like protagonists being a strong, independent woman, and that's like the standard and stuff, but that's... not realistic [for disabled women].

Disabled participants discussed how they were left to their own devices when it came to not only understanding their disability, but also understanding how they would be treated by society. Not seeing disability representation made disabled people feel on their own ("I thought I was the only one [disabled]," shared one participant) as children or teenagers, causing them to form strong bonds once they met other disabled people at college. Many discussed how if they had seen authentic disability representation, they would have felt more "confident" or "comforted" and

"[had] someone to relate to." This meant that they could have accepted their disability before they met other disabled people in adulthood, been comfortable in making friends in public, and not felt forgotten about in stories.

Sally, who has epilepsy, shared how this representation would have helped her the most when she was in middle school, since that was when she felt most alienated. When she found different worlds in books, she resonated with characters who shared her "mental health problems" as this was "the closest that I was getting at the time toward how I was feeling and experiencing the world." She can only imagine today how much more she would have felt "seen" if she had good representation in more books and other media. Sally added how instances of positive disability representation meant she could say, "'Hey, well, here's kind of what this looks like from here, feels like for me,' so that you don't have to be the only one kind of fighting that battle for yourself" when it came to educating others about disability.

Many participants shared that if there had been better representation, then they would not need to continually educate society and strangers about disability, as doing so is "exhausting." Chloe, who has multiple nonapparent disabilities such as anxiety, OCD, and depression, shared how she used to hide her experiences as a disabled person so people would not "see this much inside my mind," but years later, she watched the movie, *Turtles All the Way Down* (2024), about OCD with her family because she wanted them to understand her experiences and "see inside my mind like that."

Disability representation is not just about diversity check box in media. There is so much more in terms of disabled people feeling "seen," being able to understand and celebrate their disability identity, and offer avenues of education for themselves and others. Overall, not seeing disability representation as a child or as a teenager made disabled people feel on their own and

that “I thought I was like the only one [disabled],” which had an effect of disabled people forming strong bonds as they met other disabled people in college to advocate to make sure future generations could have good disability representation as children.

Growing Up and Disability Representation

As participants reflected on the disability representation they may have seen as children or teens, several expressed how the only representation included disabled, often elderly, adults. Keisha, a wheelchair user, reflected on how the disability images she saw in her youth never included disabled children or teenagers, but “people in their 30s and 40s.” Due to this lack of child and teen disability representation in media, nondisabled people connected Keisha to the only other disabled people they knew, like “their grandpa or their grandma…I experienced more of that, either myself making the connection or others making [those] associations.” Others indicated that they did not remember seeing any representation. A blind participant, Ahmed, explained how as a child in Pakistan, he never watched any visual media as they were not accessible to him, but that he did not recall disability representation in any of the books he read instead.

Nelly a wheelchair user, who uses a voice microphone completely rejected her disability identity as a child and teenager: because of her small frame and wheelchair, she assumed strangers were thinking, “‘Oh, she doesn’t have a brain and she can't think for herself,’ which wasn't true. So I was like, ‘Oh, I’m disabled, but I’m not *that* kind of disabled. I’m not really disabled.’” She did not want to use that word or associate herself with anything disability related because media told her that disability was a bad thing. To this, she would try to hide her disability, “like in high school, late middle school... there was like a lot of Facebook profile pictures I have that you can't really tell that I'm in a wheelchair.” She felt like her disability did

not define her because she was more defined by "my interests and hobbies, school and what I wanted to be when I grew up." Nelly mentioned how around 2019-2020, she started being analytical about disability in media. Before that time, she did not pay much attention to the representation in media or how disability was represented until she began doing book reviews and sensitivity readings for authors regarding disabled characters.

A few participants discussed superhero franchises such as *X-Men* and *Star Wars*. Opal, a wheelchair user, mentioned how there are many disabled characters with prosthetics who were never "really part of the story. I feel like that's kind of the problem with representation in the media, that disability [is] kind of tiptoed around"; in contrast to this exclusion, their favorite *Star Wars* character, Echo, has three prosthetic limbs, "both of his legs and one arm. He's a very grouchy character, but he's also really funny." Fera, a wheelchair user, expressed how the mutations of *X-Men* at a special school reminded her of having different disabilities: the characters "weren't, like, said to have disabilities outright—except Professor X—but it was the first time that these people who were different, who were originally cast out by society, would be famous superheroes" who saved the world.

On the other hand, Axel, another wheelchair user, criticized the representation of Professor X, particularly how his wheelchair floated with no wheels: "Does this classify as somewhat of a wheelchair anymore? A lot of [sci-fi] gets to cop out of true representation." Although it was good to see a wheelchair-adjacent user in the Marvel universe "doing stuff with his mind," Axel would prefer to see "someone young, someone with some oomph." They shared how "disability rep in general versus the disability rep that I identify with is very different." As a teenager, they connected with the blind superhero Daredevil, since it was "cool" seeing a

disabled superhero; even though "they pretty much nerfed [his disability] because of the way that his powers work…I still enjoy the media, even though it's flawed."

The topic of "inspiration porn" came up in many instances: Stacey, a wheelchair user, classified most of the disability representation she came across as "very cringy" inspiration porn, while Jazmyn, who has cerebral palsy and uses mobility aids, shared that the only movie she'd ever seen depicting her disability, *Music Within* (2007), was riddled with inspiration porn–coded tropes. Daisy, a rollator walker user who was diagnosed later in life, shared her experience watching *A Time to Live* (1985), which featured a character with muscular dystrophy and was "a sob story…he had a hard life, the family struggled, and then he died." This representation had a negative impact on Daisy, and made her fear her disability. She said:

> I watched it and thought, 'Oh well, that might be my future, too'…Back then, that's how disabilities were portrayed, much more negatively: you're sick, you're dying. It really portrayed the family struggle with taking care of him, and there was this family dynamic that was very difficult. I…was like, 'Oh, this is depressing and probably my life is depressing, too.'

Polly, who has been blind since the age of 14, shared a similar experience with negative disability representation: in the soap operas her mother would tape on their VCR, if the disabled character wanted something bad enough, like a romantic relationship, they just had to work hard enough in order to walk again, in what Polly described as "the 'magical cure' thing." Any time she saw representation that was resolved with the "magical cure," she felt embarrassed and ashamed for having a disability. As a child, she hadn't known "enough to say, 'Oh…this is really bad disability representation.' Rather, what I did was internalize the ableism, which was making me feel bad…because 'I am wrong.'"

Polly also reflected on not having any education regarding stereotypical representation of disabilities in media, "just a gut feeling, like bad disability representation made me feel icky…I think it was mostly shame and embarrassment [for being disabled]." James, a wheelchair user, echoed this lack of understanding regarding ableism and discrimination; in elementary school, he was made to feel like "the problem" when field trips were inaccessible, an experience that made him empathetic to how "other marginalized groups…experience that same kind of discrimination and misrepresentation." Ahmed, who is blind, described how who is blind, described how Indian and Pakistani societies were more permissive of mistakes or "incorrect" behavior if they were done by nondisabled people, while different standards were applied to disabled people. He expressed:

> If a person with disability is represented in a way that's not acceptable in general, people will label the whole community based on a single person and say that, 'Hey, all these disabled are like this and that…' [Growing up], we [my family and blind siblings] used to really think bad about it [blindness], and like, 'Why am I in this situation…what will happen in the coming life?' I was legally blind but I could see a little bit of light, so we used to try to not to tell anyone and do the things at the best [of our abilities] so that the other person does not know that this person he has some eyesight problem or like that to the extent possible.

Sally, who has epilepsy, described her struggles in navigating her disability but didn't hear the word "epilepsy" until middle school, at which point she began doing online research to learn more. Stereotypical disability representation caused her to feel "shame" and attempt to hide her disability, since most disabled characters were seen as "less than" nondisabled people or "not

‘normal.’ They’re not getting their own plot lines. It felt like, ‘Oh, I want to be normal,” explained Sally, “and so I’m going to act in all the ways that the main characters are acting**.**’”

Kristy, who is deaf in one ear, similarly wanted to hide her disability as a child. Her fear of making mistakes as a result of her disability stemmed from seeing Helen Keller get punished for being wrong or not doing something perfectly in *The Miracle Worker* (2000); after witnessing how “rough” and “frustrated” Helen’s aide and parents were about her deaf-blindness, Kristy felt scared: “I was like, ‘If I do anything that isn’t an assimilating thing, then I’m going to get yelled at.’” This made Kristy “hide certain aspects of myself or not talk about certain things” while in public or at school. People may have believed she was acting rude or selfish for not responding to others, but “I wouldn't hear them because they were talking into the ear I couldn’t hear in…I really internalized that [and] I was like, ‘Oh, if I just don’t do anything, then no one will know.”

Jazmyn, who has cerebral palsy and uses mobility aids, expressed how she too wished she could hide or get rid of her disability, in her case because of the film *Forrest Gump* (1994). She shared how other peers would bully her in this experience. She said:

> In elementary [and] middle school, I got, ‘Run, Forrest, run’ when I was running in P.E. [with my leg braces on]…I think [the character] had them because of his scoliosis…I wished that my plastic leg braces, which are constructed a lot better, would just fall off so that people would see [me as nondisabled]…I was like, ‘Oh, if people didn't have to see my leg braces, then maybe I could pass as able-bodied**.**’

Chloe, who has multiple nonapparent disabilities, expressed how the book Sick Kids in Love (2019), written by disabled author Hannah Moskowitz, changed her life as an older teen “both of the main characters are chronically ill and disabled”; while the main character’s

experience with rheumatoid arthritis was entirely different from Chloe's, "the mental narrative that she has around it and the way that she is, it comes back to how I feel like I spent so much time being told not to identify with my disability, not to, like, make it a part of my personality, and feeling so much shame around the fact that I couldn't extricate myself from that…in my head, at the time, I would go around calling myself 'the sick girl.'" The book and its focus on "being okay" as a sick and disabled person "significantly impacted" how Chloe interacted with her family about her disabilities, as even though there was "ableism in my family…it was always built on ignorance, [and] they always wanted the best for me. They were just doing what, like, literal doctors…were telling them, 'you gotta make sure she doesn't identify with her disability.'" Chloe added that the book helped her combat "a lot of the shame" she felt about her disabilities. She said:

> I never pretended not to be disabled, but sometimes I would hide the way that I identified with it and the way that little details of it defined me…[Everyone] was saying, like, 'your disability can't be your identity. You're so much more than that.' It ends up feeling invalidating, and making you feel shameful when it doesn't work like that…I've never met anybody who has actually been able to be like, 'Yeah, no, I don't think my disability defines me at all. I think it's not a part of my definition or identity at all.'

Many of these ideas, which disabled children and teenagers first learned from media and society, created internalized ableism for them until they met other disabled people as adults because they could share their own experiences, as discussed later in the sections. Like many, Nelly, a wheelchair user, embraced her disability identity as an adult, "once I started reading more and talking to people more," because it was comforting to share support, experiences, and

tips for navigating college with other disabled students. Media has the power to change perspectives of disability for not just nondisabled society but disabled people as well.

Intersectionality

When discussing representation and intersectionality, some participants mentioned how the presence of culturally and racially diverse disabled characters would have been empowering for them. Josie, a Hispanic wheelchair user, was never able to "feel connected" to any of her teachers because, from kindergarten to 12th grade, she never had "a visibly disabled teacher"; the lack of disability representation in both media and her daily life made Josie feel "invisible" and "erased from society." Claudia, a Hispanic wheelchair user, discussed how, being disabled and Hispanic, she was doubly conditioned by society to "be quiet…[which] definitely makes it harder [to speak up]." Now, as an adult, she is learning to be louder and "use [her] voice" to educate people "versus staying quiet and letting people assume things" about her disability.

Participants indicated that they wanted more "authentic" and "messy" disabled characters in media. Axel, a White wheelchair-user, said they wanted to see characters that have "louder personalities…People think disabled people are very meek and mild mannered. No!" Opal, a Hispanic wheelchair user, wanted disabled characters to be "loud and sometimes not the best at doing things…[they can] be losers and awful, like, just let them be people." Growing up, this participant's family was strict and had high academic expectations for her to do well because they were "overprotective" of her being a Hispanic, disabled girl. Opal shared:

> [Seeing] realistic representation in the media… would have helped the people around me, kind of challenged their expectations and perceptions of disabled people. It also would have made me feel less self-conscious about being very loud [and would have been exciting to be as my own self].

Keisha, a Black wheelchair user, "definitely didn't see that many disabled [Black] women or girls [onscreen], but [really wanted to]." mentioned how she had completely given up on seeking out racially diverse disabled representation because she had "always been very aware of Blaxploitation films," and if Black characters were so poorly represented, then Black disabled ones would be ever worse represented. The only Black disabled character she had seen was in *Diary of a Mad Black Woman* (2005)—a paralyzed husband whose wife left him in the shower for three days as revenge, abuse that was played for comedic effect. Keisha was horrified by this storyline, and as others watching the film cheered on the wife's abuse, she realized, "'Oh, I'm having a really different reaction than the people around me.' Like they're laughing, enjoying this…That means, at a certain level, they consider that" abuse of a disabled person as okay behavior. "I don't really trust them now, I…kind of watch my back. It was less my worth that I thought about, but more about other people's trustworthiness, like people could do this [to me]."

Some participants believed religion impacted how they were treated as disabled people, in that others believed being disabled was a sin and necessitated punishment. Some participants shared how strangers would frequently ask to pray for them or "…scream 'God bless you' across parking lot[s]." Ahmed, an Asian blind participant, grew up in Pakistan, where people believed extreme sin had made him and his siblings blind. Patronizing behaviors toward disabled people were common in the country, which Ahmed felt normalized "calling others with different names [that mimicked their disability] rather than using their names…[conveying] that disability is something bad." James, a White wheelchair user, was not interested the "healing disability" mentality his family's conservative church pushed on him; he just wanted to be "validated and humanized," but this mentality made him feel "less than" as it "ties directly to media

representation because it's a reflection of how society functions, and it is so ingrained into our society."

All of the participants indicated they wanted more diversity in terms of gender, race, occupation, sexuality, and more when it came to how disability was represented. Daisy, a White rollator walker user, expressed her interest in realistic intersectionality, where "somebody who's disabled and a person of color or disabled and not straight." Axel, a White wheelchair user, aligned with Daisy's comments when it came to the future of disability representation: "I would want to see intersectionality, I would want to see variety."

Claudia, a Hispanic wheelchair user, shared how the same disability representation does not make her feel seen "because if you're just showing the same thing, it's not real inclusivity. It's not real representation to the whole disability community." She added that how seeing someone who was Hispanic and shared her same disability would be amazing. She stated:

> Seeing a Hispanic woman or young girl as an actress with a wheelchair would definitely be so, so cool to see. It would be extra special because I feel like it's not something that is seen so much, or if we see my race represented, it is always…very sexualized or portrayed as not as intelligent. I would like to see more Latino disabled people. More women, more Latinas. And not just the White man or the petite disabled woman.

Opal, another Hispanic wheelchair user, echoed this statement as they wanted more "intersectional disability identities…as a Mexican American queer, disabled person, I don't think I've ever seen media that checks off all of the boxes." Josie, a wheelchair user and "brown, disabled, gay woman," also wished for a more diverse representation, including "LGBTQ, people of color, disabled…all of the intersecting identities, because [at my university], there's so many disabled people and I never realized how big that community was because I never saw it

represented [in media].” The diversity of disability representation is as important as having disability present in a story, and that only comes when disabled voices are included in creating their own fictional identities.

Love and Disability

In discussing disability representation, the participants dove into the topic of disability and sex**.** Many expressed feelings of infantilization from society, which treated them like children although they were fully grown adults. Nelly, a wheelchair user, explained how this concept hurt her self-esteem. She said:

> If we're seen as inspirational and angelic, like, beautiful for being alive, then we can't also be having sex…People treat us like kids…so if people see us like that, they don't want to include sex in the equation. It's unfair that we're portrayed that way because that leads to other stereotypes and the dehumanization of disabled people, because love and sex is something that's so inherent in, like, the human experience everywhere.

This plays into the trope of disabled people being inherently asexual or aromantic. Many participants shared that “no one would find me attractive” or “want to be with me…and fall in love,” because disabled people were not being depicted as people who could get married and have families. Keisha, a wheelchair user, said that media shows humans as what “a sexual person is supposed to look like,” and because disabled bodies are excluded from that definition, it’s “eas[ier] to view us as asexual than to admit that not everybody fits the same body types.

Opal, a wheelchair user, hoped to see diverse disabled characters navigating romantic relationships, particularly because “seeing [positive romantic interactions] in media helps able-bodied people realize that they don't have to be weird about being attracted to a disabled person…Men are weirder about approaching disabled women that they're attracted to, so it

would make [their interactions with me] less weird." They reflected on an episode of *Private Practice* (2007–2013) where a female character was interested in a disabled man, but did not know how to approach the situation; he later caught her reading a book about disability and sexuality. Although not the best image of disability and love, the participant did enjoy the very small scene as it was a "very refreshing moment…that specific aspect of representation is so rare." James, a wheelchair user, wanted to see a disabled lead in a rom-com sitcom with the "same kind of quirkiness and idiosyncrasies" of the show *New Girl*, "just showing that, 'Oh, we have our daily lives and relationships and [we] go to work." Axel, a wheelchair user, shared how they wanted romance to be further explored in various representations: "Like with queer media, like *Heartstopper*, for example, you can have a story that's very focused on identity itself."

Existing media depictions of disability and romance can be harmful. Fera, a wheelchair user, expressed her traumatic experience in watching the film, *Me Before You* (2016), in which a female caretaker and a disabled man fall in love; at the end of the film, he chooses to die via assisted suicide, so he was no longer a burden to her. When watching this film with her friends at the theater, Fera was initially excited, but felt angered at the ending because it "messed with me [and] definitely fed my insecurities…and tanked my confidence a lot." Afterward, she had long conversations with her friends about how the film's triggering projection of disabled people as "worthless," "a burden," and "not worthy of love." She explained:

> I was a teenager and I was struggling with my own self-worth and self-image already as it was, and struggling with dating and…all the things that a teenager goes through, but then times ten because I was disabled in a small town. That was not a good message for my teenage brain to take in. And that really hurt. The ending…impacted me for a little while,

and I stopped trying to date or liking guys, and it was really hard to battle. Like, 'What do I have to offer?'

Several participants reflected on Me Before You in a negative light, but they were hopeful for the future of disability romance representation, and what disabled people are doing to show society that they, too, fall in love. Nelly, a wheelchair user who is now married, shared how dating seemed daunting since she believed that men would be "turned off by the fact that I had a disability, so [getting into a relationship], that helped me realize that maybe that stereotype wasn't so correct." Axel, a wheelchair user, expressed how in the past, when they did not have anyone romantically interested in them, they automatically believed, "Oh, it's the wheelchair, it's definitely the wheelchair."

Many participants discussed how their confidence would increase if they saw more representation of love, disability, and successful interabled relationships. Although all participants discussed the lack of disability romance representation and the desire to see more happily-ever-after endings for disabled characters, most feel optimistic about romantic or sexual disability representation. Daisy, who uses a rollator walker, followed Lolo Spencer, a Black disabled wheelchair user, on social media; Spencer posted photos recreating sexual poses "like Kim Kardashian or something, and she's like, 'Disabled girls can do sexy photo shoots, too.' I'm like, 'Yes, they can,' which is important because it's not the normal representation of disability that includes someone struggling and then dying." Daisy also shared her excitement for Hannah and Shane Burcaw's book *Interabled*, sharing true stories of disabled couples so that disabled people do not have to "[feel] depressed and think, 'Oh, I'm never going to fall in love, nobody is going to want me.'" As an avid romance reader, Sally, who has epilepsy, loved disabled romances because she sometimes believed that "'my epilepsy makes me hard to love' or 'it's a

burden.' I think I've taken a positive belief system out of reading romances, because it's like, 'Hey, they're lovable, so then maybe I'm lovable.'"

Chloe, a book influencer with multiple nonapparent disabilities, had read many disabled romances, which "definitely just gives you more confidence to see" characters and their worlds. Even in fiction, the characters are more often set in real-world scenarios than in fantastical worlds, but "there's more grounding [of] disability in our contemporary world setting…these are just people that have love." As in all romance novels, these stories may be idealized, "but sometimes it's real and it definitely makes me more hopeful for the world in the future."

Nelly, a wheelchair user, first encountered a main character with her type of muscular dystrophy in *This is Not a Love Scene* (2018), a young adult romance novel about a filmmaker who pursues a classmate she finds attractive. Although they do not end up dating, they end up having "more [of] a physical relationship, which I thought was really, really cool and progressive to have [because] A) it's a book for teens and B) in any book, I've never really seen something like that before." This book helped Nelly feel "validated in that [romantically-desired] way and to know that other people who are reading the book could see that and understand that…especially for able-bodied people who think of us as inspiration porn and pity and stuff like that."

Although participants discussed the lack of disability representation and the desire to see more of their own representations getting happily-ever-after endings, most feel optimistic about romance representations. Axel, a wheelchair user, expressed how love and disability in media was also good "for people who have not considered dating a disabled person to know like, 'hey, this isn't abnormal, this isn't like weird,' like it's just life.'" This included wanting to see not just disabled characters as love interests but also "real disabled people in disabled roles."

The Treatment of Disabled People

The ableist tropes of infantilization and "angelic expectations" encouraged the "inspirational" treatment that the participants received from their families and society at large. Daisy, who uses a rollator walker, reflected on how people sometimes exhibit the "inspiration porn" mindset when speaking to her; even though her disability was mild, strangers would still ask, "'Oh, you have a master's degree?', 'Oh, you're a librarian?', 'Oh, you've been working for as long as I've been working?'" It was frustrating for her and other participants "somebody thinks that you deserve a medal just because you're living your life."

Opal, a wheelchair user, was "subjected to a lot of inspiration porn" during their childhood; they felt uncomfortable when strangers would say, "'You're such an inspiration.' I'm like, 'If I'm such an inspiration, then what exactly am I inspiring you to do right now?'" Opal later felt infantilized when their mother would "brag about me and the fact that I'm going to college. People don't take me seriously…and they're just like, 'That's cute.' They think it's cute that I'm, like, studying hard." Claudia, a wheelchair user, was the only disabled person in her school; people saw her getting an education as a "shock," and adults would say things like, "You're so inspirational for coming to school, for learning," but Claudia was "just there to get an education just like anyone else." Josie, a wheelchair user, once had a teacher place blame for certain ableist attitudes upon her. She said:

> In sixth grade, another wheelchair-user boy was throwing items and stuff at staff, and one of them told me, 'You should talk to him, because disabled people shouldn't behave like that.' And I was just appalled. I was like, 'How should disabled people behave?'

Josie felt like disabled people were seen and thought of as "2D people…angelic and pure and all that really ableist stuff [even though] we're regular people with, like, all these different

emotions." Talking to other disabled people about her experiences has helped Josie feel more confident showing an array of emotions and "not play[ing] this persona [to] fit into what society wants me to be. I remind myself that that's not…a way [that] I need to be."

Chloe, who has multiple nonapparent disabilities, believed that disabled people were seen and treated as inspirational or child-like by nondisabled people because of how media had represented disabled people for decades; when images of disabled people were shown in infantilizing ways, that would influence how nondisabled people would interact with them. Chloe believed that these images were established by and for older generations: "That's how they were shown how to do it and so that's how they do it. And then it just perpetuates itself indefinitely."

Due to many misrepresentations of disability being "child-like" and "inspirational," Axel, a wheelchair user, shared how their unfiltered and intelligent personality threw people off because they did not fit "that assumption" based on the way disability was shown in media. A substitute teacher once "interrupted me, and goes, 'Are you verbal?' [I'm] the type of person that if that happens, I'm gonna just start playing into it. I'd be like, 'I don't know, what do you think?'" They added that being intellectual is non-negotiable when you are disabled: "Being academically well, at some point that kind of becomes expected of me just because I'm in a wheelchair, so, like, I can't afford to not be very smart." Being "born disabled" meant that there was a certain mindset that Axel had to adopt: "I need to act like an adult. I need to never take risks. I need to be 100% put together because I don't have time to not [be].'" They reflected on how, in high school, they were "the only one there with my head screwed on correctly"; while everyone else was "smoking weed in the bathroom," Axel did not have the freedom to do whatever they wanted. They said:

> I didn’t have the luxury of being reckless with my body. I need to have as much control over myself as I can at any given time, because I'm already at a lack of control, it's this having to grow up faster because you have a lot more limits than other people have. You're like, ‘Hey, don't do this. Don't do this. Don't do this.’

The pressure on people to not be “reckless,” as their health situation may not allow for it, may translate into stereotypical perceptions of disabled people as always-happy and do-gooders, further feeding into the inspiration tropes.

Chloe, who has multiple nonapparent disabilities, described how teachers would comment on her anxiety as not being “‘as bad as you think it is.’” Chloe was granted accommodations to leave the classroom during panic attacks, but one teacher would deny her from doing so, stating, “‘Just push through it. Just pray the fear away,’ because she knew other people who had anxiety and they would be fine.” Being a “hella rule follower,” this would stress Chloe out more and make her situation worse. Chloe believed that others may not have treated her as inspirational due to her disability, because they do not “see” her anxiety the way they see a physical disability; still, she had received sayings like “you're so strong” from people that knew her, which “put a bad taste in my mouth.” Although she had found herself needing to be stronger than the average person, it was not an active choice: “It's either I survive, or I don't. And I don't necessarily want to always have to be strong…it's always just made me a bit uncomfortable.”

Sally, who has epilepsy, does not mind being called “strong,” because she believed it was okay to accept the notion that disabled people have achieved a milestone during times of hardships. Being valedictorian in high school, Sally heard people say how “impressive” she was, which made her feel “proud that I got there, even while dealing with the separate struggles from

epilepsy." However, she thought that more representation would have aided in her having to speak up for herself. She added:

> Without good disability representation for your disability, you have to be your own advocate and you have to explain yourself to everyone, 'what does this actually look like' and 'what does it look like for yourself…' which can be really exhausting, to have to disclose that information or to be the one always fighting for yourself.

Claudia, a wheelchair user, agreed that if there was better representation, it would be like "lifting the weight off my shoulders, [of] having always to, like, educate or explain everything to everyone or to those who have questions." Opal, a wheelchair user, described how exhausting it was to educate people about muscular dystrophy: many assume they were paralyzed in some way, and were "shocked" when they moved their legs. Opal found it distasteful when people assumed their disability was cerebral palsy, as "there are hundreds of thousands of different disabilities in the world…I just think that's crazy, trying to assume someone's disability." They were often asked, "'Did you fall from somewhere really high up?' And I'm like, 'No.' With kids, I have a lot more patience because I understand that it's not their fault…But with older people, I should not have to be educating you." Opal began to ask themself, "'What can ableism do for me?' Even though I hate how disabled people are portrayed in infantilized ways, I take advantage of it…[when my] voice automatically gets a higher pitch, suddenly people will do anything."

Nelly, a wheelchair user, expressed how she was tired of strangers thinking they had the right to ask why someone was disabled: "You wouldn't go up to someone and be like, 'Why do you have brown hair?' It's weird, the assumption that people can have your medical background." Like others, Nelly tried to educate people about their ableist comments, but usually

she did not. She explained how the less nondisabled people "interact with disabled people, the less they're going to realize what they're saying is harmful." When riding a train in New York, Nelly used the robotic arm that attached to her wheelchair to hold up her phone; when another passenger saw, "she was like, 'Oh my goodness, you're so inspirational. That's so cool. I have a nephew like you, and I hope that he's able to achieve everything that you'd achieve.'" Nelly noticed that the older generation tended to give her unwanted comments or prayers, while "I never had, like, a 10-year-old come up to me saying [I was] inspirational." Stacey, another wheelchair user, echoed how the older generation says, "'You poor little disabled person.' I feel like disabled people weren't in public as much as we are now…and people grew up seeing us as 'special,' 'unique,' 'different,' [thinking,] 'Oh, we should protect them' or 'treat them differently.'"

Claudia, a wheelchair user, shared how many adults steered their children away from "asking questions" about her wheelchair, but Claudia would encourage them to ask the questions. "Then I'll go to the parent, like, 'Kids are curious. Don't hinder their curiosity, 'cause that creates stigma as they grow up, you know?'" James, another wheelchair user, explained how there was a lot of stigma in representing disability in media or public settings: his disabled musician friend would get immediately rejected before even auditioning, and another friend in a wheelchair was erased from a music video because producers "didn't want to have, like, the wheelchair there in the moment, because they see that [disability] as a negative thing."

The treatment of and assumptions surrounding disabled people bleeds into employment issues as well. Nelly, a wheelchair user, observed that disabled people were not seen as "career people." In her experience with her local Division of Vocational Rehabilitation (DVR), they support and will help disabled people get "low entry-level jobs [involving] physical labor, like

working in a restaurant or coffee shop," but never career support or resources for anything past a Bachelor's degree: "They've been like, 'Oh, we can help you with this, but that's not relevant to you because you're looking for like a career and not a job.'" Nelly, who now works at Penguin Random House, had to navigate the employment system and advocate for her accommodations on her own.

Impacts of Positive Disability Representation

The overarching theme of negative or no disability representation made participants feel like they were "not seen," while instances of positive representations made them "feel seen." This came with feelings of joy, confidence, and relatability; seeing disabled characters they could identify with not only made participants feel less alone, but raised their self-esteem, validated their existence, encouraged them to seek appropriate support, and "freed" them from the weight of educating society about their disability. Josie, a wheelchair user, shared how the idea of seeing positive and authentic disability representation made her "feel so happy and just, like, seen, because…a reflection of my life would be shown for other people to see, because disability is so stigmatized [and] people don't see it." As a child, many nondisabled people would stare and point at her wheelchair as if it was an abnormality, so with "accurate, good representation, other people would also see it [in media], [and] maybe that would no longer happen…disability would be normalized."

Sally, who has epilepsy, discussed how seeing her specific epilepsy represented "would feel very validating" because media only shows the seizure element and not the other aspects "of [everyday] living with epilepsy." Representing different types of epilepsy and "all those other parts of it would make me feel more seen and less alone, and experiencing this, especially because it is a more invisible disability…It would just help [with] feeling more accepting of

myself." Chloe, who has multiple nonapparent disabilities, agreed that seeing those invisible disabilities represented would make her "feel validated and seen." She also reflected on how positive representation in literature can help explain other people's experiences. She stated:

> The more people read [disabled romance novels] and see that this [love] is a thing that you can have…then the more these stereotyped ways that we've seen in media are [in the] past. It will just continue to have a positive impact on the way that we are treated in the world and see ourselves and all of that, and I think that's awesome.

Lonni, a wheelchair user, echoed Josie's comment about "just feeling seen," expressing how disabled people could be looked at as not just their disability, but as "a person who happens to be disabled…I think it's about time that we see people being represented as people, and their disability is a part of them."

Stacey, a wheelchair user, expressed how seeing good disability representation would have made her "feel more comfortable, more seen, and not just as an oddity or an inspiration, but as an actual person in real life." As someone who lives life and accomplishes tasks "in different ways," having media show this "would open other peoples' eyes and…show more people that we're not this special thing that needs special needs, and we're a person first." Fera, a wheelchair user, shared how seeing disabled college students living would affirm that she could "live the stereotypical college life and [do] what every other person in their young 20s is doing…It would be a confidence booster, and reassurance that my disability doesn't stop me." Although Fera required accommodations for certain daily activities, she would still be participating in the college life like any other student "and getting into questionable scenarios, which I think society doesn't realize…I think they still see us as people with halos above their heads."

James, a wheelchair user, shared how positive representation is "really exciting." He brought up the show *Speechless* (2016–2019), whose lead actor had cerebral palsy; the show's family dynamic was "really relatable" for him, as one of five with two older siblings, "just like the main character." Storylines where the main character goes through caregiver struggles, such as befriending his main caregiver, were extremely "reflective of a lot of my story. It was exciting to see that and for it to be presented in a funny way, and just a very honest depiction. That brought me a huge joy in seeing that." Keisha, a wheelchair user, had to turn to international programming to see good representation, though she enjoyed the depiction of disabled characters in the US sitcom *Superstore* (2015–2021), which "felt like real life." She stated:

> I was simply just observing something that was made for entertainment… it felt like a place [*Superstore*] that I could go to as well, and it also didn't make [the disabled character] like a spectacle... I still haven't seen black women wheelchair users in shows that for me particularly don't feel voyeuristic… Sometimes it's very rare [to see] that real representation… A lot of the representation that I enjoyed, I had to go overseas to find it.

Disabled people constantly search for representation that relates and connects wo them, always eager to come across characters and storylines that can match their own.

Kristy, who is deaf in one ear, said the closest she felt to being represented was in *Finding Nemo* (2003): seeing the main character's one smaller fin, "My mom was like, 'Oh, it's just like your ear.' It's not direct representation, but I always found that comforting." Claudia, a wheelchair user, first felt represented when she saw the disabled model Jillian Mercado in advertisements and making history as the first model in a wheelchair at the 2020 New York Fashion Week. It was a "happy moment, just really seeing someone like me on the big stage…It really gave me a thought like, 'If she can do it, then I can do it too [and] not let my disability or

anyone else hinder me." She also resonated with wheelchair-user actress Ali Stroker. If Claudia had seen these types of representations growing up, it would have boosted her "confidence, [seeing] someone who represented me in the media that way."

Tammy, who is blind, expressed how a disabled character from *In the Dark* (2019–2022) opened her up to new perspectives about her blindness after four and a half years. "I know a lot of what she did was not really what she was doing, but in the audio descriptive world, it was telling me that she's walking down a Chicago street unassisted, and she's meeting up [with someone]." Tammy may not have agreed with some of the character's choices, but was impressed by her perseverance: "You can't just sit back and wait for things to happen…She was never scared to try anything." Tammy watched the show while she was attending the School for the Blind, and was able to relate to the character's actions, like "how she asked for the menu, how she educated the waiter to set the drink at a certain place and not move it and different things like that."

Ahmed, who is also blind, reflected on seeing a movie with a blind female protagonist that showed how she was able to do many things, be independent, and be loved by other characters. The representation made him realize that there were a "few things that [my blind siblings and I] can do, more than what we are doing now.' That was a positive impact on our own, you know, representation and getting more rehabilitation…Giving more idea into what our abilities are." Ahmed found this positive portrayal of blindness inspiring, especially with "keeping in mind that the general community of society, what do they believe in general about what [blind people] can do and they cannot do."

Jazmyn, who has cerebral palsy and uses mobility aids, discussed a scene from *You're the Worst* (2014–2019), in which the female main character told her boyfriend that she did not want

to get her disabilities and mental illnesses "fixed." Jazmyn brought this scene to her then-boyfriend and "was like, 'I relate to this character so much.' It was a way for me to explain" how she experienced disability. Her example expanded on how "there's still so much stigma around mental health disabilities in popular culture…Here's a representation that I'm identifying with…It allowed me to open up a wider conversation in a way that I don't think I could have articulated otherwise."

Chloe, who has multiple nonapparent disabilities, recalled *Conditions of a Heart* (2024) by Bethany Mangle, a young adult romance novel centered around a "character who spends her entire life trying to hide her disability and hide her chronic illnesses, and eventually is unable to do so, and coming to terms with that fact." Chloe realized that she did not have to mask or hide her disabilities as it was not healthy, even though "there are stories out there where it ultimately comes down to 'hiding is better,' and I'm sure that, especially in previous eras, that was more common." The book also gave Chloe an "understanding of my cousin, who has spent a lot of time hiding" her disability in order to be popular and fit in. Even though the book comes to the conclusion that hiding a disability "does more harm than good in the end…it gives you empathy for people even when they're making decisions that you don't fully understand or agree with."

Chloe went on to share how "cool" it felt to show others a piece of media that portrayed someone's exact disability: she was glad for the chance to show *Turtles All the Way Down* (2024), a film about living with OCD, with her family, "specifically my brother, and have him understand things that are so internal and invisible. Having something to be like, 'This is actually what it's like' [meant a lot], especially because OCD is often misrepresented, or just shallowly or stereotypically represented." Chloe had talked to many people who "saw their disability in media first and [realized], 'This looks like me,' and then went and found treatment and got a diagnosis.

I think that's also a really important aspect to diagnosing and spreading awareness." She wished there had been "more representation" of autoimmune encephalitis, one of her disabilities that went untreated for ten years; she believed that if people talked more "about these things, if we had media that people were aware of and discussing, then more people would be diagnosed."

Sally, who has epilepsy, was excited to see more disability representation because of "the empathy that I think it incites, if it's well done. I think it helps me understand the people that I love who have disabilities and…I think it helps other people understand us." In having a space where others can learn about lived disability experiences can incite a lot of empathy from audiences. Claudia, a wheelchair user, agreed that seeing frequent positive representation would be a great thing as "then people wouldn't think less of us or think a certain way of us. It would, I guess, take a load off of, at least for me, not having to explain or talk or repeat myself" constantly to educate others about disability.

Theme #2: Disability Representation Requests

This second section discussed participants' favorite and ideal disability representations. The four sub-themes included: 1) favorite disability representation; 2) authentic representation; 3) eliminating certain disability stereotypes; and 4) disability representation recommendation reactions. Within the first sub-theme, participants felt seen and validated in real representations of disabled people being funny, witty, messy, and sometimes awful, wanting to see a wide range of disabled characters in different types or roles. In the second sub-theme, participants expressed not only the importance of giving disabled roles to disabled actors, but the relatability and authenticity of disability that disabled people bring to these roles. For the third sub-theme, many participants discussed the media representations they hoped to eliminate, which tokenized disability and dehumanized the disabled experiences through stereotypes such as being

inspirational, pitiful, and magically cured. Within the fourth sub-theme, depending on the relationship or the recommender, participants were either upset, cautious, or excited when someone gave them media recommendations regarding disability representation. These discussions emphasized the importance of giving disabled people the right to dictate their own representation in a way that would normalize and integrate disability into society.

Favorite Disability Representation

Several participants praised disabled characters who were "messy" and "awful" instead of "inspirational" and "infantilized." Nelly, a wheelchair user, shared how she loved the character Steve, a wheelchair user with muscular dystrophy (same as her disability), from the show *Ramy* (2019-2022) because of the disability stereotypes he broke: "[He] always had a woman on his arm [and was] very sassy…He curses a lot, he's just hilarious…He's just, like, a person…and I feel like so much disabled representation is not [of] a person, it's a stereotype." Daisy, who uses a rollator walker, similarly "found Steve very refreshing, [especially because his] muscular dystrophy has progressed to the point where it's difficult for him to breathe on his own, so he wears a noninvasive ventilation mask on his nose." Opal, a wheelchair user, Tyrion Lannister from *Game of Thrones* (2011-2019); the character had dwarfism. They said:

> Tyrion was very promiscuous, which I found really refreshing just because, a lot of the times disabled people are infantilized...I really enjoyed that…he's very sarcastic and funny, which I think I might be [funny] sometimes…Seeing some characters with disabilities that are very nuanced, very complex characters, or that sometimes they're a little bit awful—that's really refreshing.

Axel, a wheelchair user, urged creators of disabled characters to "make a villain, make a good character, [make an] anti-hero. [Not like] old school Disney villains, where it's like, 'We're

gonna model villains after a minority every single time'—let's not do that, but explore the idea of that." The minimal range of disability representation means there was not many options to choose from, which Axel discussed how "there's not even really enough to make a basis on your standard thoughts of a disabled person."

Daisy, who uses a rollator walker, appreciated seeing disabled social media influencers living their life and being authors or models. Daisy applauded how Lolo Spencer, who has the neuromuscular disease ASL, was "not sitting around, waiting to die. [Lolo is] living her life and putting herself out there on TV, in a book, on social media, and I think it's absolutely great…especially given the disability that she has. You're like, 'Oh my God, you don't have much time to live.'" Opal, a wheelchair user, expressed her support for disabled influencers in real life in sharing how "seeing some characters with disabilities that are like very nuanced, very complex characters, or that sometimes they're a little bit awful. That's really refreshing."

Others discussed their enjoyment of the disability documentary *Crip Camp* (2020), which follows disabled people experiencing summer camp where they were free to do what they wanted. Daisy "loved that they [disabled actors and creators] were at the Oscars. I loved that they built a ramp for the Oscar stage, in case they won." Opal, a wheelchair user, indicated that the documentary made them "cry," as it was uplifting to see other disabled teenagers encountering life's challenges. She said:

> All of these teenagers, and they were all, like, dating each other and like being messy...that's just not something that I had growing up and I felt so seen…I thought I was the only disabled person that was like that when they were a teenager. It just made me feel a lot better, a lot more seen. And it was nice to also learn about the disability rights movement.

Opal also appreciated seeing the campers "navigate a summer camp without their parents…It was really sweet and really funny and really refreshing to see" the relationships between the campers and their parents, as Opal's mother could be very overprotective since Opal is disabled and the youngest child. Axel, another wheelchair user, appreciated the film, especially because they were not able to be "reckless" as a teenager due to being disabled and "because I wouldn't have wanted to screw around with any of that anyways…*Crip Camp* really did show…being an idiot, like, fucking around and finding out what you like."

Axel described feeling positively about the comic book appearances of Charlotte Webber, a Spider-Verse person with Ehlers-Danlos syndrome who uses a cane and a wheelchair in addition to her superpowers, as they had always connected with the Spider-Man universe and "it was good to see that [living with a disability] addressed." They grew emotional when the character made a cameo in *Spider-Man: Across the Spider-Verse* (2023): "It was only for a little bit, but it still was something that definitely stuck with me." Although the representation did not match Axel's muscular dystrophy, "I see myself in a character with a physical disability, and for it to be a media that I was already so connected with, it was just like, 'That's really badass.'"

Chloe, who has multiple nonapparent disabilities, described her conflicting feelings on OCD representation in media because "it's always just, like, a little quirk instead of an actual disability…for a lot of people, it is a disabling disability." As a social media influencer, she constantly had to explain that her OCD was not "quirky" as it was in media portrayals, and that she was not "going to be solving crimes." She appreciated *Monk* (2002-2009)'s depiction of the impact that OCD had on the title character's life, but was not a fan of the "savant stereotype" demonstrated by his excelling at everything because of his OCD. Chloe felt this was "kind of

making a joke of it in some ways, but at the same time, it's one of the first [series] where…seeing somebody have that much of an impact from [the disability], it was very validating to me."

A few participants discussed how some of the media they enjoyed included ableist messages, but the nostalgia of their past made it hard for them to hate those stories. Kim, who is blind, was "looking at my favorite books and trying to find disabled characters. Oddly, they're there when I didn't realize it." As a child, her favorite book was *A Christmas Carol*, featuring disabled character Tiny Tim, who was "designed to serve the narrative arc of another character, which is the absolute one thing that I most hate about disabled representations…in pop culture." Tiny Tim existed primarily to further the arc of Scrooge, the nondisabled main character, as he chose to become "a better person" when he learned of Tiny Tim's death. This narrative "pours on all the pitiful sauce," said Polly, which was "uncomfortable" for her to realize, as she loved Charles Dickens, who did exactly what she hated. Polly expressed further how Dickens "wrote that in Victorian England and [even now] content creators are still doing that today. It's depressing." Yet, Polly still considers the book her favorite, as it was the first book she read as a child.

James, a wheelchair user, similarly struggled with enjoying a story "that you love, but still are conflicted about the ableist undertones of it." Though *Wicked* (2003) was one of his favorite musicals, he had conflicted feelings about its depiction of a wheelchair-using character. He said:

> The character of Nessa, who is the witch that's killed in the beginning of *The Wizard of Oz*…it does a very ableist portrayal of her as a wheelchair user who, you know, she's experienced ableism but then she kind of grows up into being this grumpy, secluded governor, and then she gets a magical cure for her disability toward the end. And yeah,

> it's always rubbed me the wrong way…I still love the show, but it's the one thing that I wish they would reevaluate…I saw the musical on Broadway for the first time when I was 18 [and] I just loved the whole experience, and I was so immersed in the story, and I've loved The Wizard of Oz since I was a kid. But upon reevaluating, especially when I saw the show again last year…I'm like, I wish they would update this because there are easy ways to rework the narrative to make it better.

Still, James ultimately believed that it was okay to "still enjoy [problematic stories from childhood] and recognize that it's not perfect." Participants showed how they may not automatically hate a stereotypically represented disabled storyline character, if they have some other attachment to the story and experience with the characters.

When discussing the ideal disability representation that participants hoped to see, many indicated wanting to see disabled characters with career jobs, having bad days, or being independent. Claudia, a wheelchair user, wanted to see disabled characters simply living life: going to work, getting married, or "whatever they may be doing, and it's not being [shown as] inspirational because they're doing these things with the disability…it's who they are, right?" Outside of regular life tasks, Claudia was interested in more representation of "different types of disabilities," such as people with various disabilities using "different mobility aids like the big, bulky wheelchair, the walker that gets in the way…the person who's blind but they don't have a cane." Nelly, a wheelchair user, also wanted "regular stories" of disabled people where the plot did not solely focus on their disability. She was not interested in them "overcoming something…Why can't there just be a teacher with a disability? And it's not 'inspirational' because of the disability." Tammy, who is blind, shared that she, too, would like to see disability in "normal roles." She stated:

> We could see [disability as] normal and not be the odd man out, and not to highlight us…as 'the poor pitiful me,' but show that we do things that you do or everybody else does. Not that we're just sitting over at the corner waiting for someone to acknowledge us. Rather than just [having] somebody [disabled] that they stick in for 10 seconds…to be 'inclusive,' actually have a part and have a storyline in that series. And at the end, don't have a miraculous recovery, because that for most of us, that is not going to happen.

Disabled people want to see multi-dimensional representations that show a full range of disability experiences and livelihoods.

Ahmed, who is blind, also expressed wanting disability to be represented through everyday life experiences by giving disabled characters and stories "a space to live their general life, and giving them all those traits which people have [to] navigate and live their successful and independent lives." He added that seeing representation where disabled people "exist in every role all around…and having different characters as they exist in general life would be something wonderful." This is something Ahmed hoped will make disability more acceptable in society, "where it's not something odd or not something unusual for people." Stacey, a wheelchair user with a service dog, mentioned her desire to see good media representations of service dogs, so "maybe I wouldn't have to explain every other minute about the dog, about the rules…I'm just trying to go buy milk and I get, like, 15 questions about the dog." Stacey expressed how if you're disabled and out in public, you're invisible, but with a dog, you become "the main attraction." With greater representation of service dogs, "maybe we wouldn't have such a ramped-up problem of people using undertrained service dogs, 'cause everybody thinks their dog is a service dog, or legitimately disabled people [will] get a service dog that is not trained well in public."

Axel, a wheelchair user, “just want[s] to see more!” Due to a lack of caregiving and assistive support, they do not have the means to move to campus and thus take college classes online; they believe more stories about coming of age with a disability would have been helpful and educational, “because [for] a lot of my childhood, I was pretty sure [that] I'd be pretty normal like everybody else. And then I turned into an adult, and I was like, ‘What's going on here?’” Fera, a wheelchair user, shared how she wanted to “see more movies and more books where the person has a disability and it's not a bad thing.” The disabled characters would ideally have bad days since “that's life within itself, and it can be done in a way that's accurate and tasteful, without doing the whole pity party.” Fera wanted coming-of-age movies “where they're not worried about their disability, and it’s just a disabled student college and they go to parties, get in stupid scenarios with their caregivers...because we've all been there. We all have those stories.” Daisy, who uses a rollator walker, recalled how the show *Speechless* was cancelled right as the main character with cerebral palsy “was getting ready to go off to college. I really wish that they would have shown him learning to be independent and live on campus.” She enjoyed how the show included some instances where he was “trying to become more independent...But there needs to be more of [this kind of disability representation].”

Jazmyn, who has cerebral palsy and uses mobility aids, wanted to see characters with her specific cerebral palsy (CP) represented. She said:

> A character [who] was, like, a sarcastic jerk, and they're not this happy-go-lucky thing…I feel like it humanizes people, like, if I saw someone with CP who was sarcastic or not always a nice person—which is actually shown a little bit in Speechless—I think it would minimize the inspiration porn aspect that I see a lot.

Nelly, a wheelchair user, expressed how she would like to see her disability, spinal muscular dystrophy (SMA), represented: “I mean, obviously everyone wants to feel seen as themselves, and that includes me.” Stacey, another wheelchair user with SMA, agreed that “It would be nice to be seen…And it would be nice to see somebody with SMA and represented well. Not, like, some health episode.” Some great representation would include “a realistic person with SMA, someone who was just living their life—like, married or with kids or trying to find love, you know, the regular TV tropes. But just throw a disabled person in there…Not a special storyline or anything.” Lonni, a wheelchair user, would want to see someone similar to her age, “in [their] mid-20s or early 30s being a freaking badass, and being really good at their job. Someone being like, super intelligent, witty, like living and thriving.” Lonni had read many books with strong female character leads “and it'd be really cool to see that translated to TV with someone that's, like, genuinely a disabled person.”

Keisha recalled the first time she saw a character with “a little bit of color” and a visible disability, a Black wheelchair character in *Superstore*. She said:

> [The character] was not a perfect boyfriend. He was actually quite a lazy worker, but he did his job…The writing was just as if he was any other character, but it also didn't ignore the fact that he was using a wheelchair. And I think that's kind of unfortunate, that…some of the best representations that I've seen did not involve actors who were disabled…That's what I enjoyed, and hope to see…a lot of young adult representation kind coming of age stories.

James, a wheelchair user, enjoyed the show *English Teacher* (2024-2025), but hoped future seasons would include disabled characters: There is a focus on an inclusive, diverse cast already, and to not have [disability represented] would be a disservice, but unfortunately, it wouldn't be

surprising given that disability is often ignored even in more progressive shows." His enjoyment for the show came from his love of "humor and my kind of sitcom." He hoped to see "a slice of life stories like sitcoms... that are not these tropes and stereotypes [and] have them just be real, authentic characters. I like comedies and then also like action and sci-fi fantasy as well."

A few of the focus groups discussed whether they would choose good disability representation with a terrible storyline and ending, or a stereotypical disability representation with an amazing storyline and ending. All participants (n = 7) chose good representation with a bad storyline and ending. James, a wheelchair user, expressed how "we've had enough really harmful representations over the years and harmful narratives." Ahmed, who is blind, added, "I would definitely go with the positive representation…because [disabled people are] doing wonderful things, and it needs to be acknowledged and to be represented and displayed in media." Nelly, a wheelchair user, agreed that "there's so much bad rep that I'd rather have a rep that, if people are gonna talk about it negatively, at least they could understand that the representation was good. They could see that positive representation." Claudia, a wheelchair user, also said she would choose "a bad ending [and] the real representation of disability, the authentic one…for me, it's more about being authentic and portraying that, rather than something that's not truly authentic to us."

A few of the focus groups came to discussing if they would either choose good disability representation with a terrible storyline and ending or a stereotypical disability representation with an amazing storyline and ending, and all participants (n = 7) chose good representation with a bad storyline and acting. James expressed how "we've had enough really harmful representations over the years and harmful narratives." Ahmed added that "I would definitely go with the

positive representation...because they're [disabled people are] doing wonderful things and it needs to be acknowledged and to be represented and displayed in in media." Nelly stated:

> I think good rep and bad story just because like, there's so much bad rep that I'd rather have like a rep than if people are gonna talk about it negatively, at least like they could understand that that's the representation was good. They could see that positive representation.

Claudia, who has cerebral palsy and is quadriplegic, also said would choose "a bad ending [and] the real representation of disability, the authentic one...because for me, it's more about being authentic and like portraying that rather than something that's not truly authentic to us."

Authentic Representation

All of the participants expressed how they wanted to see disabled actors playing disabled characters. Not only would the disabled actors be given employment opportunities, but they would portray realistic disability representation. They also hoped for the inclusion of disabled writers and producers, who would do more than create disabled characters for the sole purpose of having a disability and not for a trope or a stereotypical role. For Jazmyn, who has cerebral palsy and uses mobility aids, disabled actors should play disabled characters "because representation matters." She believed that "there needs to be more actors with disabilities represented so we don't have cripface," a term for nondisabled actors playing disabled characters. She sees this as problematic because able-bodied actors playing disabled characters may perpetuate stereotypes like the "inspiration porn narrative more than if you had a disabled actor playing the same character with the same disability."

Aly, a wheelchair user, discussed how she wanted to see authentic, positive disability representation portrayed by actual disabled actors. She shared:

> It would be amazing and incredible to see more…actual disabled people and roles that are…widely known or in the mainstream media, 'cause oftentimes when there is representation, it's other able-bodied people representing disabled people, and I think that's where that disconnect happens, because they're employing people that have no idea what the experience is like. Whereas when they actually have genuine disabled actors, it says a lot about the [crew behind] the movie, that they want to help aid in that positive light of disability representation [and] showing the community at large what it's like [to be disabled].

Fera, a wheelchair user, also wanted to see disabled people playing disabled characters because it was "not widespread enough for me. I'm tired of able-bodied actors [playing a] role that they're never gonna understand unless they're living with it." Josie, a wheelchair user, agreed and added that casting disabled actors meant that the story would not revolve around them being disabled or being "the token disabled character—just them being a character who is disabled.

Stacey, a wheelchair user, stated that there were many "brilliant disabled actors who are not getting the jobs that they should; we tend to pick nondisabled actors for those roles." She believed that hiring disabled actors should be the standard, especially if the disabled character was disabled from the beginning, because disabled people would be more equipped to understand "the nuances of being disabled [and] play it better, and understand it more." She would be willing to spend money to support a disabled actor than a nondisabled one."

Claudia, a wheelchair user who is a disabled model, agreed that disabled actors are capable and willing to work if given the chance. She would feel more connected to a disabled actor in a disabled role than a nondisabled actor, as disabled actors "truly understand the disability, the circumstances, and everything that comes with, you know, being disabled versus

someone who had to act or learn or whatever the case may be." Axel, a wheelchair user, reflected how in sixth grade theater class, they would never get cast in anything because of their wheelchair, an exclusion that pushed them toward "art and animation, which is acting in its own sense," instead. Opal, a wheelchair user, believed that production companies did not cast disabled actors because having a nondisabled actors take those roles was an "easy way out" that would not require any disability accommodations for the actor. They agreed that animation was "a medium [that actually] gives artists the chance to portray [disability]...there's no excuse to not have representation in animated media forms."

Kristy, who is deaf in one ear, expressed how it was important to have disability present in writers' rooms and production studios as well, not only provide support for disabled actors, but also ensure that the disabled story was "told properly." James, a wheelchair user, thought it has long been overdue to have disabled creators, actors, and artists be in control of their own representation. Discrimination arose when disability representation was "being written or acted out by nondisabled writers, actors, et cetera. And that is a huge problem in itself." Tammy, who is blind, echoed this by adding that the more that disability representation was shown to the disability community, the more that disabled people could applaud the producers, which in turn would allow a "future of them doing the right thing and…not [casting nondisabled] actors that don't really have a clue what we deal with on a daily basis, and actually using [disabled] people who do live it every day."

Daisy, who uses a rollator walker, was a big fan of reality TV shows like *Survivor* and *The Amazing Race*, and felt excited whenever she found a reality show with "representation of a real person with a real disability, [where] however they are is however they are." She loved *Born this Way* (2015–2019), a reality show about individuals with Down Syndrome "just trying to

make their way in the world." She appreciated how their families tried to lead their relatives with Down Syndrome to be more independent, including two couples getting married.

James, a wheelchair user, enjoyed watching disabled comedians like Josh Blue and Ahren Belisle, who were hilarious, honest, and vulnerable. This "authentic representation" made James feel seen, because "storytelling is a very innate human function and desire, and when we see characters that reflect our own stories…[it] helps us feel more understood." When media portrays examples of real disabled experiences, like "finding caregivers or dealing with insurance struggles…things that people who are closest to me don't deal with, when they see that portrayed, they get a sense of what my life is like and what other disabled people are like." James added that all disabled people have their own individual experiences that he wanted to see and read about to provide him "with a deeper level of understanding and empathy."

Stacey, a wheelchair user, expressed how her form of muscular dystrophy made her body appear severely disabled, while media disability representations were often less severe and included portrayals of "normal" looking people who were paraplegic, blind, or deaf. She stated:

> I don't think the majority of society is willing to see the more [significantly] disabled people...I didn't see anybody really like me until the show *Speechless*…it really didn't match my disability [body shape], but it was probably the closest that I've seen. They picked disabled actors and consultants, to make it at least somewhat realistic to what it's actually like to be that kind of disabled. I thought it was cool.

Authentic representation on Speechless was praised by other participants. Daisy, who uses a rollator walker, liked that the show starred an actor with cerebral palsy who used a wheelchair, the same disability as his character; though the character was nonverbal and the actor was verbal, "it was somebody with a disability playing somebody with a disability, and I liked that."

Eliminating Certain Disability Stereotypes

Participants shared a range of disability stereotypes that they found problematic. The three most common tropes included disability as inspirational, killing of disabled characters as happy endings, and creating a magical cure for the disabled character. Fera, a wheelchair user, criticized the trope of "the savior narrative" in The *Fundamentals of Caring* (2016) and *The Upside* (2017), where the caregiver comes in, takes care of a grumpy teenage boy or grumpy grown man with a disability, and makes their life worth living, as if they're responsible for it and not the person with the disability.

Inspiration porn was a trope several participants were tired of not just seeing, but more importantly, being impacted by, as they were expected to be inspirational for nondisabled people. Axel, a wheelchair user, criticized various "stories that use inspiration as a weapon…A lot of people, when they place a disabled character into something, they expect a certain level of pity or…they're expecting an inspirational story out of it." Such tragic or pitiable existences are not the reality of disabled people, because being disabled means fighting for resources, care assistance, "and other stuff like that…shit that won't magically turn itself around" like it appears to in media.

Nelly, a wheelchair user, expressed disinterest with seeing disability as inspiration porn; being disabled is not always easy, "but I don't want other people to tell me how hard it is, you know? That's not something they've experienced. [It] dehumanizes us, to just be treated with pity and [never be shown to] achieve and accomplish things." Chloe, who has multiple nonapparent disabilities, was likewise not a fan of inspiration porn because "it almost implies that there's a right way and a wrong way to be disabled. She continued:

> If you're performing your disability in a way that is inspiring to others, if you're out there living a life with less accommodations or in a way that appeals to able-bodied people, you're, like, inspiring. But if you're a person who can't do those things or chooses not to…[nondisabled people are] like, 'Oh, this person in a wheelchair is doing this, and this other person also is a wheelchair, but they're not doing this, so obviously they're not trying as hard or working as hard.' It's just like they're prioritizing different things. There are a million ways to be disabled, and there's no, like, right or wrong to do it.

Kristy, who is deaf in one ear, added that these narratives of inspiration porn "perpetuate a lot of things that [nondisabled people] think about such a big community…I think the generalization is really a big issue."

Claudia, a wheelchair user, was not a fan of the inspirational trope, as she is merely living her life by going to college or being a model, which "is not inspirational just because I'm disabled, right?" She added how she also doesn't like the helpless because she had people treat her like she could not achieve something like being a veterinarian. However, that "doesn't mean you have to exclude me or it doesn't mean I can't do what you can do, it might be done differently, but I can definitely do it." She wished that people saw her as capable as any nondisabled person, as her disability "doesn't mean you have to exclude me, or it doesn't mean I can't do what you can do. It might be done differently, but I can definitely do it." She wants people to ask questions rather than assume disabled people cannot do something, as this would make the world more inclusive because "we would, as a whole, become in a sense more equal."

With the trope of "disability as helpless" comes the normalization and celebration of killing off disabled people as a "happy ending." Claudia questioned why such storylines were written, as she did not find them entertaining; instead, they gave the impression that creators

were “pitying us, or [they] think we're not worthy of living, which is not the case…[The disabled life] is difficult, but…it doesn't mean we don't want to live.” The participants widely disagreed with the idea that disabled people want to die, which begs the question of why producers would believe disabled people want to see that representation. “That's not how we should be perceived, [and] not how I perceive myself,” continued Claudia. “Many of us aren’t just sitting there and saying, ‘We're not worthy to live.’ Like, what are you really telling us?” These storylines seemed to not take into account the impact this stereotype would have on disabled lives, as many disabled people were not interested in ending their lives.

Stacey, a wheelchair user with a service dog, shared how the “better off dead than disabled” trope annoyed her, especially as “it's seen as a selfless act” in films like *Me Before You* and *Million Dollar Baby* (2004). The idea of such plotlines would make her feel “very rage-y. Like, I don’t get why it’s thought, ‘How dare they live with disability? It's much better for them to die.’” She found a *House* episode where a character with spinal muscular dystrophy (SMA) chose to die upon discovering a cancer diagnosis “very cringy. It's kind of insulting, because it started off so well: he was independent, driving, travelling. And then we saw him say, like, ‘Let me die.’”

Stacey theorized that the same stereotypes get recycled in media because change was hard for people to accept, and seeing the same disabled representations meant that people wouldn’t have to feel uncomfortable having to think “about their perceptions. People don't like to be uncomfortable…to see that their perception of things isn't actual reality. They would prefer to perceive disabled people as, you know, ‘different’ [or] ‘special,’ than just a regular person.” James, a wheelchair user, described how he does not appreciate “the whole ‘better dead than

disabled' mentality, which basically boils down to, 'disability is miserable and…you're better off living without it.'"

The common alternative to killing off disabled characters was to go in the opposite direction and cure their disability. James critiqued an arc from *Arrow* (2012–2020), where a character who becomes paralyzed and has to use a wheelchair remains the same intelligent, helpful character she was before; however, "later on in the [season], they do a magical healing narrative, and I hated it." James said:

> There's a lot of ableism like that in comics and pop culture, where even when they have a good angle, they still fall into that temptation of, 'Oh, but let's heal them later.' That one just frustrates me continually…it very much mirrors the same thing that DC did…with Barbara Gordon, Batgirl, who also becomes Oracle…she gets magically healed later on. I wish they would commit and say, 'Hey, disability is not a bad thing. We can have disabled characters and let them stay disabled.' I think a lot of people treat disability as such an inconvenience on their end that, you know, accessibility is, like, 'too much effort.'

Daisy, who uses a rollator walker, theorized that going against the stereotypical grain of disability may backfire because writers and producers may be scared and believe that audiences "are gonna be like, 'Oh, you [made] that character mean 'cause they have a disability and that's bad...' They're concerned about representation of a lot of minorities and vulnerable populations." Fera, a wheelchair user, explained representation needed a refocus. She said:

> Getting rid of the infantilization that comes with ableism and how we're not thought of as grown adults. We're still thought of as kids, and so because we are thought of as kids, we can do no wrong. We're so sweet. We're so innocent. We're so pure. No, we're regular

> humans developing like all other humans…The two overlap, a lot of the ableism and the infantilization, and until media portrays regular life—with a person with a disability and how it's not that much different than someone without—we're not really gonna move past that narrative.

These tropes not only evoke anger over the inaccurate disability stereotypes that disabled people are fed up with, but over enforcing an ableist society through these media representations.

Disability Representation Recommendation Reactions

When discussing participants' initial reactions to someone suggesting content with disability representation in it, the majority of the participants had similar responses: some felt a sense of caution, but their reaction depended on who was suggesting the content, such as a stranger versus a close friend; others were curious about the disability representation regardless of who recommended it. Jazmyn, who has cerebral palsy and uses mobility aids, was wary of people recommending any media with disability representation to her because, "Oh, God, is this gonna be inspiration porn…It comes from my internalized ableism…I have this concern that the representation is gonna be construed as [just inspiring]."

Fera, a wheelchair user, discussed how in the past, any type of disability representation recommendation came with "a little…sense of dread." When she was a teenager, a friend was excited to suggest seeing disability representation in *Me Before You*, the plot of which Fera had no knowledge. It was the first time she saw a main protagonist with a disability in a movie, but she didn't enjoy the experience. She said:

> I'm so angry. I'm not having a good time. And then the ending. The way it's portrayed and like I get it, it's his choice [to have assisted suicide as a happy ending]. The fact that he felt there was no alternative made me like, as a teenager, feel not so great about my life.

> ‘Oh, I'm not really worth like living,’ so it’s triggering...So since then, whenever someone's like, ‘Oh, like there's disability representation,’ I wonder is this going to make me feel really, really good about myself or really, really bad? And there's like no in between.”

Fera was mad at her friend, who was aware of the ending, for not giving her a heads-up or trigger warning. However, that evening they “talked about it for a couple hours…I know they felt bad on their end. I shouldn't let a movie interfere with friendship.”

Lonni, a wheelchair user, shared that “there's always been this negative light on disability, like, stereotypes attached to people with disabilities, so I guess my first thought is, ‘What kind of disability do you mean?’” In the past, Lonni was kind of nervous when people said, “‘Oh, watch this because this reminded me of you.’ People will say, ‘We should watch this, because look, you're kinda represented on there,’ without really knowing the whole context of the story…I feel like that gets into tricky territory.”

Josie, a wheelchair user, often questioned whether the representation being recommended was good or bad. The hesitation came from the thought of, “Is this going to be something beautiful where I see myself and my friends…or is it something that's going to damage the perception of my disability and further push this internalized ableism into myself?” To her, considering a recommendation from a “close friend is different because I'm, like, very open about disability and awareness and advocacy,” implying that her close friends understood what type of disability representation was crucial. Josie would dismiss recommendations from strangers or “do my own research on what other disabled people are saying [about it].”

Keisha, a wheelchair and BiPap-mask user, compared the difference of recommendations from disabled people versus nondisabled people recommendations: “When someone

[nondisabled] says something like, ‘Oh, there's this person in a wheelchair,’ I was like, ‘Well, why would you think that that would catch my interest?’” When her friends with disabilities gave her recommendations, they oftentimes included why they believed that someone would be interested in the representation. She shared:

> They’ll say ‘Hey, it's really funny’ or ‘They've got action in this film.’ They'll tell me in a way that reflects how most people give movie reviews…and then, because they're disabled, they might add in that there was this authentic representation as well, and, like ‘I totally connected to the character.’ People that might not have the disability that I have, or anything remotely like it, they're ignorant to the things that positively and negatively affect this population, and some of it is…ignorance.”

Josie shared a theory that nondisabled people feel eager to share all kinds of disability representation, whether it is discriminatory or not because “they don't really understand the difference between good and bad. They just see a disabled person on screen and they're like, ‘Oh, it's all the same, you can see yourself there.’ They don't understand what's appropriate and what isn’t.” This could be due to the fact that nondisabled people do not have experience living with a disability, and that creators of disability media-based stories on their own perceptions of disability and what nondisabled audiences would enjoy. Josie added how nondisabled people like to recommend media with disability representation to disabled people as a way to try and “find some way to connect with you and relate to you, even though they'll never know or understand what we go through every day, or the disabled experience in general.” Josie expressed how this could be a way of understanding a disabled person, which “may not always come out the best way, but I always believe that it comes from a good place. They just want to connect with you.”

Nelly, a wheelchair user, was skeptical about people recommending media with disability representation in it, "depend[ing] on who's giving me the recommendation." She is more trusting of recommendations from close friends because they "understand disability and what is good representation versus bad representation…based on my life and what they've experienced with me." When it comes to family members' representation recommendations, she does not trust their suggestions, as some do not understand ableism: "When someone says something weird to me, like 'God bless you' or whatever [prayer thing], in public, my family says, 'Oh, they're being so nice.' Whereas I see it as ableist."

Kristy, who is deaf in one ear, does get very excited if recommendations come from a close friend, unless "they say something more stereotypical…It definitely depends on the person and the context and the actual content." She had "mixed feelings" about the representation in *The Miracle Worker*—there was some "comfort" in seeing someone close to her disability, yet the film was inspiration porn where "they all treated it like a miracle that she was able to communicate, which I found very odd"—but appreciated that her mother was trying to find media for her daughter, and this was the best that she could do. Her mother's encouragement to request accommodations and "speak up for these things" helped Kristy openly talk about her disability in college and advocate for herself.

Claudia, a wheelchair user, would initially be intrigued by recommendations because she wants to see more representation, but at the same time, would wonder "'What type of representation are you talking about?'...For me, it's more curiosity and…I'm so used to seeing the same thing that…I'm, like, asking to really know if it's real inclusion." James, a wheelchair user, felt excited when disability representation "pops up. I absolutely get excited by good, authentic representation in media." As someone who worked with a "publisher that focuses on rare

diseases and disabilities," he wrote and spoke on the importance of seeing disability in media. Living in the storytelling space, he believed that "it's a human desire to want to identify with the stories we consume and to be seen there in an authentic way, not in something that's forced or misrepresented, by something that's genuine and makes our [disabled] stories reflected."

Chloe, who has multiple nonapparent disabilities, gets very "excited" when talking to others about their disability representation recommendations because "I always like to at least give things a bit of a shot. [I'm] definitely apprehensive, but mostly excited." Sally, who has epilepsy, shared in her "excitement" for disability representation recommendations as well, because "I'm always optimistic that it's going to be good and beneficial and I can learn something from it or see myself in it." Axel, a wheelchair user, recalled a positive experience when a friend recommended a disability-centered movie, *The Fundamentals of Caring* (2016) saying, "'This would literally just be us if we met up,' because we're long distance [friends]." Axel enjoyed the movie's humor, because "I feel like a lot of these stories [regarding disability] tend to be a lot of doom and gloom, and there's no levity. It's like, 'Please, I'm silly, let me be silly.'"

Theme #3: Fighting for Inclusion and Support

This section discussed societal treatment that intervened with the first section regarding disability stereotypes in media. This third section explores the support participants wish they had and how they create their own advocacy to combat ableism. The five sub-themes include: 1) family and disability; 2) being disabled is advocacy; 3) the fight to be included; 4) disability community support; and 5) hope for the future. Within the first sub-theme, many participants faced discrimination, neglect, and internal and external ableism in their own family dynamics due to lack of disability awareness. In the second sub-theme, participants recalled acting in ways

that counteracted certain stereotypes, and how they have to advocate just to be included in public spaces and receive resources for societal inclusion. This is followed by the third sub-theme, where participants discussed examples of fighting to be included in spaces, the way other disabled people have pushed forward disability rights in the USA, and how, without disabled people's advocacy, there would not be a strong community of support for each other.

The fourth sub-theme expressed how participants felt less alone and like they were not the only ones going through challenges when they met other disabled people, usually in college. This also included finding their own disability pride, sharing experiences, coming together to support and understand each other, and commenting on stereotypical media representations. The fifth sub-theme concludes final theme by exploring the hope and excitement disabled people have about the future of accurate and authentically cast representations, where disabled people take charge of their own narratives and bulldoze over outdated, stereotypical depictions. These discussions also focused on reoccurring disability stereotypes shared throughout other themes, with the main focus on what participants do to change how they have been treated and represented.

Family and Disability

Although lacking or harmful representation of disability in media created feelings of internalized ableism and loneliness for participants, families of disabled people either supported and tried to be there for them or fed into the ableism. Sometimes parents were just as much in need of disability representation as their disabled child. Ahmed, who is blind, discussed how his family struggled to find any understanding of blindness in Pakistan, and wished there was more representation and information available. Although he and his siblings did not get "rehabilitated" until they were teenagers, "my parents and siblings, they were wonderful…they were helping us

out and everything, in our studies and everything." Upon getting the services and support that they needed, Ahmed and his siblings thought, "'Hey, we were just living the life of darkness where we didn't know,' like, blindness is not something bad…and being blind is not a problem, and we can live our life happily and independently." This realization came from themselves because there was no media or information for them; they had to find the energy to "do something meaningful that will help other people just like us, because when we didn't know we were worried, and we were just complaining all the time." Information and messaging about disability impacts how families lived their life and navigated through different disabilities.

Jazmyn, who has cerebral palsy and uses mobility aids, believed if she saw her own disability in media, then "it would feel validating, and maybe if my family saw it, they wouldn't [believe] that whole 'inspiration porn' as much, right?" She expressed how her family and others placed the trope of inspiration porn onto her for simply doing "normal" things like working or getting an education. "[On a] family trip, I was talking about my disability and my aunt…was just like, 'But you've overcome so much in your life.'" Many shared her frustrations with others treating them as "inspirational" for doing basic life activities like going to school or riding a train. Jazmyn brushed off those comments from strangers, but it was harder to do with family that had known her for years. She said:

> It's harder to challenge their perception of you as problematic because honestly, they get offended when I try to say, 'You know, this is problematic…saying that my life has been inspiring, when there's other people with my disability that have done the same things. I have two master's degrees and I've achieved this…because I've worked really hard. But you still get that infantilization, like 'You're disabled and you've achieved this.'

Jazmyn only embraced her disability pride later in life due to how "ableist my family was growing up…I didn't embrace my disability identity until later, until I met other disabled people… [I didn't have] disabled friends until college.

Daisy, who uses a rollator walker, shared how ableist her family was while she was growing up in the 1970s. Her very negative outlook regarding her disability not only came from the stereotypical representation in media, but her family's relationship with disability. Her father had the same muscular dystrophy as Daisy, and passed away when she was nine years old, which "greatly influenced my life. The fact that he died so young—he was only 41. There was a lot of sort of shoving it under the rug in my family, like, 'Let's not talk about Daisy's condition.'" This lack of communication regarding her disability negatively impacted Daisy and made her depressed about her disability, until she went to college and bonded with other disabled students. Chloe, who has multiple nonapparent disabilities, shared a similar experience with "hiding" her disability because of her family's attitude toward disability, which was always the opposite of her personality. She stated:

> I've never been a person with that motivation. I come from a family where I have people in my life that are also disabled and most of them very much felt like, *I need to like mask and I need to pretend, I need to like put on this show*. It's just not...where I went with it. It's just not my internal motivation or my instinctual motivations.

Chloe, same as Daisy, and many other participants, began to embrace her disability when she met other disabled people, usually as adults in college or online.

Aly, a wheelchair user, was not impacted by stereotypical representations growing up because of her strong family support: "I've always been so headstrong…because of [my] upbringing…If I didn't have my family, and if I didn't know myself as a person, that

would…have had a negative impact on my life." Kim, who is blind, took every opportunity to talk to her two teenage children about stereotypical representation, and was proud of them when they called people out on ableist language like "'If you can't see that, you're just blind'...as a synonym for, you know, stupid or ignorant or something." There were many layers to how media affected disabled people, and much of it came from seeing disabilities represented, which impacted how families and disabled people talked about their experiences.

Being Disabled Is Advocacy

As an inherent response to seeing stereotypical representation and society treating disabled people in unfavorable ways, participants found themselves becoming active advocates for changing the narratives that were unwillingly placed on them. Some participants discussed going against disability stereotypes or proving certain stereotypes wrong to strangers as identity-activism: Opal, a wheelchair user, shared how growing up, they were seen as the "good girl" and a "major nerd," and how, in high school, they were always being "the responsible one." Now in college, Opal takes on the role of the "reckless one" in their friend group. This "reckless" behavior was something that nondisabled strangers do not expect, and are often shocked when they witness Opal drunk or high. This could be because "people aren't used to seeing me in that way or in that light, and I think it goes back to just the general infantilization of disabled people. I'll be doing a shot and they're like, 'Whaaat?'" Opal also recalled how in elementary school, a classmate told her she "shouldn't cuss because it didn't suit me, and I was like 'What?'" This moment stuck with her as she constantly thought about how "he meant that [because] I'm disabled, he thinks that I'm just supposed to be cute and quiet."

Fera, a wheelchair user, shared a similar experience with a male caregiver friend who had never witnessed any disabled people "unfiltered." She described how he saw her talking to

another disabled roommate, “talking like girls in their 20s—not exactly filtered.” The following evening, “he was like, ‘That floored me. That is not what I was expecting, not what I'm used to.’” She explained how distraught he seemed, to which she frankly responded. She said:

> ‘You do realize that I am a person, right? Like, the wheelchair doesn't add any layer of innocence to me or anyone else who uses one’...It challenged everything he knew or everything he was taught by society. I don't think [nondisabled] people are ready [to see disabled people portrayed as regular people because] that's them being forced to look at their ableism…people just aren’t ready to admit that their views are wrong.

Fera explained one possibility for these views was due to media depictions, where disabled people are thought of as “‘Oh, you need care, therefore you're like a child because [a] child needs care.’” Although Fera needs assistance with some activities, it “doesn't mean I'm a kid that needs to be taken care of.”

Polly, who is blind, shared a similar experience of “shocking” people with her reckless behavior as a blind college student. Growing up, she felt “wrong” for being disabled based on the bad representation that she saw in media, which developed into internalized ableism. She went against that in college, and began to smoke as a way to “shock” people. She believed that smoking would “make me be more normal…it would offset the blindness. It started happening when I started being around more disabled people and we started talking.” It was in college that Polly was able to process her internalized ableism and reaction to stereotypical representation with the support of other disabled peers, which helped her understand and accept her disability.

Fera, a wheelchair user, shared how growing up, there was a lack of good disability representation; most disabled characters “were either the punch line or the joke, or they were the villain…always portrayed as kind of weak and whiny and evil and, like, not great…They were

always a side character…and used at the plot's expense." Not wanting to see this type of representation or be associated with it, Fera would "do the opposite" of these stereotypes. She always tried to "be outgoing and nice and strong-willed and very blunt, which I still am. I didn't want to be portrayed as, like, just a whiny person that, like, hates life because I'm disabled." Some of this behavior stemmed from Fera being someone who has "never been one to go with the flow and fade into the background." She elaborated:

> I always felt the need to overcompensate and, like, be so out there because of media and then society's views in general about a disabled person...I wanted people to see that I wasn't the narrative everyone thought of when they thought of a disability, like I wasn't hiding in my mom's basement, I wasn't in a facility. I like could go to school, I could do all these things, and I just wanted to prove people wrong.

This was, in a sense, her way of advocating for the right, authentic representation by using herself, because she did not align with the representation of disability that she saw in media. Josie, a wheelchair user, expressed how she would tell people "this is not good disability presentation, don't watch it." She managed a disability advocacy social media account for better awareness because "a lot of able-bodied people don't realize it's harmful, so [I was] kind of making them aware of how it is harmful. But yeah, I've kind of pushed against" the traditional media disability representation. Participants discussed advocating for better representations or creating their own representation, as well as feeling how more authentic representation would mean that they would have to spend less time and energy reeducating society on disability misrepresentations.

Opal, a wheelchair user, expressed wanting to see characters to identity within realistic situations like relationships. Building onto the idea of "feeling seen and like that helping me

enjoy the media more, I would like...for it to more normalized" where disabled people would tell nondisabled people that seeing this positive representation would make them better allies. The desire to have realistic depictions of disability would take "the task of having to educate people about disability and kind of tear down like harmful stereotypes that they've previously seen before. I think that would be a lot easier if we had more positive representation and realistic representation."

Axel, a wheelchair user, discussed how due to the accessibility boundaries regarding their interests in theater, they pursued art and animation instead, since, as a disabled person, they "have dealt with so much" ableism and discrimination, "and creating art was a form of escapism." Since they were not able to pursue an acting career due to inaccessibility, they became passionate about creating the disabled characters that they would want to play to impact the disability community in a positive way. Axel expressed how the "severe lack in representation" means that they found themselves "in characters who aren't disabled, but it would be nice to see something that checks all the boxes of this part of my [disabled] life, portrayed along with relatable characters." Fera, a wheelchair user, was writing a humorous romance novel that would include some focus on disability, "but not in a really blatant way. It's just the way life is for us. I definitely think it would be super, super funny to see that and see how real it is." Kristy, who is deaf, considered creating her own stories or working with others who share her same disability to combat the inadequate disability representation, as creating accurate representations was important to her.

Nelly, a wheelchair user, does sensitivity reading for disability representation to advise writers and creators on how to better their representations of disability. She was not interested in creating disability stories, but rather telling creatives, "'Hey, what you're doing is wrong or right

or you should do this instead.' [It] kind of does feel like advocacy…I know that I'm trying to help the next generation accurately tell stories about disabled people." Nelly expressed that just by existing in an ableist society, disabled people are being activists, and many disabled narratives center around activism. She expressed:

> If you're disabled, you kind of automatically have to be an activist in some way…just living in society and being a part of society is a form of activism because society doesn't want you to do that. They don't believe that…you should have a job and get married and have kids, travel or do whatever it is you do.

Disabled people have come to advocate for simple things in society that should be their right to have due to the inaccurate representations of disability; they deserve empowering narratives. Just like other audiences.

The Fight to be Included

Being disabled in public spaces comes with a lot of fights. Disabled people do not have the luxury of simply existing or being part of society without proving to others that they belong. Claudia, a wheelchair user, agreed that "activism is…a part of being disabled," because the disability community had always advocated for their rights and the need to change laws that support them in an ableist society. When she expressed interest in being a veterinarian as a child, one of her teachers asked, "How is she going to be a vet if she can't move her hands a certain way? Being a vet is very hands-on, and she can't do that." Claudia then advocated for herself by stating that she "'can be the brain and somebody else can be the hands…' Just because you think I can't use my hands doesn't mean I can't necessarily use my hands or we can't find a way to do it."

Daisy, who uses a rollator walker, shared how while working at a library and with a disability organization, her colleagues plan "disability etiquette …video segments, where it'd be like, 'This is the wrong way to talk to somebody with a disability; this is the right way,'" as a way to combat the misconceptions from media about disabled people. As someone in her late fifties, she addressed how "there's a lot of ageism thrown into having a mild disability." Two years ago she began relying on "a walker, and a rollator screams, 'You're an old person.' When I first started using it, people…had this shocked look, like, 'Oh, what happened?' and 'Oh, I'm so sorry.' And I have not approached it that way." Daisy instead had approached the assistive device as something that helped her from falling, which could significantly impact her life. She sent an email telling her colleagues that she was going to start using this assistive device, allowed folks to ask questions, and introduced the device as "Poppy." She said:

> I gave it a name as a way to kind of make it more fun. Her name is Poppy. And so I went to work, and the people that [were] okay with it came up and said, 'Hey, Poppy, how are you?' and the people that were uncomfortable, they just kind of ignored it. And, you know, it was fine, but I'm really all about normalizing assistive devices because they really help us in our lives. They keep us safe.

The process of explaining disabled needs and their support systems was part of educating others on disability and making sure that nondisabled people were comfortable with a disabled person. Outside of mobility devices, service animals also come with a process of explaining.

Stacey, a wheelchair user, shared how her mom always told her to self-advocate. In high school, she became friends with another person who had muscular dystrophy, and any time they went out in public places that were not accessible, Stacey "would be, like, moving stuff in the store, saying when the elevators were broken, you know, telling to the staff when we're trying to

get prom dresses, which had fitting rooms that weren't accessible." She considered herself a "loudmouth, the one who got stuff done." Stacey may not go out in public much nowadays, but when she does, she experiences discrimination, like not being allowed to enter a restaurant due to her service dog. Stacey would explain that "I'm allowed to be here, it's the federal law, and then everybody there was just like, 'No, that's what we're doing. Good luck with that.'" Stacey theorized that changing things made people uncomfortable and that "people think that if something gets changed to help someone else, it will be worse for them…If we make it accessible, it's somehow going to hurt all the nondisabled people, even though that's not true." Because society has historically been built to exclude disabled people and experiences, advocacy was seen as part of merely surviving in society.

Polly, who is blind, wished she would have started working on the disability movement sooner as it would have been good for her, since as a young adult, "success to me was living life like I wasn't disabled." She added how she advocated for disability rights with other disabled people once she got to college because "the ADA was great, but if we don't keep pushing, there will be regression." Tammy, who became blind later in life, reflected on witnessing disabled people being misrepresented when she was nondisabled, and feeling bad for their lack of inclusion in society. While gradually losing her sight, she felt guilty for not putting herself in disabled peoples' shoes and not advocating to do more until she experienced being blind, feeling "guilt that I didn't do more, other than think about [how] it was bad and it was wrong" to see disabled people discriminated against. She wished to have been more involved with disability advocacy before "it affected me personally…[Because] 'we' as humans should want the best for everyone, regardless of your circumstance."

Ahmed, who is blind, expressed how the negative treatment of society and the lack of information about blindness inspired him and his family to advocate for more education so disability would not be so stigmatized in Pakistan. Once they received the support for "rehabilitation," they realized that hiding their disability due to negative treatment from others was "not the right way to do it." They participated in disability rights movements once they came to understand their disability situation, and "[tried] to advocate and to rehabilitate more [blind] people in a way that [emphasized] this is something normal and something okay, and it's not the end of life…and spread the light around." It brought Ahmed and his family much joy to help others "live their life as they want to live it…getting more education and…going for employment…[We thought,] 'Why not spread it around?...Because [there are] a lot of people out there who don't know, as we didn't know before." Disabled people not only have to find ways to understand their disabilities, but also how to navigate the world with their disabilities, which can be challenging without the support of other disabled people.

Disability Community Support

Participants discussed how coming together to talk to other disabled people gave them support, guidance, and shared experiences as adults. Due to the lack of representation in media, disabled people felt as though they were the only ones disabled, creating an empowering sense of belonging when meeting and sharing experiences with other disabled people. Sally, who has epilepsy, described how growing up, there was a lot of "trial and error in my own life, 'cause I didn't know anyone else who was dealing with it." With the continued efforts of learning more about her disability, she "found talking to other people about it [was] helpful," particularly in peer support groups because "if you don't have those people to talk to, to kind of help you understand yourself, then sometimes it's hard to figure it out." Additionally, she wished for more

disability representation in media so she could "see myself in media and to understand myself better."

Nelly, a wheelchair user, was in awe of seeing representation via inspiration porn, realizing that, "'Whoa, so it's not just me [who gets treated like this].' There are other people experiencing this. It's not just able-bodied people reacting to me, this is the thing that happens to a lot of disabled people." This made her reach out to the disability community and share some of these similar experiences, while learning from others as well. Polly, who is blind, expressed how once she found other disabled people to discuss different experiences, she no longer left that something was 'wrong' with her, but rather that there was something 'wrong' with the world. In an example, she explained:

> Having peer support and being around other people with disabilities is so important, because you think you're the only one…I thought I was the only one who would cringe at bad disability portrayal because it was 'me' problem…I think my life would have been so much fuller, and I would have accepted myself so much earlier, had I had more disabled people around me sooner.

Polly came from a small town in Kentucky, where the only other blind people were older adults, which emphasized her loneliness and internalized ableism, as "there was no one there to tell me that disability is natural [until] I talked to disabled people more [in college]." Polly further expressed how she wished she had disability pride growing up, because "once I got to college…you realize the things that you thought when you were young…weren't necessarily gospel truth." When reading books about disability experiences, Polly realized, "this person and I, we felt the same thing. And then I talked to other disabled people and we felt the same thing. It's the importance of community." Ahmed, who is blind, agreed that learning from other blind

people helped him and his family not feel as though they were “the only one[s] disabled.” They realized that “it is not something really bad, or this is not something you're always complaining about” once they met more people and shared different accessibility hacks. As a blind person living in “this whole world that is designed for [people] with sight,” Ahmed came to realize the importance of disability pride and “understanding that ‘Hey, these people are doing wonderful.’ We came to realize that, ‘Hey, independence is something we can live with, and we can do everything on our own.’”

Daisy, who uses a rollator walker, said it wasn’t until she got to college where she “really learned disability pride and the importance of being visible and all that, with the friends that I made…it was sort of disability [activism] and all that.” Now, Daisy enjoyed seeing disability social media influencers help move the representation needle “in the right direction.” Stacey, a wheelchair user, discussed how she used a Yahoo message group for those with spinal muscular dystrophy, before Facebook groups existed, to actively discuss bad disability representation or complain about medical shows where they killed off the disabled character with others. She felt fortunate to grow up with the support of the online community, because “it's always nice to be able to share with likeminded people who understand and are able to put in their own two cents and [add] my own.” Claudia, a wheelchair user, discussed how her disability pride increased when she was nineteen and “social media became more prominent”; she used Instagram to connect with other disabled people and learn about the community, helping her find her disability pride. Opal, who uses a wheelchair, also shared how their presence on social media gives them the support that they never experienced as a child, because “my online community is a lot of art people, [who] I think are very accepting people in general, but when I was younger, that wasn't necessarily the case.”

All of the participants agreed that talking to disabled people and connecting through social media helped them belong and be more positive about their disability, which was seen as a "bad" thing as they grew up. Chloe, who has multiple nonapparent disabilities, shared how social media helped her find a community where she could share how having several multiple chronic illnesses had affected her throughout her life. She explained:

> I had severe agoraphobia and mild psychosis alongside that, because I have a form of autoimmune encephalitis, which means my immune system attacks my brain…in an acute flare, I'm not capable of comprehending and taking in these changes to my identity, which is when I'm most disabled…I definitely feel like social media was a huge help, especially [since] they always make jokes about [how] POTS is, like, a social media disease. Everybody's just diagnosing themselves with it…I know a lot of people that got their diagnosis because of social media, and I think that's totally awesome.

Chloe emphasized that seeing different people going through those same things as her helped her come to terms with the ways that her disabilities were affecting her, and "feeling less alone in that, and coming to terms with an identity of being disabled." As a disability book influencer, she recognized how before social media, she was told for a long time that she should not let her disability define her or be a part of her identity, even though disability "is just a part of your everyday life, and that's always going to have some sort of significant impact. And it's not a moral failing to have that be a part of your identity."

Hope for the Future

Despite the historical representations of disability in media, disabled participants are hopeful about getting more positive and progressive representation. They had confidence that the next generation of creators will "do better" when it came to representation and giving access to

disabled creators. Kim, who is blind, reflected on her discussion of *A Christmas Carol* (1938) with the disabled character, Tiny Tim, who was a disabled token character the if written today, it would be "lazy writing. It's just lazy creativity. They could do better because 'you know better, you do better.'" Axel, a wheelchair user, shared how there were neurodivergent characters and characters with other nonapparent disabilities characters that were "starting to bridge the gap."

Jazmyn, who has cerebral palsy and uses mobility aids, had been cynical about disability representation but found some hope as she listened to everyone share their experiences in the focus groups. She may have felt "cynical for how I approach my own disability, but I'm hopeful for the future." Jazmyn shared her excitement for modern disability representation, because she believed that bad disability stereotypes were "a generational thing…and that's why I'm so excited…and hopeful…about this next generation of disabled people, myself included…we're just gonna see each other as humans."

James, a wheelchair user, was optimistic about the progression of disability representation because he was witnessing representation conversations that did not exist when he was growing up, which "is a step forward…there are more disabled creators out there [now] with social media." Although disabled people "still have a ways to go," there was "hope" in the disabled voices that were speaking up on social media spaces. James added:

> The more that we talk with each other and share our stories, people will know that 'Oh, we want our stories told too.' And there are a lot of talented disabled storytellers, whereas once it just wasn't even a consideration. Now it's starting to change, slowly but surely. If we do overturn [these ableist] systems and say, 'We don't wanna live this way anymore,' it would look totally different…in terms of representation, in terms of quality of life for

us and access to everything, we would feel less isolated from the world and more active participants in it.

He added the need to "move forward" in storytelling and "strive to make something better. I think it's important to look at both the positive and negative examples…and look for, 'Okay, where can we go from here and how can we make better stories with better representation?'"

Fera, a wheelchair user, believed that representation has "gotten better as I've gotten older, and now [media] is getting more representation…I'm kind of optimistic because it definitely isn't as bad as it was." Daisy, who uses a rollator walker, also mentioned how disability representations have "come a long way." She expressed that there was still more work to be done, but there was a rise in seeing "disabled characters…[and] people with disabilities are trying to become writers, producers, directors, and…writing books with disabled characters in them. Seeing a lot more real-life situations and not all of them, like, 'You struggle and then you die'." There were more opportunities for disabled influencers on social media to share their stories and be hired in other creative roles, like the disabled comedian Zach Anner writing and consulting for *Speechless* or a woman with cancer "that you live with" writing her experiences into *Grey's Anatomy* (2005—).

Kristy, who is deaf in one ear, reflected on her excitement about the future disability representations regarding anything: for example, assorted disabled characters in *The Boys* (2019-2026) "are part of the story and they have a whole arc. I get really excited for that inclusion…I love the idea of more disabled creators making things either on their own or collaborating with bigger production companies." Kristy was supportive of more people writing and creating content from their own experiences, "and the fact that we're able to notice just from looking at it? I think it's, yeah, a good sign." Chloe, who has multiple nonapparent disabilities, also expressed

excitement for the future of representation in books by disabled authors; as a disabled book influencer on social media, she was "really hopeful" about "how [many] more [books] there [are] now than there [were] even in the last five years." She had created a spreadsheet where she catalogued books with disability representation that housed hundreds of titles, but would never put books with "really bad representation…People recommend *Me Before You*, and I'm just like, 'I'm not putting that in there. I'm really not'...It's not always perfect, but it's at, like, 1,600 books." The number of disabled book releases from traditional publishers seemed to increase from year to year, which was "just really incredible, to see how much more we're getting and how much more specifically from lived experience we're getting…whereas, like you know, five years ago, we [only] got *Five Feet Apart* (2019)."

James, a wheelchair user, expressed his support for John Oliver shedding light on disability challenges in a September 2024 segment regarding disability benefits. This news was not shocking for James, but was good to see to that the harsh realities that force disabled people into poverty and the "issue of people not having access to Medicaid and…living in constant fear of losing their benefits with…the slightest amount of money that goes over the cap limits" being shared so nondisabled people realize the systemic oppression and ableism ingrained in society. It may be a battle to get disabled people in positions of power in media, where representation was fully in their control. Courteny, a wheelchair user, expressed how people in privileged positions were probably not ready or willing to give something up to level the playing field and create equality.

The findings ranged from feelings of loneliness and lack of navigating life to excitement regarding relatable disability representation and yearning to see diverse representations of intersecting identities. Participants shared their childhood memories of the negative impacts of

having no disability representation or stereotypical representation that cultivated into internalized ableism. As participants experienced life, they came to not only understand that the negative images of disability were not accurate or true, that they were not the only disabled people. Upon connecting with a disability community, their advocacy efforts took root to educate others on the misrepresentations of disability and be comfortable shattering "inspirational" and infantilized narratives about disabled people. As much as progressive disability representation can aid in a more inclusive and empathetic society, the representation gives guidance for disabled people and their families, romantic partners, and friends. Although there is hope for the future, disabled voices still lack access to a sit at the table to voice how they want their representation to be represented, pushing many disabled people to create their own imagery on social media and in their own books.

CHAPTER 7

DISCUSSION

This dissertation examined how disability representation in media impacts disabled people through the frameworks of representation theory, controlling images, and intersectionality. Results indicated negative effects when dealing with stereotypical representations or no representation, and positive effects when witnessing authentic representations. In summary, the first theme expressed participants' reflections on disability in media and its impacts, the second theme discussed participants' thoughts on different examples of disability representations in media, and the third theme examined participants' advocacy efforts due to disability experiences and representations in media.

These themes, many of which could be seen as interdependent, helped illustrate the impacts that media and disability had on participants. These results showcased how media narratives affect how disabled people operate in society, manage relationships with others, and internalize ableist messaging. Ideally, this data will solidify the importance and consequences of representation and guide future creation of disability narratives. The following sections are divided by each research question.

RQ1: Disability Representation and Disabled People

Disabled people watch and engage with media just as nondisabled people do: in childhood, as teenagers, as adults; with friends, with family. However, because media is framed to cater to a nondisabled audience, the narratives around disability representation require a closer examination, particularly through controlling images and representation theory. This includes how disabled people see themselves based on media messages, and their thoughts on how media represents disability based on stereotypes rather than actual disabled experiences. In connection

to certain tropes dictating the narratives of disability in media, Collins's (2000) controlling images examines the collection of stereotypes that work to control the image of how disability is seen by and treated in society. To this, the first RQ asks: *How have disabled people experienced disability representations in media throughout their lives?* This section, which reflects on the positive effect of disability representation and its rarity in media, is split into two parts: impact on self (dealing with internal impacts and influences) and influence of society (dealing with external impacts and situations).

Impact on Self

The first point of discussion is centered on the consequences of disabled people not seeing disability represented in media, with an awareness of the fact that participants interacted with media in different ways (e.g., since blind people don't normally consume visual media, as it is often inaccessible to them, they instead relied on written works like books for their media consumption). Participants shared feelings of loneliness, as well as not knowing how to navigate the world as a disabled child, teen, and adult, due to the lack of disability representation in and accessibility to media. As the guiding literature states, media plays a crucial role in shaping people's understanding of the world around them, especially as children, when "developing perceptual abilities play an important role in their developing ability to learn from a screen" (Richert et al., 2011, p. 84). This applies to disabled children, not just nondisabled children.

Disabled children's self-esteem and emotional health can be connected to how nondisabled people treat and socialize with disabled people, usually picking up on attitudes about disability from media (Groce, 2005). As seen in stories such as *The Hunchback of Notre Dame* (Norden, 2013; Whittington-Walsh, 2002), main characters in narratives around "difference" were looked at and treated as individuals to fear and isolate, representations that made

participants feel “cringe.” These are examples of controlling images (Collins, 2000), where disability is normalized as “less than” by being tied to ableist stereotypes. Oftentimes, stereotypical examples lead to disabled children, teenagers, and adults feeling alone, isolated, and like there was something “wrong” with them, sparking a need to do everything in their power to be seen as “normal” and fit into societal norms. Disabled participants wished they had guidance for how to advocate for themselves, find others to relate to, come up with solutions or answers to what they were experiencing and feeling as they were growing up. Literature lacks adequate insight into the representation and impact of disability in children’s media, and begs for more research.

Through the lens of controlling images, participants discussed several stereotypes, such as inspirational or not intelligent, that were met with feelings of “cringy.” They indicated that as children, they did not understand ableism, but could recognize feelings of discomfort after experiencing uncomfortable interactions with nondisabled people. Ableism is a discriminatory social-level oppression involving “ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalised . . . and largely invisible ‘others’” (Chouinard, 1997, p. 380). In this sense, the stereotypical controlling images create ideological acceptance of the narratives presented. Many participants internalized media stereotypes, impacting their self-esteem and social interactions. Individuals with disabilities like autism and attention deficit hyperactivity disorder, which were not widely understood or talked about, said they felt unsafe to speak about their disabilities in fear of retaliation or not being heard (Simon et al., 2024; Smith et al., 2023). Research on stigmatized minority groups revealed that people who experience discrimination, such as ableism, internalize

those beliefs, which are often based on recurring messages in media (Earnshaw & Quinn, 2012; Feinstein et al., 2012).

This leads to a concurring emphasis from disabled participants on feeling unseen, invalidated, and like the only disabled person in the world—all conclusions in line with the normalization of not seeing disabled people depicted as important or having a voice, a form of "othering" through controlling images. No representation could even be seen as a stereotype itself, further erasing already-isolated disabilities from view and allowing viewers to fall into the mentality of "out of sight, out of mind" (Palmer, Smith, & Strawser, 1993). This completely ignores the importance of disability and allows a group of humans living in society to only be seen through stereotypes. This is known as symbolic annihilation, which is when media contributes to a group's disempowerment or erasure from public consciousness, denying them space and visibility in mainstream media, and trivializing them as props rather than people (Tuchman, 1978). Both representation theory of constructing meaning through various imagery (Hall, 1997) and controlling images of socially constructed frames of reality come together to support the workings of symbolic annihilation, as making disabled people voiceless in order to manipulate their image to please dominant groups only benefits those in powerful media positions.

After years of fighting the ways media depicts disabled people alone, it was not until participants found counter-stereotype imagery or met other disabled people in college or online that their disability pride and acceptance took root. This can be related to trauma healing, where recognizing and talking about personal experiences can help individuals solve problems together (Herman, 2015). Trauma healing is a common theme within literature and psychiatric theory—think of when Winnie the Pooh helped Eeyore, the melancholic donkey, recognize that he had

lost his tail after Eeyore was not able to identify what was causing him to feel wrong. The solution for disabled people to shatter controlling images and the constraints of representation theory seemed to be advocacy, taking control of personal agency, and telling their own disabled stories, including the interwoven experiences of intersectionality (Crenshaw, 1999).

Non-white participants yearned to see Hispanic and Black disabled characters because then they would have had someone to relate to and learn from regarding how to navigate the world. Resemblance and identity align closely with how much children may trust or feel close to a fictional character (Bandura, 1989). For example, a Hispanic participant reflected on how she felt invisible in middle school because there was a Black teacher that her peers could connect with, and she wanted to experience that as well with any racially diverse wheelchair-user character or person in real life. If disabled children do not see themselves in media, they may not feel as important as children who see themselves in fictional characters (Hurley, 2005). This is another way that representation theory works to construct societal knowledge bases it can control: by erasing disability altogether. When viewers connect with characters they share an identity with, they exhibit positive social and behavioral changes because the viewer and character have developed a close relationship over time (Brown & Cody, 1991; Papa et al., 2000), especially if there is a lot of similarity between the character and viewer, from life experiences to demographic information (e.g., gender) (Appiah, 2001; Austin et al., 1990; Harwood, 1999).

Many identities such as race, gender, and class are social constructions that can be connected to the way narratives are shaped by cultural myths that are articulated in media, specifically popular culture (Denzin & Lemert, 2007). When examining the intersectionality thread, some participants indicated that their family was a great support system that came

together to support disability advocacy, while others participants shared how in their cultures, disabled people were expected to be quiet and mannered. These controlling images of disability being associated with unimportance and helplessness made them suppress their desire to have loud or messy personalities. This can be explained as valence, or the attachment of a particular value to an observed event by the viewer (Tan et al., 2009), or Bandura's social cognitive theory, which asserts that viewers learn about the world and how to behave from media (1989). When positive disability representations are rewarded, viewers can develop positivity toward being disabled, whereas negative representations that punish disability can make them reject disability. This includes representations of intersectionality: for example, a Black disabled mother may be depicted as exhausted and overwhelmed by housework, while a white disabled mother may be sown being celebrated for all her accomplishments. Seeing diverse representation could have helped change society's perceptions of disabled people needing to always be meek, and encouraged support from their cultures or families.

Fictional characters cater to and fit into our cultures and inform our social knowledge by propelling stereotypical traits and ideologies to their viewers (Eder et al., 2010). The most popular disability stereotype discussed, along with the pity and misery labels, was inspiration porn, a trope meant to "inspire" nondisabled people with narratives of disabled people "overcoming" their disability or simply performing mundane tasks (Black & Pretes, 2007). For example, when discussing *The Miracle Worker* (2000), a participant felt that the deaf-blind Heller Keller was seen as inspirational only once she miraculously overcame her disabilities. This messaging made participants, when they were children, believe that if they were not reaching incredible accomplishments in spite of their disabilities, they were not trying hard enough.

This stereotype represents disability in a controlled way, turning disabled people into meaning-making machines, rather than a truthful way regarding what it means to live with a disability. These images of disability can impact the way disabled identities are formed, oftentimes causing disabled people to adopt unhealthy coping strategies in order to deal with stereotypical representation and devaluation in society (Davis, 1975). While some disabled people make efforts to minimize the stigma attached to disability and be confident about being disabled, others experience low self-esteem and negative self-identity in response to being essentially disqualified from social standings (Anspach, 1979; Davis, 1975). Inspirational imagery of overcoming disability is another example of controlling images, representation theory, and even intersectionality, as "overcoming disability" is not only centered on erasing disabled experiences and pushing disabled people to "work hard" and "overcome" their disability, but also dismisses that real life challenges that arise when different disabilities and other identities (e.g., gender, race, class) intersect.

On the flip side, good disability representation would have helped participants feel seen, valued, and guided. For example, the television show *In the Dark* (2019–2022), which showed ways of navigating the world while blind, helped a newly blind participant adopt the behaviors and tactics into her own life. Without this representation, the participant would have had to navigate the world as a disabled person on their own, relying only on themself to understand themself from a young age. If there were positive representation available, they would have been comfortable with making friends, felt confident in themselves, and accepted their disability earlier on. Disability identity is often constructed and maintained through representation found in media (Haller et al., 2006); it is no surprise that participants were influenced by what they saw or did not see regarding disability narratives, as inaccurate representations of non-dominant groups

can impact those audiences' perceived identities (Ben-Zeev et al., 2004). Participants believed that being disabled should be normalized and accepted, and they should be treated like regular humans who have dreams, try out relationships, make mistakes, and are unfiltered.

Due to the rarity of disability portrayals in media, many of the representations discussed were riddled with stereotypical representations. Some participants had a beloved story as a child (e.g., the musical *Wicked* (2003) or the book *A Christmas Carol* (1938)) that later, as adults, they realized included stereotypical disability representations. Though participants felt uncomfortable and frustrated to recognize the representation theory involved in these stories, because they had grown up loving that media, it continued to mean a lot to them even after this realization.

Disabled participants felt excited about seeing positive disability representation for the first time, often creating specific bonds with a well-represented disabled character: due to the presence of harmful disability representation they saw in their life or media growing up, a singular good representation could mean even more. One participant, a Marvel fan, cried while watching a Spider-Verse character who had a disability for a short scene, while another found joy in watching the show *Speechless* (2016–2019), which had a premise that was funny, honest, and similar to their own life.

Overall, disabled participants were tired of seeing stereotypical, childlike, and infantilized disabled characters, because disabled people are the same as everyone else, not merely inspirational quotes or supercrip heroes. It was refreshing for them to see disabled characters being rude, selfish, or unfiltered, behaviors which completely shattered the controlling images that media tries to force upon them. Participants wanted better representation, specifically through relatable content that depicted teenagers and young adults with personalities, dreams, and "badass-ness" to combat the inaccurate frames of representation theory's meaning-making.

Influence of Society

Beyond the internal impacts that controlling images and representation theory had on participants, a larger picture needs to be drawn encompassing society. When examining how the outside world influenced participants, most had less-than-good experiences to discuss. For one, some participants were cautious about taking disability representation recommendations from others because they did not want to see the likes of inspiration porn or the magical-cure happy ending.

Garland-Thomson (1997) regards the construction of disability representation as "normative": the disabled image contrasts with a socially constructed and idealized version of a person with desired "normal" characteristics relating to physical appearance, intelligence, and independence. Through this lens, disabled embodiment becomes understood as deviant, or a "diminished state of being" (Campbell 2001, p. 44), situating fictional characters with disabilities outside the norm and reinforcing their social oppression via ableism. According to Bogart and Dunn (2019), ableism is a form of discrimination, prejudice, or social bias against disabled people, and is used in controlling images and representation theory to fix a particular, often negative, meaning to this group in society. This can be presented through certain beliefs about disabilities, actions towards disabled people, or institutional practices that stigmatize and devalue disabled people, including the stereotypical narratives and representations in media.

The social construction of disability representations in media can tell readers how disability is defined, how it challenges a person's life, how it affects a family dynamic and social circles, and how it is acceptable to treat disabled people (Adomat, 2009). Nondisabled people's acceptance of disability stereotypes affects their relationships with disabled people; for example, participants discussed being perceived as incapable of sexual interest or intimacy in romantic

settings because they were portrayed as “innocent” in media. Because viewers saw disabled characters as childish or infantilized, it remained common for society to treat disabled people like children or elderly people: kind but incompetent, and therefore, meant to be disregarded and ignored (Cuddy et al., 2007).

Participants trusted the recommendations of close friends and other disabled individuals, but always kept a questioning eye of whether the representation would be “good or bad,” and not cause emotional harm to their identity. These hesitations are valid, as literature has illustrated the plethora of stereotypes found in much of media (see Table 1). More than anything, participants wanted to see authentic representation that would not feed their internalized ableism, would give them a chance to relate to the characters, and would take steps to shatter frames of fixed meaning set up by dominant groups and allow disabled people to control the narrative about themselves. However, participants felt that the idea of disability was always tiptoed around in media when it came to representation, production, or casting, as evident by the nondisabled groups in power who control the production of media for a specific agenda. Disabled people face many accessibility barriers and typecasting issues when trying to break into the entertainment industry (Raynor & Hayward, 2009), keeping them out of the conversation about representation. The presence of a narrow understanding of disabled people in media casts an umbrella over all disabilities, boxing disabled characters and people into one-dimensional traits that remain inaccurate (Ellis & Goggin, 2015), as evident by representation theory.

As much as participants wanted to see positive, authentic disability representation for their own enjoyment, they also deeply wanted their family and friends to see these representations so that they had an understanding of their true experiences, rather than the ones created by nondisabled people. Participants wanted to learn how to navigate the world as a

disabled person, their families and society to be aware as well, and to combat the images popularized by inaccurate frames and stereotypes, which were not created by them. For example, a participant who initially did not want anyone she knew to read *Turtles All the Way Down* (2017), so they could not see her experiences due to her family's insistence on "hiding" being disabled, but later she wanted her family and friends to see the film adaptation of the same name (2024) so they could understand exactly what was happening in her brain.

How families discussed disability and treated disabled children significantly affected participants. Several participants indicated how growing up in an ableist family setting created shame for being disabled because that was how media taught them to view disability, bringing controlling images and representation theory inside the home and forcing the disabled participants to mask their disability or completely ignore that identity and never talk about being disabled. A participant shared how validating it would feel if her family could see good representation so they would stop putting her into the inspirational trope category.

Family ableist beliefs can stem from the era of "newgenics," where parents were encouraged to abort their genetically tested unborn children due to their detected disability (Hampton 2005; Tremain 2006)—another way of normalizing the erasure of disabled people. The ideology that supports erasing or hiding disability is further seen in families who are influenced by the media narratives that perpetuate negative views of disabilities as "abnormal mysteries," and thus treat their disabled children as "less than" (Dosch, 2011). Historically, ableism tends to be connected with the medical model beliefs and older cultural forms of stigma where the physical and mental status of someone become markers of moral worth, individualism, and success (Davis, 2013; Garland-Thompson, 2009; Stephens & Cryle, 2017). Participants agreed that members of older generations (versus those of younger generations) viewed

participants based on stereotypes found in media more often than not. In the face of such treatment, representation becomes much more than just a controlled image or framed meaning-making: it encourages self-policing and self-rejection, normalizes ableism and segregation, and makes stereotypes a present reality.

This media misrepresentation forces participants to educate others and advocate for themselves. Educating nondisabled people that disabled people were just people like everyone made participants feel exhausted and as though they were the only ones fighting the battle of making society understand them, which is likely why controlling images work so well. This emotional labor (Hochschild, 1983) is common when marginalized communities bear the weight of advocating for inclusive practices, causing them much stress, isolation, and burnout (Anderson, 2020; Arnold et al., 2021; Guillaume & Apodaca, 2022; Porter et al., 2018). This is also the consequence of the burden of representation, where the mainstream perception of disability falls on a singular representation in media due to its rarity (Tagg, 1993), another victory for controlling images and representation theory, as showing limited representations— ones chosen by dominant groups, who are unlikely to give up their power to members of the marginalized communities being misrepresented— lets stereotypes flourish.

In summary, throughout their lives, disabled people are impacted by disability representation, controlling images, and representation theory in both internal and external ways. Internally, having no representation made them feel unimportant and on their own, having no characters to relate to or identify with as they navigated childhood and teenager years. Externally, participants were treated with ableist beliefs in family or social settings, and wished they did not have to carry the burden of reeducating others about disability in the hope that people in society stop treating them as angels who were not allowed to get emotional or be rude.

That was why good representations were met with great excitement, as they gave disabled people validation and tools for showing others what living with a disability was really like, despite common misrepresentations and stereotypes.

RQ2: Impacts of Disability Representation

To narrow down further from the previous section, this section dives deeper into the impacts of representation and how disabled people respond to them. Disability representation in media has both positive and negative effects. Hall's (1997) representation theory explores how nondominant groups are framed in ways intended to impact people's lives in society; including popular stereotypes like disability as helpless or disability as evil (Barnes, 1992). To this, the second RQ asks: *What kinds of impacts have different disability representations had or may have on disabled people?* This section will be split up into two parts that include: disability is a bad thing and fighting against the stereotypes.

Disability is a Bad Thing

Disabled people have had little control over or say about how they are represented in media (Barnes, 1992), an exclusion that lets controlling images roam free, elevating dominant groups and suppressing nondominant groups in order to regulate certain beliefs and behaviors and to normalize social hierarchies. As discussed in the literature review, most disability representation is riddled with stereotypes (Barnes, 1992; Biklen & Bogdan, 1977; Black & Pretes, 2007; Holcomb & Latham-Mintus, 2022), which was evident in participant responses. Disability representation in media profoundly impacted participants' lives on personal, interpersonal, and societal levels. This aligns with Collins's (2000) controlling images and Hall's (1997) representation theory, both of which illustrate ways in which media positions and frames

nondominant stories that impact their lives in negative ways, while catering to dominant groups' benefits.

Stereotypes such as helplessness, burden, death-as-happy-ending, being cured, and infantilization led participants to adopt harmful perceptions of disability, such as feeling shame for being disabled, wanting to hide their disability, or fearing being disabled, beginning at young ages. One participant rejected being disabled or associated any disability as part of their identity because media portrayed disability as something that was bad. This can be seen as rejecting intersectionality by distancing oneself from the challenges of an identity to avoid certain discriminations. These examples illustrate Collins's controlling images (2000) as well, since the collection of stereotypical imagery shapes perceptions of disability, including in disabled people themselves, to normalize the fixing of perceived flaws that do not align with dominant ideals.

Lacking media that helped them understand the disabled world left participants feeling lonely and like something was wrong with them, a fear often supported by strangers asking disabled people, "What's wrong with you?" (Calder-Dawe et al., 2020). Participants felt shame for being disabled due to the negative representations of disabled characters being punished and isolated, and tried to hide their disability by making sure to act as "normal" as possible. In school, some participants feared asking for accommodations; one participant would purposefully position herself in photos to hide her wheelchair from view. Since media frames of representation theory and controlling images are created by those in power, it is natural that nondisabled people inaccurately see disability as something to cure in order to be part of society. With a vast number of negative representations in media (Donaldson, 1981; Nelson, 1994), it can be assumed a large majority of disabled viewers are negatively affected by the oppression of disabled characters in fictional worlds (Haller, 2010; Steele, 1997).

The reasons that participants hid their disability or their need for accommodations was based on what they saw in media, an example of Bandura's social cognitive theory that audiences learn how to behave, imitate behaviors, and learn about acceptable nuances from media (1989). For example, one participant hoped that if she ran fast enough, like the title character in the film *Forrest Gump* (1994), then her leg braces would fall off and she would be "normal enough" to prevent bullying from other kids in her school. Appearing nondisabled granted disabled people inattention from strangers (Goffman, 1963; Garland-Thompson, 2009) and the "freedom from the relentless diagnostic surveillance" (Calder-Dawe et al., 2020). In some instances, participants felt scared that they would make mistakes due to their disability and be punished, making them rationalize hiding their disability.

For religious participants, the narrative that disability was a punishment tied to sin made them feel "wrong" for being disabled, as though they had done something bad. As social cognitive theory teaches viewers to observe how characters are punished and rewarded, media unfortunately reinforces the concept of disability as a punishment by depicting disabled characters experiencing segregation or death, while showing that becoming "normal" and "cured" was rewarded with acceptance. Media stereotypes translated to how participants were treated in society: strangers would offer to pray for them or tell them how inspired they felt seeing someone in a wheelchair out in public. Seeing that the Bible teaches readers being disabled is due to an act of sin, and thus, prayer will cure that sin, it may not be so surprising that those beliefs and actions are interlinked (Martin, 2020; Norden, 1994).

At times, media taught participants that they had to be "normal" to be accepted into society, equating success with being nondisabled and oftentimes prompting disabled people to hide their disability or not ask for accommodations. The minimizing and hiding of disability or

"overcoming" of stigmatized attributes can be seen as individualistic coping strategies in order to be socially accepted and pass as a member of a non-stigmatized group (Branscombe et al., 2012; Turner et al., 1987), distancing disabled people from intersectionality and the acceptance of all aspects of their identity so as to avoid certain forms of oppression. Collectively, disabled people can combat stigmatized traits by embracing them and uniting with other disabled people to promote social justice activism (Branscombe et al., 2012) and the shattering of controlling images they were taught to accept and believe.

Participants questioned why being alive and happily disabled was never an option in response to the "better off dead" trope, seen in films like *Million Dollar Baby* (2004) and *Me Before You* (2016). The "better off dead" trope's message that disabled people were burdens to their family traumatized one participant to the point that they feared their disability, believing that disability equated to living a depressed life. Another participant explained how the "better off dead" label worked through the association of misery and helplessness with disability, leading to the conclusion that not living was the preferred choice. This is in line with Reynolds's (2017) research, which discussed how narrative tragedy builds a pathway to viewing the killing off of disabled characters as an acceptable action—supporting the foundations of how controlling images and representation theory work together to not only frame imagery but normalize oppression. Media portrays disabled characters as too burdensome for loved ones and denies them a "happily ever after" ending besides death—thus, this media seems to conclude, disability is bad.

Just like being disabled and happily alive, being disabled and sexy was not depicted as acceptable in media. Common representations of disabled bodies are assumed to align with aromance and asexuality, since desirable, sexual bodies are not supposed to look disabled in any way. When nondisabled people see a disabled body, they immediately perceive a stigmatized

identity, one that is “abnormal” (Byrd et al., 2019). Incorporating disability in romantic narratives could help society and disabled people themselves see their bodies as romantically and sexually desirable. For example, a participant was excited to see a major film (*Me Before You*) with a lead disabled character with their nondisabled friends in theaters. In the end, though, the participant was left traumatized and feeling unworthy of dating anyone due to the negative representation of disabled life, culminating with the disabled character choosing assistive suicide because he felt like a burden to his nondisabled love interest. Cue controlling images and representation theory: romantic narratives involving disability promote killing oneself as an act of love, a way to normalize the killing of disabled people by portraying it as an “honorable” choice, a selfless act for the good of their loved ones and society in general. This is referred to as sexual ableism, which “articulates how different types of bodies experience oversight and regulation of sexual and reproductive behavior” (Gill, 2015, p. 22) and controls which bodies are allowed to be desirable and sexual and which ones are not. Inversely, witnessing disabled characters in healthy relationships in fiction, on social media, or in real life made participants feel like they were lovable and were free to explore their sexualities.

The magical-cure happy ending indicates that something is wrong with being disabled, and the only way someone can be happy is if they “cure” their disability and become a “normal,” nondisabled member of society (Hayes & Black, 2003). The “healing” of disabled characters frustrated participants, as it portrayed disabilities as something to be “solved” and becoming nondisabled as the biggest life goal one could strive for. The ableist rhetoric of a cure for disability, prevalent to the point where “many of us have been seduced into believing that the need to eliminate disability and ‘defectiveness’ is intuitively obvious” (Claire, 2017, p. 27), can be viewed through the lens of intersectionality: many of those outside of the normative hierarchies (cisgender, nondisabled, white, male) maybe feel pressured by controlled imagery to

find a cure to correct any "imperfections" or "flaws" in their identity (Claire, 2017; Jeffres et al., 2023). However, participants noted, there never seemed to be any urgency to cure evil disabled characters, who existed as a continued plot like Disney villains.

The harmful imagery of disabled stereotypes are often unchallenged and seen as a "normal" thing by nondisabled people, who already have negative attitudes about disabled people (Vilchinsky et al., 2010) due to the ideals that dominant media leaders project onto society through media framing, as seen in representation theory. This leads much of society to have minimal or negative exchanges with disabled people—believing disability to be bad, that there is something wrong with that person, and that they should be feared (thus normalizing institutionalization, sterilization, or mercy killing)—limiting their understanding of and exposure to disability to the misrepresentations found in media and leading to awkward (or worse) exchanges with disabled people due to their reliance on negative stereotypes (Bogart & Dunn, 2019; Livneh, 1988). In many instances, participants found that the only way to escape these stereotypes was to fight against them.

Fighting Against the Stereotypes

Media provides viewers a safe resource for exploring what is unfamiliar to them, but when it is the primary source of information about a subject, such as disabilities, it can negatively influence certain societal attitudes through narratives like "menace to society, victim, and the eternal child" (Safran, 1998, p. 475) or "pitiable and pathetic" (Black & Pretes, 2007, p. 67). As much as disabled people are impacted by this representation, the nondisabled viewer is also impacted regarding what to think about and how to treat disabled people. For example, many participants who found the representation of inspiration porn "cringy" to watch also believed that it dehumanized disabled characters for the purposes of inspiring nondisabled

people. Many of these narratives had the disabled character serve as lessons for the nondisabled character's growth, and encouraged nondisabled viewers to act as "saviors" to "helpless" disabled people, as shown in films such as *The Fundamentals of Caring* (2016) and *The Upside* (2017). This can be portrayed is a power dynamic element that says that disabled people are expected to be inspiring for society, and if they are not, then they have not proven their worth in being part of society, thus, normalizing eugenics-based practices.

In many of these entertainment purposes, the narratives "simultaneously provide viewers with information about disabilities, and, through the filmmaker's lens, they project representations of how individuals fit into a nation's social and political landscape" (Safran, 2001, p. 223). These depictions of fiction bleed into how participants are not being taken seriously about their careers or being seen as lacking intelligence, with the extreme being treated as though they are incapable of answering any questions in school. This can be labeled as the "spread effect," where it would be assumed a wheelchair user was also mute, because "the potential impact of disability is dramatically inflated and extends far beyond the logical nexus between impairment and functional limitation" (Keller & Galgay, 2010, pp. 254-255). In the helpless category of the "poor disabled person" trope, participants were tired of having to prove their worth to disprove this stereotype.

The narratives, created for entertainment purposes, "simultaneously provide viewers with information about disabilities, and, through the filmmaker's lens, they project representations of how individuals fit into a nation's social and political landscape" (Safran, 2001, p. 223). These fictional depictions bleed into how participants are treated in society, from not taken seriously in their careers to being seen as lacking intelligence in academic settings. This is known as the "spread effect," where "the potential impact of disability is dramatically inflated and extends far

beyond the logical nexus between impairment and functional limitation" (Keller & Galgay, 2010, pp. 254-255)—for example, a wheelchair user might be assumed to be mute as well. While there were some positive discussions about being seen as strong for conquering their challenges or impressive for reaching certain accomplishments on top of having to manage the medical side of a disability, participants primarily felt tired of having to disprove the "poor disabled person" trope.

The reoccurrence of negative stereotypes set by controlling images made participants devalue themselves. The lack of disability pride in stereotypical media caused participants to negatively internalized the representation available; however, once they found a community of friends in college or online, they gradually found their disability pride and felt happy to identify with their disability and community, which then pushed them to call for better representation. Online spaces gave disabled people a place to acknowledge their disability, share their experiences, and build a community (Mulderink, 2020; Shew, 2023) where they were no longer the outcast or the only "different" person. Identifying with other disabled people can be connected to social identity theory, where individuals connect with a community that shares similar experiences as them, through which they gain a sense of identity and belonging with others (Tajfel & Turner, 1979). Disability pride offers participants visibility, an understanding that being disabled was not a bad thing, confidence in living their own lives, and safe spaces to vent about the terrible media representation of disability with each other.

The rarity of disability is used in strategic ways in order to fix preferred and dominant meanings to disability for society. To this, it pushes disabled people to rewrite the controlling images and representation frames to create voices of intersectionality. Meaning that this is where the fight for authentic representation builds in advocacy to combat the narrows perceptions of disability based solely on media (since disabled people get locked away as they are seen as being

a “bad thing.”). Rejecting media’s frames and imagery can be connected to Hall’s (1993) reception theory of how media is understated and interpreted. Sometimes audiences respond through an oppositional reading, which does not align with the preferred or dominant meaning and messages intended for audiences as coded by representation theory (Hall, 1993]. The acceptance of media imagery at face value is embedded in how society trains everyone to treat stereotypes and rhetorical ableism as normal; these systems are what disabled people are constantly fighting against, as evident by the literature on disability representation.

As discussed earlier on, disability stories are created for nondisabled by nondisabled people—as explained by the power structures in media control of representation theory—which stems from historically rooted ableism (Barnes, 1992; Black & Pretes, 2007). Participants chose to counteract stereotypical representation by outwardly challenging them. For example, to disprove that disabled people are helpless and weak, one participant wanted to act reckless, while another decided she would be blunt and outgoing to show she was not an innocent child. A third participant picked up smoking as a college student to combat childlike disability narratives.

These acts of individual expression to distance themselves from stereotypical narratives eventually evolved to include collectivist forms of advocacy to fight for real, authentic representation. Some participants who partook in risky behaviors like smoking or getting drunk to prove people they were not the stereotypical representations seen in media could be explained in a few ways. For one, this is a time where young adults are exploring and experimenting areas such as drinking (Salvatore, 2018). However, it is important to point out that minority groups such as the LGBT population tend to engage in risky behaviors then non-LGBT populations (Kann et al., 2016) due to various reasons such. One reason can be overprotective family dynamics—which participants in this study indicated ableism practices in their family units (Markham et al., 2003). Another reason could be minority stress, which stems from social stress

theory (Meyer 2003), which is intertwined the prejudice and oppression that minority groups experience due to the negative social stigma effects (e.g., Goffman, 1963; Link & Phelan, 2001). There is then a response from the disconnect from mainstream society that has social norms and structures, which leads to a lack of connection to normalness and therefore dismisses then becomes a stressor for the individual, causing negative outcomes (Merton, 1968).

In support of discussing disability grassroots organizations mentioned earlier, disabled people come together to build community and advocate (for example, starting a hashtag movement or spotlighting "crip drag") (Ruse, 2021; Shew, 2023). Being around other disabled people helped participants accept their disability and unite to share their experiences and advocacy efforts. Some were interested in writing their own books with the representation they wanted to see, creating disability etiquette training, and pursuing modeling careers to prove that disabled models can exist. When society did not want disabled people in public spaces or believe that they could do certain activities, participants found themselves fighting for their own inclusion in stores, restaurants, and classrooms. This is a common scene: disabled people have to prove that they belong in this world, oftentimes learning how to advocate for themselves, like in the passing of the ADA (Public Broadcasting Service, 2011). This is important, as building community fuels advocacy efforts (Brown, 2021; Ladau, 2021; Shew, 2023); as one participant put it, just existing is a form of activism, because that does not fit into society's frames and controlling images of disability.

The misrepresentation and mistreatments of participants pushed them to advocate for themselves, including when their disabilities weren't immediately noticed by nondisabled people who questioned if they "looked" disabled or not (Calder-Dawe et al., 2020). The intrusive nature of unwarranted questioning about someone's medical information regarding disability creates a diagnostic site of intervention for cures and treatment from strangers (Calder-Dawe et al., 2020;

Kitzinger & Frith, 1999), including a push to normalize the image of mobility devices and service dogs as part of the intersections of identities. Many believed that positive stories could cause nondisabled people to have greater empathy for disabled people and help them feel more understood, so they would not be constantly tasked with debunking disability stereotypes and reeducating society about disability. Furthermore, disabled people, as a nondominant group, have to "manage different identities, styles of conduct, languages, [and] habits of thought and feelings" when balancing their subculture of shared experiences within the disability community, as well as subscribe to the dominant culture in order "to operate effectively with other members of the larger society in meeting their general survival needs" (Beck, 2022, p. 185). Positive controlling images that situated disability in an accurate light would not only benefit disabled people, but also social belief systems.

In summary, participants just want to be valued, validated, and humanized, not "healed" of their disabilities. Many times, disabled characters and people are seen as being inspirational for the wrong reasons, and disabled people are fed up with it. When participants were left to their own thoughts about disability from stereotypical representations, this created negative beliefs about being disabled, such as low self-worth, being disabled is bad and will be punished, wishing to hide disability away and become as "normal" as possible. However, as participants interacted with other disabled people either in college or online, their disability pride grew, and efforts for advocacy and positive representation gave them their identity and worth back.

RQ3: Ideal Disability Representation

Findings so far took the disability stereotypes studied over the decades and explored how those internally and externally impacted disabled audiences, from the consequences of having or not having disability representation to fighting formerly negatively internalized stereotypes.

Next, we explore what the present and future of disability representation ideally looks like. Due to the lack of representation or stereotypical representation, disabled people advocated for representation by writing their own stories or supporting disabled creators or influencers to fulfill the need to see good representation. Participants had hope for the future, wanting to see more intersectionality and authentic casting. To this, RQ3 asks: *In what ways do disabled people believe disability representations have evolved or may evolve?* The two sections below are split into: praised disabled stories and the importance of authentic and diverse representation.

Praised Disabled Stories

As in past studies discussing stereotypical representations (Barnes, 1992; Biklen & Bogdan, 1977; Nelson, 1994; Black & Pretes, 2007), disabled participants were tired of seeing the gentle and innocent versions of disability that infantilized disabled people rather than expressing their real, raw feelings. They wanted to see uncontrolled images of disabled characters that made mistakes, were funny, had some "oomph," were sexy, and had big personalities. Some participants even preferred films with a horrible plot and performances but good representation to those with a well-executed story and developed characters but stereotypical representation—there were enough bad representations, and participants were tired of society believing said bad representations of disability as a "bad thing." Much of the stigma attached to disability in society starts with teaching children to have negative views of disability (Dyson, 2005); many of these socialized attitudes and beliefs are attributed to television, which helps children learn about those who they lack real-life interactions with (Van Evra, 2004). These findings build on these studies, and show the importance of underrepresented groups' representation when teaching children about those who may be "different from them."

Other requests included no more stereotypical disability frames, such as inspirational, pitied, or a miraculous recovery. Instead, participants hoped to see disabled characters in coming-of-age narratives or regular roles, like lawyers, rather than a plot device for nondisabled characters' moral lessons about appreciating life (Barnes, 1992; Panol & McBride, 2001). Participants wanted characters that were hilarious, loud, and imperfect, as these representations could set the basis of what society sees disabled people as capable of and could prevent nondisabled people from assuming what disability "should look like," publicly questioning disabled people about their disability, or assuming they are faking a disability because they do not "look disabled" (Calder-Dawe et al., 2020) (an assumption explained by the fact that wheelchair users are synonymous with what disability "looks like" for nondisabled people based on media representations (Panol & McBride, 2001; Ellis & Goggin 2015)).

There was a lot of hope from participants for the future of positive representation that lets society see them as other human beings. There were several favorite disability representations that were celebrated. Among the most discussed was the documentary *Crip Camp* (2020), which showed disabled people having fun, getting into trouble, and doing wild things at a summer camp run by hippies; its campers were represented as whole people and not one-dimensional, tokenized characters. The show *Speechless* (2016-2019) also had high praises due to its authentic casting of an actor in a wheelchair and storylines with a disabled main character navigating family matters, dating, and independence. The book *This Is Not a Love Scene* (2018) focused on exploring disability romance, combatting asexual tropes; the show *Ramy* (2019-2022) framed a wheelchair user as very sexual and abrasive; and the show *You're the Worst* (2014-2019) featured a female lead who openly discussed her disinterest in her clinical depression being "fixed." The use of counter-stereotypical representations of marginalized groups can provide positive effects for both the disabled viewer's self-perception and how society perceives nondominant groups (Ortiz &

Harwood, 2007; Schiappa et al., 2008; Wojcieszak & Azrout, 2016), a positive instance of Hall's representation theory (1997), which presents images through imitation and meaning-making in order to fit certain narratives and shift social thought about the imagery of disability. Many participants indicated that even though some good disability representations had flaws, they still appreciated the representation and that it was there, even if sometimes it was not fully accurate or depicted by a disabled actor.

Participants loved the idea of funny characters and real experiences, rather than stereotypes like infantilization and inspiration, because they enjoyed seeing their real lives reflected in media; it allowed them to relate more to the characters, and they felt confident telling others to watch a certain representation in order to understand their experiences. Since oftentimes, negative representations reinforced what the public understands about disability and shapes inaccurate social discourses that disabled activists must set straight (Zhang & Haller, 2013), more prominent good representation would mean that disabled people would not need to carry the burden of reeducating society about how inaccurate disability stereotypes in media were. Disability activists have brought up how their exclusion from media and the use of stereotypes contributed to misunderstanding about disabled lives, creating additional social issues and barriers that generally excluded disabled people from society and each other (Haller, 2010).

Importance of Authentic and Diverse Representation

Although there were discussions about disabled people never getting their "happily ever afters," real disabled people on social media have shown that they can have loving relationships. From documentarians to models and social media influencers, disabled people were changing the stereotypical narratives themselves; for example, when it came to the topic of love and disability—often treated as taboo when it came to disabled characters in media—one disabled

influencer shared “sexy” photos of her with a male model, and another influencer couple published a nonfiction book that featured interabled couples’ stories. Having public platforms have disabled content creators these opportunities to share their stories, however, this focus of re-educating society about disability once again falls on the shoulders of disabled people, creating the emotional labor for them.

The best representation came from characters or fictional worlds that participants already enjoyed, or from seeing their disability and other identities portrayed in authentic ways by disabled actors or creatives. This made them feel closer to the characters, because they knew exactly what being disabled meant, as opposed to disabled characters portrayed by nondisabled actors or creatives who could not understand the full scope of what it was truly like to be disabled.

Participants supported authentic representation over the idea of “cripface” or “disability drag,” which take place when nondisabled actors play disabled characters, as able-bodied actors may perpetuate certain disability stereotypes (Ruse, 2021) that inaccurately normalize how certain identities should behave, communicate, and appear. Participants compared this to “blackface,” which was derived of white people acting in stereotypical ways that made fun of and promoted offensive ideologies about Black people (Robinson, 2007). Similarly, “cripface” or “disability drag” applies to able-bodied actors playing disabled characters and being praised by their performances while preventing disabled actors from performing their own representations (Ruse, 2021).

These practices pose risks to the distorted realities about disabled people, further granting the narrative power to nondisabled and dominant groups to control and create whatever narrative serves them. Participants did not fully connect with disabled characters played by nondisabled actors because their representations came off as inaccurate or fake. It was important to not erase

such experiences of disability identity, especially where intersectionality brings multiple experiences together where they would normally be dismissed. Additionally, this took away opportunities from disabled actors, who could understand how to portray disability accurately because they have lived those experiences of those stories. Seeing disabled actors would give a more holistic representation of disability while employing actors who might otherwise be typecast into stereotypical roles (Zuckerman et al., 2003). Participants also believed that disabled people should be included in the writer's rooms that were creating these stories, because "it is in the nature of fiction depicted on film that it plants its seed in a ground of truth which the viewer can identify" (Holzer & Slater, 1995, p. 83)—whether that viewer is disabled or not.

Although progressive representations have a ways to go, they have undeniably come a long way from traditional stereotypes. As one participant indicated, that many modern representations of disability were not all centered on the disabled person struggling and then dying, was a good sign. There was also a rise in young adult books featuring disabled characters being written by disabled authors, which excited many participants, especially considering the potential for future film adaptations of those stories. When a person can point to a real, authentic representation and say that that is how they experience the world, they feel seen, and like their experiences matter. Children, whether disabled or not, can benefit from positive, authentic, and diverse disability representation, as they can develop compassion and deep understanding for each other, becoming better informed about disabilities (Adormat, 2014). Teacher-guided exploration of disabled book characters was where "children … learned about … characters with disabilities as full and complex beings, similar in many ways to themselves" (Adomat, 2014, Discussion section). This study additionally found that as disabled children were recognized and appreciated, they were valued.

The biggest topic of need regarded the intersectionality of disabled characters. Participants wanted to see more representations regarding the diversity of disability, because there were many experiences that should be shared; more importantly, they wanted intersectionality to be part of the character and their storyline, to add more depth and arc to the disabled characters. Intersectionality is about sharing nuanced experiences of multiple identities, such as gender and disability. Participants pointed out that white, straight, male wheelchair-user characters were the most commonly seen in media depictions of disability (Atkinson, 2024; Dewinter et al., 2017). One participant pointed to how they did not see very good representation when it came to Black disabled characters, or Black disabled women in particular; the two examples of Black disabled characters they could think of were either depicted as lazy or experienced violence.

Participants expressed that it would just be "cool" to see an authentically diverse range of disabled characters that they could relate to, laugh with, and learn from. Seeing diverse disabled characters and their experiences may lead others to identify with a particular disability and seek support or diagnosis. The more awareness of certain conditions there are in media, the easier it is to discuss such topics and not let people feel so alone; the more stories that are out there, the more empathy and understanding people could have for disabled people. Dom Evans, a disabled filmmaker and consultant, stated that "better visibility of disabled people—truthful, meaningful portrayals of the lives they actually live—might've salved [his] wounded self-esteem growing up" (Mattlin, 2023, p. 95). Positive representations can help those who may be facing bullying or familial abuse as they grow up to look toward a hopeful world, one that includes a positive place for them (Haller, 2024).

Concluding Thoughts

Overall, the more disability diversity there is in media representation, the more society could see disabled people as diverse, rounded individuals who should not be solely focused on being cured or dying, as this does have real negative effects for disabled people, including isolation and depression. Sometimes, a surprise disabled character was exciting for participants to see; sometimes, cheering on a fellow disabled person in a show helped make content relatable; sometimes, diversity of disability opened up new conversations about the vast range of disability. With the amount of literature that lists the harmful disability stereotypes found in media, it's easy to understand the reasons behind participants aching for positive representations. When disability is not tied to solely one form of disability (often a physical one), strangers can stop questioning whether disabled people's disability is what disability "should look like." The topic of what disability "should look like" could further be examined when it comes to media persuasion and people's beliefs about disability.

Thus, counter-stereotyped representation can shift the narratives away from one-dimensional characters and toward whole people, integrated into society and experiencing a full life. Without this representation, disabled people may be affected negatively with the stigma of disability they see in media and society, and cope in unhealthy ways. This can align with ideology such as transnormativity (Miller, 2019) and homonormativity (Duggan, 2003): transnormativity refers to how transgender people may adopt or imitate dominant cisgender behaviors of gender expression to be accepted by society, while homonormativity involved gay or lesbian people's adoption of heteronormative and capitalist standards and ideals, such as marriage, with the hopes of gaining social acceptance. This research proposes a similar phenomenon, where disabled people aim to appear as nondisabled as possible just to be accepted into society: "disabnormativity." Within critical disability studies, normativity and ableism often intersect (Goodley, 2013), where "ableist normative" puts forth images of "normalcy" as

nondisabledness and excludes all things disabled, usually related to ideal beauty standards (Campbell, 2009; Flynn, 2020; Goodley, 2014).

The research supported past literature regarding stereotypes of disability, as well as showed what disabled people want to see in terms of future representation. Certain themes of disability—including disability as a burden, unable to partake in society, and better off dead—translated from the screen to the person, evidenced by representation theory, controlling images, and intersectionality. The negative impacts of the way disability was portrayed affected how both disabled and nondisabled people behaved, what they believed, and how they interacted with themselves and others. Disability frames teach children, both disabled and nondisabled, of the world around them and how to make sense of things; when harmful stereotypes are perpetuated in media, internalized ableism takes root. It is only through individuals and communities who advocate for disability rights and good representation that the intersectionality experiences push forward a movement, controlling images transform into powerful messages, and representation theory begs the question of what is true.

CHAPTER 8

CONCLUSION

This dissertation explored many oppressive systems that uphold media's influence on disabled people, and the ways disabled people combatted or lived within controlling images. Systemic oppression is a constant for disabled people, who must advocate to combat stereotypes in their relationships (e.g. self, family, teachers) and in society. In exploring how disability representation in media impacted disabled audiences, several important conclusions can be made.

First, the absence of disability representation in media meant that not only did participants not see themselves in media, making them feel isolated and like they were the only people who were disabled, but their existence was ignored by nondisabled people in their lives and society as a whole. On the rare occasions that disability was present in a work of media, it was depicted in stereotypical ways and with negative connotations, making participants feel wrong for being disabled and motivating them to behave as "normally" as possible. Some hid their assistive devices or accommodation requirements, while others counteracted media stereotypes to the extreme in order to disprove them (e.g., being overly blunt to not appear childlike). These instances of poor representation also affected how they were treated by society, where ableist beliefs and discriminatory behaviors further fed into internalized ableism. Participants rarely had any individuals or media to relate to, learn from about how to navigate being disabled, or see living a full life with disability pride and acceptance. The combination of stereotypes and one-dimensional framed messaging, otherwise known as representation theory, is how controlling images lock disabled people into boxes of oppression, make them believe that they cannot be happy if they are disabled, and endorse the need to reject disability and strive to be nondisabled.

The result of this ableism, however, was advocacy, which participants partook in primarily once they met other disabled people, usually in college. As participants found disability communities, they were able to share their frustrations with discriminatory experiences and stereotypical representations, allowing them to find a sense of belonging and pride in their disability. With this new disability pride came the burden of rewriting common narratives, in order to show that disabled people's goal in life was not inherently to either be cured or choose death. From doing disability training to writing stories, disabled people wanted to give their own voice to their own representations. When they found good and authentically cast disability representation, many participants felt overwhelming joy and hope; this helped them when sharing their experiences with nondisabled loved ones, so they could understand what they were going through. On a social level, positive representations meant that the emotional labor of reeducating society on harmful stereotypes would be lifted, and disabled people could be accepted and treated better in society. More importantly, participants wanted to see the intersections of diversity and disability, to learn more about their disabled peers and have characters whom they could connect with on a disability *and* cultural, gender, racial, or other level. The impact of representation that was not created by or for disabled people has many negative personal, social, and systemic implications, and the way forward is giving disabled people their power back to create entertainment that rings true to them and is not used to miseducate nondisabled people.

The findings of this research highlighted the urgent need for more accurate, nuanced, and empowering representations of disability in media and further investigation into the long-term effects of media stereotypes on the well-being of disabled individuals. Stereotypes controlled the images of disabled people, taking away their power and allowing others to make decisions for them. More research into the structures that silence disability, and therefore allow it to be

deemed unimportant, could shine a light on why disability is perceived to be rare, including pathways toward infrastructural inclusion.

Further Research

This study discussed disability stereotypes found in media, their impacts on disabled people, and the hopes for better representation (e.g., the employment of disabled actors). Though qualitative in nature, a quantitative methods survey approach could be proposed to draw upon generalizations of a larger number of participants. These focus groups could be the building blocks of conducting a larger-scale study to examine the relationship between and significance of disability in media and its impacts on disabled people. Such a study would be able to reach a larger audience, be more diverse in nature, require a lower commitment from participants, and examine comparisons of media and different disabilities.

Another study to propose would include a meta-analysis of the lists of disability stereotypes present. This study combined stereotype lists from Biklen and Bogdan (1977), Rubin and Watson (1987), Barnes (1992), Nelson (1994), and Black and Pretes (2007) into one list. However, in nearly 20 years, there have been other lists, such as Holcomb and Latham-Mintus's (2022) report on disability representation in Disney and Pixar animated films. A new, redefined analysis of the major lists could call for updated definitions and words to be added to this study's list of stereotype descriptions, or for the creation of new categories altogether; for example, the stereotypes of fixing, healing, and curing disability—which focus on disabled persons striving for normally, such as Clara in *Heidi* or Colin in *The Secret Garden*, both of whom receive "happy endings" where they are able to walk—could expand into the theme of "curing" differences to be "normal" members of society, often through a convoluted method (e.g., magic poison or advanced technology). With these portrayals, research can further explore this study's

proposal of how disabled people are influenced to reject their disability and be seen as nondisabled in order to be accepted into society through "disanormativity."

Another potential category or expansion to an existing stereotype based on this research would be "happily-ever-afters" for disabled people as well as representation with overall disability pride. This would identify happy endings (or rather, unhappy endings) for the disabled character, not ones meant to be "happy" for nondisabled characters or society in general. Based on popular media, an ideal happy ending could be the disabled person getting married and having a child while owning a business. Researchers could seek out media from the last twenty years that portrays a disabled main character with emotions and feelings, who is integrated into society and the community, and navigating everyday tasks or milestones (e.g., going to college, starting a law practice). Another expanded stereotype category could examine the use of assistive devices—for example, prosthetics being used as weapons or tools in films like *Hook* (1990), *Kingsman: The Secret Service* (2014), *Mad Max: Fury Road* (2015), and *Skyscraper* (2018)—and how they can potentially serve as an extension of a person.

Lastly, this study had limited data to examine gender differences found in disability representation as they related to the focus groups. Thus, a deeper dive into the research of disability, sexuality, gender, and classism representations in media could examine how disabled men and women are represented in media as the majority of disabled characters are white men (Barnes, 1992) who are rich (e.g., *Rain Man* (1988), *Me Before You* (2016), *Upside* (2017)), and therefore able to survive in an ableist world where most disabled people are forced into poverty to survive (Public Broadcasting Service, 2011). In the US, disabled people are only allowed to have a certain amount of income and resources, usually below the poverty line, in order to qualify for services and medical expenses such as wheelchairs and caregivers (Public

Broadcasting Service, 2011). Media representation of the intersections of gender and disability representation within media vary (Simpson, 2020; Stibbe, 2010), and should be examined based on how those gendered representations impact or do not impact disabled people and their perceptions.

Limitations

This research had several limitations and cannot be generalized, as this was a small qualitative sample size. For one, the demographics were limited, with the majority participants being White women with a physical disability. Although there was some diversity in gender, more men, non-binary, and trans people would have helped diversify the study. This could include participants who were nonverbal or who have caregivers making decisions about their participation or access to society and were not able to participate on their own accord. Additionally, all but one of the participants were raised in the United States and did not have cultural experiences outside of the country. It is important to acknowledge that different parts of the world see and treat disability and other related identities differently, some with harsher and some less-harsh beliefs about disability (Saran et al., 2020). In low-income countries, for example, disabled people are seen as incapable of being part of society, and therefore should never be seen in public places, eliminating any change for accessibility (Saran et al., 2020). Greater cultural, gender, and disability diversity would have provided deeper analysis of intersectionality and diverse experiences of disability while living in the United States. Lastly, participants chose to participate also seemed to be advocates for themselves, wanting their voices to be heard. This is a limitation because not all disabled people are able to advocate or want to speak on their experiences, thus swaying the results towards a more activism-centered participant population.

Another limitation was the focus on U.S. media. One participant had mentioned in passing how she enjoyed British media's relatable disability representation, but since others couldn't engage with conversations about British media, it was difficult to further discussions about positive representations outside the U.S. Participants also did not always remember media characters at the start of each focus group, so who remembered what representation in which group affected which representations were and weren't discussed. It is also possible that not everyone was able to recall an important media representation that could have been beneficial to the study of this research. The eligibility survey did include a request for interested participants to list an example of disability representation in media. Those who could not provide an example were not chosen for the focus groups.

A third limitation was that these focus groups were conducted in summer of 2024, limiting access to media released after that date. This meant that any media with disability representation—like *Out of My Mind* (2024), a Disney film about a nonverbal girl with cerebral palsy, and *The Ride Ahead* (2024), a PBS documentary about wheelchair user navigating dating, college, and moving out—was not part of the study. However, on social media, disabled participants and others shared their excitement and praise for the authentic casting in *Out of My Mind* and relatable storyline on a major platform like Disney. It is possible that if participants had access to clearer examples, their experiences with disability would have changed; for example, the Iris Center House lists hundreds of films and children's books that have disability representation, which could have been directly referenced to participants. Participants instead focused on disability they saw in mainstream media that a majority of audiences would have known and seen as well.

Recommendations

As shown in participant responses, having disabled people part of the writing, acting, and production process is crucial. Disabled people not only deserve to share their stories their way, and not through the eyes of nondisabled people, but also deserve a say in the portrayal and representation of such stories. As mentioned *CinemAbility* (2012), disabled people should be given access to play not only disabled characters, but nondisabled characters as well. Normalizing disabled people in media will normalize their existence in society. Disabled people need to be part of the creation of media on all levels, "so disabled children and teens can see possibilities for their own futures" (Haller, 2024, p. 12). Media does more than just affect disabled audiences, it erases their experiences and creates a space of loneliness that is only found in the corners of other disabled people. As human beings, connection and relatability to familiar experiences via media to guide people through life's uncertainties can take a toll on disabled lives and how they are or not part of society.

APPENDIX A

RECRUITMENT SURVEY

Q33 Disability Representation Impact on Disabled People Form

Q36 If you are in the USA, please list which **state** you live in most. If you are outside the USA, please list your country:

_____

Q591 How did you hear about this study?

_____

Q61 Let's begin! Click the bottom right arrow to answer some questions about your media use.

Page Break

End of Block: Intro, Title & Consent

Start of Block: media use

Q260 **Survey Part 1 of 2: Media Engagement**

Q143 How often do you consume different forms of media? Please rate each media type below in terms of frequency use.

	Used several times a day (1)	Used several times a week (2)	Used several times a month (3)	Used several times a year (4)	Not used at all (5)
Social Media (1)					
Movies (2)					
TV Shows/Series (3)					
Podcast (4)					
Books (ebook, paperback, etc,) (6)					
Video games/VR (8)					
Print Media (comics, magazine, etc.) (9)					
Audio Media (e.g., music, audiobook) (10)					
Other (7)					

Q589 How often do you use various technologies?

	Used several times a day (1)	Used several times a week (2)	Used several times a month (3)	Used several times a year (4)	Not used at all (5)
Flat Screen Television/TV Set (1)					
Tablet (2)					
Laptop/Computer (3)					
Smart Phone (4)					
Assistive Technology (5)					
Audio (e.g., headphones) (9)					
Other (7)					

Q585 If you wish to expand on any of your answers above, please do that below:

_____

Q254 On average, how much screen time [recreationally/for entertainment purposes] do you engage with on a daily basis?

- less than an hour a day (1)
- 1-2 hours a day (2)
- 3-5 hours a day (3)
- 6-8 hours a day (4)
- 9-11 hours a day (6)
- 12+ hours a day (7)
- Other (5) _____

Q592 Please reflect on at least one example of disability representation (e.g., characters, stories, campaigns) that you have come across in media (e.g., film, book, ad, video game).

_____

Q576 The next section includes basic demographic questions. Please click the bottom right arrow to continue.

End of Block: media use

Start of Block: demographics

Page Break

Q241 **Survey Part 2 of 2: Demographics**

Q51 Please share whatever demographic information you feel comfortable answering below. All information will be kept confidential. You may opt out at any time for any question. Please hit the ARROW at the bottom right to SUBMIT when you are done.

Q52 What is your **gender identity**?

- Man (2)
- Non-binary (5)
- Transgender (6)
- Woman (1)
- Other: (3) _____

Q53 What is your **age**?

- 18-22 years old (4)
- 23-27 years old (5)
- 28-35 years old (6)
- 36-44 years old (7)
- 45-55 years old (8)
- 56-67 years old (9)
- 68+ years old (10)

Q58 Do you identify with a **disability**+? (select all that apply)

- [ ] None (12)
- [ ] Chronic illness (6)
- [ ] Hard-of-hearing/deafness (11)
- [ ] Intellectual disability (13)
- [ ] Learning disability (14)
- [ ] Limb difference/amputee (15)
- [ ] Mental Illness/psychiatric disability (7)
- [ ] Neurodivergence (5)
- [ ] Physical disability/limited mobility (4)
- [ ] Visual Impairment/blindness (10)
- [ ] Other (9) _____

Q140 Do you use any **devices or support** that assist you? (select all that apply)

- [ ] None (6)
- [ ] Glasses/Contacts (1)
- [ ] Wheelchair (2)
- [ ] Fidget Toy (3)
- [ ] Walker or Leg Braces (4)
- [ ] Hearing Aid (5)
- [ ] Service Animal (8)
- [ ] Walking/White Cane (9)
- [ ] Other (10) _____

Q588 If you would like to elaborate the devices that support you, feel free to explain it below:

_____

Q586 When was your **disability onset age** (the disability that affects your daily life the most)? Write how old you were when your disability was first realized (diagnosed or not). You can also write "since birth."

_____

Q32 What is your **background**?

Asian/Asian American (12)

Black or African American (5)

Hispanic or Latino or Spanish Origin (6)

Indigenous or Alaskan Native (4)

Multiracial (9)

Native Hawaiian or Other Pacific Islander (7)

White/European (8)

Unknown (11)

Other (10) _____

Q587 How would you describe your **sexuality orientation/identity**?

- ☐ Bisexual (4)
- ☐ Heterosexual (5)
- ☐ Queer (11)
- ☐ Homosexual (6)
- ☐ Asexual (7)
- ☐ Pansexual (8)
- ☐ I don't know (10)
- ☐ Other (9) _____

Q144 What is the highest **education** level that you have completed?

High School or GED (1)

Associate's Degree (2)

Vocational Program (6)

Bachelor's Degree (3)

Professional Degree (MA/MS/MFA, PhD, MD, JD, etc.) (4)

Other (9) _____

Q145 What is your **occupation**? (if you are a student, list your college)

_____

Q146 What is your **annual income**?

less than $15,000 (1)

$15,001-$29,000 (2)

$29,001-$46,000 (3)

$46,001-$62,000 (4)

$62,001-$79,000 (5)

$79,001-$94,000 (6)

$94,001-$125,000 (7)

$125,001-$150,000 (8)

$150,001+ (10)

I don't know (9)

Q578 What is your **availability** for a 90-120 minutes (breaks included) Zoom focus group for the next few weeks? Please include your time zone (e.g., PST, EST).

_____

Q584 Please provide your email so we can reach out to schedule the focus group. We will only use this email for purposes of the study.

Email (1) _____

Q31 Would you like us to keep your eligibility information on file for other disability-related research opportunities? This information will be kept for up to three years after submission.

Yes, you may keep my information and contact me with other research opportunities. (1)

No, do not keep my eligibility information outside of this current study. (2)

Q38 Thank you for all of your help! You can also add any comments or questions that you have right now:

_____

Q32 **Thank you for your answers! Click on the bottom right arrow to submit the eligibility survey form. You will not be compensated for participating in the eligibility survey form or receive a copy of your responses.**

End of Block: demographics

APPENDIX B

FOCUS GROUP QUESTIONS

Focus Group Introduction: My name is Luda and I am a disabled researcher at University of Oregon. I study disability representation in media and for this research, I want to know how disability representation impacts disabled. This is a voluntary focus group and you do not have to answer any question you do not feel comfortable doing so. The session on average may take about an hour and forty-five minutes with at least one break. You will receive $50 for your participation in a few weeks. You can take breaks when needed or not answer a question if you do not want to. If there is a pause, I am just taking notes. The recording will only be used to for research purposes. Your information will be kept confidential and names will be changed to protect everyone's privacy. If for some reason you need to turn off your video, feel free to do so, I just ask if the video can be "on" when you are speaking, if possible. Do I have your consent to record and collect your answers for my research? Are there any accommodations you have before we get started or questions?

Focus Group Questions: a breakdown of three sections that includes the focus of disability representation in media, the impact of disability representation, and desired representation in 11 questions that include probing questions or additional questions depending on the direction of the focus group discussion.

Representation

1) Can you share about a favorite fictional or nonfictional character you admire and why.
2) When someone mentions there's "disability representation" in a story, what is your initial reaction?
    a. Can you elaborate more about this reaction?
3) Growing up, how did you understand/learn about your disability?
4) Thinking back, what have been some disability images/stereotypes that media (tv shows, films, news, ads, books, video games) has shown/taught you about disability?
5) If you have seen your own disability represented in media, what did that mean to you? If you have not, what would it mean to you to see your own disability represented in media?
    a. This can also include your own disability representation and the first time you saw it (type or disability diagnosis).
    b. How would that representation have impacted/impact your life as a disabled person then and/or now?

Impact

6) How do these disability representation examples in media make you feel/impact your understanding of disability? This can be a positive, neutral, or negative feeling or a combo of both.

7) Thinking about disability in media, can you share any moments where the representation influenced how you saw yourself as a disabled person?
    a. Can you share any moments where you adopted/conformed to (or went against) the behaviors or beliefs about disability from media?
8) Can you share any moments where your relationship with your disability (or how you wanted to be perceived as a disabled person) changed due to the disability representation you saw/read?
    a. And how you wanted to be seen in society due to the disability representation you saw or adopted/not adopted from media?/Changed your attitudes or behaviors due to the representation.

Disability Inclusion

9) Can you think of any disabled characters that you felt relatable with/connected with? This can be a satisfactory or unsatisfactory relationship with the character from start to end of a story, for example.
10) If you had to select, which one would you choose: a well-made movie and ending with a negative stereotypical disability ending or good disability representation with an unsatisfactory movie.
    a. What made you make this selection?
11) What disability representation is missing in media?
    a. What is the representation that would make you the happiest to see?
    b. What excited you about disability representation?

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