

**The Quest for Authenticity:  
Complicating the Portrayal of Disability in Stephen Hawking Representations**

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THESIS

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## SUMMARY

The disability community is notoriously misrepresented in disability representations with oversimplified and tired narratives. Authenticity has been put forward by the disability community as the solution for our misrepresentation. “The Quest for Authenticity: Complicating the Portrayal of Disability in Stephen Hawking Representations” critiques authenticity as a rhetorical tool used to inform cultural understandings of disability. This topic requires critique, as authenticity cannot truly capture the complexity of disability. Authenticity as a solution pigeonholes our understanding of disability representations because it offers a neat set of standards to which to ascribe. Instead of seeking an answer, I put forth that we must pursue questions that expose the inherent complexity of disability, knowing that a conventional narrative can never be representative of the disability experience.

This thesis works to unpack the issue of authenticity in disability representations through an analysis of Stephen Hawking representations as a case study. It uses Hawking representations as an example to help conceptualize how authenticity is implemented in and around disability representations. Hawking is a pervasive cultural figure expertly positioned to teach consumers about disability as a result of the perceived authenticity of both his public persona and representations. This thesis situates Hawking representations to represent disability authentically with the assistance of disability scholars and the examination of the discourse that surround these texts. This enables me to expose that authenticity does not exist inherently in representations, but rather is a rhetorical tool that changes and evolves at the hands of the representation’s creator.

## 1. INTRODUCTION

My interest is in examining the role that claiming authenticity plays in defending particular disability representations. The goal of many creators of disability representations is for their narratives to be perceived as authentic, relatable, and believable. While this may seem like an obvious goal to have, I am interested in how creators appropriate disability in creating an “authentic” disability representation. Henry Louis Gate, Jr. (2012), in his short story entitled “‘Authenticity,’ or the Lesson of Little Tree,” recalls film producer, Samuel Goldwyn’s claim, “authenticity remains essential: once you can fake that, you’ve got it made” (522). Goldwyn’s observation that faking authenticity is the key to a film’s box office success demonstrates an understanding of authenticity as a paramount tool in crafting a narrative. Authentic portrayals are more immune to critique and prone to box office success because authentic narratives are understood as presenting reality—albeit in a truncated, glossy format—and you cannot criticize reality. Goldwyn’s argument also uncovers a paradox: how can representations use claims to authenticity to reinforce tired tropes that are anything but authentic? This paradox reveals what disability studies scholar Carrie Sandahl (2016) would call a ‘representational conundrum,’ or a space of complexity such paradoxes reveal. Sandahl argues for exploring challenging questions these spaces raise rather than seeking to resolve unsolvable paradoxes. In so doing, those who are engaged in the discourse around disability representations can find comfort in the intricacies of disability and create a path forward. I will use representational conundrums as a framework for my analysis throughout this thesis.

In this thesis, I analyze non-fiction literary narratives and films. This genre inherently makes claims to authenticity (non-fiction) while at the same time acknowledging its own constructedness (literary), thereby making an ideal case study for laying out the complex facets



of disability representations and how claims to authenticity render complexity simple. While these claims simplify the complexity of the disability experience, disability studies scholars, artists, and activists have perpetuated the notion that the expansion of authentic narratives about the disability community is an effective means of combating stereotypes. The thinking being, as disabled blogger Esme Mazzeo (2015) argues in her article “Not a Costume: Disability and Authenticity in the Media,” that increasing authenticity will better represent “realities of disability... portrayed [...] truthfully and casually.” I understand the desire to normalize disability through more “accurate” portrayals in representations, but I believe overemphasizing the importance of authentic disability representations diverts our attention away from asking the necessary questions about how and why we use authenticity in the first place. I suggest that we shift the focus of the conversation from creating authentic narratives to creating a discourse that allows for complex and even contradictory thinking about disability and narratives thereof. In other words, authenticity as a solution pigeonholes us into seeking a false standard for disability representations by determining what *is* and *is not* authentic. Society thinks identifying authenticity solves the issues of representation that distort the lived experience of disability; however, this strategy only works to create another filter through which to view representations.

The effort to create representations that “get it right” about disability overshadows the necessary work of engaging with the conundrums that surround disability and authenticity. Representations are by definition not authentic because they *represent* reality. For this reason, I work under the assumption that authenticity in disability representations does not exist. Narratives are always constructed and manipulated, but dominant culture produces the *perception* of authenticity. My assumption that authenticity does not exist does not imply that I believe facts are unimportant, rather, I critique authenticity in order to illuminate what is at stake

when a story is called “true.” Society generally understands authenticity as something to be determined—something either is or is not authentic, but once this determination has been made, authenticity is considered a static concept that is not to be interrogated. Determining something as authentic encourages a rigid understanding of that item’s traits and characteristics, invalidating other interpretations of the given item. While consumers need facts as they offer a vital way in which we organize and validate information to make sense of the world around us, the rigidity of decontextualized facts only work to narrow our view of the world.

It is necessary to take a moment to discuss my choice to use the term consumer throughout this work. I use “consumer” as opposed to “viewer”, “audience member”, or “reader” because I want to keep the terms consistent throughout the various chapters and mediums examined. I also use consumer as a way of gesturing to the process of interacting with a disability representation. Individuals first must *consume* a representation before they can determine whether they want to incorporate the meaning of said representation into their disability framework. Consumers also determine to the degree to which they engage with the meaning of the given representation. Enlisting the term consumer also speaks to representations as a commodity or cultural product that individuals share among one another.

I understand the push for authenticity being thought of as a means of progress due to the correlation that scholars, Zhang and Haller (2013) presented in their article “Consuming Image: How Mass Media Impact the Identity of People with Disabilities” between disability representations and stigmatizing attitudes of the disability community (322). Disability representations shape not only cultural perceptions of the disability community, but also every-day interactions with the disabled (Zhang and Haller 323). Given the taken-for-granted relationship between cultural representation and the ways in which disabled people are treated, it

stands to reason that if we can change the representation (by making them authentic), then we can change the disparaging attitudes those representations often yield. I believe this thinking neglects the inherently diverse and complex lived experiences of the disability community.

Therefore, I claim that seeking authentic representations will not lead to the progress desired by the disability community because authenticity, in simplifying disability, essentializes our relationship to and understanding of disability.

This thesis explores various facets of disability complexity by examining the role authenticity plays in disability representations. Examining the phenomenology around authenticity will carve out a space to critique the argument that representations will automatically become more authentic by getting disabled actors in front of the camera, disabled directors behind the camera, and disabled writers behind the keyboard. This action, while potentially increasing the prominence of disabled voices in the arts world, masks the potential to delve deeper into the issues surrounding disability representation including the structural barriers to the arts for the disability community. We have to acknowledge the inherent complexity of disability in present day. We must accept from the beginning of the conversation that there are no real or right answers to disability or disability representation, but a spectrum of perspectives and approaches. We should strive to expose the conundrums of disability as well as invite in complex analysis and interaction with disability in order to validate that representations impact disabled peoples' lives. My hope is that eventually we will enter into disability and disability representations with the expectation that disability will be messy, complicated, and contradictory.

In order to provide further context for exploring representational conundrums, I will provide a tangible example in the experience of a long-time British, disabled performer and

activist, Mat Fraser. Mat Fraser is perhaps most well-known for his role in the television show, *American Horror Story*, but scholar Elizabeth Stephens (2005) also discusses in her article “Twenty-First Century Freak Show: Recent Transformations in the Exhibition of Non-Normative Bodies,” Fraser’s role in reimagining Stanley Berent’s freak show in his one-man solo performance entitled “Sealo the Sealboy” (4). Bernet and Fraser shared the same impairment, which allowed Fraser to play on his own experience as well as bring Sealboy back to life. It could be argued that Fraser and Bernet sharing impairment status “authenticated” Fraser’s performance because consumers can validate the performance based solely on appearance. But the danger of this validation lies in neglecting the narrative entirely in favor of the embodiment.

The conundrums inherent in Mat Fraser’s career are numerous and significant for the purpose of identifying and studying authenticity and disability representation. By taking on the role of Sealboy, Fraser positioned himself within the conundrum of simultaneously reinforcing the historical representations of disabled people as freaks and powerfully rejecting that history by reclaiming the identity of freak. Sharing Bernet’s impairment authenticated Fraser’s role in “Sealboy: Freak” because he could physically embody Sealboy in a way a performer without Bernet’s impairment could not. Fraser plays with authenticity as his performance fuses the impairments of the two performers and in doing so, critiques positionality of disabled people making a living off of portraying freaks.

Following this and other work that explored freakery, Fraser was offered the part to play Paul, the Illustrated Seal Boy, in *American Horror Story*. While this was a huge break for Fraser professionally, Ben Walters (2014) reveals in his article “AHS Freak Show’s Paul – aka Mat Fraser – on Being a Sex Object, Bradley Cooper and ‘Crip Confidence’” that Fraser had some concerns about playing a freak not of his own invention. Fraser was also concerned about the

fact that his nondisabled colleagues, instead of disabled actors like himself, would portray struggles of freakery they had not experienced themselves. In the end, Fraser took the role, in part because it would increase visibility of disabled actors on screen, even if the role was centered on the character's impairment. Following *American Horror Story*, Fraser hoped that his prominent role in American television would open up more avenues for him as an actor, particularly in roles that did not portray him as a freak (Walters).

Fraser's experiences as a disabled actor reveals the often-challenging positions disabled actors are placed in. Fraser took the role in *American Horror Story* because it was a mainstream show that could increase visibility of disabled actors. While Fraser's role undoubtedly increased visibility for disabled actors, being on the series did not provide him with the professional leverage one would expect from a hit show (Walters). Fraser has since been cast as the famous hunchback Richard III, a disabled character often played by a nondisabled actor, in the London-based Hull Truck Theatre and Northern Broadsides' Shakespearean production (Northern Broadsides). Fraser being cast in a role typically played by a nondisabled actor demonstrates a shift in conduct of disabled actors however, he is cast to play a disabled character, the only conceivable type of character he can play "authentically" which works to reinforce his positionality as a disabled actor. This conundrum begs the question that if a series as successful as *American Horror Story* is unable to leverage a disabled actor's career, what series or film has this capacity?

I use Mat Fraser's career as an example not only to demonstrate the inherent conundrums in disability representations, but also to express how the suggested solution to harmful disability representations—giving disabled artists the opportunity to represent themselves—does not resolve the problem. Mat Fraser was a disabled actor in a hit television show and while the

disability exposure resulting from his role in *American Horror Story* was significant, the exposure does not mitigate the dangers of disability representations within the current social structures. Increasing visibility of disabled people on television is only the first hurdle in a marathon of exposing complexities and contradictions within disability representation and the quest for authenticity.

Before moving further, it is critical that I clarify how I apply authenticity to my analysis. “Authentic” as defined by Merriam-Webster (2016) means, “conforming to an original so as to reproduce essential features.” From this definition, I think the logical question to ask is, “what is the original disability representation?” I would argue the original, in this case, is not an empowered representation supported by disability culture, but an original that a general audience can relate to; in other words, commonly identifiable tropes we have seen in disability representation since Shakespearean times. The essential features that a representation seeks to replicate in order to be authentic are based on a narrative that demonstrates a social norm of how a disabled person should look, act, move, think, and interact. Zhang and Haller explain, “Media portrayal is salient if it is perceived as realistic. The more realistic media messages are, the more likely they will affect media consumers” (323). That is to say, readers and viewers authenticate representations when they perceive them as realistic based on the set of assumptions they enter into the experience with.

To extend the definition of authenticity, I think of it as a lens and structure used to frame dominant narratives about disability. Authenticity works to reinforce cultural “truths” or assumptions about disability. Creators of disability representations enlist authenticity as a tool to convince an audience that these cultural “truths” represent lived experience of disability, thereby validating the disability representation. Validating a representation allows that representation to

be an authority on disability. I believe authenticity exists dually in the context of dominant culture as well as disability culture, which Sandahl (2006) in her encyclopedia entry “Disability Arts” defines as, “A term that describes a subcultural community of diverse disabled people (in terms of impairment type, race, class, gender, and sexuality) who nevertheless share certain experiences, values and perspectives,” which contends that authenticity is a socially constructed phenomenon (3). The assessment of authenticity differs between the two contexts because each context has different standards by which they judge the quality. For this reason, Haller (2010) in her article “Media Advocacy and Films: The ‘Million Dollar Baby’ Effect” argues that there is a clash between disability representations that come out of dominant culture and those that come out of disability culture because dominant culture’s representations are not representative of disability culture (176). I want to be clear I am not trying to determine the authenticity of disability representations; instead, I am exploring how authenticity is deployed in disability narrative. While I use authenticity as sitting somewhere within the parameters laid out above, my purpose here is to flip authenticity on its head and reveal authenticity as an elusive target.

### 1.1 **Significance of Work and Preliminary Thesis Statement**

The study of disability representations is instrumental in the work of disability studies as a field as well as among disability activists and artists because representations are the primary way in which society is educated about disability. Openly critiquing the representations that teach society such misinformation about the disability experience is vital work done in order to advance the social position of disabled people. By identifying conundrums, encouraging complex thinking around disability, and understanding the experience of disabled individuals to be contradictory to the manner in which they are often represented the hope is that we will be able to attain a more extensive understanding of disability representation. Positioning ourselves

with a clearer grasp of the complexity of disability representations will better equip us to recognize the ways in which representations reinforce a larger system of oppression that structures the lives of the disability community.

I pull from the fields' work on disability representation as grounding for this text to analyze and critique cultural disability representations. My task is also, in some ways, to turn the critiques inward to stimulate new avenues to conceptualize disability representation. In this moment of transition within the field as we begin to shed the harsh binaries of medical and social models and are drawn to a more fluid and inclusive way of interacting with the disability experience, it is time to move away from our investment in "authentic" disability representations and expand our thinking around complex disability representations. The hope is that this work will highlight the important groundwork done around disability representation thus far and demonstrate potential ways to disrupt our marriage to authentic representations, allowing for broader, more diverse representations. Using this framework, I present my preliminary thesis statement for this work: authenticity is used as a rhetorical tool to inform cultural understandings of disability through disability representations as a way of reinforcing a cultural truth about disability. In order to better inform cultural understandings of disability, we must expose conundrums and complexities inherent in disability representations as a way forward.

## 1.2 **Literature Review and Scope**

I explain my choice of primary sources for this work, as a way to fully illuminate current disability representations and their quests for authenticity. Then, I present the primary theoretical sources I use as a framework, as well as the various popular and literary criticisms of the primary texts. I contextualize current representations by exploring representation and authenticity in freak



shows of the early twentieth century, which leads into an historical application and trajectory of authenticity to better understand how it is used to enhance modern representations.

### 1.2.1. **Primary sources**<sup>1</sup>

*Music to Move the Stars* (1999) and the revised version, *Travelling to Infinity* (2007) by Jane Hawking

I chose to use these two texts that present J. Hawking's interpretation of her life with Hawking in order to analyze the ways in which Hawking is represented through someone else's eyes. I also use the comparison between the versions to reveal how authenticity is a tool to be manipulated, in that both versions can be understood as "authentic" while they create different narratives. I put *Music to Move the Stars* in conversation with *Travelling to Infinity* in order to reveal the complexity between the representations of Hawking, by J. Hawking.

*My Brief History* by Stephen Hawking

I chose to use Hawking's autobiography *My Brief History* (2013) as a primary text for numerous reasons. Hawking is a very well know and *inspirational* disabled individual who is frequently used to represent disability in the media. However, he does not represent the disability community in a way that is empowering, nor does he appear to possess a disability consciousness. That being said, I view representations of Hawking as an interesting paradox in terms of disability representation. There are many works by and about Hawking that provide a significant amount of material to analyze and interact with. I am specifically using Hawking's autobiography to ground my analysis in his representation of himself. This allows me to do a

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<sup>1</sup> It is worth noting that when I refer to the authors of the primary texts, I use "Hawking" for Stephen Hawking and "J. Hawking" for Jane Hawking. Whereas when referring to their characters within the texts I refer to them using their first names.

cross-analysis between the ways Hawking artistically chooses to represent himself and the way that his former wife, Jane Hawking, chose to represent him in her memoirs.

*The Theory of Everything* directed by James Marsh

Using the biographical film *The Theory of Everything* (2014) creates another filter of complexity, as another Hawking representation categorized as “authentic.” Of course, the narratives’ variability themselves reveal the precariousness of authenticity. *The Theory of Everything* is a critically acclaimed Hollywood film that is touted for its accurate representation of motor neuron disease. Eddie Redmayne, who portrayed Hawking on screen, embodied him so authentically, Hollywood recognized him with the best actor Academy Award in 2014. The film also provides an avenue to I analyze public perceptions of Hawking’s representation in the context of numerous reviews and critiques of the film. Using film as a medium is helpful in creating a well-rounded understanding of disability representation, especially as film is the primary medium through which society receives information about disability.

### 1.2.2. **Disability studies theory**

Robert McRuer’s *Crip Theory* (2006) lays out how cultural norms develops using his theory of compulsory able-bodiedness. Able-bodiedness is seen as a “nonidentity” because it is viewed as a normal way of being, unlike its counterpart, disability (McRuer 1). Individuals strive for compulsory able-bodiedness in their everyday lives because the alternative—being disabled—is a deviant identity. It is worth noting that compulsory able-bodiedness and compulsory heterosexuality are correlative concepts, and similarly maintain their “nonidentity” status as a form of protection from the deviant identities of homosexuality and disability (McRuer 2). Part of the success of these compulsory identities is that they possess the illusion of choice, so as to convince individuals that they choose adherence over deviance on their own by

“coming-out” as heterosexual in order to maintain their superiority over homosexuality (McRuer 12). This coming-out accounts for heterosexuality and able-bodiedness’ lack of origin story (McRuer 1); they are understood as naturally occurring, which ultimately erase individual autonomy and convinces individuals that able-bodiedness and heterosexuality are organic concepts, meaning anything that opposes this “nature,” in this case disability and homosexuality, is *unnatural* (8).

Compulsory able-bodiedness affects not only able-bodied individuals, but disabled individuals as well, because they are expected to *want* to adhere to the norm of able-bodiedness, even when they demonstrate contentment or even affinity with their disability identity. There is a fear about the precariousness of ability held by the able-bodied population. This fear is assuaged by disabled people who are expected to affirm that, if they had a choice, they would not choose to be disabled (McRuer 8). This assumption is then manifested through repetitive interactions that reinforce the belief that an able-bodied life is superior to a disabled life. And, of course, this manifestation goes far beyond an individual or even a cultural belief about ability. It manifests in the ways in which ability is represented as valuable in that nondisabled people operate effectively in the face of inability. People who are understood as valuable are considered “‘flexible and innovative’ [and able to] make it through moments of subjective crisis” (McRuer 17). Ultimately, this flexibility relies upon the boundaries of perceived inability of the disability community to give the ability to be flexible value.

Examining representation and authenticity through the lens of compulsory able-bodiedness helps reveal the techniques used to frame the disability experience as undesirable in the eyes of dominant culture. Understanding the lack of value directed at disability also helps illuminate how the expectation of desirability for able-bodiedness seeps deep into the

subconscious of nondisabled people in that disability can be used to leverage ability, particularly in acting. An example of this is the able-bodied actor, Daniel Day Lewis, winning best actor in 1989 for his expert embodiment of Christie Brown, a man with Cerebral Palsy who learned to paint with his left foot in the biographical film *My Left Foot*. The skill of the actor is understood as valuable due to his flexibility of representing ability through acting disabled. The reception of this process depends upon perceiving disability as the antithesis of the actor's ability. In other words, disability is often portrayed as tragic and miserable, highlighting the actor's ability in capturing disability in stark contrast to that portrayal. This example is one of many, but is significant because it demonstrates how feigning disability is seen as challenging for an able-bodied actor, but also, somehow, uniquely powerful, perhaps because it is such a reach for the actor.

The concepts in Tobin Siebers' *Disability Theory* (2008) can help further enlighten McRuer's idea of ability with his model of ideology of ability, which encapsulates a spectrum of claims about ability and the body. One premise of the ideology of ability is the conundrum between a cultural understanding that bodies in their physical form do not matter (the body is simply a container for the emotional self), while simultaneously claiming bodies must be perfected (cured of disease, fixed of genetic flaws, and beatified) (Siebers 7). The second premise of ideology of ability is the cultural understanding of humans in a historical context. Our history tells a story of the fragile and finite beings we are, and yet, society maintains hope for an idealized future in which we "triumph over death" (Siebers 7).

In order to combat ideology of ability, Siebers develops the concept of complex embodiment, a process of the body that fluidly evolves in an environmental, representational, or physical context over a life course (27). The understanding that knowledge is situated is central

to the concept of complex embodiment. Situated knowledge is based on positioning the body in a social context, which determines an individual's lived experiences (Siebers 23).

Ideology of ability and complex embodiment provide a basis to analyze disability representation because it reveals why the patterns of representations persist. Representations are hyper-focused on the manifestation of impairment in disability narratives and Siebers' work pokes holes in the thin veil that obscures those representations. Siebers contends, "Disability has served throughout history to symbolize other problems in human society" (48). Disability is the perfect metaphor for revealing society's flaws because it is obvious and unquestioned. The simplicity of disability representations often enables them to be read as authentic because audiences often lack a point of reference for disability. Applying this thinking to disability representations then exposes the precariousness of authenticity and the effort to maintain the ruse that disability is only a personal tragedy of the body.

Alison Kafer's political/relational model in *Feminist Queer Crip* (2013) pairs nicely with Siebers' work on complex embodiment because they both offer concepts that stress the importance of context when discussing the disability experience. Kafer recognizes the limits of the medical and social models in framing disability and a need for a model that conceptualizes the nuance of disability and allows for a "collective reimagining" of disability (9). The political/relational model not only contends that both disability and impairment are socially constructed, but it also acknowledges that the physical realities of impairment are equally as important to conceptualizing disability (Kafer 7). Drawing upon both Kafer's work and Siebers' work on complex embodiment allows for us to acknowledge, "How a disabled person's response to impairment shifts over time or by context and how the nature of one's impairment changes, or especially how one's experience of disability is affected by one's culture and environment"

(Kafer 4). By situating disability in a socio-cultural historical context, it creates “a set of practices and associations that can be critiqued, contested, and transformed” and used to politicalize disability (Kafer 9). Politicizing disability is significant as it shifts the framing of disability and the type of questions offered in the effort to politicize disability. This investigation into the political nature of disability reveals the interconnectivity between social institutions such as medicine and the “cultural practices and ideologies” held about disability (Kafer 6). Clearly, the boundaries around disability and impairment are not as secure as society would like to believe.

I use Kafer’s political/relational model as a framework to analyze how authenticity is conceptualized in disability representations. It allows me to structure a path forward that not only allows, but encourages, new and diverse representations that help shed the marriage to authentic representations. This approach is supported by Audre Lorde’s oft-quoted words from *Sister Outsider* (2007), “*for the master’s tools will never dismantle the master’s house*” [author’s original emphasis] (112). Kafer has provided us with our own tools created to re-build our own house where disability is fluid and representations reflect the diverse experiences that exist in the context of disability. Another noteworthy concept I enlist from Kafer is “compulsory nostalgia” which speaks to the socially ascribed desire that disabled people are expected be “[nostalgic] for [their] lost able mind/body” (42).

Rosemarie Garland-Thomson closely examines literary narratives’ use of disability representations in *Extraordinary Bodies* (1997) and fractures the harsh boundaries around disability’s use as a metaphor in literary works. Garland-Thomson claims that disability representations allow people to organize and make sense of subjects they rarely encounter. Yet, she also warns that “If we accept the convention that fiction has some mimetic relation to life, we

grant it power to further shape our perceptions of the world” (Garland-Thomson 10). In other words, while representations are often enlisted to simplify initial learning, we must be careful not to invest too much in their framing. Garland-Thomson goes on to explain that the reception of a representation by the consumer is dependent on it being interpreted by as probable or accurate as well as the consumers’ application of cultural assumptions to the representations presented (11). This is a process by which audiences categorize and incorporate new information in order for it to be knowable to them (Garland-Thomson 11). This is a significant process by which culture creates an understanding of disability through constant reproduction. Garland-Thomson’s insight into how disability representations exist in dominant culture help illustrate the need to complicate disability by resisting the typical simplification of disability representations.

To enhance our grasp of Garland-Thomson’s work on literary representations, David T. Mitchell and Sharon L. Snyder’s text *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000) further demonstrates how disability is enlisted as a narrative device. Mitchell and Snyder’s text establishes the concept of narrative prosthesis, the idea that disability is literally an assistive device for a narrative that allows it to function effectively. This is a critical concept that can be seamlessly applied to the analysis of representation and authenticity. In an entry entitled “Narrative Prosthesis” in *The Disability Studies Reader* (2013), Mitchell and Snyder lay out how “disability pervades literary narrative, first, as a stock feature of characterization and, second, as an opportunistic metaphorical device” (222). In other words, literary narratives depend on disability tropes (the disabled character as inspiration, tragically disabled, evil, etc.) and use disabled characters as metaphors for something else typically unrelated to disability. Mitchell and Snyder identify a representational conundrum in that “while stories rely upon the potency of disability as a symbolic figure, they rarely take up disability as

an experience of social or political dimensions” (222). This conundrum demonstrates that disabled characters are used specifically because they possess an innate power to provide anomaly and interest to an otherwise lackluster literary narrative. Disability is taken advantage of as a catalyst in a narrative arc and those who enlist disability as a metaphor never seem to consider exploring the social or political positionality of disability.

Narrative prosthesis is quite applicable to this work because it provides insight into why disability representations are omnipresent, yet simultaneously obscured. Disability representations exist to highlight and formulate other concepts, but is never examined itself. While the implementation of authenticity in these representations may make the presence of disability more visible, this does not prohibit disability from being exploited for its metaphorical use.

### 1.2.3. **Popular criticism**

#### 1.2.3.1. **Stephen Hawking**

Journalist Ruth Hessey (2011), in a piece entitled “Hawking's Ex Writes Second Memoir,” argues each of J. Hawking’s two memoirs are interpreted contrarily to the other. For example, Hessey contends *Music to Move the Stars* is an exercise in “purging the bitterness” of Jane and Stephen’s divorce while she dubs *Travelling to Infinity* J. Hawking’s “rapprochement” book. Journalist Joan Smith’s (1999) review of *Music to Move the Stars*, entitled “Books: Stephen Hawking: The Man Who Mistook his Wife for a Nurse,” describes the memoir as a “story of a marriage based on a pairing of male ego and female submissiveness”. *Music to Move the Stars*, while very sympathetic to the strain on Jane as a carer and wife, frames Stephen as a man who is forced to overcompensate for his deteriorating body by demonstrating that he can be a man in other ways—by becoming of God-like importance. Contrastingly, Ruth



Hessey notes of *Travelling to Infinity* that J. Hawking “has tempered the truth with acceptance”. There is a subtle, yet significant difference between the versions in that they represent Stephen in contrasting ways because of the emotional space J. Hawking was in her life and as a writer when she wrote each version. The incongruities between the versions serve as an inroad to study authenticity. Each version comes from the same writer with the same experiences, but the narrative varies because the context in which she writes is different. Although Hessey fails to reconcile this conundrum by portrayal J. Hawking as a phoenix rising from the ashes, it remains that the context alters the representation of Hawking and results in a breakdown of the perceived authenticity of Hawking.

Journalist Ian Sample (2013) reviews Hawking’s memoir *My Brief History* in an article entitled “My Brief History: A Memoir by Stephen Hawking-Review” where he gets at the crux of the conundrum surround Hawking. Sample claims, “The trouble with being the world’s most famous scientist is that when you come to write your memoir, much has been said before” (3). It seems with this assertion that while Hawking finally puts his personal experiences into the world (as opposed to his research) the authenticity is not as palpably felt by readers of Jane Hawking’s memoirs. Journalist Chuck Leddy (2013), in his review entitled “My Brief History by Stephen Hawking,” expresses Hawking is clearly “more comfortable looking up at the universe than into himself”. These reviews interpret Hawking’s representation of himself as sheltered and pragmatic, which serves me well when contrasting them against other representations of him that play with authenticity. Leddy understands Hawking as “understated... [and someone who] reveals very little” in his memoir which problematizes the authenticity of the in-depth look readers get into Hawking’s life through J. Hawking’s memoirs.

The biopic created about Hawking's life, *The Theory of Everything*, was both widely praised and critiqued for the authenticity of its portrayal. Journalist Scott Jordan Harris (2015), in an article entitled "Why the Theory of Everything is a Disappointing Depiction of Disability," justifiably critiques the film for being made "to make able-bodied people feel good about themselves and to win Oscars". Authenticity is the tool used in this film to ease the audiences' anxiety about disability. The audience can feel as though they are learning something about disability because of its "realness" while simultaneously knowing that the actor playing Hawking is not actually disabled. This allows the audience to experience disability in an insulated environment and relieve some of the anxiety they feel towards disability. Harris' critique of *The Theory of Everything* is important for my argument in that the authenticity presented in the film is created by and for nondisabled people as a way of teaching the audience about disability. Issues arise when comparing the film's perceived authenticity as the barometer of quality and the lack of understanding of disability in Hollywood. There is a great worry that the film will be interpreted as representative of the disability experience without a true contribution from those who understand the disability experience.

#### 1.2.4. Literary criticism

G. Thomas Couser's (2004, 2009) works on life writing provide an important framing of disability representation. His theoretical framework is, at times, ethically founded and other times politically founded. For instance, one of Couser's texts, *Vulnerable Subjects: Ethics and Life Writing* (2004), comes from the standpoint that there is an ethical dilemma in representing oneself in life writing because one cannot represent oneself in isolation from one's interactions with others. One must represent others in order to represent oneself (*Vulnerable x*). The concern in the ethics of representing others is that some could be vulnerable subjects who

may be subject to misrepresentation and unable to resist said representation (*Vulnerable x*).

Couser contends that representation of vulnerable subjects consists of mimetic and political features in that a narrative “speaks *about* its subject... [and] *for* its subject” respectively [author’s original emphasis] (*Vulnerable x*). Thinking of the vulnerability of writing subjects in life writing will prove to be quite significant as I explore the ways in which J. Hawking represents herself through the representation of Stephen in her memoirs.

Couser’s text *Signifying Bodies: Disability in Contemporary Life Writing* delves into the ethical, political, and rhetorical issues that arise in disability life writing (*Signifying* 12). Couser explores the vulnerable subject again, but this time seeking how authors might go about “[serving] the best interests of the vulnerable subjects” in their representations (*Signifying* 19). He argues that creators of representations must concern themselves with the ethics of representing their subjects by contextualizing their subjects in relation to the social history of oppression and misrepresentation of disabled people. In doing so, they acknowledge the role they have in preventing further misrepresentation in their memoirs. I use Couser’s take on vulnerable subjects in *Signifying Bodies* as a way of critiquing J. Hawking’s obligation to align with Hawking’s predictable representations in her memoirs. I relate this critique to Couser’s belief that disabled people are expected “to conform to, and thus confirm, a cultural script” when representing their experience (*Signifying* 17). Applying this belief to J. Hawking allows me to further explore her delicate dance in her creation of both her memoirs.

#### 1.2.5. **Authenticity**

Robert Bogdan (1996) explores the social construction of freaks in his entry “The Social Construction of Freaks” in the collection, *Freakery: Cultural Spectacles of the Extraordinary Body* edited by Rosemarie Garland-Thomson. Bogdan examines the history of the

freak show and the manner in which it is critiqued as reprehensible in the twentieth century (23). Freak shows are some of the earliest examples of disability representation that comment on authenticity but, as Bogdan explains, freak shows, above all else, were created to turn a profit (25). Similarly to current representations, the commercial success of the freak show depended on the prevalence of *misrepresentation*. There may have been disabled people in the freak roles, but the context in which they were presented was always manipulated and embellished in order to create a more intriguing story—which is also often found in current representations. If the orator was persuasive enough, the crowd would pay the dime to enter (Bogdan 27). That dime was a small price to pay to have the possibility of encountering a real live freak. In other words, the task of freak show *was not* to present genuinely authentic freaks, but to create the *illusion* that the freaks were genuinely authentic. This historical framing of authenticity and representation in the profit driven industry of freak shows, mirrors the circumstances of current representations in film and literature. Both historical and current disability representations seek commercial success and wealth, even at the cost of misrepresenting the disability community through enhanced or fabricated character depictions presented as “authentic.”

Henry Louis Gates, Jr. explores the idea of authentic representations in terms of race in his piece “White like Me” about a black man named Anatole Broyard who passed as white writer because he did not want to be categorized as a black writer. This piece frames passing as a “sin against authenticity and [contends that] ‘authenticity’ is among the founding lies of the modern age” (Gates 353). Here, Gates expresses that personal authenticity is created through a process of culture reflecting on the individual. Namely, Broyard’s personal desire to be first and foremost a writer is a reflection of his cultural knowledge that if he identified as a black

writer, he would have to write about black issues. This sort of writing was not of interest to him, so he chose to pass (Gates 349).

Gates reinforces his perspective towards authenticity in his piece “‘Authenticity,’ or the Lesson of Little Tree,” with his statement “all writers are cultural impersonators” (520). This statement reveals authenticity to be a socially constructed concept. Seeing authenticity as socially constructed uncovers that no one is inherently authentic because it is a learned and performed behavior. Gates also observes that once we “start interrogating the notion of cultural authenticity...our most trusted critical categories come into question” (521). With this statement, Gates simultaneously points out the illusory feature of authenticity and how dependent people are on authenticity to organize and navigate their lives. I use Gates’ understanding as a foundation for how I examine authenticity in this work.

Lionel Trilling’s (1972) *Sincerity and Authenticity* exemplifies the conundrums Gates’ work addresses. Trilling presents sincerity as the backbone of authenticity. He claims sincerity was historically used metaphorically to mean a man’s morals were guided by beneficence, but soon regressed to mean the absence of dishonesty (Trilling 12). This is problematic, particularly in relation to representation, because someone can be sincere even when they are ignorant to the truth; they are not being dishonest *per se* if they are unaware of the reasons a representation is inaccurate. It may be helpful to note in comprehending the relationship between authenticity and sincerity that something that is sincere can be inauthentic, but something that is insincere would be difficult to make authentic. In other words, sincerity is the intentionality behind the action that can be determined to be authentic or inauthentic. One could argue that many disability representations are placed in the position of attempting to be read as authentic without underlying sincerity in that they attempt to relay messages to

consumers that are authentic, but insincere. While Trilling understands that defining authenticity is elusive, with its vast contemporary application, authenticity can be generally understood as being a more concrete principle that not only deals with the ways individuals guide their own lives, but how those lives are contextualized in and transparent to culture (9). For the purpose of this work, it is particularly important to see how this ambiguity of the term sincerity affects the contrast between authenticity in relation to the self by being true to oneself for one's own purposes and this work's use in a way of understanding the relevant disability representations.

### 1.3 **Methodology**

I employ Kafer's political-relational model as methodology in my analysis of the quest for authenticity through disability representations as a way of reconceptualizing traditional notions of disability. To bolster Kafer, I use Carrie Sandahl's concept "representational conundrums" to explain the importance of asking questions. I use discourse analysis to study the constellation of texts surrounding the disability representation I chose to analyze. To assist with my analysis of the film *The Theory of Everything* I use Stuart Hall's (2006) encoding/decoding model of communication which is rooted in reception theory. I then go into my process of selecting my primary and secondary sources. I conclude this section with a discussion of how I enlist a critical disability studies lens as a method to perform close readings of the primary sources examined in this work.

Kafer's political-relational model acknowledges impairment's significance to the lived experience of disability as "*both* impairment and disability are social" (7). Kafer emphasizes the precariousness of the harsh binary between the medical and social model and puts forth the need to recognize the inherent fluidity of disability "as a site of questions rather than firm definitions" (11). I choose to raise questions about disability rather than provide answers because answers are

finite whereas questions create new spaces for knowledge and understanding about disability. I use Kafer's model to question the ways disability representations are validated when determined to be authentic and how disability representations are constructed to meet the evasive standard of authenticity. I also use Kafer to question the effort to *increase* authenticity as a means to an end. Questioning the rigidity of disability creates a path to explore the depth of disability as a complex entity in ways that enrich my analysis of disability representations. I reinforce Kafer's method of questioning with Sandahl's concept of "representation conundrums," which she uses to encourage her students to ask questions rather than seek answers as a way to engage critically with difficult material. This allows her students to play with their approach to questions in areas that require deeper analysis. Beyond of the pedagogy of Sandahl's concept, "representational conundrums" reveal the spaces that are neither simple nor easily critique, yet require consideration.

Using discourse analysis provides me with an opportunity to explore how these various cultural texts deploy notions of authenticity to create and critique meanings of disability in representations. I implement discourse analysis as a way of seeing disability representation as a self-reinforcing web of knowledge. In other words, the information created in response to a given representation results in that representation either reinforcing or challenging current notions about disability. In thinking about disability representations in terms of discourse, I put the various primary texts in conversation with one another and put the discourse around these texts in conversation with one another as a way to identify and analyze patterns and inconsistencies of those patterns.

I stumbled upon Hall's encoding/decoding model of communication presented in his chapter "Encoding/Decoding" in the anthology *Media and Cultural Studies* during my research

into the analysis of *The Theory of Everything*. The premise of Hall's theory is that a given cultural text, such as a film, television show, or even a news broadcast, creates a "communicative exchange" between the creator and consumer (Hall 166). Hall identifies the creator as performing the encoding, which infuse the text with intentional "meaningful discourse," while the consumer performs the decoding, which incorporates and then situates the meaning of the text within a consumer's extant contextual framework (165). This process is heavily influenced by social determinates including race, class, gender, sexual orientation, disability, age and also can interact with discourse the consumer may have engaged with about the cultural text prior to their consumption of it. This act of decoding can "influence, entertain, instruct[,] or persuade" and, as Hall argues results in "the structure of social practices" (165). Hall's theory is significant to my analysis of *The Theory of Everything* because it sheds light on how consumers attribute authenticity to the film.

The primary sources I examine are the memoirs by Jane Hawking and the autobiography by Stephen Hawking as well as a biographical Hollywood film, *The Theory of Everything*, directed by James Marsh. I discovered these texts and film in Sandahl's disability studies course entitled Visualizing the Body. I chose the film because it is a relatively recent Best Picture depiction of disability ripe to be analyzed using a critical disability studies lens. It is also a complex representation, as the film script was adapted from J. Hawking's second novel *Travelling to Infinity*, which reflects a happier, more pleasant account of her life with Hawking as opposed to her first novel, *Music to Move the Stars*, which reveals a much more brutal look at her life with Hawking.

Including the Hawkings' memoirs and autobiography rounds out and further complicates the representations created by Marsh and again allows me to raise questions regarding



positionality and authority. This intersection between disability, authenticity, and public interest in the texts makes them apt for analysis using a disability studies lens, as they challenge traditional notions of the disability experience. These texts raise questions about *who* has the power or authority to create a given disability representation. The secondary sources that I use to analyze the primary sources come in the form of web-based popular criticisms, literary criticisms, academic articles found through the JSTOR database, and academic texts within and beyond disability studies.

I use a critical disability studies lens as a way to conceptualize disability as existing beyond the binary of the medical and social model, requiring a more complex framing of disability and resulting work on disability. This lens enables me to see the power of dominant culture to determine when authenticity is “achieved” in a disability representation and the need to seek a reformation of this power. I aim to frame disability representation using critical disability studies in order to identify the social problems inherent in the quest for authenticity in disability representations as we currently understand them and to strive to determine a more empowering manner to frame the concept and condition of disability.

#### 1.4 **Breakdown of Chapters**

Authenticity and disability representation is a complex and multi-faceted issue requiring consideration in this cultural moment. In order to investigate this subject from distinct angles, I use my first body chapter to lay out Hawking as a popular culture icon and his pervasive representations. My second body chapter uses J. Hawking’s memoirs to explore the complexity of perceived authenticity of Hawking representations and multiple truths. My third body chapter uses *The Theory of Everything* as a case study to further explore Hawking representations.

Collectively, the three chapters provide a dynamic exploration of the material of disability representation and authenticity.

My first body chapter, “The Ubiquitous Stephen Hawking: His Representations as the Exception and the Rule” examines Hawking as a cultural icon. I explore the discourse around Hawking and representational conundrums that allow me to lay out guiding questions. For instance, Hawking often represents the disability community because of his visibility, even though he neither claims to represent anyone beyond himself, nor engage with the disability community. This prepares me to question what statement this conundrum makes about the authenticity of literature about Stephen Hawking and the literary techniques enlisted to make representations of the disability experience universal. To accomplish this, and ask further questions about Hawking as a cultural figure, I draw on his autobiography *My Brief History* as well as a biography by Helene Mialet entitled *Hawking Incorporated*.

My second body chapter, “Traveling through Disability: How Stephen Hawking is Authenticated through Representations” focuses on works about the physicist, including J. Hawking’s *Music to Move the Stars* and *Travelling to Infinity*. But first, I put forth an explanation for cultural understanding of disability, disability culture, and disability representations as cultural products. I then consider how disability is represented through cultural representations as well as how these representations influence cultural understanding of disability. This creates a space to identify the inherent complications in disability representations and highlights the centrality of authenticity in an analysis of disability representations.

I also use this chapter to further define and explore my understanding of the term authenticity that is applied to the case studies I examine. I explore questions including what is authenticity generally and contextualized in disability, what are the inherent problems in

authenticity, and what are the constructs that create perceived authenticity. Setting up the parameters that frame my analysis is necessary work that will situate the readers within the lens I am using throughout.

I then venture into an exploration of Hawking representations. I use *Music to Move the Stars* and *Travelling to Infinity* written by J. Hawking to offer points of comparison between the two narratives. To further complicate the representation, I gesture to how Hawking represents himself in *My Brief History* and how he is represented as a cultural figure. Using these narratives provides an opportunity to examine the ways in which voice and positionality influence portrayals that read as “authentic”. Comparing these various narratives provides a space for me to assess how Hawking’s representations in the texts counteract or contribute to the authenticity *The Theory of Everything* attempts to create.

My third body chapter, “The Theory of Acting Authentically: How Embodying Deterioration Leads to an ‘Authentic’ Representation in *The Theory of Everything*,” explores Hawking’s biographical film *The Theory of Everything*. I argue that every breakthrough Stephen makes in the film is marked by a physical change in the progression of his disability, making these feats increasingly impressive to the consumer. In the first section of the chapter, I walk the reader through a close reading of the film. I examine many of the film techniques enlisted in production to create a certain narrative about Stephen. In the second section of the chapter, I put the film in the context of the broader discourse surrounding the film. This allows me to explore the role of authenticity in the discourse and further problematize the hold authenticity has on disability representations like *The Theory of Everything*.

My conclusion creates a space for me to turn the conundrums I have identified thus far inside out as they relate to authenticity and Hawking representations. By turning them inside out,

I mean that I reconfigure the approach and questions to these inconsistencies, enabling me to reveal authenticity as a tool to be manipulated for a specified end. I confirm that multiple truths can exist simultaneously, rendering authenticity an unreliable and elusive target. I address where this research on representation and authenticity can go from here in considering what authenticity in the Hawking texts mean for cultural representation of disability. Through this, I illuminate the ways in which authenticity is enlisted as a narrative device to bolster the representation as characteristic of lived experiences. I again, divulge the various pitfalls of the enlistment of perceived authenticity in disability representations by pointing to the ways in which these “authentic” disability representations reinforce cultural norms about disability.

## 2. THE UBIQUITOUS STEPHEN HAWKING: HIS REPRESENTATIONS AS THE EXCEPTION AND THE RULE

Stephen Hawking is a popular culture icon. He is known as the brilliant and limit-defying disabled theoretical physicist with a good sense of humor to boot. Sitting down to an evening of television, a consumer can find a plethora of representations centering on Hawking, hereinafter “Hawking representations.” Hawking has been portrayed by Eddie Redmayne and Benedict Cumberbatch in film, represented as a cartoon in *The Simpsons*, and heavily referenced in television dialogue. Consumers also experience Hawking representations through the numerous fiction and non-fiction books written by and about Hawking. There is even an entire Wikipedia page devoted to organizing the vast representations of him in popular media entitled “Stephen Hawking in Popular Culture.” With so many Hawking representations out there, I ask, what makes Hawking *so* compelling? Why are Hawking representations *so* pervasive in popular culture?

Hawking is both the exception and the rule when it comes to disability. He is extraordinary—a genius—*despite* his disability. He transcends disability in many ways with his nonchalant and witty personality. These features humanize him in a way that jars with most representations of disabled people. Yet, he is often reduced to nothing more than his disability—he is famous *for* his disability. How is it that a man can both transcend disability and be defined by it? What are the consequences of this sort of disability representation? We in the disability community are expected to overcome our disabilities to meet the societal standard that may be reinforced by Hawking representations. We must aspire to his success in order to make meaning out of “tragedy.” Yet, there is an underlying current in this discourse that Hawking is one in a million and we should be grateful to simply be associated with him in terms of disability.

Hawking representations create an elusive and unattainable standard for the disability community to live up to, forcing us to exist in the shadow of his version of disability or, rather, the version of disability shaped in Hawking's image.

His image reinforces the tropes that are so common to disability representations—the inspirational and overcoming narrative. Society sees the potential of the disability community in these narratives and in figures like Hawking who do not let their disabilities stop them from doing what they love. If disabled people can just work hard enough, try hard enough, we will transcend disability and contribute like our nondisabled peers. This assumption is ultimately damaging to the disability community because the simple narrative seeps into structural entities such as governmental policies and social programs. For instance, the late historian Paul Longmore (2003) discusses in his text, *Why I Burned My Book and Other Essays on Disability*, burning his 1988 book entitled, *The Invention of George Washington*, in protest of losing his Supplemental Security Income benefits. He was told he would lose his benefits due to his book royalties being considered “unearned” income. Longmore thoughtfully decided to make a protest out of his book burning and ultimately drew a large crowd of disability activists on October 18, 1988, “in front of the federal building...in downtown LA” (Longmore 252). Longmore later asked his friend, fellow activist, and disabled psychologist Carol Gill why the protest was so emotional for the crowd. She responded, “The entire protest, and especially the burning of the book, gave tangible form to the pain they felt about their own lives” (qtd. in Longmore 253). Longmore continued, “They too felt thwarted by a government that stymies their efforts to work and make a life. They too felt dehumanized by a society that devalues them” (qtd. in 253). Disabled people are often deemed a drain on the system because there is always an underlying expectation that we should overcome our disabilities. If Hawking can, why can't we?

What is important to take away from this story is that Longmore, as an Supplemental Security Income (SSI) benefit recipient, *was* working and doing what the Social Security Association hopes of their recipients—to *overcome*. And yet, Longmore still ran up against barriers to his goal of teaching American History at a university—he was not doing *enough*, working hard *enough*, to support the care his disability required. In many ways, he was working *too much*, he was *too* successful to require the support of SSI. He was not poor *enough* to require SSI once he became a published university professor. Although Hawking dealt with similar barriers in obtaining funding for care, evinced by J. Hawking’s narrative *Music to Move the Stars*, this fact is often obscured underneath Hawking’s more predominant persona of the inspiring genius who overcame. There were and still are systematic barriers to the disability community living successful, enriching lives. The overarching narrative that persists in media and in Hawking representations work to perpetuate the expectation that we should all overcome like Hawking has with his disability. This narrative has been successfully infused into our cultural discourse of disability with the assistance of a representational script executed in Hawking representations.

There are core tenets to Hawking’s public persona that are found in all Hawking representations that work to authenticate them. Each representation must entail standard features or physical and personality traits of Hawking that highlight a slouched white man with a crooked smile and glasses steering a power wheelchair with an attached speech synthesizer. Of course, speaking with his iconic robotized voice, often making a quip—these features are *quintessentially* Stephen Hawking.<sup>2</sup> Even facts suggested by Mialet (2012) such as “the role of his wife in his survival, and his capacity to think in a geometrical way” help shape the public

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<sup>2</sup> These features are quintessential because they meet a predetermined standard of how culture receives and engages with Hawking representations.

persona that Hawking assumes, contributing to the authenticity of any given Hawking representation (8).

How do analyzing Hawking representations enhance an analysis of the authenticity of disability representations? This chapter explores this question and work to expose the structure of authenticity in disability representations. This chapter will also work to unravel the discourse surrounding the public persona of Hawking and begin to piece together the ways in which authenticity bolsters Hawing representations to universalism.

## 2.1 **Universalism of Stephen Hawking**

Stephen Hawking personifies disability. Hawking is the face (and in many ways the body) of disability, so when consumers see a photograph of Hawking they can tangibly understand what the term “disability” means. He has met and exceeded all normative expectations set by dominant culture—he is successful, he is rich, and he is famous. While his success may be independent from his disability, his fame is intricately interwoven with his disability. Having a career *while being disabled* has made his cosmological discoveries much more extraordinary. Hawking has been portrayed as superhuman in comparison the disabled community because society’s expectations far exceed the devastatingly low for the broader disability community. Stephen’s career gives his life and persona a social status that is not afforded to most disabled people. McRuer’s concept of compulsory able-bodiness helps me demonstrate how the cultural value of ability relies on disability. McRuer argues that there is a “contradictory space between a cult of ability (centered on discipline and domesticity) and cultures of disability (centered on networks of interdependency),” which exposes Hawking’s treatment as a double standard (4). Hawking is positioned to reside in both spheres.



Analyzing Hawking's framing as superhuman enables me to understand that his persona works to reinforce cultural narratives of disability—*the only disability in life is a bad attitude*. Hawking has overcome his disability and exceeded social expectations so that consumers believe that he has transcended disability with the help of a witty, positive attitude. While Hawking's scientific feats are weighty on their own, he becomes extraordinary in accomplishing those feats because he is simultaneously defying the odds of motor neuron disease. Would Hawking be the cultural figure that he is without his disability? Or even without his ability to write accessible books about physics? I doubt, it because if he were famous simply for his physics or ability to write about physics for the general public, his colleague Roger Penrose, whose work inspired Hawking to study black hole singularities, would also be a household name. The journalist Michael D. Lemonick (2014) uses his article "Hawking Gets Personal," to argue "it's the disability, though, and his fierce determination to carry on regardless, that makes the [2014 documentary] film so engaging and [Stephen's] life so uplifting—and perhaps makes people want to overstate his accomplishments." It is the juxtaposition between the god-like status of scientists and the tragic status of disability that I believe, in part, makes Hawking so enticing to consumers. Or, as Lemonick (1993) relays an interview with Hawking in his article "Hawking: Is He All He's Cracked Up to Be?" that "though Hawking argues that the public bought his first book largely because of the ideas it contained, his readers were probably just as interested in the man himself. 'No one can resist the idea of a crippled genius,' Hawking says, with an edge of displeasure." McRuer's (2006) theory of compulsory able-bodiedness can be applied here to Hawking's perspective on his representation and celebrity because McRuer's theory suggests that "able-bodied identities [and] able-bodied perspectives are preferable and what we all,

collectively, are aiming for” reinforces Hawking’s understanding that it is his reputation as a genius that makes him irresistible (9).

Consumers are often intrigued by the obscurity and intangibility of disability which makes disability representations like the Hawkings’ enticing because they help them understand disability better. The other side of this intrigue is that consumers feel a disabled scientist like Hawking is extraordinary because culturally, we do not expect disabled people to succeed professionally. Consumers are surprised that a *disabled* person can achieve what Hawking has in his career. Consumers are enticed by Hawking’s talents, almost viewing him as if he were a unicorn—magical, rare, and unlikely to cross our paths again. This juxtaposition uncovers the conundrum that, while Hawking embodies the very definition of disability and is often the disability community’s unofficial spokesperson,<sup>3</sup> providing consumers with a visual understanding of disability, he has never been held to the low expectations of his fellow disabled folks for whom he represents.

Perhaps Hawking is the face of disability because he embodies the feel-good message of overcoming disability that culture desperately desires when faced with disability. Disability representations tap into consumers’ deep seated fears of losing their ability and becoming dependent on others. Representations like that which center Hawking let the consumer off the hook in that the consumer can interact with disability in an insulated environment without having to think critically about the representation. The journalist Kristen Lopez (2017), in an article comparing representation of disability and racism in film entitled “‘Get Out’ and the Overlap of Disability and Racism,” astutely points out “Hollywood [believes] that only an able-bodied audience will respond to a person who was once ‘like them,’ i.e., able-bodied and struck down in

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<sup>3</sup> Much to the disability community’s dismay

their prime.” This observation illuminates the potential for consumers to be more engrossed by a disability narrative when a nondisabled character becomes disabled because they can identify with the “trauma” of losing ability. Consumers experience the carnage representations make disability out to be and are viscerally relieved when the character (in this case Hawking) “overcomes” his disability at the end of the film and is restored to his prior glory, a character the consumers can again identify with.

The ending scene in *The Theory of Everything* presents Stephen being recognized and awarded for his contribution to science. This scene enables Stephen to overcome his disability by daydreaming about agilely picking up a dropped pen. Stephen’s desire to regain his ability reinforces the narrative that what disabled people want most in the world is to be nondisabled, an opinion often imposed upon the disability community without consent (McRuer 8). Authenticity plays an important role here because it convinces consumers that the disability experience that is represented on film or in literature is what disability is *really* like—disabled people really *do not* want to be disabled, disability *is* as Eddie Redmayne’s portrays it in *The Theory of Everything*, or it *is* as J. Hawking describes it in *Travelling to Infinity*. Hawking’s disability is presented as a concrete fact of the body, while his research is understood as expansive. Disability anchors us to a reality that many fear, while cosmology is about exploring the vastness of the universe as we look towards the stars. So, to have these two truths juxtaposed against one other creates an equilibrium not typically associated with disability in dominant culture. This resolve is yet another reason Hawking is used as a symbol of disability—he neutralizes it.

## 2.2 **Stephen Hawking as a Representation**

Beyond Hawking’s centrality to our cultural understanding of disability, he is an intriguing figure because the core tenets of his representations make his representations easily

reproducible and authenticated. A Hawking representation, like other representations seeking authenticity, must only “reproduce essential features” to be authenticated based on the Merriam-Webster (2016) definition of authenticity. For this reason, a consumer can experience Hawking in a variety of different mediums (film, interview, article, and even cartoon) and be fully convinced that the representation represents the *real* Hawking if it meets a certain standard. Consumers believe Hawking representations when the representations reinforce the core tenets of Hawking that are already ingrained in our cultural narrative.

The authentication process of Hawking, relative to his core tenets, can perhaps best be represented on a Likert scale, enabling the authenticity of his characteristics to be understood on a spectrum and in a matter of degree.



Figure 1. “Eddie Redmayne Portraying Stephen Hawking in *The Theory of Everything*.” *Expats Post*, Jennifer Kiley, 15 Jun. 2015, <http://expatspost.com/entertainment/film-review-the-theory-of-everything/>.

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<sup>4</sup> Image description: Eddie Redmayne portraying Hawking in *The Theory Everything*. He wears a suit and glasses and sits pensively in a metal and red leather power wheelchair with a square metal speech synthesizer in front of a blue background.



Figure 2. “Stephen Hawking - Appeared as himself in ‘They Saved Lisa's Brain’.” *The Verge*, Nathan Cykiert, 25 Aug. 2014, <https://www.theverge.com/2014/8/25/6049525/the-simpsons-celebrity-cameos>.

**TABLE I**  
**EXAMPLE CRITERIA FOR JUDGING A HAWKING REPRESENTATION**

Feature	Present		Very Bad (1 pts.)	Bad (2 pts.)	Moderate (3 pts.)	Good (4 pts.)	Excellent (5 pts.)
	Yes	No					
Power Wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Robotic Voice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech Synthesizer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glasses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Crooked Smile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smiling Eyes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Scrawny White Man	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Overall Authenticity</b>			<b>/8</b>	<b>/16</b>	<b>/24</b>	<b>/32</b>	<b>/40</b>

<sup>5</sup> Image description: A cartoon version of Hawking in *The Simpsons*. He is seated in his power chair against a blue and white sky background and has a deadpan expression on his face. He is wearing a grey suit with blue button-down shirt using his left to operate his computer controller and his right hand to operate his joy stick.

Imagine a film reviewer or even a particularly astute consumer sitting down to judge the authenticity of Redmayne's portrayal of Hawking in *The Theory of Everything*. They might use a version of the aforementioned Likert scale checklist to aid in their determination. The consumer's identification of the various features is the first step—whether or not the power wheelchair or the smiling eyes, for instance, are present on screen—“yes” or “no.” The next step for them is to determine the quality of the portrayal or use of feature. On a scale from “very bad” where they would award the feature only one point, all the way to “excellent” where they would award the feature five points. Once the viewer makes the determination of quality for each feature, they tally the points, which determines not only whether the disability portrayal is authentic or not, but also *how* authentic the portrayal is on screen based on the Likert scale titles. For instance, if the viewer thought all features were “excellent”, the features would receive a combined score of forty points, making Redmayne's portrayal of disability “excellently authentic.”

Thinking about assigning authenticity using the aforementioned chart assists me in breaking down how representations are authenticated. People are socialized to think about disability and disabled people in a particular way that aligns with acceptable social norms, which are then reinforced through representations. While this socialization often occurs unknowingly, the consumer does not have to be consciously aware of their knowledge of disability to be able to apply that knowledge when they encounter a disability representation. A consumer is able to determine the *authenticity* of a Hawking representation in part by whether or not it aligns with what they already know about Hawking or disabled people broadly. What makes this tricky, however, is that part of what we learn about disability is that it is mysterious and unknowable. We are equipped with notions of disability, but little that is concrete and tangible. We are taught

that in order to interact with disabled people, *we have to know what is wrong with them*—we have to make them knowable (Garland-Thomson 11). As a result, consumers engage differently with disability because we are generally less familiar with it as a subject. Believing a representation is authentic enables consumers to assume they know something real about disability which, Garland-Thomson warns, is particularly risky when we lack “direct knowledge” of the subject (10). To compensate for this gap in disability knowledge, consumers automatically put more faith in representations on topics they are unfamiliar with because we assume the representation know better than we do.

An authentic Hawking representation, like all disability representations, works to “[conform] to an original” (Merriam-Webster 2016) which “relies upon the cultural assumptions” of the consumer to enter into the representation with a framework for it (Garland-Thomson 11). The task of the creator of said representation is to meet the expectation not only of the consumer, but the Hawking representations that have come before them that teach the world about the genius. Through these reproductions, Hawking becomes easily identifiable and simplifiable to the point that the consumers need not ask critical questions about why he represents disability or why he is inherently authentic—he just *is*.

Hawking exists as an authentic cultural figure because consumers have been inundated with Hawking representation in their exposure to disability. His representations are so effectively reproducible that consumers take them at face value. Mialet (2012) suggests specific tenets or life events<sup>6</sup> associated with Hawking become “the established one... [and that version is] taken as a ‘given’” (85). These traits become who Hawking is to our culture. Even when the representation presents contradictory traits of Hawking like with J. Hawking’s portrayals, the

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<sup>6</sup> Examples of these life events or core tenets include, but are not limited to his speech synthesizer and physical body or the story of how Hawking discovered black hole radiation.

media assists in this process by developing and disseminating Hawking representations that often “organize themselves around [a specific set of] quotations ... [that] resemble one another down to the last word” (Mialet 82). Through my extensive research on Hawking representations, I have begun to see the repetition of the same quotations—even to the point that I can find the same string of quotes that reveal or construct the same argument in different articles. For instance, the following quotes are found in *Music to Move the Stars*: Stephen is an “all-powerful emperor” (564) and “masterly puppeteer” (555). This string of quotes was used in a number of unrelated articles to challenge the angelic persona of him that oozes throughout media. That is to say, even something as seemingly benign as the manner in which quotes are used in a given article, can enhance the perception of authenticity of Hawking representations.

The life events of Hawking are shaped, produced, and regurgitated to such an extent that they become uncontested truths that float around our cultural unconscious. Hawking himself is quoted in Mialet’s *Hawking Incorporated* as saying, “Anything that has appeared in print so many times has to be true” (qtd. in 85). This statement feels disconcerting, as though Hawking himself is complicit in the construction of these representations consumers broadly take as true. The important element to remember is twofold: one, we, as consumers, will never be able to determine one way or another what is true about Hawking or whether Hawking is the puppet master of his representations and two, that is *not* the question we should be asking—these competing truths are implemented as a distraction from critically critiquing the representations themselves. We should be asking what Hawking’s statement means for thinking about authenticity as a tool and how his statement represents the secures the boundaries around authenticity.



### 2.3 **Stephen Hawking as a Case Study**

The specific Hawking representations I examine in this text are J. Hawking's memoirs *Music to Move the Stars* and *Travelling to Infinity*, Hawking's autobiography *My Brief History*, and James Marsh's biographical film about Hawking *The Theory of Everything*. These representations offer the most stimulating cultural locations to study authenticity of Hawking representations that are created in close collaboration with Hawking and J. Hawking, resulting in the texts' uncontested authentication on the part of the consumers.

Each of these memoirs are interpreted as authentic to consumers, despite the fact that they, at times, contradict one another in the manner in which Hawking is portrayed. The facts *do* change from representation to representation in that some are left out and others included to align with a certain portrayal of Hawking. However, these selections are subtle and unobvious to the general consumer so as to not negatively affect the representation's perceived authenticity of the public figure. General consumers are not going to notice the little inconsistencies between the representations and they do not have to because the image and narrative of Hawking is sufficiently engrained in our culture as to take the responsibility of perceptivity off the consumer. But, as a critical consumer who has spent a great deal of time examining and analyzing these representations, the inconsistencies are clear and illuminate the implementation of authenticity. For instance, *Music to Move the Stars* was published in 1999, soon after the Hawkings' divorce which shapes the manner in which Stephen is represented. Smith (1999) noted "just before their marriage breaks down, she reveals to a journalist that her role no longer consists of promoting his success but of 'telling him that he was not God.'" (8) This quote palpably portrays Hawking as egotistical and self-serving, not the inspiring Hawking we all know and love. Consumers get closer to the Hawking we have come to expect in the 2007 republishing of J. Hawking's text,

about which Marttila (2014), a commenter on *Amazon* believed “The writer gets across her overwhelming struggle without ever diminishing her husband.” This comment helps clarify the shift in representing Hawking from J. Hawking’s first memoir to her republished memoir. J. Hawking makes a large leap from her initial portrayal in *Music to Move the Stars* to *Traveling to Infinity* that the general consumer is not positioned to question. Each of these texts are deemed authentic and yet they tell different stories—they create different truths.

A few years later, in 2013, Hawking wrote an autobiography, entitled *My Brief History*. This text is also interpreted as authentic, but he paints quite a different picture of himself from the one we see from J. Hawking. In his autobiography, Hawking represents himself as a blasé genius who finds the details of his personal life uninteresting, but arguably recognizes that he can use his autobiography as a platform to demystify the process behind his incredible discoveries that consumers are so enthralled by. Hawking exploits the appeal of superhuman intelligence as a *disabled* man with long passages of his research, without revealing much of anything about his experience as a disabled person. Hawking feeds into his representation as the exception and the rule with the following statement he made in a forum with college students “[The media] just [wants] a hero, and I fill the role model of a disabled genius. At least, I am disabled, but I am no genius” (Mialet 86). Here, Hawking toys with his public persona and the ways in which consumers idolize that persona. The consumer then wants to support his success because of humility, heightening the authenticity of Hawking representations. Mialet argues in this way, Hawking has a great deal of control over his persona (86). This argument is particularly poignant in the context of Mialet’s perspective that “[Hawking] himself either plays the game and lets the media exploit his writings or rebels and intervenes in the construction of his own myth” (85). Mialet’s point exposes authenticity as an instrument to be implemented to reach a desired end. I

attribute this control directly to the role authenticity plays in representations because it is the authenticity of his quotes and public appearances that create the guidelines of the more fabricated representations in film and literature.

The biographical film about Hawking directed by James Marsh, *The Theory of Everything*, was released in 2014 to rave reviews from consumers and critics alike. The film is of interest as an authentic Hawking representation because it is based on J. Hawking's *Travelling to Infinity* which, as noted earlier, softens the portrayal of Hawking. What is most intriguing in Hawking representations is what "facts" are and are not included in a given representation and how that contributes to the manner in which Hawking is presented as authentic. Again, each of these representations is authenticated by the core tenets of Hawking's "broad dimpled smile" (*Travelling* 44) or his "electrically powered wheelchair [allowing] Stephen maximum independence" (*Travelling* 214). Beyond the core tenets that create a streamlined image of Hawking, there are numerous faces of Hawking found in the nuance of Hawking representations

Another intriguing element of Hawking representations is the aspect of authentication that comes from the approval of the film by the individual and family being represented, in this case, Hawking and his family. Redmayne befriended Hawking's son, Tim, during his time working on the film, so he eagerly awaited Tim's opinion of the film when it came out. Redmayne mentioned in an interview with Jeff Labrecque (2014) entitled "TIFF: 'Eddie Redmayne and Capturing the Smiling Eyes of Stephen Hawking'"<sup>7</sup> that Tim texted him after him and his sister, Lucy, had finished watching the film. Redmayne relayed the text message, "At the end, when Stephen gets up, they both said the fact that they could see, for a second, what their father may have looked like able-bodied was incredibly moving for them. And in turn, very

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<sup>7</sup> TIFF: Toronto International Film Festival, where *The Theory of Everything* was screened as a special presentation.

moving for me”<sup>8</sup> (qtd. in Labrecque). By including this anecdote in the interview, Redmayne humbly demonstrates the Hawking’s approval, offering a rich location to analyze authenticity. A necessary question to ask is how does Redmayne’s quote demonstrate the Hawking’s approval and what meaning create about disability? I would argue the most significant element of the quote is the inclusion of “they could see, *for a second*, what their father may have looked like able-bodied” [emphasis added] (qtd. in Labrecque). The italicized portion draws attention to Hawking’s childrens’ seemingly deep-seated desire to see their father as abled-bodied—Hawking in his “authentic” form. The childrens’ perceived longing also uncovers their adherence to Kafer’s (2013) notion that the “fears of disability ... are often bound up in a kind of *compulsory nostalgia* for the lost able mind/body, the nostalgic past mind/body that perhaps never was” (42). In essence, the film is moving to the Hawking children because it enables them to bathe in the nostalgia for an able-bodied father.

Analyzing Hawking representations and the discourse around them reveal thought-provoking complexity to these seemingly innocuous representations that treat Hawking like a universal figure in that he embodies the exception and the rule to disability. There are different versions of Hawking depending on the author of the representation. Namely, when Hawking represents himself in his autobiography, consumers get the most alignment to his public persona perhaps implementing the core tenets of Hawking to identify him as the stoic genius. *The Theory of Everything* and *Travelling to Infinity* also fit this persona to a certain degree, but each include more emotion and personal facts because it comes from J. Hawking’s expressive writing.

Hawking’s character in *Music to Move the Stars* fails to fit the features of the public persona

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<sup>8</sup> It is worth noting that the fact that Hawking’s children wanted to be able to imagine their father able-bodied demonstrates how effective representations like Hawking’s are in structuring our understanding of ability.

consumers know so well and, in fact, arguably works to contradict the persona all together by revealing a side to Hawking consumers have never seen before. For how simple each of his representations seem on the surface and when experienced individually, they are quite complex once they are put in context of one another.

### 3. TRAVELING THROUGH DISABILITY: AUTHENTICITY AS IT RELATES TO JANE HAWKING'S REPRESENTATION OF STEPHEN

Hawking representations rightly center around Hawking's physics and disability, but an analysis of said representations would be wholly incomplete without due attention to Hawking's former wife, J. Hawking. In *Travelling to Infinity*, J. Hawking relays a story of Ruth Hughes, a volunteer organizer at Caltech who knew the Hawking family during their year in California. J. Hawking explains, "[Ruth] had said to herself that there must be someone equally courageous behind [Stephen] or he simply would not be there" (*Travelling* 234). This remark is revealing of the significance of J. Hawking's involvement in Hawking's success, regardless of whether she received the credit she deserves. There are moments in *Travelling to Infinity* that illuminate the thankless role J. Hawking played in her twenty-five-year marriage. One moment in which Jane describes Stephen receiving Fellowship of the Royal Society honor reveals J. Hawking's unsung role poignantly:

With my arms round each of the children, I waited at the side of the room for him to turn towards us with a smile, a nod, just a brief word of recognition for the domestic achievements of the nine years of our marriage. It may have been a mere oversight in the excitement of the moment that he did not mention us at all. He finished speaking to general applause, while I bit my lip to conceal my disappointment. (213)

J. Hawking's role in Hawking's success and, more importantly for my purpose, her role in the construction of his representations through her memoirs *Music to Move the Stars* and *Travelling to Infinity* is central to understanding the tangled web of Hawking representations and the ways in which they are constructed to read as authentic.

### 3.1 **Authenticity and Representation**

Authenticity is a nebulous and ambiguous concept. In the simplest terms, authenticity can be described as the quality of possessing integrity and honesty. But what does it mean for something or someone to have integrity or honesty—to be authentic? Humans seek authenticity in family and friends, but also in their entertainment. While it may be challenging to define, people know it when we see it. Sociological scholar John Carroll (2015), in his article “Authenticity in Question,” argues authenticity is the answer to “a post-religious era” where people have shifted their belief system away from God, but still desire something to help make sense of it all (611). Carroll continues, “authenticity has proved to be one of the leading ideals” in the 21<sup>st</sup> century, making it far reaching and ripe for analysis (611).

Authenticity structures much of the determination of quality of a representation and core tenets, like that which are found in Hawking representation, help consumers quickly identify determine the authenticity of a representation. But, I wonder, do these tenets allow us to conclude that Hawking representations are authentic or do they simply fit a familiar Hawking narrative? Do consumers use authenticity less as an entity held to a high standard or more to provide comfort and consistency in disability representations? Is it authentic if the Hawking representation is written by a nondisabled person? Is it authentic because it was written by Stephen’s wife of twenty-five years? Can something be authentic that has shaped and shifted into so many versions? Can the film be authentic if it cherry-picks from the “authentic” memoir—slanting the story towards the inspirational narrative? Should authenticity be able to be manipulated and, if it is, is it necessarily soiled? These are some of the questions to keep in mind as I begin to dissect the two memoirs written by J. Hawking that I use to call attention to how authenticity can change and evolve—how truth is not always singular.

Questions of authenticity are important to study because when something or someone reads as authentic, it is understood as fact that then has the authority to be widely disseminated. However, just because something *reads* as authentic does not mean that it *is* authentic. In fact, authenticity is a socially constructed phenomenon which creates a social understanding of authenticity against a certain standard that is reproducible and makes it knowable to an audience (Garland-Thomson 11). Studying authenticity is particularly imperative in the field of disability studies because knowledge about disability is reproduced through disability representations in film and literature that, if read as authentic, are subsequently used to teach society about disability.

Authenticity is a complex animal that many in the disability community strive for perhaps only because it is better to strive for authenticity than to settle for the unsavory misrepresentation that has seeped into our cultural understanding of disability. Keeping Kafer's (2013) political-relational model in mind, we need to become more comfortable with disability as a location to ask questions, rather than find clear answers (11). Often, the argument for increased authenticity is to get disabled actors into acting roles and disabled writers and directors in those roles. Let the disability community speak for themselves and represent themselves to the masses as a way of slowly undoing the damage of narratives that represent disabled people one-dimensionally as the "tragic crip" or "inspirational savant." It feels like an answer to the disability communities' rightful dissatisfaction, but it is too simple. This answer neglects the complexity of authenticity in that something is not simply authentic or inauthentic. Kafer demonstrates with her political-relational model that disability requires complex thinking if we are to move forward in the way we interact with it as a social concept by "[exploring] the creation of [discrete and self-evident disability] categories and the moments in which they fail to



hold” (10). Kafer’s conception creates the space for me to contend, disability is too complex to be constrained by the either/or of authenticity. There is not one pure example of authenticity that can be applied across the board, and yet, authenticity is thrown around haphazardly in everyday conversation both in context of disability and non-disability related topics like there is a clear-cut definition. Perhaps authenticity has become a leading ideal—enough for people to be able to understand authenticity when we see it and use it to organize information. But ultimately, my assessment of authenticity is that it is murky and elusive—it changes shape at the hands of the creator as if it were clay, so that there can be innumerable Hawking representations that present Hawking in distinctly different ways that can all be read as authentic.

### 3.2 **Representation of Stephen in *Music to Move the Stars***

*Music to Move the Stars* was published in 1999 by J. Hawking following her separation from Hawking in 1990 and subsequent divorce in 1995. J. Hawking says in a 2011 interview with Ruth Hessey, “It was cathartic and painful [to write *Music to Move the Stars*] but in a sense I knew it was a salvation. It unburdened me of my memories. I really feel that having consigned it to paper, I don’t have to carry it around anymore.” The memoir’s cathartic nature is palpable with its meticulously detailed descriptions of events and emotions. Perhaps because of the context in which the memoir was written, J. Hawking harshly represents Hawking, which clashes with more mainstream representations of Hawking as the disabled genius. This tell-all memoir flips that persona on its head, making the consumer question what we think we know about Hawking. Was it all a ruse? Beyond the general consumers, critics and reviewers noted the surmising angst of the memoir. The journalist, Offman (1999) most notably concludes his review entitled “Stephen Hawking’s Ex-Wife Writes Tell-All” by characterizing *Music to Move the Stars* as a “610-page tome of woe.” When someone publishes a memoir about a story the public

is already familiar with, it has to reveal something new and scandalous in order for it to sell. J. Hawking's text is positioned well to accomplish the task of selling a story about the ubiquitous Hawking.

The memoir takes consumers through a detailed journey of Jane's life with Stephen, beginning prior to their first formal meeting at a friend's New Year's Party on the first of January 1963. Long before the party, as a young girl, Jane spots "a boy with the floppy, golden-brown hair who used to sit by the wall in the next-door classroom" (*Music* 9). The second spotting comes years following this encounter, when a school friend points Stephen, "shielded from the world under an unruly mass of straight brown hair" out to Jane across the street from where she and her friends were standing (*Music* 10). Beginning the memoir from the very moment Jane sees Stephen for the first time foreshadows the sheer amount of detail J. Hawking packs into her memoir. Perhaps beginning at this moment allows her to access and share her feelings towards Hawking.

When Jane and Stephen finally meet at the New Year's party, Jane feels drawn to him. She recounts that Stephen "was someone, like [herself], who tended to stumble through life and manage to see the funny side of situations" (*Music* 18). The consumer must maintain a grasp on these initial feelings Jane has towards Stephen as partial justification for why she stays with him as we are taken through the story that seems overwhelmingly melancholic. The couple had yet to begin dating when Jane hears through the grapevine that Stephen is ill and in the hospital. Jane is disheartened by the news, but soon after, they run into one another on the train where "he behaved so convincingly as if everything was fine" (*Music* 25). Little does Jane know, this sentiment would follow her throughout their long relationship. Already showing mild physical effects of motor neuron disease, Stephen asks Jane to accompany him to the posh May Ball

where Stephen notoriously informs Jane of the luminosity of men's dress shirts following a washing in Tide or Daz (*Music* 31). Jane begins to fall in love, knowing that "because of his illness, any relationship with him was bound to be precarious, short-lived and probably heart-breaking" (*Music* 38). As their relationship progresses, Jane notices of Stephen that "as his gait became more unsteady so his opinions became more forceful and defiant" (*Music* 43). While it is obvious that Stephen is an antagonist by nature, it seems to intensify following his diagnosis, driving a wedge between the young couple that only seems to expand with time. Nevertheless, Stephen whispers a proposal in Jane's ear and brings a new optimistic outlook on their life together (*Music* 52). Their happiness and confidence in the face of their uncertain future does not, unfortunately, prevent Frank Hawking, Stephen's father, from intimidating Jane about the uphill battle she was about to embark on with Stephen. Siebers' concept, ideology of ability, can be enlisted here to clarify the characters' individual responses to looming disability. Stephen ignores the reality of his diagnosis. The ability to communicate his ideas and research is imperative for Stephen to give his life value. Siebers' feature of "ideology of ability" is helpful in thinking about the body as a container for the emotion or, in this case, the intellectual self (7). "Ideology of ability" reveals how the cultural belief that the body is to be perfected frames Frank's mourning for the impending loss of his able-bodied son (Siebers 7). Jane's actions can also be understood in context of "ideology of ability" in the historical context, using optimism to will Stephen's body to defy the odds that we hope for his body (Siebers 7). The fear present in Frank's reactions feels authentic to consumers based on the premise of "ideology of ability ... "affects nearly all our judgments, definitions, and values about human beings" (Siebers 8). J. Hawking paints a universal and tangible fear of disability that reinforcing the perceived authenticity of the portrayal.

The young couple marry and soon set off on their first of many academic journeys across the pond. Jane works very hard to ensure that Stephen experiences all life has to offer, including arduous hikes, lofty academic pursuits, and fatherhood. As J. Hawking explains, “if the future had acquired a reassuring aura of certainty, the key to that certainty lay in managing the present” (*Music* 134). With the arrival of their second child, Lucy, there also comes the reality of Stephen’s progressive illness paired with his “adamant resistance” to using a wheelchair, which makes Jane’s role as mother and carer that much more difficult (*Music* 174). Hawking has no interest in acknowledging, let alone discussing, his illness arguably because of internalized ableism, the action whereby disabled people incorporate the negative dominant assumptions about disability into their conception of self. Hawking’s behavior speaks to McRuer’s concept, “compulsory able-bodiedness” which explains the cultural adherence to ableness resulting in Hawking’s internalized ableism. Compulsory able-bodiedness assumes that all people want to be able-bodied because able-bodiedness is the ideal non-identity (McRuer 2). Stephen is not immune to this cultural narrative when he becomes disabled. He still wants to understand himself and be understood by others as normal. In this way, Stephen reinforces compulsory able-bodiedness as a structural cultural concept. The consumer feels Stephen’s resistance to disability throughout the text.

As Stephen’s career begins to gain notoriety and he is invited to “conferences in far-flung places,” Jane begins to feel as though “divided loyalties were beginning to tear [her] apart. Stephen pursues his career with iron will” while clearly neglecting the emotional partnership at home (*Music* 194). The wedge is driven deeper between Stephen and Jane as Stephen works to secure his status as “master of the universe” both professionally and personally (*Music* 378). He spends hours and sometimes even days “like Rodin’s *Thinker* with his head bent low, resting on

his right hand, transported to another dimension” (*Music* 217) to the point that Jane can no longer decipher “whether [he is oblivious or indifferent] to [her] need for communication” (*Music* 219). Jane puts so much stock into fighting against the illness as a team that the lack of communication is the hardest to bear. She is left alone in this tireless fight.

Stephen blares Wagner records to block himself off from the world as he thinks about physics. J. Hawking writes, “Wagner came to represent an evil genius, the philosopher of the master race, the spirit behind Auschwitz, a threat to my optimism and potentially an alienating force in our marriage” (*Music* 219, 220). The reference to Auschwitz in this account is jarring as a consumer, as it elicits a vivid image of inhumane cruelty and suffering. This addition perhaps primes the consumer for J. Hawking to enlist Auschwitz and the Holocaust numerous times in the memoir as a metaphor and comparative tool related to Stephen’s behavior. But because I suspect consumers read this text with a framework of Hawking as the inspiring genius, reading these descriptions of him framed in such a contradictory light in some ways makes the characterization feel fabricated. Consumers feel as though the inspirational characterization of him *must* be true because of its pervasive nature in popular culture. But, we also feel intrigued by the characterization because it is contradictory. The consumers’ perception of Hawking both as a cultural figure and character in J. Hawking’s memoirs is significant as it relates to authenticity and will be addressed in further depth in the section on inconsistencies between the texts. The contradictory nature of J. Hawking’s portrayal exposes how disability representations entice consumers with an extreme presentation of disability in this case, comparing the experience of disability to the Holocaust, which J. Hawking uses to draw the consumer in by presenting a portrayal in conflict with the dominant narratives of Hawking. This technique works to enhance

authenticity because it touches consumers' deep-seated curiosities about the "horrors" of disability.

Stephen never wavers in his commitment to his belief that he and his family are normal, forcing Jane to spend "every waking moment...devoted to convincing [herself] that [they] were leading normal lives" in order to maintain the public ruse (*Music* 234). Throughout the text, there is this tug between the Hawking's public appearance and their private reality. Publicly, they appear well-off, comfortable, and of course inspirational as they clearly overcome disability in order to allow Stephen to make great contributions to the science community. And yet, J. Hawking primarily presents the private sphere in *Music to Move the Stars* as an exhausting and unwavering struggle to balance the needs of her family alongside Stephen's academic pursuits. Despite Jane's efforts to enable Stephen to pursue his celebrated career, she receives little to no acknowledgement of her role in his success. Twenty-five years of love and care and she does not receive so much as a thank you from Stephen (Hessey). In many ways this text is about the sad life that Jane leads. Framing the narrative as bad and sad helps personify disability as evil, getting Stephen off of hook for his role in Jane's difficulty. Mitchell and Snyder's concept of narrative prosthesis is useful here to expose how J. Hawking isolates disability as the active agent for which all her stress and strain stems. For example, J. Hawking relay, "Stephen's reluctance to expend any effort on polite small-talk, tended to offend some of our more sensitive neighbours ... I frequently had to apologize, explaining that my husband had to put all his concentration into remaining upright" (*Music* 114, 115). The way J. Hawking presents this anecdote demonstrates the importance of disability in her ability to excuse Stephen's behavior because without it, Stephen (or more likely, Jane) would have to take responsibility for his

behavior. Her burden is not the result of Stephen's attitude or behavior, but what disability is doing to his body and mind.

Jane's resentment becomes more palpable as the consumer moves through the text. She presents unexpectedly biting insults including, "intellectually Stephen was a towering giant who always insisted on his own infallibility and to whose genius I would always defer; bodily he was as helpless and as dependent as either of the children had been when newborn" (*Music* 328). The abrasive addition is as if J. Hawking is peeling off layers of old wallpaper to reveal the side of Hawking that has been so effectively covered by his public persona. Regardless of whether the consumer believes this representation of Hawking, it is jarring because it so starkly contrasts the easily digestible representation of everyone's favorite inspirational genius. While comments on the manifestation of Stephen's disability work to authenticate the narrative because they speak to J. Hawking's intimate knowledge of caring for Stephen, it also reinforces the belief that disability is infantilizing and, therefore, demoralizing. Thinking of disability as demoralizing then isolates the disability experience and makes the consumer grateful that they are able-bodied because J. Hawking's frames disability as evil-spirited.

Jane soon finds some solace in a new friend, the choirmaster Jonathan Hellyer Jones, who becomes an integral part of the Hawking family and eventually Jane's second husband. Jonathan would come by the Hawking house on the weekends "to teach Lucy piano," then he would "stay for supper" or even assist "with Stephen's needs, relieving Robert of all the chores which had oppressed him for so long" (*Music* 332). Jane sees Jonathan as a great blessing to her and the family with her observation, "he was the only person who was prepared to save us from the brink of despair" (*Music* 338). Jonathan is not only able to share Jane's burden, but the burden of her children, which relieves a great deal of her guilt. Beyond what Jonathan can assist Jane with,

Jane relates to Jonathan. She explains, “I had met someone who knew the tensions and the intensity of life in the face of death” (*Music* 333). They bond over the fact that they “[are] both lonely, deeply unhappy people in desperate need of help” (*Music* 336) and soon devise a plan that “the well-being of Stephen and the children would be the justification of [their] relationship” (*Music* 338). It was never Jane’s intention to leave Stephen or abandon her children for Jonathan, but rather fold him into her life to ease her heavy burden. Their plan works marvelously, and even “Stephen became gentler, calmer, [and] more appreciative” of Jane’s help (*Music* 339). His only condition for the affair is that Jane “continued to love him” (*Music* 339). Jonathan plays an important role in the fabric of the family in that he enables Jane to maintain her dedication to Stephen’s success, both professionally and medically. It is clear to the consumer that without Jonathan’s presence in the Hawkings’ lives, Stephen’s success might have remained a question.

Jane becomes unexpectedly pregnant with her and Stephen’s third child, just as her family and Jonathan settle into a routine. Jane fears that this news will upend her relationship with Jonathan and the concomitant support for her family. But her fears are unfounded. Jonathan “declared that his commitment to [the family] was unchanged” by the news of the baby (*Music* 350). Jonathan’s support during Jane’s pregnancy helps her transform her anxiety into “hopeful anticipation” (*Music* 350). Unfortunately for Jane, not everyone is as supportive of the pregnancy as Jonathan. Following the birth of Timothy, Stephen’s mother, Isobel, accuses Jane of infidelity when she claims, “I have a right to know whose child Timothy is. Is he Stephen’s or is he Jonathan’s?” (*Music* 361). Jane feels demoralized by this accusation as though “all the discipline” she and Jonathan develop in order to keep her family above water is not only going unacknowledged, but is also being used against her. While Jane’s relationship with her in-laws had never been easy, this accusation is the straw that breaks the camel’s back (*Music* 361).



McRuer's work on the connection between "compulsory heterosexuality" and "compulsory able-bodiedness" shines some light on Isobel's accusation. McRuer argues heterosexuality, like able-bodiedness, operate as "the natural order of things" (McRuer 12). Using McRuer's logic, it is unnatural for Jane to have an extra-marital affair, even if it is an emotional affair. So, when Jane and Stephen's heteronormativity is called into question, not only does it paint Jane as unnatural, it further devastates Jane because she tries so hard to be moral and natural in her pursuits.

Despite the unsavory assumptions from the Stephen's parents, Jane and her family march on, turning their attention to Stephen's "appointment to the coveted Lucasian Chair in Mathematics" (*Music* 371) in 1979, the chair that had once been held by Isaac Newton—"Stephen was now unequivocally ranked with Newton" (*Music* 372). Stephen's professional successes do not slow the onslaught of medical complications due to motor neuron disease. He falls ill again and his doctor "[recommends] a short spell" in a nursing home to aid recovery (*Music* 373). Upon returning home, Stephen finally agrees to allow nursing care in the home which begins "a new era... for the master of the universe and, by extension, for the rest of us" (*Music* 378). They assume that the assistance will alleviate a great deal of strain for Jane and allow Stephen to maintain control of his care. What actually transpires during this period is surprisingly arduous for Jane. Getting consistent funding for Stephen's home care is the first, but not the last challenge Jane faces in relation to his care. It proves difficult for Jane to find and retain reliable nurses who respect the integrity of the home as a space that needs to accommodate the whole family. Too soon, the nurses begin to accuse Jane of disloyalty to Stephen and spend their time fawning over the deserving genius. Stephen revels in this attention and uses the nurses' allegiance against Jane when she declines his offers to accompany him on trips abroad because of her responsibility to the children. The represented dynamic between Jane, the nurses, and

Stephen calls the authenticity of the representation into question in that J. Hawking paints herself as the victim in this dynamic, rather than Stephen. Couser's work on disability and life writing enables me to question J. Hawking's motivation for her characterization of the aforementioned events. Is J. Hawking keeping Stephen's best interest at heart with her representation of the contentious dynamic or, perhaps a more important question, what is her obligation to keep Stephen's interest at heart? Along with this central question, it is worth pondering what role authenticity plays in relation to the representation of a disabled person's best interests. Arguably, it is not in Stephen's best interest to represent him as a narcissist, but what if that is the authentic representation? In this case, does authenticity trump Stephen's interest?

Despite the tumultuous dynamic in the Hawking home, Stephen's nurses do accompany him on trips often along with his research assistants as it is the most logical option. His nurses are with him in Geneva when he falls dangerously ill again and is put in a drug-induced coma. When Jane hears the news she questions "how [she] could ever have let Stephen go off alone with his entourage, deprived of the protection of [her] intimate knowledge of his condition [and] his needs... [as she was] his mouthpiece" (*Music* 429). The nurses are able to ease the burden on Jane, but her expertise of Stephen's condition exceeds everyone else's. Jane and the family travel to Geneva to learn that the physician wants to give Jane the option to "disconnect the ventilator," but Jane adamantly objects and responds, "Stephen must live. You must bring him round from the anesthetic" (*Music* 435). As soon as she can, Jane has Stephen airlifted out of Geneva to return to England for further observation and care. Jane and Stephen's whole relationship up until this point has revolved around Stephen defying the medical odds, so it is unsurprising that the thought of losing the fight of Stephen's life is forcibly unacceptable to Jane.

After many long months of serious illness and hospitalization for Stephen, he is finally strong enough to return home. J. Hawking recounts, “it was like bringing a new baby home” (*Music* 451). While this comment feels infantilizing towards Stephen, it reveals the way Jane perceives her care towards Stephen—gentle, nurturing, protective, maternal. Unfortunately, Stephen does not prove to be easy to care for as “he had little respect for the intelligence of other people at the best of times. Now, at the worst of times, he is inclined to regard [all nurses] as morons” (*Music* 451). Jane tries to be understanding as she says, “it was natural that he would want to reassert himself but no one disputed his right to be king of the universe, master of the house and father to the children. It was difficult therefore to understand why he seemed to want to make the daily routine more fraught than usual” (*Music* 455). McRuer’s concepts of “compulsory heterosexuality” lends another hand here because Stephen’s behavior reveals how able-bodiedness and heterosexuality are intertwined as they work to reinforce the other (McRuer 2). Stephen arguably feels threatened and even defeated by the introduction of nurses in the home exposing McRuer’s analysis that, “The spectacle of sexual, bodily, or mental difference was preferable to that of a visibly threatened masculinity or heterosexuality requiring deviance to define and sustain itself” (11). In this way, Stephen overcompensate for his physical state by asserting his domineering personality on the nurses, reestablishing his superiority as a man.

Whatever Stephen decided to do with his daily routines was supported by the nurses, ostracizing Jane and the children in the process. It is clear that any contribution Jane makes in ear shot of the nurses is “further evidence of [her] disloyalty” to Stephen (*Music* 505). This portion of the texts reads as though the nurses are intentionality out to get Jane as a way of proving their loyalty to Stephen. It makes the consumer wonder whether the nurses act on their own volition or if Hawking is the puppet master with an unidentified motive. J. Hawking explains that “the rest

of [the family] became second-class citizens...[while] the Florence Nightingales – administered to the deity – the master of the universe” (*Music* 460). Jane and the children “suspected that [they] had become the scapegoats for the frustrations which the nurses could not vent on Stephen himself” (*Music* 467). This discomfort goes on to a point that Jane and the children feel obligated to apologize for their presence alongside “the man of genius” (*Music* 481). Jane’s observation is enlightening because it points to the nurses’ perspective that they could not air their frustrations with Stephen because of his high social status as a genius. The nurses wanted to be in Stephen’s good graces and were willing to disregard the feelings of the family to achieve their goal.

The most noteworthy nurse Jane employs on Stephen’s behalf is Elaine Mason, the ring leader of the nurses and orchestrator of much the drama that comes from the nursing staff as well as Stephen’s future wife. Elaine reads as a bad egg, someone who a consumer would want to avoid as she spoils those around her. She is also the nurse who is arguably closest to Stephen as she offers her willingness to accompany him on trips that Jane decline. As time passes, Stephen’s “sense of humor seemed to be evaporating; towards [Jane], the limpid eyes were becoming hard and unrelenting and the candour which long ago had drawn [her] to him was fading” (*Music* 500). And yet, Jane’s commitment to Stephen’s success and survival is too strong to abort.

With the great deal of world-renowned success Stephen receives at the hands of his popular book about the universe, *A Brief History of Time*, Jane searches for something to fill the void that grows inside her. She finds it in the idea of buying and renovating a second home for the family to enjoy in the French countryside. This project brings a welcome distraction away from her feeling that “[her] life and everything in it, however private, had become such public property that [she] was at the mercy of the idle curiosity of all strangers” (*Music* 525). Whereas Jane hides from this publicity, Stephen laps in it. J. Hawking suggests, “[Stephen’s] fame in the

face of a skeptical and sometimes hostile society represented the triumph not only of his mind over the secrets of the universe, but also of his body over death and disability” (*Music* 527). In many ways, even though Jane is critical of Stephen’s representation, both her and Stephen feed into the inspirational narrative that is so pervasively disseminated. Stephen believes that, “any publicity was good publicity” (*Music* 527), but Jane prefers to be more in control of her representation.<sup>9</sup> She is starkly aware that she must be honest in her representation of her and Stephen’s experience of disability as the perpetuated “if Professor Hawking can do it, why can’t you?” narrative can affect disabled people’s lives (*Music* 536). Jane understands the pitfalls of the public “[believing] in Stephen’s immortality and infallibility” in isolation of “the reality of his condition” (*Music* 537). Clearly, J. Hawking is aware of the mechanism of representation and the potential fallacy of it. I delve deeper into this subject in the subsequent sections of this chapter.

Jane’s need for privacy is clear when she organizes a getaway to the French vacation home following the completion of the renovations. She invites many family and friends, including Elaine Mason and her family, in hopes of easing the palpable tension in the Hawking house back in Cambridge. Her efforts are hopeless as the trip only works to enhance her unhappiness that “[Stephen’s] smiles and his interest were reserved for someone else” (*Music* 554). On top of this sadness, Jane suspects that Elaine can and is manipulating Stephen for her benefit. The match that lights the fire comes when Elaine whirls accusations of disloyalty hard and fast towards Jane after “one particularly disruptive night” orchestrated by Elaine (*Music* 557). To find some separation, Jane and her youngest son, Tim, stay at the French house while the rest of guest leave enabling them to “quickly [settling] in a routine which [Jane] was

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<sup>9</sup> It can be argued that Stephen also wanted to be or was in control of his representations. See Mialet (2012).

confident... [they could] sustain” (*Music* 559). But, all too soon, the master puppeteer pleads and persuades them to return home, only for Jane to receive a “frosty” welcome (*Music* 559).

Stephen’s intentions crystalize when, a week following their homecoming, he informs Jane that he will be moving in with Elaine (*Music* 560). He clearly wants to have his cake and eat it too.

This period is tumultuous to say the least as Stephen and Jane fight to get back at one another. It reaches the point that violence ensues with “bricks being hurled through windows, [which shatter] the glass and whatever fragile sense of security Tim and [Jane]” have left (*Music* 562). These toxic interactions between Stephen and Jane go on for months, always oscillating between hatred and remorse. Jane characterizes Stephen in these moments as, “the all-powerful emperor [who] spurned the image of [a] lost child” (*Music* 564). J. Hawking is hurt and it is clear with lines like these just how cathartic the writing of this text must have been for her. The silver lining of all of these trying times come: “in taking his decision to leave... Stephen had unwittingly relinquished his power over [Jane]” (*Music* 570). Stephen leaving enables Jane and Jonathan to finally be together, but because they “had never contemplated the possibility of a future together without Stephen” it is a bittersweet release (*Music* 563). While the separation is not the end of Jane and Stephen’s tumultuous exchanges, it does mark their separation, enabling Stephen to marry Elaine and, years later, Jane to wed Jonathan. The narrative that J. Hawking creates presents a certain tension that is felt from early on in the story. Jane’s optimism and efforts were never a match for the cynical, but blasé Stephen.

*Music to Move the Stars* provides a crucial look into the ways in which authenticity is manipulated because it offers such a distinct representation of Stephen from both *Travelling to Infinity* and the biographical film, *The Theory of Everything*. J. Hawking walks consumers through this marathon of a text that makes us question what we think we know about the

inspirational genius, Hawking. Enlisting Bogdan's (1996) analysis of the freak show enables me to suggest that, in essence, J. Hawking assumes the orator role of the freak show in her writing of her first memoir. Her positionality to Hawking situates her well to create a persuasive story used to entice consumers, allowing them to get a good glimpse at a real live freak in all his crippled glory, quenching the thirst of their intrigue. On one hand, *Music to Move the Stars* is an opportunity for consumers to learn more about their favorite genius while on the other hand, it is an opportunity for consumers to get the inside scoop on Hawking, which inherently seems *more* "authentic" because it counters the dominant representation. The cultural thirst for this sort of look at disability did not go away simply because freak shows fell out fashion and became morally reprehensible, it is just that the format of the gaze changed.

Considering J. Hawking an orator also illuminates authenticity in that if Jane's role is to entice consumers in a freak show-like fashion, a "for profit activity" that "[purposefully distorts]" (Bogdan 24) disabled people on display because "Fabrications and misrepresentations were just part of the taken-for-granted hype of the freak show world" (Bogdan 25), then is J. Hawking also distorting the representation for a monetary gain? Is the certain of Hawking representations' authenticity called into question if we associate J. Hawking with ulterior motives for writing?

### 3.3 **Representation of Stephen in *Travelling to Infinity***

*Travelling to Infinity* is "the abridged version of the original memoir" *Music to Move the Stars* (*Travelling* 478). Ruth Hessey (2011) calls it J. Hawking's "rapprochement" book because it feels as though she is making amends with herself and who she was and what she felt when she wrote *Music to Move the Stars*. Due to the fact that *Travelling to Infinity* follows the same general plot as *Music to Move the Stars*, it would be repetitive to go through the entire plot

summary again. So, instead, this section focuses more on the how the representation of Hawking differs in *Travelling to Infinity*, altering the characterization of Hawking and, as a result, the authenticity of the text.

It may seem obvious to point out that *Travelling to Infinity* greatly softens the representation of Hawking, but it is important in order to truly grasp how authenticity is molded and maintained through these two texts. It must be understood that the shift in representation is a subtle one—it is as though J. Hawking is gently sculpting the soft clay of history; a raw material that she has the power to manipulate. It is in the tone that the consumer feels the most difference between the texts. J. Hawking does not seem as spiteful. She is still honest because “as [she] saw it, if [she] continued to perpetuate the myth of cheerful self-sufficiency without even mentioning the hardships, [she] would be cheating the many disabled people and their families [that were impacted by Hawking’s public representation]” (*Travelling* 477), but time had tempered her emotions towards this history (Hessey).

As a way of demonstrating the inconsistencies between texts, I present some “sister” quotes from *Travelling to Infinity* that align with the quotes presented in the previous section from *Music to Move the Stars*. In the beginning of *Travelling to Infinity*, consumers find the exact quotes that they would find in *Music to Move the Stars* such as J. Hawking’s comment on the correlation of Hawking’s gait and opinions as well as how the certainty of the future lays “in managing the present” (*Travelling* 122). It is as the consumer progresses through the text and comes upon the more contentious period of Jane and Stephen’s relationship where we begin to see the shift in portrayal. The authenticity is convincing because so much of the content of the two texts overlap. So, it takes a critical consumer to identify the gentle shifts that soften both Jane and Stephen’s characters in *Travelling to Infinity*.



The following quote about Stephen's fading affection towards Jane is not in *Travelling to Infinity*: Stephen's "sense of humor seemed to be evaporating; towards [Jane], the limpid eyes were becoming hard and unrelenting and the candour which long ago had drawn [her] to him was fading" (*Music* 500). The quote's sentiment is loss—Jane losing a hold on Stephen, losing what they have built together, what they have conquered together. It is intriguing that J. Hawking chose not to include it in *Travelling to Infinity* because without it, she frames she as more practical and less emotional, painting herself as less hurt by Stephen's actions. What I suspect is that it reveals a deeply painful realization for J. Hawking and *Travelling to Infinity* was a way for her to patch all the raw emotion presented in *Music to Move the Stars*.

Another quote present in *Music to Move the Stars*, but absent in *Travelling to Infinity* is, "my life and everything in it, however private, had become such public property that I was at the mercy of the idle curiosity of all strangers" (*Music* 525). Here, J. Hawking presents herself as an animal held captive in a cage, without agency or control. In this way, it is understandable why J. Hawking left it out of the abridged version of *Music to Move the Stars*. Another unsurprising exclusion from *Travelling to Infinity* is as follows, "the all-powerful emperor spurned the image of [a] lost child" (*Music* 564). This severe description of Hawking goes a long way to vilify him and his treatment of Jane. In removing the description, J. Hawking softens her portrayal of Hawking, affecting not simply the way consumers interpret him, but also their interpretation of his behavior towards her.

What begins to come into focus when the variations between the versions of the texts are paralleled is that much of what J. Hawking removed in *Travelling to Infinity* is about herself or reflects back on her character. This comparison does not just affect the consumer's understanding of Jane, but also Stephen. In altering her representation of herself, she

subsequently revises Hawking's representation as well because their representations are so entangled in one another. Not including the detail in *Travelling to Infinity* that frames her as entrapped in a life she did not anticipate, not only affects how consumer's read her character, but also how she presents her feelings about Stephen's role in her unhappiness which then influences the consumer's understanding of Stephen's character.

J. Hawking's memoir, even in its abridged form, presents a surprising complex portrayal of disability. It, of course, fits representational tropes that present Hawking as an inspirational genius, but analyzing how J. Hawking's representation of Hawking is intertwined with her own complicates his portrayal because it calls the constructive nature of narrative into question because J. Hawking's bias is suspect.

*Travelling to Infinity* is certainly more complex than the film which is based on the abridged version of her memoir. While this lack of complexity in the film is perhaps expected, it is still disappointing as it became a critically-acclaimed movie based on its *authentic* story. Dean's (2014) review of *Travelling to Infinity* in her article, "The Theory of Everything Does Jane Hawking a Diservice" explains, "the memoir, in short, reveals a much more complex courtship than the film captures, and a newlywed bliss much less self-conscious about the weight it would come to assume. While obviously no film could precisely replicate the inside experience of a marriage, it feels like the film-makers didn't even try. They simply made up another." While consumers can justify these inconsistencies by the change in medium, they have a marked effect on the overall narrative. *Travelling to Infinity* presents a more nuanced account of their life in comparison to *Travelling to Infinity* which heavily relies on the dominant narratives of disability.

### 3.4 The Inconsistencies Between *Music to Move the Stars* and *Travelling to Infinity*

Perhaps the most obvious inconsistency between *Music to Move the Stars* and *Travelling to Infinity* is the tone of the writing and the details that reinforce that tone. As noted previously, *Music to Move the Stars* feels as though J. Hawking is ridding herself of the encumbrance of her twenty-five-year marriage to Hawking. Particularly as the text progresses through her marriage, she is angry and biting towards Stephen. J. Hawking's attitude towards Stephen in the text ensures that her feelings about her experience are heard loud and clear by the consumer. In many ways, it feels as though she writes *Music to Move the Stars* less as a reflex to her pain and more as a way to seize an opportunity to finally be in control of her experience. A detail that helps her reinforce and clarify her feelings towards Stephen is when she describes him using references and descriptors related to the Holocaust. While she references it throughout the text, the most unpleasant references come when she compares Stephen's body to that of a Holocaust victim. She writes, "the functions I filled for [Stephen] were all maternal rather than marital... it was becoming difficult – unnatural, even – to feel desire for someone with the body of a Holocaust victim and the undeniable needs of an infant" (*Music* 328). As a consumer, it is uncomfortable to read because it is *too* honest, it feels like, as an adult, she should know better than to share these deeply-rooted feelings about Hawking's physical body. It also seems contradictory to the frustration she expresses towards the ignorant attitudes Stephen encounters in public. This addition just seems irresponsible. It feels both careless and intentional that J. Hawking repeats this reference again near the end of the text when Jane and Stephen are separated. J. Hawking, incensed by Stephen's behavior, depicts him as "all mind and no body, an all-too-powerful rational mind and an enormous fund of restless energy trapped in a pathetic paralytic shell of a body, as emaciated and enfeebled as any victim of Belsen [concentration camp]" (*Music* 566).

J. Hawking's portrayal of Stephen as a Holocaust victim becomes particularly significant in terms of representation in the context of *Travelling to Infinity* because the only reference to the Holocaust in that text is when J. Hawking mentions Jewish friends "whose families had been ravaged by the Holocaust" (*Travelling* 417). Any mention of Stephen's body wasting away like a Holocaust victim is erased in *Travelling to Infinity*, along with any unsavory representation of herself as the creator of those abrasive images. When the representations in these texts are placed side by side, it becomes clear that each text alters the way Stephen's character is represented to the consumer and, as a result, how Jane is characterized as well. Namely, the way in which J. Hawking portrays Stephen reflects back on her because she constructs the representation. In *Music to Move the Stars*, J. Hawking recounts Stephen receiving the Fellowship of the Royal Society in 1974. At the award ceremony, Jane is hoping for some acknowledgement from Stephen for his family's support in achieving professional success. She explains:

He finished speaking to general applause while I blinked back prickly tears of dismay.

Had Stephen forgotten us, forgotten all that I had tried to do for him, forgotten that while his mind roamed the outer reaches of the universe, my horizons had shrunk to the four walls of our narrow house, forgotten his pride in his two beautiful children – or did he consider all that irrelevant to the scientific importance of the occasion? (*Music* 240, 241)

Whereas in *Travelling to Infinity*, J. Hawking removed these lines expressing her deeply hurt feelings and replaced them with the simple and less emotional, "he finished speaking to general applause, while I bit my lip to conceal my disappointment" (*Travelling* 213). This new quote presents Jane as measured and practical rather than vulnerable as to better align with the overall tone of *Travelling to Infinity*.

Another difference between the two texts occurs following a nearly fatal illness of Stephen's in "the spring of 1976" (*Music* 299). In *Music to Move Stars*, J. Hawking explains, "No sooner had [Stephen] been released from the clutches of the demon illness than the goddess physics urgently reclaimed him as her own, sweeping him up and away from his family to resume his throne high among her pantheon of demigods" (*Music* 302). Interestingly in *Travelling to Infinity*, J. Hawking removes this sentence entirely, jumping to the following sentence which benignly explains, "That Easter Monday, still in the early stages of convalescence, he summoned his students, commandeered the car and set off for a five day conference in Oxford" (*Travelling* 258). J. Hawking removes much of her emotional investment in Stephen's decision-making with her removal of the quote present in *Music to Move the Stars* and absent in *Travelling to Infinity*.

A noteworthy inconsistency between J. Hawking's consistent representation in *Music to Move the Stars* and *Travelling to Infinity* and Hawking's *My Brief History* centers around Stephen's relationship with the famous astronomer Fred Hoyle who "had rejected Stephen's postgraduate research application" (*Travelling* 54). In both *Music to Move the Stars* and *Travelling to Infinity*, J. Hawking explains during Stephen's time at University of Cambridge in a lecture of Hoyle's where he was unveiling his new "theory of steady-state universe," "Stephen struggled to his feet and proceeded to tell Hoyle and his students, as well as the rest of the audience, that the calculations in the presentation were wrong" to which Jane adds, "Relations between him and Fred Hoyle never advanced after this incident" (*Travelling* 54). Clearly, "Stephen's conviction that intellectual arguments were never...personal" did not influence Hoyle's frustration with Stephen's arrogant spectacle (*Travelling* 54). Later in *Travelling to Infinity*, J. Hawking notes, "It was unlikely [Stephen would secure employment at the Royal

Society] so far as long as Fred Hoyle remained director since he had never forgiven Stephen for his notorious intervention at the Royal Society lecture some years before” (*Travelling* 151). It is worth noting this sentence in *Music to Move the Stars* reads as, “[The Royal Society] was unlikely to provide him with a paid position as long as Fred Hoyle remained its director since Stephen has notoriously antagonized him at the Royal Society lecture several years before” (*Music* 166). Whereas in *My Brief History*, Hawking represents this lecture and subsequent interaction with Hoyle in a different manner than both of J. Hawking’s texts. Hawking claims, “in the question period [of the lecture], I said that the influence of all the matter in a steady-state universe would make his masses infinite” (Hawking 45). Hawking recounts, “Hoyle was furious...[but] later gave me a job, so he apparently didn’t harbor a grudge against me” (46).

The contrast between J. Hawking’s representation and Hawking’s representation of these events are revealing of their unique character and perspective. Putting these representations side by side crystalizes not only Stephen’s oblivious airs, but also the gentle manipulation of authenticity. From both representations, the consumers can conclude that Stephen made an embarrassment out of Hoyle, but that is where the comparisons end. With J. Hawking’s representation, the consumer takes away that while Stephen is clever, there are consequences for his actions, namely that he was unable to research with the Royal Society until Hoyle had left. Whereas, in Hawking’s representation, he gives consumers the impression that even though he publically humiliated Hoyle, there were no hard feelings when it came down to it, and reinforces his belief that intellectual arguments are not personal. This storyline that spans over the three texts is one of the most poignant locations to understand how Stephen interacts with the world compared to Jane. He has this conceitedness that shields him from being self-aware of the ramifications of his actions. Putting this observation in context of J. Hawking’s representation of

him in *Music to Move the Stars* in particular then illuminates a great deal about his character as well as his behavior and attitudes towards Jane that cause her so much turmoil. This reveals how vulnerable creators of representations, like that of Hawking, are in molding narratives that correspond to their ideal self. In this case, Hawking created a narrative that paints him as nonchalant which perhaps meets his ideal self. Whereas J. Hawking, who is less invested in the narrative because it is not about her presents a narrative that does not align with Hawking's narrative.

These inconsistencies are subtle. If someone were to fact check J. Hawking's two texts against one another as a way of proving authenticity, they would both check out and be deemed authentic. What becomes blaringly obvious when these texts are compared side by side is the sentiment of the words and how the sentiment changes the reception of the content. It is the context and mindset in which J. Hawking writes these texts that unveils the distinct quality to them. Each of these texts represent J. Hawking's truth at the time that she wrote them, but that is the thing about truth and authenticity—it changes and evolves, making it difficult to pinpoint.

### 3.5 **Multiple Truths of Hawking Representations**

The various inconsistencies between J. Hawking's texts have consequences for their perceived authenticity. The obvious consequence being that the stories present different truths, different representation of events and characters. Accepting the different truths feels counter-intuitive because authenticity is often presented as singular. But, depending on whether consumers believe that authenticity means “worthy of acceptance or belief as conforming to or based on fact” or “conforming to an original so as to reproduce essential features” determines whether we feel as though the inconsistencies call the authenticity into question (Merriam-Webster 2016). In some ways, J. Hawking calls the authenticity of *Music to Move the Stars* into

question by re-writing and publishing a new version. However, because it comes from the horse's mouth, consumers are unlikely to question J. Hawking's truth, keeping her authenticity intact.

Here in lies the conundrum of multiple truths. J. Hawking represents multiple truths in her memoirs because the contexts, and her experience within those contexts, changed and evolved over time. The truths presented in each memoir were arguably true to J. Hawking when she wrote them even though they are presented differently. It is unlikely that she set out to deceive her consumers by manipulating the portrayal, but wanted to represent her life in a way that felt more *authentic* to her. In her perceived intention lies another representational conundrum of authenticity in that J. Hawking's authenticity does not necessarily match the perceived authenticity of the consumer. So, where does that leave authenticity? Can multiple truths be authentic or is authenticity allowed to change and evolve along with people?

In many ways, J. Hawking succeeds at what she set out to do with *Travelling to Infinity*. She rewrote history. With this act, not only does J. Hawking temper her representation of Stephen, but she also tempers her representation of herself. To the consumer, she feels much more submissive in *Travelling to Infinity*. But by writing *Music to Move the Stars* she stands up to Hawking, even if she rarely stands up to Stephen in the plot. It feels as though she wrote *Music to Move the Stars* as a way of controlling the circumstances of her life that had always been dictated by Hawking. *Travelling to Infinity*, on the other hand, feels as though she regrets her uninhibited account and republishing is a way to remedy her previous characterization of Stephen. This interpretation is bolstered by the fact that *Music to Move the Stars* is nearly out of print in 2017.



### 3.6 **Jane Hawking as a Representative for Stephen Hawking**

J. Hawking's representation of Hawking in each of her memoirs offers a fascinating look into Hawking representations because it is clear as a consumer that J. Hawking is aware of her role in representing Hawking and that she understands that representations do not exist intrinsically, but rather are constructed and manipulated. As J. Hawking explains in an interview, "one of the things I have learned is that you can't write exactly as you think" (qtd. in Hessey (2011)). This comment is a revealing admission in that it forces the consumer to question the authenticity of her texts because this quote makes it seem as though J. Hawking strategically chose what to include, which of course is something writers do, but I would argue authenticity is culturally associated with stream of consciousness. J. Hawking's comment also exposes a tension between her representation of her and Hawking's life and the way the media represents Hawking's life. In the memoirs, J. Hawking subtly includes mentions of this tension, revealing yet another quiet struggle of hers. She also offers insight into her role in the media's representation of Hawking and how the representations influence her life. This insight exposes some of the inherent representational conundrums in J. Hawking's representation of herself and Hawking as well as the ethical implications of her representing herself through Hawking.

In *Travelling to Infinity*, J. Hawking writes, "it was still one of my worst fears that, in the hands of the wrong producer, Stephen might be portrayed as some sort of grotesque, wheelchair-bound boffin, twisted both in body and mind, destructively intent on the pursuit of science at all costs (*Travelling* 322). J. Hawking seems to understand the danger of representing disability tragically or stereotypically. So, it is unsurprising that J. Hawking ended up writing a memoir where she was in control of Hawking's representation. She likely felt she was the best person to represent their life together, due to both her proximity and concern. At the end of *Music to Move*

*the Stars*, J. Hawking reveals her motives for writing the text which illuminates how she consciously manipulates the representation to enable her to maintain control over it. She writes that if she were to write a memoir:

[She] would be revealing truths which were so deeply and painfully personal that [she] could not bear to think [that someone else would represent it]. Writing the story in [her] own way, [she] would be able to relieve [herself] of the burden of so many contrasting and conflicting experiences and exorcise the strain, the tensions and ultimately the overpowering toll of unhappiness. The exercise would certainly be cathartic. It might even be healing. (*Music* 586)

J. Hawking also discusses her decision to write the memoirs in an interview with Ruth Hessey (2011) where Hessey explains, “whistleblowers often suffer vilification, and her first memoir exposed the Hawking marriage as a grueling spiritual and emotional marathon. Writing the second-time round, she has tempered the truth with acceptance.” This poignant characterization paints a compassionate picture of J. Hawking’s experience as a writer towards her possible desire to be associated with something other than her husband. I suspect that the memoirs were a way for her to write herself into Hawking’s history and representations. There are numerous points in both texts that reveal a sadness to Jane feeling left out of Stephen’s success, her diligent support that goes unacknowledged by Hawking representations that overemphasize “the self-sufficient genius” (Mialet 6).

In her memoirs, J. Hawking presents the conundrum between the representations of Hawking’s private and public spheres. Each sphere relies on the other for survival, but are often represented in isolation, calling the other into question. J. Hawking shares, “The very paradox of [Stephen’s] situation had made him the darling of the media...his success was proof that he had

conquered motor neuron disease and therefore the battle was won: we could not possibly be in need of help” (*Travelling* 326). Here, she addresses the pitfalls of representations and how they ultimately impacted their lived experiences—the *appearance* that they had everything under control overshadowed the reality of their experience and thwarted Jane’s efforts to obtain necessary assistance.<sup>10</sup> This quote reveals the power of representation in that it affected the Hawking’s lives as Hawking’s public persona clashed so harshly with his private home life.

The world needed their invincible genius and Jane had to keep up appearances. Here in lies the real danger of authenticity because the representation can present a narrative that people take at face value, like that of the disabled genius who defies all the odds in the name of science, without tethering that representation to the understanding that it is a *representation* of reality. This passage from *Music to Move the Stars* reinforces this separation when J. Hawking states:

In the early 1980s the popular press began to take a more active interest in the phenomenon of the man himself. The contrast between the restrictions placed on [Stephen] by his shrunken frame and his croaking speech on the one hand, and the power of his mind which allowed him to roam the outer reaches of the universe on the other. (*Music* 383)

J. Hawking’s comment gets at the heart of the paradox because we, as consumers, can see that there is an imbalance between the spheres of representation and real life, but it also feels like an insurmountable feat to recalibrate them. Society needs Hawking to be the exception to the rule of disability because it gives spectators something to believe in—if he can overcome disability, maybe there is hope for the rest of us. His media representations temper the fear of disability because he still does incredible things. *Music to Move the Stars* and *Travelling to Infinity* to

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<sup>10</sup> This, of course, was also affect by Stephen’s adamant rejection of the reality of their situation and any suggestion that Jane needed help caring for him and the children.

some extent, pulls the curtain back, portraying the less glamorous side of disability, lifting the smokescreen in front of Hawking.

Another paradox of Jane's negotiation with media is that her maintenance of the obligation that she "keep up a normal façade in totally abnormal circumstances ... depended on [her relationship with Jonathan] which society condemned" (*Music* 401). Hawking and the outside world encouraged this façade. But it was not enough for Jane to simply maintain it. She was to do it single-handedly. J. Hawking divulges that "There were a lot things said [by the media] ... that were not true [about her and Jonathan's relationship]" (Hessey). She was expected to reinforce Stephen's public persona—to be the perfect wife and mother—and when this task became impossible, she only had herself to blame.

J. Hawking walks a fine line with her representations. She wants to represent her experiences honestly for the sake of the disability community, but also wants to maintain her privacy. While J. Hawking is arguably thoughtful and intentional about her representations, there are still ethical concerns for her representing herself through Stephen. Tom Couser (2004) presents an analysis of the ethics of writing memoirs about disabled individuals that help flush out the ethics of J. Hawking's writings. Couser contends that there are ethical implications for people, such as J. Hawking, who represent themselves through a disabled loved one like Hawking because he is a vulnerable subject. Couser defines vulnerable subjects as, "persons who are liable to exposure by someone with whom they are involved in an intimate or trust-based relationship but who are unable to represent themselves in writing or to offer meaningful consent to the representation by someone else" (*Vulnerable* xii). It can definitely be argued that Stephen is a vulnerable subject because of his speech synthesizer. The implications of this framing of Hawking reveals the power dynamics at play in Hawking representations. J. Hawking's intimate

knowledge of his condition has the potential to exploit Hawking from her position of power as the writer. J. Hawking ultimately gets to decide how *she wants* to portray Hawking, which may or may not align with Hawking's interests. Is *Music to Move the Stars* an ethical violation? Perhaps, particularly because of the context in which J. Hawking wrote the text and why—she “speaks *for* [Hawking],” representing him for her intended purpose, not his [author's original emphasis] (*Vulnerable* x). But, there are other elements that make the creation of the memoirs that further complicate the ethical concerns. At one point in *Travelling to Infinity*, J. Hawking writes, “when I offered to collaborate with him on a proposed autobiography, a project which I hoped would bring us closer together, his reaction was dismissive: ‘I should be glad of your opinion’” (*Travelling* 412). I maintain this comment greatly dilutes the ethical concerns of this situation to some degree because J. Hawking wanted Hawking to speak for himself.

With her memoirs, J. Hawking unearths doubts about our understanding of Hawking. These doubts percolate in our minds, forcing us, as consumers, to question what authenticity is and what role it plays in convincing us that representations presented to us, whether on the page or screen, represent reality. I understand the draw of authenticity, wanting to believe we are not being deceived by the representation, but what these texts teach us upon analysis is that authenticity collapses under the weight of consumers' expectations of honesty. As pure as J. Hawking's intentions may be in writing her memoirs, they cannot withstand the complexity that come with representing authenticity.

#### **4. THE THEORY OF ACTING AUTHENTICALLY: HOW EMBODYING DETERIORATION LEADS TO AN “AUTHENTIC” REPRESENTATION IN *THE THEORY OF EVERYTHING***

James Marsh's 2014 film *The Theory of Everything* is celebrated by critics and viewers alike for Eddie Redmayne's physical embodiment of Stephen Hawking. But, like many Hollywood films, *The Theory of Everything* problematically portrays disability using an inspirational trope by emphasizing Hawking overcoming the struggle caused by his physical body. Eddie Redmayne's physical portrayal of Hawking's body in *The Theory of Everything* influences the way Stephen's character is represented as inspirational. Every breakthrough Stephen makes in the film is marked by a physical change in the progression of his disability, making these feats seem more impressive to the consumer. When Stephen finally has his PhD breakthrough, he trips and falls, which leads to his diagnosis. Following his diagnosis, he marries and starts a family. When he begins using two canes, he finishes his PhD. When he can no longer dress himself, he has a revelation about black hole radiation. When he can no longer speak, he writes a book. In the first part of this chapter, I provide a close reading of the film production choices that foster the inspirational narrative in the film. Then I transition into an analysis of how social forces outside the film validate the film as authentically representing disability. I conclude by presenting the way the film is constructed for the consumers to read *The Theory of Everything* as authentic.

##### **4.1 A Close Reading of the Film**

The film begins with Stephen fully able and represented as an active young man who cycles and is the coxswain of his Cambridge team. He is portrayed as a handsome intellectual who instantly attracts Jane Hawking with a casual smile as she spots him walking into a New

Year's Eve party. Stephen is at the top of his game, which is a rhetorical tool used to contrast Stephen as a disabled man throughout the rest of the film. The consumer needs to experience Stephen as someone they can relate and aspire to in order for them to appreciate his inspirational successes *in spite of* his disability later in the film. Soon after his ableness is established, the plot begins to drop hints that his circumstances are not as perfect as they seem. The first sign of the shift in ability is when Stephen agilely jumps down from his bunk bed only to clumsily push his coffee cup off his desk, ruining his homework; it is subtle, but clear—his loss of bodily control has begun.

While walking down a hill at the May ball with his date, Jane, he briefly loses his footing and spills a splash of his champagne. The consumer can brush it off as an inebriated gesture, but it is another sign that something is to come. This worry becomes clearer to the consumer as Stephen's ability is contrasted against his athleticism at the beginning of the film, when Stephen must run to catch a train with his friends and nearly misses it.

The most obvious sign of impending disability occurs when Stephen is working through the creation of a physics equation on a chalkboard. His writing has become shaky as if he were writing in a car, and yet, the consumer can still chalk this change up to his eagerness to create his equation, which is aided by a string crescendo. But, at the last second of this scene, the camera angles down to show his hand trembling right before the big fall in the next scene that shifts the film from a movie about a young physicist to a movie about a disabled man. The big fall is in some ways expected, and yet completely shocking for the consumer who *feels* the film shift with the use of sound effects (a loud realistic smack to the pavement) and camera angles that present a vertical close-up of Stephen's growing grin with excitement about his PhD breakthrough. The camera then shifts to an altering horizontal close-up as Stephen trips over his feet while

preoccupied with his excitement causing a collision between his face and the pavement culminating with his head bounces off the pavement before passing out. In some ways, the collision gestures to the cost or consequences of Stephen's genius—he has to pay with his withering body.

The next scene shows Stephen in a similar close-up horizontal frame with his body angled down on a squeaky x-ray table with his face void of emotion. Stephen has become a patient in one fell swoop. By this point, the film has signaled Stephen's transition from abled to disabled in the eyes of the consumer, and now we have to learn alongside Stephen, what his body is or rather is *not* capable of. This is accomplished with shots such as Stephen attempting to push against his physician's arm with his foot and count on his fingers which no longer move like nimble hands, but are now crippled and tense. The close-up shots of Stephen's limbs take center stage as the eerie music begins in the background to build tension so the consumer can begin to grasp the tragedy that Stephen is experiencing.

The music peaks as the physician's diagnoses Stephen with motor neuron disease. The fish eye camera lens becomes more distorted as the physician provides greater detail calmly and clearly delivering the list of functions Stephen will lose as a result of the disease. The lens is used to distort the diagnosis the way the disease will distort Stephen's future. The physician concludes by giving Stephen a life expectancy of two years. *The Theory of Everything* (2014) presents Stephen's only response to this news with a question—“what about the brain?”—that suggests he is less concerned about his impending physical deterioration than the preservation of his intelligence. This comment helps paint the picture of Stephen as inspirational because anyone else would be terrified by this diagnosis, but not Stephen. He believes as long as his brain is capable, he can handle the rest.



Following his diagnosis, Stephen spends an unusual amount of time alone researching because he believes since his time is limited, he must produce a scientific breakthrough before he is unable to do so (*The Theory of Everything*). Because of this mindset, he also pushes Jane away, gesturing towards the isolation of disability. But Jane refuses to leave Stephen, which counteracts this isolation with joy of young love. She demands that he play a game of croquet if he wants to be with her to which he spitefully agrees with a tone that illustrates she will regret her request. This is the first time Jane sees Stephen as impaired and imperfect. She cries when imagining what the future holds for him. Nonetheless, she convinces him she loves him, tilting his earth upright again. Stephen seems reinvigorated by love *even as* he appears in the frame using a cane. More prominent than the cane, however, is his gait, which sways as he uses the balls of each inwardly turned foot to inch himself forward. With hope restored, Jane commits herself to fighting the disease together with Stephen and his family; even after Stephen's father, Frank Hawking does his best to convince her to leave Stephen and illustrates the struggle ahead by explaining, "the weight of science is against you and this will not be a fight, Jane. This will be a very heavy defeat" (*The Theory of Everything*). Frank's explanation is troubling because he positions himself as the authority on the situation and infantilizes both Jane and Stephen by assuming the young couple does not understand the gravity of Stephen's diagnosis. This scene contradictorily frames disability as a death sentence and something that can be conquered by love, presenting disability as extremes on both end of the spectrum. This framing reinforces that dominant narrative that disability cannot be neutral category.

*Despite* Stephen's impairment and his family's skepticism, Jane and Stephen marry and start a family. What follows is a very happy and fulfilling montage of young love that portrays Stephen not as a chronically disabled man, but as a new husband in love with his wife. Their

marriage in this scene is presented as the perfect nuclear family with a new house and, soon after, a new baby son; everything is perfect. The rhetorical device used to frame Stephen as just a “normal” husband, makes him inspiring. The montage prompts the consumer to think, “isn’t that nice? He is disabled, but still, decides to marry that girl!” But, as the montage comes to a close, the consumer is brought back to reality by seeing Stephen shimmy down the stairs to grab his two canes. The camera utilizes a close-up shot of Stephen walking with his canes to his PhD defense, which calls back to the previous scene of Stephen using one cane. However, this time his body moves lethargically and his toes drag.

Once at the defense, Stephen is asked to sit down, but he declines as he is still too prideful to truly accept his physical state and perhaps wants to keep his dignity as a student in front of his mentors. When he returns home as Dr. Hawking, Jane holds a dinner party in celebration of him with his friends. The consumer witnesses Stephen’s struggle to eat for the first time. Stephen looks up from his spoonful of peas only to enviously observe in slow motion his friends’ dexterity. He leaves the table, physically representing his isolation from able-bodied people. He stands up to go upstairs to visit his infant son, Robert who looks concerned for his father who struggles in an attempt to pull himself up the flight of stairs. The scene ends with Stephen near tears as the disconnect between his mental ability and his body’s ability finally begins to sink in.

*The Economist’s* review (2014) explains the dinner scene as “heart-wrenching [for the consumer to] watch as [Stephen’s] body deflates.” He can no longer get up the stairs, but Stephen’s failing helps the consumer understand that his ability to control his body is drastically diminishing. The following scene makes the consumer more aware of the contrast between Jane’s proper postures and Stephen’s impaired slouch at the breakfast table. The somber feeling of Stephen’s inability at this point in the film is compounded by Jane wheeling in Stephen’s first

wheelchair. There is a moment in which the camera views the chair through Stephen's eyes and then the camera angle changes to capture Stephen's expression directed at the chair. The chair becomes a symbol for Stephen's growing dependency. As he dramatically slumps into the chair, he utters to Jane, "this is temporary," reinforcing his unwavering discomfort with his diagnosis.

Nonetheless, Stephen remains relatively optimistic as he is forced to adapt to his evolving reality. Stephen and Jane move their bed into the kitchen, to which Stephen chuckles, "it's convenient for breakfast" (*The Theory of Everything*). The two share an intimate moment in which they kiss and Stephen maneuvers his hand around her arm, implying sexual intimacy. The next shot shows the pair with a new baby girl, Lucy. The lack of physical intimacy in this scene is unsatisfying because it creates an illusion to the act. It does lead the consumer to the correct conclusion about what takes place between them, but it feels half-hearted as an actual sex scene. Portraying an impaired man's struggles to have sex with his wife is rendered unnecessary; the consumer already understands he is emasculated by his disability. Perhaps as a way for Stephen to reclaim some of that lost masculinity, he has a scientific revelation about black hole radiation in bed, which reinvigorates his commitment to his career.

Thanks to his revelation, Stephen is able to present his new physics theory to a room of physicists at Cambridge. Part way through explaining his theory, the screen cuts to a scene of his friends at a bar watching Brian passionately demonstrate Stephen's theory, the same theory being presented to the physicists by Stephen himself. This switch back is subtle, but it would appear that as Stephen's speech becomes more indecipherable, the director put in "translators" for him in order for the consumer to be able to fully understand Stephen's lines. As journalist Aftab (2014) quotes in their article, "The Theory of Hawking - Eddie Redmayne Tells Kaleem Aftab the Secret of His Acclaimed Portrayal of the Theoretical Physicist," the director, James Marsh,

“didn't want to use subtitles.” Similarly to Brian’s role as translator, the highly regarded professor Khalatnikov in the audience is used to validate Stephen’s theory as being important to the field. He demonstrates his validation of Stephen’s theory with the statement, “the little one has done it!” which simultaneously demonstrates his approval of Stephen’s work and undermines his physicality by infantilizing him (*The Theory of Everything*).

Stephen’s physicality is undermined again when celebrating his breakthrough with his friends and Brian asks him if his disease affects everything. Stephen informs him that sex uses a different system, that it is “automatic” (*The Theory of Everything*). This interaction is used rhetorically to explain that *even though* Stephen is losing control over his bodily, he can still maintain his sexuality. This is the first, but not the last, time Stephen’s sexual competency is called into question and then re-established.

The years fold away and it becomes clear to the consumer that Jane is overwhelmed by her dual caregiving role as a mother and wife. She tells Stephen she needs help, but Stephen forcefully contends, “we are just a normal family;” Jane disagrees (*The Theory of Everything*). Soon after, her mother notices her exhaustion and suggests she join the church choir. At choir practice, she meets Jonathan Hellyer Jones, “the drippy choirmaster” whom Jane soon positions as the help the family has been waiting for (*The Economist*). Upon Jonathan and Stephen’s first meeting, Jonathan presumptuously attempts to feed Stephen peas when Jane walks away from the table for a moment. On seeing Jonathan’s intention, Stephen shoots him something that can only be described as a death glare. Jonathan, embarrassed, fumbles over his words and goes back to eating.

Stephen goes on to emphasize his PhD degree in the dinner conversation to counteract Jonathan’s patronizing gesture directed at him. Although this interaction could be analyzed in a

variety of different ways, for the purpose of my argument, I connect it back to the infantilization of Stephen because of how effectively the camera angles and body language of the actors depicts the power differential between Stephen and Jonathan. For example, a medium shot presents both Jane and Jonathan as taller than Stephen sitting the dining table. Stephen is hunched in his chair with his eyes on his plate. When Jane leaves the table, Jonathan's glances at her and back at Stephen's plate demonstrating his discomfort with being left with Stephen. With nervously darting eyes, Jonathan hesitantly picks up the spoon to feed Stephen as if interacting with a friend's child. From the beginning of Stephen's diagnosis,<sup>11</sup> he has been infantilized because of how his body makes him appear small and weak. This understanding then impacts him being viewed as inspirational because the consumer imagines a child standing up to Jonathan, instead of a grown man.

Interestingly, Jonathan becomes a central member in the Hawking's daily lives. So much so, that when Jane has her third child, Timothy, the family believes Jonathan has fathered him. It does not appear possible for Stephen to father a child in his physical state. This assumption points to the perceived parallels between Stephen's deterioration and his desexualization/infantilization. He is seen as incapable and undesirable. Due to these accusations, Jonathan feels the need to distance himself from the family. This decision impacts Stephen's chance to go to the Bordeaux Opera because students need to accompany him instead of Jonathan, the more qualified carer. While at the opera, Stephen's contentment melts into terror as he realizes he is beginning to choke. He shifts his head as much as possible to get his student's attention to help him. When she finally notices, she puts a napkin to his mouth. Upon pulling the napkin away from his mouth, it reveals a dribble of dark red blood contrasted against the white

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<sup>11</sup> Frank Hawking reinforces Stephen's infantilization when he talks with Jane about motor neuron disease being an impossible fight.

linen—the music crescendos as Stephen is whisked away on a gurney. He falls ill with pneumonia and is put in a coma. Jane arrives at his side only to be given the choice between having Stephen’s ventilator disconnected or giving him a tracheotomy. The consumer holds their breath in anticipation as Jane responds with conviction, “there’s no question, Stephen must live!” (*The Theory of Everything*).

Now that Stephen can no longer speak, a personal assistant is enlisted to rehabilitate him. This required rehabilitation is how he meets Elaine Mason, his future wife. With Elaine in the picture, Stephen again is galvanized to work and writes a book to share the thoughts he can no longer utter. As Stephen and Elaine become better acquainted, he feels reinvigorated by her positivity and belief in his intellect and ability. She even helps resexualize Stephen by assisting him in viewing *Penthouse*, which, for a moment, reminds the consumer that Stephen is still human even in his continuously impaired state. So, it is unsurprising when Stephen falls out of love with Jane and in love with Elaine.

In the final scene, Stephen’s Cambridge professor introduces him to a crowd of friends and fans with Elaine sitting in the front row. The professor explains, “it has been one of the great joys in my life to watch [Stephen] defy every expectation both scientific and personal” (*The Theory of Everything*). Stephen glides forward to the microphone and begins answering fans’ question. But, the scene is interrupted as Stephen longingly watches a woman in the audience brush a pen off her desk. In a fantasy sequence, he glances down at his joystick, to which the camera uses a close-up shot to watch him miraculously extend his hand and de-cripple his feet as well as re-center his knees. Another glance at the lonesome pen is enough to force Stephen to step out of his chair as an able-bodied man who marches down the steps of the stage (accompanied by alluring music and echoing sound effects from his steps) to effortlessly bend

down and pick up a dropped pen before the camera cuts back to Stephen looking heartbroken in his chair. This interaction signals to the consumer that even after everything the character has accomplished in the film, in the final scenes his one unwavering hope is to regain his ability.

Stephen reenters the present space to conclude his speech by explaining, “there should be no boundary to human endeavor, we are all different; however bad life may seem there is something you can do and succeed at, while there is life there is hope,” leaving open the possibility of him going back in time and changing fate (*The Theory of Everything*). Stephen’s speech seamlessly leads consumers into the final scene in which the entire film is reversed to freeze on an image of Stephen in his able-bodied prime. While my description of these ending moments may seem hyper-sensationalized, the consumer, after spending two hours journeying through time with Stephen, eats this ending up with a spoon.

#### 4.2 **Redmayne’s Performance and Crippling Up**

The performance by a nondisabled actor, such as Redmayne, Journalist Frances Ryan (2015) argues, “use prosthetics or props to alter their appearance in order to” depict a disabled character in film and television is known in the disability community as “cripping up.” This practice, while praised by the film community for actors’ who have the skill to *truly embody* disability is detrimental to the representation of the disability community because it appropriates an identity for the sake of entertainment. Crippling up enhances the perceived authenticity of the film because it is the artful sign in Hollywood of rare skill. It makes the story in a film believable and works to convince consumers that the portrayal they are viewing represents disability because it *feels* real. Ultimately, this practice does a disservice to the cultural understanding of disability because consumers and critics alike value the performance without critically engaging

with how it negatively impacts the representation of disability and, as a result, lived experiences of the disability community.

Cripping up is a challenging concept to unpack because there are a variety of opinions on the matter. Dominick Evans offers his opinion that, “Disability is presented as one of the ‘greatest’ challenges a non-disabled actor can take on, often one they take in hopes of winning the highest honors for their craft” (qtd. in Robb 2017). I understand this perspective because acting is a learned craft that at its core involves embodying an experience the actor is likely unfamiliar with. However, it is the consequences of the representation that makes crippling up truly problematic. The counter-argument to the acting argument is that, in contemporary media, society should not praise crippling up as a skill that an actor should aspire to at the expense of an underrepresented and marginalized population. A proposed alternative to crippling up laid out by Davis (2011) is to have disabled actors play those roles. Unfortunately, this perspective is an oversimplification of this issue, as it implies there is a large pool of disabled actors for production teams to choose from. Gill and Sandahl (2009), in their article, “Arts Career Outcomes and Opportunities for Americans with Disabilities,” argue, on the other hand, that the pool does not exist because of the systematic and attitudinal barriers to disabled artists training as well as the economic instability of acting as a profession (15, 19).

Again, crippling up for a role as an actor is not only accepted but encouraged and praised in Hollywood; it demonstrates dynamic skill. Frances Ryan in her article, “We Wouldn’t Accept Actors Blacking Up, So Why Applaud ‘Crippling Up’?” argues, “the ability to play ‘disability’ is a definite asset for an actor, a source of genuine acclaim” because without the actors’ ability to physically and emotionally embody these roles, these films centering on a disabled character would not be believable. The actors would not be awarded for their skill and the consumer would



not be so convinced that the film portrayed lived experiences of disability accurately. What is worse, Hollywood has a history of praising and awarding biographical films about disabled people, specifically the actors who use their craft to embody a specific disability. Journalist Stephanie Levy (2015) elucidates in her article, “Oscar-Winners Often Play Disabled Characters. So Why Don’t We See Disabled Actors?” that, “since 1989, 14 of the 27 Best Actor winners have played a character with a disability”. These sorts of disability representations have unfortunately become commonplace in the film industry. In 2015, Eddie Redmayne won best actor for his role in *The Theory of Everything* alongside Julianne Moore, who won best actress for playing a woman with Alzheimer’s in *Still Alice*.

One argument for why crippling up is valued in Hollywood is “non-disabled actors playing disabled characters leads to success: audiences find it reassuring” (Ryan). Or, as the playwright Christopher Shinn believes, “the act of watching a disabled character being played by an actor who we know is really fit and well [allows for] society’s ‘fear and loathing around disability’ to be ‘magically transcended’ with clips such as Stephen rewinding time at the end of the film” (qtd. in Ryan). The audience can flirt with disability, knowing that it is make believe. Sieber’s theory of ideology of ability, which puts forth a two-tiered argument about ability helps analyze the success of crippling up. Firstly, that bodies simultaneously matter because they must be perfected and that they do not matter because they just contain our more important spirit (Siebers 7). Secondly, that bodies are finite and fragile, but that we must hope for a future when we overcome these human characteristics (Siebers 7). Crippling up reinforces this theory because it presents the perfect body of an able-bodied actor against the portrayal of the disabled body. The actor demonstrates that while they are human, they can triumph not over death, but

disability. This demonstration imparts hope upon consumers that they may never will be affected by disability.

It is not lost on me that actors work diligently, often with good intentions to prepare for these roles, perhaps even in collaboration with disabled people. For instance, Eddie Redmayne claims to have spent months “[training his] body like a dancer” (qtd. in Kellaway) in preparation to represent Stephen’s motor neuron disease in *The Theory of Everything*. Redmayne’s physical embodiment which he was able to capture in the role with “infinite subtlety” would be impressive if it did not also embody harmful characterization of a marginalize group (The Economist). Regardless of the effort able-bodied actors put into their preparation to play a disabled person, they will never be able to capture complex embodiment of disability, another concept from Siebers. Complex embodiment understands disability as a holistic experience recognizing that our bodies evolve in contextualized spaces over time (Siebers 27). We, as disabled people, have had years, if not a life time, of adapting, learning, and interacting with our bodies. This knowledge makes the experience of living in our bodies often much more mundane than the stark struggle disability representations make it out to be. Complex embodiment gets at a level of understanding that experience that an able-bodied actor could not possibility tap into. This unattainable aspect often makes “authentic” portrays of disability far too lackluster for the disability community to digest because the portrayal is often of a “normal” person slowly, tragically declining.

Cripping up persists because these portrayals leave the general consumers feeling as though a film *authentically* represented disability. Again, the acting skill of crippling up has a wow factor. Crippling up is also used by consumers and critics as a way to measure performance quality. If embodied *well enough* to be deemed authentic, it is especially impressive, and

consumers and critics give the film and the actors a stamp of approval in the form of being nominated for Academy Awards.

Unfortunately, authenticity is often the solution to crippling up, even in the disability community. Authenticity is often touted by disability activists as the cure all for crippling up because of the poor portrayals of disability that sorely misrepresentation the disability experience. Dominick Evans (2017), a disabled director and activist, suggests in his article “Please Stop Comparing Crippling Up to Blackface,” “[I think] the level of authenticity and accuracy would be greater coming from someone with that particular lived experience.” Here, authenticity is put forth as a solution for crippling up because of the need to remedy the damaging misrepresentation at the hands of nondisabled actors. To some degree, I agree with Evans that personal experience breeds a better representation, but my critique is that authenticity is used too broadly and haphazardly to truly be the solution the disability community seeks for misrepresentation. Implementing Kafer’s political-relational model here is useful because it reminds us that disability should be a location for questions rather than answers (11). We need to embrace disability not a secure definitive experience, but one that will change and evolve over time. I think that we in the disability community must tread lightly when it comes to striving for solutions as a way of solving larger cultural dissonance as it relates to understanding disability. I worry the damaging tropes are already so woven into our cultural fabric that adding more clearly defined answers, like that of authenticity, as a way out of misrepresentations, will only hurt us later.

Regardless of the discourse around crippling up or even how well Redmayne portrays Hawking on film, Redmayne’s performance nonetheless reinforces dominant narratives as it

elicits consumers to respond to specific moments of interest in the film<sup>12</sup> with sympathy for Stephen's as a disabled person. Simultaneously, the consumers admire Stephen for his strength of character and not ending it all because of his disability as many peering into his struggle might consider. Redmayne being able to capture motor neuron disease on screen so convincingly as an able-bodied actor is an incredibly effective tool used to equip the consumer with *the reality of* disability. The consumer admires Redmayne for having the skill and dedication he demonstrates by really *embodying* Stephen's physicality. Redmayne's artful embodiment allows the consumer to experience disability without really experiencing disability (similarly to Redmayne playing a disabled physicist as an able bodied actor). The consumer can sit with disability for a few hours, which concludes with an inspirational speech, and then go on about their day thinking they know something more about disability because they saw a convincing portrayal of motor neuron disease.

#### 4.3 **Media Authentication of *The Theory of Everything***

The media discourse around *The Theory of Everything* sets the stage for the authentication of the film because it works to reinforce what is presented in the film. Meaning, the film in and of itself cannot be authentic. It has to be authenticated by the media in order for it to be determined to be authentic in dominant culture. It is the task of critics to view and critique the film to determine the quality. This decision is intertwined with authenticity. Once reviews of a film are published (if they are positive), they work to enhance the cultural perception of the film often resulting in authentication.

Beyond critics, I include the Hawking family in media authentication as I see them as influential to the consumer reception of the film and distinct from a general consumer. The

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<sup>12</sup> The moments I am referring to are for instance, when Stephen sways into his dissertation defense on crutches or when he can no longer feed himself.

family is arguably the most crucial way in which the film is authenticated because they lived through the events portrayed in the film. The Hawkings endorse the film with comments like those from Hawking quoted in journalist Andrew Grant's (2014) review in his article that the film was "broadly true" and in journalist Rebecca Hiscott's (2014) article when the Hawkings' daughter, Lucy, explains, "that was my life." These comments go a long way to convince consumers that the representation of disability in the film is representative of lived experiences. There are two glitches with the logic that this film is representative of the disability experience. One, the film adheres to the tired inspiration trope which is not representative of the disability community. Secondly, while this portrayal may be true for Hawking and his family, media positions the authenticity of this film as proof for its generalizability to the broader disability community when, in fact, Hawking experiences a unique privilege as a disabled person unlike many in the disability community.

I would like to take a moment to disclaim that my intention here is not to disempower Hawking or discount his experience (as represented by his former wife, J. Hawking in her memoir *Travelling to Infinity* which was used as the basis for the film), but to say that in the production teams' quest for authenticity, Hawking's personal and professional successes are hijacked by the inspirational trope, doing his work as well as his role as a representative for the disability community a great disservice. Hawking has his own truth as it relates to his life and lived experience of disability that is separate from his representations and even how he represents himself publically. The production team interprets Hawking's story in a way that aligns with intentional meaning they infuse into the film. Redmayne also has a different truth and task as it relates to his understanding of Hawking. The lines between these truths become clear in interviews with these key players in the way they each present their interpretation of the story

differently. To be clear, while these truths can all be true simultaneously, the truth that is broadcasted most effectively and, as a result, believed to be authentic, is what is represented in the film. Like most films that use disability as a metaphor, *The Theory of Everything* flattens these multiple truths (or rather complexity), in an effort to portray a digestible love story about disability. While most Hawking representations simplify disability, J. Hawking's depiction of her life with Hawking is relatively dynamic and complex in comparison to the film, which reduces the story to a one-dimensional disability tale.

Another significant facet of the media authentication of the film centers around Eddie Redmayne's convincing portrayal of Stephen's embodiment. This portrayal is believable as to effectively guide the consumer through Stephen's disability as intended by the production team—to convince the audience of Hawking's inspirational journey. Unfortunately, the discourse around Redmayne's performance shifts the focus of the film and conversations around the film from Hawking (or even J. Hawking) and Hawking's life story to Eddie Redmayne's acting ability. This refocusing is troubling because if the film, as James March explains to journalist Sasha Geffen (2015) in her article "The Theory of Everything: An Interview with James Marsh," is "from the point of view of the wife, the carer, and her struggles and burdens [because] that perspective felt to me to be very interesting" as "the great man and his genius —... felt like a tired idea." Marsh's intention gets totally obscured against the media's lavish praise of Redmayne. Media is able to shift the conversation from the disabled genius to an actors' ability, once again using disability as a platform for a nondisabled agenda as presented in Mitchell and Snyder's concept of narrative prosthesis. In essence, the conundrum is this: while the authenticity of Redmayne's portrayal works to enhance the prominence of a film about disability (albeit, a problematic one), ultimately the media's choice to focus on Redmayne's adroit

performance, derails the cultural discourse around the film, removing any possibility to redeem this film's representation.

#### 4.4 **Audience Authentication of *The Theory of Everything***

The nature of Redmayne's high-profile performance enhances the intrigue of the film and encourages consumers to see the performance for themselves. We want to see the magic of Redmayne's portrayal of disability—we want to gaze at the “disabled” body. Garland-Thomson's (2009) *Staring: How We Look* lays out an analysis of staring in which she explains, “the goal of observation—of staring for the sake of knowing—is to make the unknown intelligible, to incorporate the unusual into our understanding of the usual (*Staring* 48) ... We enlist intense visual scrutiny to gather knowledge, answer questions, shape narratives, and explain dissonance” (*Staring* 49). Applying this thinking to film reveals that consumers stare at Redmayne's portrayal to learn about disability. Consumers use representations as a way to help them understand disability which often feels unknowable and intangible to us. What is critical is that it is specifically because the representation we are staring at in the film is perceived to be authentic that we believe the film is an appropriate cultural location to gather knowledge about disability. It is assumed that because the body consumers observe looks disabled, the film must also be presenting an authentic disability narrative.

To “gather knowledge” is one reason to stare, but the reasons people may stare are numerous (*Staring* 49). Staring in a low-lit theater enables us to stare at our leisure and without accountability. This act can be likened to baroque staring, defined by Garland-Thomson as, “the state of being wonderstruck and confounded. It is gaping-mouthed, unapologetic staring” (*Staring* 50). We, as consumers, are captivated by Redmayne's realistic performance because our culture is fascinated by the disabled body. The fascination with the disabled body has a long

history beginning perhaps with the freak show where carnival-goers were not only able, but encouraged to gawk at disabled bodies. While the freak show, and staring, for that matter, are taboo today, culture has devised new ways to stare at freaks—in film. *The Theory of Everything*, particularly in a theater setting, encourages us to baroque stare without any of the negative social consequences of staring. We stare because we are *supposed* to be in awe of the realistic transformation Redmayne goes through. We are almost *more* intrigued by the disabled body when it is depicted by an able body because the detail required to make that body authentic feels painstaking. The portrayal is shocking to consumers because it seems so authentic that we cannot believe the body we are staring at is *not* disabled, which only works to further intrigue us.

Consumers work to incorporate *The Theory of Everything* into their usual knowledge of disability in large part because of its authenticity. This process of audience authentication can be illuminated by Hall's (1980) theory of encoding/decoding model of communication in which the film presents a "meaningful discourse" or message about disability and it is the task of the consumer to decode that message in order to create our own meaning from the film's message (165). Hall further argues, there is no guarantee that the encoding, of *The Theory of Everything* in this case, which is infused with intentional meaning (170) is going to be "realized" through the decoding by the consumer (165). Encoding is typically invisible to the consumer. They decode it, but they do not realize it was intentionally encoded to begin with. The consumers, in essence, authenticate the film by incorporating their interpretation of the film into their framework for disability. In order to incorporate this new knowledge, the consumer has to believe it is true or else they would not incorporate the knowledge into their existing framework.

The focus on Redmayne's embodiment authenticates the narrative that runs throughout the film, naturalizing the inspirational trope of disability representation and conditioning the



viewers to accept the representation unquestioningly. Redmayne's authentic embodiment then leads the consumer to feel that the film is an authority on disability, which they can draw on to expand their own understanding of disability broadly. This authentication is dangerously problematic when as the consumer receives knowledge about disability from a film, "based on a book by an able-bodied person, adapted by an able-bodied screenwriter, and directed by an able-bodied director, and [starring] able-bodied actors" (Harris). The disabled population has been spoken for and about by nondisabled people for far too long and in a film about a man who identifies or is at least positioned as a disability advocate, it seems particularly troublesome that disability empowerment is a missing piece in the film and in what the consumer likely takes away from the film.

#### 4.5 **Complicating Authenticity of *The Theory of Everything* with *Hawking***

*The Theory of Everything* reads as an authentic depiction of disability. Consumers can use *The Theory of Every* to better understand disability as well as Hawking. That is the power of perceived authenticity. But, there are an endless amount of Hawking representations. The diverse Hawking representations that exist sometimes contradict one another which is an important piece of an analysis of authenticity because it seems so counter-intuitive that two separate representations that present contradictory narratives can both be perceived as authentic. We saw these inconsistencies between J. Hawking's two memoirs, but there are also contradictions between *The Theory of Everything* and the earlier biographical film about Hawking starring Benedict Cumberbatch entitled *Hawking*.

There is one scene in particular, present in both films that reveals just how much authenticity can be manipulated. The scene presents a conversation between Stephen and Jane at the May Ball, where he is telling her about the effects of UV light on the fluorescence in washing

powder. While the premise is the same in both *The Theory of Everything* and *Hawking*, they present the story in distinctly different ways, altering the authenticity. In *The Theory of Everything*, the scene is close enough to the beginning of the film that Stephen is still understood as able bodied and appears very suave both to the consumer and Jane. The two are leaning against the tent poles in their best attire casually holding champagne coupes and in lighting that radiates a blue hue over the whole scene. Looking out at the slew of dancing couples under the tent, Stephen says, “you see how the men’s shirtfronts and their bow ties, how they glow more than the women’s dresses?” (*The Theory of Everything*). To which Jane replies with sweet interest, “yes.” Stephen continues, “do you know why?” (*The Theory of Everything*). “Why?” Jane laughs (*The Theory of Everything*). “Tide” with a modest smile, replies Stephen. He goes on to explain, “the fluorescence in the washing powder is caught by the UV light” (*The Theory of Everything*). They giggle at each other and Jane with a bright white smile asks, “why do you know that?” (*The Theory of Everything*). Stephen, humbly impressed with his smooth moves, ultimately relates the knowledge back to physics, making him all the more endearing to our leading lady. This scene is used to a way to kindle the love blooming between them and it works—the consumers find the interaction totally endearing.

Interestingly, *Hawking* is represented completely differently in the same scene in which Jane and Stephen discuss washing powder at the May Ball in the 2004 film *Hawking*. In this film, the scene is closer to the conclusion of the film and it appears that Stephen’s condition is more advanced than in *The Theory of Everything* scene. He is perhaps impaired by both nerves, alcohol, and disability. Nonetheless, the scene transpires as follows: the scene is located inside a low-lite jazz club crowded with tables and noise. The camera spots the neon white shirts as Stephen begins to explain the phenomenon to Jane. “The blue lights are picking up the

florescence you get in washing powder. That's why their shirts are illuminated" clarifies Stephen (*Hawking*). To which Jane simply replies with a smile, "they're very strange!" (*Hawking*). Stephen continues, "the dresses are new. They haven't been washed, so they are not florescent" (*Hawking*). As the jazz picks up, Stephen maneuvering his mouth and swaying his body with the grip of his cane, continues, "you see? Great scientists—I can tell you all about how washing powder reacts under blue light. One of the great questions of our time, whether Tide or Daz under blue lights—do you want to dance?" (*Hawking*). He asks this question so urgently as he stands that it leaves Jane without a chance to respond or follow. This moment is clearly a turning point in the film—should Jane stay or go? Stephen is isolated or perhaps isolates himself in this scene, making it clear to the consumer how bizarre Stephen is, particularly in relation to sweet, innocent Jane. Hawking is portrayed as erratic and unappealingly brilliant—too smart with too few social skills.

It is clear with the comparison of the same scene in the different films how each scene presents authenticity in unique ways. In *Hawking*, Stephen appears quite disabled and out of sorts, making the scene feel realistic because of its chaotic nature, while *The Theory of Everything* uses the scene to bolster the affection Jane and Stephen have for one another. The scene in *The Theory of Everything* also feels authentic because at this moment in the film, before disability appears and ruptures their lives, the consumers just want them to get their happy ending.

The washing powder scene is not the only inconsistency between the two films. For instance, the diagnosis scene in each film create different meanings of the experience with subtle shifts in the physician's dialogue. In *The Theory of Everything*, in response to Stephen's question, "what about the brain?" the physician responds, "the brain isn't affected. Your thoughts

won't change, it's just that... Well, eventually, no one will know what they are" (*The Theory of Everything*). The scene is presented to the consumer primarily from Stephen's perspective looking at the physician through a distorted fish eye lens. Both characters are in a close up frame, but Stephen's head, tilted to the side, is in closer frame enabling the consumer to see the detail of his face twitching as he receives the news. The frame also allows us as the consumer to really experience the physician's concerned sympathy. The scenes following the diagnosis offer no hope—Stephen will die in two years.

*Hawking* on the other hand, presents the scene as follows: "What about the brain, the brain itself?" Stephen asks the physician urgently (*Hawking*). The physician responds evenly, before walking away, "untouched, the brain is left untouched" (*Hawking*). Consumers watch this scene unfold from behind the physician as to frame Stephen in a close-up frame of his neck and head. The consumers do not have an opportunity to explore the physician's expressions as he offers the grave news. While the news is unquestioningly somber, there is some hopefulness in the subsequent scenes that Stephen will be able to complete his PhD and fulfill his brain's potential. The method of diagnosis alters the way consumers read motor neuron disease as a diagnosis and as a result, what the consumer may take away from the films about the disability.

Here again, it becomes clear how authenticity can be manipulated as a narrative device. Two different films present the same scene and information in different ways, yielding different meaning in each. In *The Theory of Everything*, the news is a death sentence, obvious by the word choice of the physician who describes total isolation for Stephen. Alternatively, in *Hawking*, although the facts of the news are the same, the word choice is not as severe, leaving room for vagueness, interpretation—possibility. This shift is assisted by the camera techniques that either enable or restrict the consumers' ability to draw their own conclusion.

#### 4.6 The Authenticity of *The Theory of Everything*

It is critical to identify and contextualize the web of discourse around this film because it has a great deal to do with the ways in which the film is interpreted as authentic by consumers. The film's perceived authenticity hinges on Eddie Redmayne's convincing embodiment of Hawking's impairment and the reception of that embodiment.

*The Theory of Everything* is presented as *authentic* and endorsed as representative of the disability experience by both critics and consumers with a *Rotten Tomatoes* (2017) critic score of seventy-nine percent and an audience score of eighty-four percent. Jasmine Damon (2017), an audience reviewer on *Rotten Tomatoes*, gushed *The Theory of Everything* was "A heart wrenching film with lovable characters, talented actors based on a true story. Eddie Redmayne did a remarkable job playing such of a difficult character." *The Mary Sue* film critic Carolyn Cox (2017) critiqued *The Theory of Everything* for *Rotten Tomatoes* claimed, "The Theory of Everything charts the universes inside of us: inscrutable, expanding, human." *The Toronto Sun* film critic Jim Slotek (2015) pointed out in his *Rotten Tomato* review of *The Theory of Everything*, "There's a mischievous quality to Redmayne that seems a good match with the wit Hawking has always managed to convey with a raised eyebrow and a mechanically-voiced quip." All of these reviews rely on reading the film as authentic. But to the disability community, not only does it fail to represent the disability experiences, it falls into the same traps of reproducing the dominant disability narratives that culture so often perpetuates. Consumers can easily incorporate *The Theory of Everything* as an authentic depiction of disability into their disability framework *because* of the cultural adherence to these dominant narratives. In other words, *The Theory of Everything* adheres to the cultural scrip of disability, making it appear authentic when context of other disability films that also adhere to the dominant narrative.

Because of how pervasive the overcoming narrative is to the general consumer's understanding of disability, they are unlikely to engage with or critique the portrayal of disability in the film. What the consumers are more likely to engage with is the quality of portrayal based on Redmayne's acting ability. The quality helps us determine how authentic we believe the representation to be.

The authenticity of *The Theory of Everything* gives the film unearned validity because despite the admiration around Redmayne's performance, the production team does not present anything in the film that would make this film an exception to disability portrayed in a long list of award-winning films. With the understanding that the narrative structure is always shaped, as scholars, Tom Brown and Belen Vidal suggest in their 2014 podcast on current biographical films, by the knowledge of "what we know the person will be great for" (Vidal & Brown). The trouble with *The Theory of Everything* is that the knowledge of what Hawking is great for *is being* an inspirational disabled physicist. This fact then seamlessly lends itself to frame Stephen's character as inspirational in the film in an attempt to make the film authentic by aligning with his public persona as inspirational.

The big moments in the film were selected specifically to show the consumer why they should be inspired by Stephen—to demonstrate how he perseveres to overcome his disability. Unfortunately, the production team got distracted by Stephen's ability achieve milestones in the film because for "a good half-hour ... [the consumer] forgets that Jane's husband is a scientist at all. [Stephen] could be any disabled man, and [Jane] could be any carer, which surely defeats the point of a biopic of the Hawking" (The Economist). But at the same time, forgetting Stephen's identity as a scientist makes the film more digestible than had he been portrayed as a prolific disabled scientist because disability and success are seen as incompatible.

The film is simply another example of an able-bodied actor whose ability to *crip up* awarded him an Oscar. Redmayne spent many months preparing to play Hawking, a scientist with motor neuron disease in a film that portrays key plot points alongside devastating bodily deterioration (Kellaway). Redmayne's portrayal was done so convincingly that Hawking himself has said: "at certain points in the film [I] thought [I] was watching [myself]" (Hiscott). This sort of endorsement authenticates the inspirational trope that is woven into the film; justifying the representation disseminated to consumers who can walk away from the film feeling inspired by Stephen's determination and grateful for their own ability.

The appearance of inspiration throughout the film and the repetition of the inspirational trope of Hawking makes the consumer read the film as authentic because it feeds the disability narratives that they are already equipped with. The inspirational trope used in the film simplifies the complexity of disability. The film could have never presented Stephen Hawking as the funny disabled physicist because it simply does not captivate the consumer the way that the tragedy of disability does. The production team had to construct the narrative in a way that would entice the consumer to feel invested in Stephen's character, which was a success specifically because of Redmayne's authentic portrayal of motor neuron disease. The film encourages consumer investment using key moments that build Stephen up with a success before knocking him down with a new physical obstacle. For instance, as Stephen has his academic breakthrough, he has the great fall resulting in his diagnosis; when Stephen can no longer dress himself, he has a revelation about black hole radiation, and when he can no longer speak, he writes a book to communicate his thoughts.

These key scenes inspire the consumer to root for Stephen's future achievements and celebrate his past ones, while also feeling his physical loss with him. It is a delicate dance that is

a success if the consumer walks away with the hope that “as long as the smile is there and the wit is there, you can endure a lot” (qtd. in Hiscott). This quote by the producer of *The Theory of Everything*, Anthony McCarten clearly reveals the production team’s intentions surrounding the film. It was created to inspire and it does just that. But, it is important to reinforce that it was inspiring *because* of Redmayne’s performance which ultimately shifted the focus of the film as well as the discourse around the film from Hawking to Redmayne, which is troubling for a film that aims to champion disabled people.

The production team at points in the film forget Stephen is a physicist all together, making the narrative a tale about *any* person with motor neuron disease is an attempt to allow the portrayal of disability to be far-reaching. The director, James Marsh explains, “Stephen is a good example of every minute, every second, every day counting. That, perhaps, is embedded in the film as a moral” (qtd. in Hiscott). In reality, the film is not far-reaching at all because it is a movie about Hawking, who is by no means an average disabled person. Average disabled people do not have technology companies inventing new communication methods for their benefit. *The Theory of Everything* “is far from progressive in its depiction of disability. And if a film about the most famous, limit-defying disabled person in the world cannot challenge the limits of the way we portray disabled people on screen, it has to be seen as a lost opportunity” (Harris). This film had a great deal of potential to not only alter the inspirational portrayal of Hawking, but also to challenge consumers to reconceptualize how disability is represented on screen. Regrettably, *The Theory of Everything* failed to accomplish either of these possibilities and will be cataloged alongside many of the films that has come before it that also work to reinforce the detrimental narratives around disability that teach society that disability is a condition that must be overcome.



## 5. CONCLUSION

Disability representations are a powerful way in which cultural knowledge about disability is created and disseminated. Authenticity is the rhetorical tool that is implemented to give disability representations validity. It is because of authenticity that consumers believe a given representation is a qualified instrument to learn about disability.

This work used Stephen Hawking representations to explore perceived authenticity of disability representations. I critiqued authenticity as an innate feature of disability representations. It became clear through my research that authenticity is a highly esteemed solution to misrepresentation, both within the disability community, in Hollywood because authenticity sells. In response to this reality, I set out to contend that authenticity is not the key to misrepresentation because it pigeon-holes representations into “getting it right.” This idea prevents the really valuable work of creating and disseminating complex and even contradictory representations as a way of untethering us from the constraints of authenticity.

It was important to define authenticity as I conceptualized it for this work because of how nebulously it is used in casual conversation. I framed authenticity as a rhetorical tool that is implemented in a narrative and manipulated to create or reinforce “cultural truths” about disability and elicit a particular reaction. With this grounding, I put forth my thesis statement: authenticity is used as a rhetorical tool to inform cultural understandings of disability through disability representations. In order to better inform cultural understandings of disability, we must expose conundrums and complexities inherent in disability representations as a way forward.

### 5.1 **Review of Thesis Structure**

The primary sources I chose to use to unpack this thesis statement were Jane Hawking’s memoir *Music to Move the Stars* and her abridged version *Travelling to Infinity* because they

offer rich locations to study the representation of Hawking. I enlisted Hawking's *My Brief History* briefly as a point of comparison to reveal how Hawking chose to represent himself in writing. I also chose to include the biographical film, *The Theory of Everything* in my analysis as it offered a different medium to experience representations through, which in some ways was more powerful and certainly more pervasive method for informing consumers about disability. It also proved helpful that *The Theory of Everything* was based on J. Hawking's *Travelling to Infinity* and that there was a great deal of material representing the discourse about the film to analyze.

My thesis presented an analysis of the perceived authenticity of disability representation using Hawking representations as a case study. In order to execute this analysis, I employed disability studies theory as well as popular and literary criticism. The methodology I enlisted to frame my analysis include Kafer's (2013) political relational model and Sandahl's (2016) concept, representational conundrum. I applied the theories and methods to my analysis of my primary sources in each of my three body chapters to analyze how authenticity is used as a rhetorical tool that is implemented and manipulated in disability representations. My first body chapter, "The Ubiquitous Stephen Hawking" explored Hawking as a cultural figure and the various and sometimes contradictory ways he is represented and represents himself. My second body chapter, "Travelling through Disability" offered an in-depth comparison and analysis of J. Hawking's memoirs *Music to Move the Stars* and *Travelling to Infinity*. My final body chapter, "The Theory of Acting Authentically" outlined an in-depth analysis of the representation of disability in *The Theory of Everything* allowing for an exploration of how authenticity is implemented and used in film to create meaning about disability.

## 5.2 Closing Statements

Exploring disability representations and authenticity, particularly as it relates to film, illuminates the body's centrality to establishing authenticity. We saw authenticity's centrality to the body in *The Theory of Everything* with the film's authentication stemming from Redmayne's physical portrayal. Authenticity resulting from the body leaves little need for a representation to create a more complex or dynamic narrative because it is viewed as superfluous. Production teams can get away with this imbalance because as Garland-Thomson argues, a representation "relies upon [consumers' understanding of] cultural assumptions to fill in the missing details" of a narrative from their own understanding of disability (11). This assumption unburdens the production team of representations that offer a rich narrative that frame disabled people as dynamic and complex characters. Disability representations too often still overemphasize the medical model of disability that considers disability as residing in the body with little regard of understanding disability as a social construct, which ultimately impacts the lived experience of disability.

Mitchell and Snyder's (2013) theory of narrative prosthesis reinforces the perspective that authenticity relies on embodiment. Mitchell and Snyder propose, "The corporeal metaphor offers narrative the one thing it cannot possess—an anchor in materiality" (234). Narrative prosthesis provides the language we need to understand how authenticity is used in disability representation. The concreteness of disabled body becomes the focus of a narrative, leaving no room to consider disability as a complex social phenomenon (Mitchell & Snyder 222). It almost as if authenticity *encourages* the use of disability as a metaphor because it literally reinforces the perceived reality of disability. Once an actor has captivated an audience with their physical

embodiment of disability, the production team can create whatever meaning about disability they please and consumers are none the wiser.

There is such a push for authentic representation without a critical and in-depth understanding or even a conversation about the consequences of what this push may mean. The problem is, authenticity will never be clear cut and universal because each representation only represents one story, one perspective. Instead of being hyper-focused on authenticity, it would be more beneficial to have diverse representations that, at times, contradict one another so that we begin to dispel the myth that disability follows a script.

We must release our tight grip on “getting it right” in order to leave room for a myriad of representations that interpret the social and political experience of disability in diverse ways. Disability constitutes the largest minority in the United States, making us a complicated group. Culturally, we must begin to embrace this fact. The disability community consists of unique individuals who experience disability uniquely. These experiences may contradict one another; one person’s disability experience may not resonate with other disabled people, but it still deserves to be represented. We cannot expect that a few narratives can be generalizable to an entire population. I query what could be *more* representative than complexity and contradiction? Authenticity is not going to solve the stark misrepresentation of the disability community because an inspirational narrative can be authentic to someone—*The Theory of Everything* is authentic to Hawking— but it will never be universal.

In my study of these various Hawking memoirs, it became clear that authenticity collapses under close analysis because authenticity is manipulated based on context, which cannot be constrained by the cultural expectation of accuracy. Although authenticity is defined as, “conforming to an original,” this definition does not account for people, as the agents who

implement authenticity to *reconsider* their perspective (Merriam-Webster 2016). If consumers did not accept J. Hawking's reconsideration of her perspective, then *Travelling to Infinity* would not be the publishing success it is. Consumers give J. Hawking the benefit of the doubt because she lived through the events she portrayed in her memoirs, so regardless of what she adds or removes between versions, she is the authority on her experience. J. Hawking's position jumbles the security of authenticity. To some degree it feels counter-intuitive that J. Hawking has the ability to rewrite history as she sees fit, but J. Hawking's positionality is what enables me to critique authenticity as the Holy Grail for a number of reasons. The way we culturally use authenticity is quite black and white—it either is or is not authentic and there is no grey area. But as we discovered with the Hawking's texts, there *can* or *are* multiple truths that can exist simultaneously for both Hawking and J. Hawking.

Disability representations are not inherently authentic. Authenticity is a constructed and manipulated rhetorical tool that is implemented in representations in hopes that the cultural discourse around the representation will reinforce that authenticity. We have seen how authenticity is used to convince consumers of its representation of disability within the Hawking texts examined in this work. Hawking representations are widely perceived as authentic because they generally present narratives that align with the public persona based on the core tenets that make Hawking an easily recognizable figure. The danger of authenticity lies in that perception of truth. Authenticity creates a filter for our experience as consumers so that instead of critically engaging with the consequences of the representation, we believe them unquestioningly. We must become critical consumers of disability representations if we are to expand our cultural understanding of disability.

Authenticity creates a boundary for disability to work within. If we have learned nothing else about disability from this work, I hope it is that disability is inherently complex and dynamic and in trying to ascribe to the elusive target of authenticity, we will always be disappointed in disability representations. Our discourse on disability representations must learn to accommodate unique and contradictory narratives of the lives we lead as disabled people knowing that every representation does not have to resonate with every disabled person. Only then will consumers begin to understand the truly rich diversity the disability community has to offer.

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### EDUCATION:

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2015-Present	Ph.D. Student in Disability Studies University of Illinois, Chicago
2010-2015	BA English Education BA Sociology California State University, Chico

### AWARDS, PUBLICATIONS, CONFERENCE PRESENTATIONS:

Fall 2017-Present	Ethel Louise Armstrong Endowed Ph.D. Fellowship of the Department of Disability and Human Development
2017	“Disability and Sociology.” Disability in American Life: an Encyclopedia of Concepts, Policies, and Controversies. Forthcoming.
2017	“The Desexualized Genius: The Implications of Representations of Stephen Hawking” (Emory University’s Critical Juncture Conference)

### ACADEMIC APPOINTMENTS:

Spring 2017	Teaching Assistant, Disability in US Society, Department of Disability and Human Development, UIC.
Fall 2016	Teaching Assistant, Disability in American Film, Department of Disability and Human Development, UIC.
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