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## Disability Representation: Sites of Grassroots Activism on Grief and Insidious Trauma

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DISABILITY REPRESENTATION: SITES OF GRASSROOTS ACTIVISM ON GRIEF AND  
INSIDIOUS TRAUMA

SHAWNA SHEPERD

135 Pages

This thesis investigates how disability communities are transforming disability representation in the mainstream by using social media and other intermedial platforms to push against stereotypes that portray the disability experience as pitiful or monstrous. People with disabilities, such as Alex Darcy and Shelby Lynch, are creating realistic, nuanced representation on Instagram and Tik Tok that does not shy away from discussing their grief or insidious trauma. Darcy and Lynch are grassroots activists who change how disabilities are perceived in the mainstream and create representative models that navigate disability, trauma, and grief in anti-ableist ways. This thesis also looks at how disability communities are using intermedial platforms, such as the Disability Visibility Project (DVP) to grieve as a collective and to critically mourn injustices and insidious trauma people with disabilities have endured. By putting grief, insidious trauma, and disability representation in conversation, this thesis aims to inform and transform disability studies and trauma theory's relationship to one another and continues to create relatable sites of identification for ordinary disabled folks, like myself.

**KEYWORDS:** Disability; trauma; grief; mourning; digital media; social media; representation

DISABILITY REPRESENTATION: SITES OF GRASSROOTS ACTIVISM ON GRIEF AND  
INSIDIOUS TRAUMA

SHAWNA SHEPERD

A Thesis Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of

MASTER OF SCIENCE

Department of English

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2022

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DISABILITY REPRESENTATION: SITES OF GRASSROOTS ACTIVISM ON GRIEF AND  
INSIDIOUS TRAUMA

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S.S.

## CONTENTS

	Page
ACKNOWLEDGMENTS	i
CHAPTER I: INTRODUCTION	1
Critical Disability Studies Attuned to Grief	4
Trauma Theory in Relation to Disability and Grief	7
Disability Representation and Navigating Grief	13
CHAPTER II: THE NEED FOR NUANCED DISABILITY REPRESENTATION	19
Mainstream and Representation	20
<i>House</i> and Desexualizing Disability	23
<i>American Horror Story (AHS)</i> “Freak Show” and Ableist Grief Models	30
Conclusion	42
CHAPTER III: CONTENT CREATORS’ COLLECTIVE CARE: NAVIGATING GRIEF AND INSIDIOUS TRAUMA	44
Social Media: Connectivity or a Risk?	45
Care Work, Crip Time, Content Creation	51
Alex Darcy: Navigating Desexualization	55
Shelby Lynch: Navigating Hypersexualization	67
Conclusion	74
CHAPTER IV: THE DISABILITY VISIBILITY PROJECT (DVP): INTERMEDIALITY AND COLLECTIVE GRIEVING	75
Intermediality, Paratext, and the Disability Visibility Project (DVP)	80
Disabled Content Creators and Critical Mourning	85

Collective-Care and Critical Mourning within the DVP	89
Crip Time and Critical Mourning within the DVP	92
Models of Grief within the DVP	96
The DVP and Collective Grieving	102
Conclusion	106
CHAPTER V: CONCLUSION	108
WORKS CITED	115

## CHAPTER I: INTRODUCTION

We the disabled, the chronically ill, and the Mad carry within us archives. We are intergenerational memory banks filled with the labor, organizing, and artmaking of our radical disabled, queer of color contemporaries, elders, and ancestors. We carry stories of resilience and survival, stories of growth and trauma. In sharing our cripp stories, we unearth legacies of colonialism and nondisabled supremacy.

We, dear reader, craft ourselves new routes to follow—Shayda Kafai<sup>1</sup>

I was reading a 2021 Forbes article, “How the Digital Age is Reinventing (Almost) Everything,” and its discussion of how phones, cars, restaurants, insurance, etc. have become sites where anything “slow, expensive, disagreeable, impersonal” has turned into something “quick, easy, personal, agreeable, cheap or free.”<sup>2</sup> This got me thinking about how people have used technology in extraordinary ways to make lives more accessible, but yet there is public resistance to facing or acknowledging the disagreeable, downtrodden moments of our living. When it comes to being a disabled woman of color myself, I depend on technology quite a bit for everything because of my academic career, day-to-day interests, and reliance on rehabilitative technology. My Erb’s palsy was the result of birth-trauma—brachial plexus—from a negligent labor and delivery team. My nerves were ripped from my spinal cord, resulting in paralysis on the right side of my body, and after two major traumatic surgeries and therapeutic rehabilitation, I was able to regain some function. I now live with a form of paresis that is extreme muscle weakness on the right side of my upper body, which still requires everyday rehabilitation exercises. Because of the injury, and my disability, I needed to learn how to manage the

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<sup>1</sup> Shayda Kafai, *Crip Kinship* (Vancouver, Arsenal Pulp Press), 2021, 71.

<sup>2</sup> Steve Denning, “How the Digital Age is Reinventing (Almost) Everything” *Forbes*, <https://www.forbes.com/sites/stevedenning/2021/09/05/how-the-digital-age-is-reinventing-almost-everything/?sh=5992ecde7f32>, 2021.

continual “pins and needles” feeling, the inability to feel heat or the cold, and occasional unbearable pain. As a child, I went into every activity headstrong, not knowing or understanding my body needed extra care and time to do certain things—and as I grew more aware of my difference to my peers, I grieved the things I thought I could do, but couldn’t. And I grieved for my body, a body that wanted much more—so I thought—than I could give. During an ordinary day, I must face the disagreeable, or unpleasant moments, but I have often felt the need to ignore or suppress those moments, as the *Forbes* article insinuates, which belittles my lived experiences. The line of thinking that represses grief and makes it taboo in popular culture restricts the representational models that are created.

Growing up, one movie I distinctly remember clinging to was *Soul Surfer*, featuring Bethany Hamilton—played by AnnaSophia Robb—who had lost her arm through a shark attack, and after losing her arm learned how to surf again.<sup>3</sup> As a form of disidentification, I admired and clung to Hamilton’s representation, and she encouraged me to try all the activities I could since I could not find anyone who had Erb’s palsy within mainstream movies and television. For viewers who have multiple intersecting identities, such as being BIPOC, queer, a woman, or non-binary, audiences are forced to disidentify or to “read oneself and one’s own life narrative in a moment, object, or subject [that] is not culturally coded to ‘connect’ with the disidentifying subject.”<sup>4</sup> Even though I had a different physical disability than Hamilton—my disidentifying subject—I would think to myself, “if she can surf with one arm, I can definitely try or face whatever sport, activity, fear I wanted to.” The movie, *Soul Surfer*, was crafted to be an inspiration story that depicts Hamilton overcoming her disability. However, that overcoming

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<sup>3</sup> Sean McNamara, *Soul Surfer*, (United States: TriStar Pictures, 2011).

<sup>4</sup> José Esteban Muñoz, *Disidentifications: Queers of Color and the Performance of Politics* (Minneapolis: University of Minnesota Press, 2015), 12.

narrative becomes a form of ableist exploitation that disability studies scholars have termed “inspiration porn.”<sup>5</sup> *Soul Surfer* trivializes the psychological impact of the traumatic shark attack and focuses on Hamilton’s journey to get back into the water again and competitively surf. Hamilton’s grief and pain, consequently, is solved once she rigs a handle on her surfboard that prevents her from falling off the board while paddling, demonstrating a use of technology that makes a surfboard more accessible, but also suggests there were no long-term challenges she must face beyond learning to surf again. Although I now understand that inspiration porn portrayals are often rooted in ableist interpretations of disability, as a confused teenage girl who was trying to learn to love and exist in my body, the movie became a lifeline.<sup>6</sup> I wish I was presented with more realistic models of representation that showed disabled joy but also did not shy away from the complicated emotions of grief, pain, and loss that living with a disability could entail.<sup>7</sup>

These negative feelings are encompassed and expand upon queer theory’s engagement with the “affective turn,” specifically queer negativity.<sup>8</sup> Using the term “negative affects,” which involves *feeling down* and *feeling backwards*, will help to analyze why it’s important that people with disabilities have representations that do not need to overcome the challenges that disability can pose.<sup>9</sup> I began with a discussion of my positionality to justify centering disability topics in my research, and to note that the representational models that I grew up with are now

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<sup>5</sup> Stella Young, “I’m Not Your Inspiration,” *Australia TEDx*, April 2014, [https://www.ted.com/talks/stella\\_young\\_i\\_m\\_not\\_your\\_inspiration\\_thank\\_you\\_very\\_much?language=ab](https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much?language=ab).

<sup>6</sup> Katie Ellis, “Disability and Spreadable Media: Access, Representation and Inspiration Porn” in *Disability and Popular Culture*, (London: Routledge Press, 2015), 149-168; Madeline R. Meade, “The Impact of Ableist Microaggressions on Identity Formation Among Adults with Disabilities” *ProQuest Dissertations Publishing*, 2022.

<sup>7</sup> Alice Wong, *Disability Visibility: First-Person Stories from the Twenty-First Century* (New York: Vintage Books, 2020).

<sup>8</sup> Sara Ahmed, *Living a Feminist Life* (Durham: Duke University Press, 2017), 3.

<sup>9</sup> Ann Cvetkovich, *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* (Durham: Duke University Press, 2003); Wen Liu, “Feeling Down, Backward, and Machinic: Queer Theory and the Affective Turn” *Athenea Digital*, 2020.

dramatically shifting to more nuanced, robust models because the new digital age allows ordinary people with disabilities to use every day digital media to share their stories and experiences in ways that are attuned to grief. Many young adults across the globe, particularly in the U.S. from where I theorize, now have access to virtual communities and people who share similar experiences. As a young adult, I have come to know, cherish, and love many of the advocates I follow on social media because they are doing the work that changes lives, such as providing a way to express grief in anti-ableist ways. This would have assisted me earlier in my life in my own troublesome navigation of guilt for grieving a body I could not—and now do not want—to change.

In my thesis, I argue that disability representation within new media communication platforms, such as social media and blog sites, has critically diverged from disability representation within mainstream movies and TV shows. I present one reason behind this split being that social media and blog sites are working towards centering disabled voices—and the resulting representation of people with disabilities have emerged as nuanced, complicated, and realistic. I further argue that in this nuanced representation, disability advocates are attuned to representing grief and responding to trauma and ableism in anti-ableist ways.

### **Critical Disability Studies Attuned to Grief**

The social model understanding of disability acknowledges the political, cultural, and historical intersections of lived experiences.<sup>10</sup> The social model, as encouraged by Susan Wendell, makes a distinction between impairment and disability as a way to recognize society itself as disabling, as imposing barriers that make life difficult to navigate for people living with

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<sup>10</sup> Dan Goodley, Bill Hughes, and Lennard Davis, *Disability and Social Theory New Developments and Directions* (London: Palgrave Macmillan, 2012), 161.

disabilities.<sup>11</sup> A common illustration this model uses calls attention to a building without wheelchair accessible accommodations. A building without accommodations—without a ramp—acts as a societal and disabling barrier for wheelchair users. The onus in a social model of disability for solving disabling barriers and providing accommodations, is placed on society, not on the individual with disabilities.<sup>12</sup> This model was a reaction to the medical model’s understanding of disability, which suggests that a person’s disability is an individual issue that needs to be “fixed or cured.”<sup>13</sup> Throughout my thesis, I will be drawing on Alison Kafer’s reimagining of the social model through her book *Feminist, Queer, Crip*.<sup>14</sup> Building upon the social model’s premise of disability (society is disabling and disability is not an individual burden), Kafer suggests using a political/relational model of disability.<sup>15</sup> The political/relational model does not rely on the impairment-disability distinction.<sup>16</sup> Further, this model suggests it is impossible to separate disability issues from the political realm.<sup>17</sup> Instead, the political/relational model addresses people’s lived experiences with pain and fatigue—how they cope and manage their disabilities—and interact with institutional and societal infrastructures in an anti-ableist framework.<sup>18</sup>

I chose the political/relational model to theorize with because in critical disability studies (CDS), feelings of grief are often minimized within scholarship, reflecting scholars’ fears that discussing these emotions would contribute to narratives of weakness, vulnerability, and

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<sup>11</sup> Susan Wendell, “The Social Construction of Disability,” in *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge Press, 1996), 61.

<sup>12</sup> Ibid.

<sup>13</sup> Angelica Guevara “The Need to Reimagine Disability Rights Law because the Medical Model of Disability Fails Us All,” *Wisconsin Law Review*, vol. 2, 2021, 269.

<sup>14</sup> Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013).

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> Ibid.

<sup>18</sup> Ibid.

tragedy.<sup>19</sup> For instance, within the medical field, when a person acquires a disability through an injury or accident, often a quick diagnosis of depression, posttraumatic stress disorder, and complicated grief disorder may soon follow if an individual's temperament changes post-injury, adding to the narrative that "falling into" a disability is tragic.<sup>20</sup> However, individuals who acquire a disability, or even those born with disabilities, will go through periods of grief for a myriad of reasons.<sup>21</sup> I argue that speaking of grief can be discussed in an anti-ableist manner without perpetuating harmful stereotypes and tropes, as Kafer's model suggests. Moreover, avoiding grief within disability narratives diminishes the complexity of the very same narratives into a palatable story to present to a nondisabled audience.<sup>22</sup> The process of making disability narratives more consumable, by erasing or limiting grief, is ableist as it works under the assumption that living with disabilities is already undesirable, thus, expressing grief within these narratives makes those individuals' lived experiences unimaginable.<sup>23</sup> In reality, grief is almost universally experienced, and not exploring how these affects contribute to our understandings of disability does a disservice to CDS scholarship.

Seeing this grief/disability dilemma, scholars such as Liz Crow, Susan Wendell, Alison Kafer, Alyson Patsavas, and Cara E. Jones have contributed to our understanding of how pain and grief informs disability, reimagining new conceptions of disability.<sup>24</sup> For instance, Liz

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<sup>19</sup> Alison Kafer, "Unsafe Disclosures Scenes of Disability and Trauma." *Journal of Literary and Cultural Disability Studies* vol. 10.1, 2016.

<sup>20</sup> Shoshana Kessock, "Falling/Burning: Hannah Gadsby, Nanette, and Being a Bipolar Creator" in *Disability Visibility First-Person Stories in the Twenty-First Century* (New York: Vintage Books, 2020), 237.

<sup>21</sup> Wendy Smith, "Grieving an Acquired Disability" *Good Therapy*, 2010, <https://www.goodtherapy.org/blog/grieving-acquired-disability/>.

<sup>22</sup> Joel Michael Reynolds, "'I'd Rather Be Dead Than Disabled' The Ableist Conflation and the Meanings of Disability" *The Review of Communication* vol. 3, 2017.

<sup>23</sup> Kafer, "Unsafe Disclosures," 4.

<sup>24</sup> Liz Crow, "Including All of Our Lives: Renewing the Social Model of Disability," *Encounters with Strangers: Feminism and Disability* (London: Women's Press, 1996); Susan, Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia* vol 16.4, 2001; Alison Kafer, *Feminist, Queer, Crip*; Alyson, Patsavas "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse," *Journal of*

Crow, in her autoethnographic-based article, critiques the inability of the social model to represent and express her personal experience with “pain, fatigue, and depression,” calling for a reimagined understanding of disability that works under the political/relational model.<sup>25</sup> Kafer also writes on the importance of connecting disability scholarship to trauma studies and explores the role trigger warnings can play in being simultaneously accessible and inaccessible to certain audiences, noting that “our failure to engage with the traumatic effects of disability – and, potentially, of disability disclosure – constructs both our theories and politics.”<sup>26</sup> Similarly, Cara E. Jones proposes a “pain-centric” model of disability that politicizes pain while drawing on lived experiences with endometriosis.<sup>27</sup> Susan Wendell writes on the importance of distinguishing internal discrimination between “healthy” and “unhealthy” disabled people – seeking for a way to address chronic illnesses in a more robust fashion.<sup>28</sup> Lastly, Alyson Patsavas writes on navigating chronic pain in anti-ableist ways by introducing scholarship to the term “cripistemology of pain,” which situates pain within systems of power and privilege.<sup>29</sup> These scholars in conversation, show that introducing grief and pain into disability studies can be done in productive, anti-ableist ways, and I will lean on their work as a framework to attend to my own arguments around the importance of centralizing grief in robust representations of disabilities within the mainstream and digital media.

### **Trauma Theory in Relation to Disability and Grief**

When analyzing the representation of grief and disability, major concepts in trauma theory are also relevant. In the thesis, I will be looking at the historical silencing and

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*Literary and Cultural Disability Studies* vol 8.2, 2014; Cara E. Jones, “The Pain of Endo Existence: Toward a Feminist Disability Studies of Endometriosis,” *Hypatia* vol 31.3, 2016.

<sup>25</sup> Crow, “Including All of Our Lives,” 4.

<sup>26</sup> Kafer, “Unsafe Disclosures,” 4.

<sup>27</sup> Jones, “The Pain of Endo Existence.”

<sup>28</sup> Wendell, “Unhealthy Disabled.”

<sup>29</sup> Patsavas, “Recovering a Cripistemology of Pain,” 205.

marginalization of people with disabilities, drawing on early theories of temporal delays in processing traumatic moments. I will also be looking at insidious trauma, intergenerational trauma, and ideas of critical mourning. Angela Carter argues that “we must redefine trauma from the theoretical junctures of [disability and trauma studies] if we are to *fully* attend to the embodied experiences, material realities and sociopolitical causes and consequences of trauma.”<sup>30</sup> I aim to continue Carter’s work of redefining trauma studies and how disability scholars engage with these concepts.

Trauma and grief are closely interconnected, as both have been intertwined and medicalized from early on. Sigmund Freud developed and enacted psychoanalysis to treat his patients who suffered from traumatic experiences – such as theorizing hysteria’s relationship to women and later shell shock’s relationship to the trauma men faced in World War I.<sup>31</sup> Shell shock, or war neurosis, was later recognized with Freud’s help as post-traumatic stress disorder (PTSD).<sup>32</sup> The medicalization of trauma early in the 1980s was perpetuated when the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) classified PTSD as a “psychologically distressing event outside the range of human experience” with characteristics such as “intense fear, terror, and helplessness.”<sup>33</sup> Thus, from the onset, trauma and grief were often theorized within this patriarchal medical model perspective, making it difficult for other forms of trauma to be recognized or theorized thoroughly.

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<sup>30</sup> Angela Carter, “When Silence Said Everything: Reconceptualizing Trauma through Critical Disability Studies” *Lateral Journal of the Cultural Studies Association*, Issue 10.1, 2021, <https://csalateral.org/section/cripistemologies-of-crisis/when-silence-said-everything-reconceptualizing-trauma-through-critical-disability-studies-carter/>, 75.

<sup>31</sup> Judith Herman, *Trauma and Recovery: The Aftermath of Violence – from Domestic Abuse to Political Terror* (New York: Basic Books, 1997), 12.

<sup>32</sup> *Ibid.*

<sup>33</sup> American Psychiatric Association, *Diagnostic, and statistical manual of mental disorders (3<sup>rd</sup> ed.)* (Washington D.C, 1980), 236-8, 248.

Bridging and expanding Freud's work, in the 1990s, Cathy Caruth, Shoshana Felman, Dori Laub, and Geoffrey Hartman had been influential scholars who theorized on how and what trauma looks like in Western cultural settings, such as suggesting that trauma cannot be meaningfully linguistically coded or represented.<sup>34</sup> Caruth draws upon Freud's writing to formulate her own theories of trauma, such as Freud's theory of latency, which is that during a traumatic event "someone gets away, apparently unharmed" until the following weeks where a development of traumatic neurosis after an "incubation period" occurs, influencing memory perception extraordinarily.<sup>35</sup> Caruth expands upon the idea of latency to suggest that a person has the "inability fully to witness the event as it occurs, or the ability to witness the event fully only at the cost of witnessing oneself" which is "at the expense of simple knowledge and memory."<sup>36</sup> Caruth further insists that trauma itself will prevent meaningful linguistic representation and involve a "temporal delay that carries the individual beyond the shock of the first moment."<sup>37</sup> Trauma, to Caruth, often refuses to be integrated into a narrative memory, to be "verbalized and communicated," and thus remains entirely "incomprehensible."<sup>38</sup> Following this model, it is believed that the external experience irrevocably changes a person's identity, and the narrative would only appear through "unique" narrative expressions.<sup>39</sup> The narrative expressions could

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<sup>34</sup> Cathy Caruth, *Trauma: Explorations in Memory* (Baltimore: John Hopkins University Press, 1995), 156; Shoshana Felman, "Education and Crisis, Or the Vicissitudes of Teaching" in *Trauma: Explorations in Memory* (Baltimore: John Hopkins University Press, 1995); Geoffrey Hartman, "On Traumatic Knowledge and Literary Studies" *New Literary History*, vol. 26.3, 1995; Dori Laub "Bearing Witness of the Vicissitudes of Listening" in *Trauma: Explorations in Memory* (Baltimore: John Hopkins University Press, 1995), 16.

<sup>35</sup> Sigmund Freud, *Moses and Monotheism* (1939), 84 qtd. in Cathy Caruth, *Trauma: Explorations in Memory* (Baltimore: John Hopkins University Press, 1995), 7.

<sup>36</sup> Caruth, *Trauma: Explorations in Memory*, 7.

<sup>37</sup> *Ibid*, 10.

<sup>38</sup> *Ibid*, 153-154.

<sup>39</sup> Felman, "Education and Crisis," 16.

appear as literary texts or contemporary works of art using testimony as “the subject of their drama and as the medium of their literal transmission.”<sup>40</sup>

However, I have trouble with Caruth and the other mentioned scholars’ insistence on the fragmentary nature trauma imposes on a person, even if it is true for some survivors, as this model may exclude variations of trauma that exist and devalue or gaslight marginalized voices who do speak out about their trauma. To insist that trauma is inherently amnesiac or has latent qualities excludes the temporality of other forms of trauma and minimizes the impact of speaking out, such as insidious trauma and intergenerational trauma. Further, it fails to adapt to the new digital age, in which trauma is no longer considered incomprehensible. People have turned to archiving, sharing, and connecting through their trauma by meaningfully linguistically coding their experiences on social media, blog sites, and other auto-ethnographic texts.

Joshua Pederson suggests that traumatic amnesia “is a myth, and while victims may choose not to speak of their traumas, there is little evidence that they cannot.”<sup>41</sup> Pederson goes on to suggest that to engage with trauma in literature, focus needs to be on the text itself, and readers should seek evidence of “augmented narrative detail,” and depictions of experiences that are “temporally, physically, or ontologically distorted.”<sup>42</sup> Pederson is pushing against Caruth’s theory that trauma cannot be spoken or vocalized.<sup>43</sup> Although I do agree with Pederson that trauma can be spoken and shared, I do not necessarily believe that when someone shares their trauma it must be distorted in one way or another – although it can be. Moreover, Sam Durrant agrees with Pederson that it’s not a matter of not being able to share trauma, but rather of the

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<sup>40</sup> Ibid, 16.

<sup>41</sup> Joshua Pederson “Speak, Trauma: Toward a Revised Understanding of Literary Trauma Theory,” *Narrative* vol. 22.3, 2014, 334.

<sup>42</sup> Ibid, 339.

<sup>43</sup> Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History* (Baltimore: John Hopkins University Press, 1996).

decision to keep silent instead.<sup>44</sup> Durrant introduces “critical mourning,” noting that silence can be a choice in collective trauma and mourning; staying silent may become more powerful than speaking up in certain situations.<sup>45</sup> I agree with Durrant’s premise of critical mourning but suggest that critical mourning can take place by either choosing to stay silent or choosing to speak up, depending upon how one navigates expectations of their own particular circumstances.

I propose in Chapter 4 that one way the disability community engages with grief and critically mourns is by engaging with what Andi Schwartz describes as engaging with the ugly (not shying away from the ugly things in life) through “online femme mourning,” practices that disrupt traditional processes for mourning.<sup>46</sup> The idea of disrupting or doing the opposite of what is expected, I posit, is a form of critical mourning. For instance, one of the representational stereotypes I’m interested in deconstructing is the desexualization and hypersexualization of individuals with disabilities and how microaggressions perpetuate cycles of insidious trauma. I argue that people with disabilities who are often silenced or marginalized in mainstream spaces can enact critical mourning as a collective by speaking out against their everyday or insidious trauma, which consists of continual events or experiences that don’t often come from amnesiac or latent places. Further, these individuals’ stories are not grounded in distortion nor are they hyperbolic, augmented qualities like Pederson would suggest. Thus, although I am drawn to more recent pluralistic models of trauma which resist pathological fragmentation as answers, there are even more cultural dimensions and diversities of trauma that need to be analyzed and theorized.

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<sup>44</sup> Sam Durrant, “Undoing Sovereignty: Towards a Theory of Critical Mourning,” in *The Future of Trauma Theory* (London, Routledge Press, 2013).

<sup>45</sup> Durrant, “Undoing Sovereignty,” 94.

<sup>46</sup> Andi Schwartz, “Put on All Your Make-Up and Cry It Off in Public:’ The Function of Ugliness in Femme Grieving Practices” in *On the Politics of Ugliness* by Sara Rodrigues and Ela Przybylo (Cham: Springer International Publishing, 2018), 79.

One trauma theory that does pay attention to cultural diversity works to analyze gender trauma, bringing together a queer feminist lens on affect, body studies, and trauma theory. Queer theory has paid particular attention to how feelings function in political and social contexts. Ann Cvetkovich's *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Cultures* investigates the role of trauma in the day-to-day lives of lesbians.<sup>47</sup> Cvetkovich starts with everyday trauma, and this is important because it suggests that trauma goes beyond an isolated event or shock, pushing against Caruth and other early scholars. Everyday trauma is considered to be insidious trauma, which is a term discussed by Maria Roots that "offers a way to think about the repetitive, daily injustices and vulnerabilities" or the "persistent marginalization created by institutional structures that value certain subjectivities over others."<sup>48</sup> Roots suggests that insidious trauma occurs when marginalized subjects feel constantly threatened by the prospect of violence, and this trauma becomes internalized.<sup>49</sup> Violence can appear in many ways, physical and verbal. Westengard extends Roots' theory on insidious trauma by discussing the role of microaggressions, or how verbal assaults or suggestions can be just as traumatic as physical violence.<sup>50</sup> Using the term insidious trauma, for both constant physical and verbal abuse that individuals with disabilities face, for instance, will give me a lens that fundamentally adheres to the political/relational model, where the trauma that is cultivated in day-to-day life is not due to the individual's impairment but to how society and the political institutions react and interact with an individual's disability. Further, the analysis of insidious trauma can be buttressed by other pluralistic models of trauma in existence. Cvetkovich's queer approach to sexual trauma

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<sup>47</sup> Cvetkovich, *An Archive of Feelings*.

<sup>48</sup> Laura Westengard, *Gothic Queer Culture: Marginalized Communities and the Ghosts of Insidious Trauma* (University of Nebraska Press, 2019), 15, 17.

<sup>49</sup> *Ibid*, 15.

<sup>50</sup> *Ibid*, 14.

can be complemented by Amy Hungerford’s pondering on reading, experience, and memorialization, Naomi Mandel’s argument for more variable multinational representation models, and Heather Love’s move to centralize affect theory (and negative affects such as shame, isolation, and self-hatred) that are associated with one’s queer identity formation.<sup>51</sup>

In the following chapters, I aim to investigate how the affective turn in academic discourses, often invoking “the body’s capacity to affect and be affected” through emotions—and particularly “negative affects,” encompassing grief’s linked to trauma—is crucial to gaining a deeper understanding of disability representation.<sup>52</sup> I argue that grief in disability contexts can be represented in anti-ableist ways that break constructed stock characters, which perpetuate harmful stereotypes, and in doing so can enact healing justice practices that break intergenerational trauma cycles. I also argue that having nuanced representations of people with disabilities (PwD) that are created, imagined, and enacted by and for people with disabilities is essential to transforming popular discourses. One way this is occurring is by having more diverse representational models for ordinary people, like myself, to look to as they cope, manage, and address their day-to-day insidious trauma and fight internal and external ableism.

### **Disability Representation and Navigating Grief**

Grief occurs when people are faced with loss, such as the loss of a loved one, a nation, a job, support services, body parts, language, friendship, cognitive functioning, personal objects, a place they belong, or part of who they are, and encompasses the process of navigating feelings of pain, fear, anxiety, and depression.<sup>53</sup> Further, grief is associated closely with internalized

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<sup>51</sup> Amy Hungerford, “Memorizing Memory” *The Yale Journal of Criticism*, vol. 14.1, 2001; Naomi Mandel, *Against the Unspeakable: Complicity, the Holocaust, and Slavery in America* (Charlottesville: University of Virginia Press, 2006); Heather Love, *Feeling Backward: Loss and the Politics of Queer History*. (Cambridge: Harvard University Press, 2009), 146.

<sup>52</sup> Erin Rand, “Bad Feelings in Public: Rhetoric, Affect, and Emotion” *Rhetoric and Public Affairs* vol. 18.1, 2015, 161.

<sup>53</sup> *Ibid.*

feelings, such as the loneliness, panic, yearning, anxiety, or emptiness one may feel.<sup>54</sup> Grief is noted to be the natural emotional response to loss, but requires mourning to process the loss.<sup>55</sup> The process of mourning has been recognized to be the externalized actions that people do to show their grief.<sup>56</sup> Common practices of mourning are crying, journaling/letter writing, drawing, composing music, etc.<sup>57</sup> Grief itself has a history of being analyzed through psychology, psychophysiology, neuroscience, and immunology lenses to create a vast amount of literature that attempts to trace the shape and development of the mourning / bereavement process.<sup>58</sup>

Grief from the loss of the normate body is especially stigmatized, preventing mainstream television and movies to have healthy, open conversations about grief without falling into ableist tropes. Even more so, the stigmatization of people with disabilities navigating grief is compounded. For example, from a psychological perspective, grief research has been focused on the process of returning to “normalcy” after a loss. Elisabeth Kübler-Ross and David Kessler in 1969 came out with the five stages of grief: denial, anger, bargaining, depression, and acceptance.<sup>59</sup> The stages of grief were critiqued by William Worden, who proposed rather the four tasks of grief that must be completed before readapting to “normal” life.<sup>60</sup> He suggests a person must (1) accept the loss, (2) acknowledge the pain of the loss, (3) adjust to a new environment, and (4) reinvest in the reality of a new life.<sup>61</sup> Beyond just streamlining the bereavement process, grief models provide temporal constraints—if feelings of intense grief do

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<sup>54</sup> Anne C. Poinier “Grief and Grieving” *University of Michigan, Michigan Medicine*, 2020, <https://www.uofmhealth.org/health-library/hw164282>.

<sup>55</sup> Ibid.

<sup>56</sup> John S. Stephenson, *Death, Grief, and Mourning: Individual and Social Realities* (New York: Free Press, 1985).

<sup>57</sup> Ibid.

<sup>58</sup> Mary-Frances O’Connor, “Grief: A Brief History of Research on How Body, Mind, and Brain Adapt” *Psychosom Med*, vol. 81.8, 2019.

<sup>59</sup> Elisabeth Kübler-Ross and David Kessler, *On Death and Dying* (New York City: Macmillan Company, 1969).

<sup>60</sup> William Worden, *Grief Counseling and Grief Therapy*, (New York City: Springer Publishing), 2008.

<sup>61</sup> Ibid.

not subside within a year a diagnosis of complicated grief or prolonged grief disorder may be given (DSM 5).<sup>62</sup> Prolonged grief disorder “may include difficulties accepting the death, feeling one has lost a part of one’s self, anger about the loss, guilt, or difficulty in engaging with social or other activities.”<sup>63</sup> The resistance to acknowledge alternative timelines to process grief or solely acknowledging certain causes of grief diminishes people with disabilities’ distinctive relationship to grief, and how their grief is represented.

When mainstream movies and television shows discuss grief in relation to disability, the representation of grief often creates and perpetuates ableist imaginings of disability—such as disability as monstrous, pathetic, or tragic. Many early movies that featured disability were used to “heighten the effect of slapstick comedies and melodramas, and frequently presented the stereotypes of individual as victim or villain, or as seeking revenge for their disability.”<sup>64</sup> Colin Barnes, one of the first scholars to write on disability representation, observed the commonly recurring media stereotypes, including portraying disabled characters as pitiable/pathetic, objects of violence, sinister/evil, atmosphere/curio, super cripple, objects of ridicule, their own worst / only enemy, burdens, sexually abnormal, incapable of participating fully in community life— noting that disability often aligned with “heterosexism, homophobia, racism, and sexism.”<sup>65</sup> Jeffrey Preston expands and suggests that disability representation is often misguided, and that abled-bodied creators “do not present us with the lived experience of disability but rather are the story of the normate, an anxious subject revolted by their own vulnerability to the point that they

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<sup>62</sup> Paul A. Boelen and Holly G. Prigerson, “Prolonged grief disorder as a new diagnostic category in DSM-5” in *Complicated Grief: Scientific Foundations for Health Care Professionals* by Margaret Stroebe, Henk Shut and Jan Van Den Bout (New York and London: Routledge, 2013).

<sup>63</sup> O’Connor, “Grief: A Brief History.”

<sup>64</sup> Stephen P. Safran “The First Century of Disability Portrayal in Film: An Analysis of the Literature” *The Journal of Special Education*, vol. 31.4, 1998, 468.

<sup>65</sup> Colin Barnes, *Disabling Imagery, and the Media: An Exploration of the Principles for Media Representations of Disabled People* (Halifax: Ryburn Publishing Limited, 1992), 15.

hide from it...the stories we tell ourselves in the media are about placating this anxiety, this terror, and stigmatizing the disabled in the process.”<sup>66</sup> Although I do agree with Preston that the stereotypes and tropes that are portrayed are often created by able-bodied individuals from a place of misunderstanding, fear, and anxiety, I also believe that the portrayal of grief can be relevant to the disabled experience and be represented by disabled individuals in anti-ableist ways.

Although scholars have recently started to scrutinize global media representations of disability in the hopes of challenging these stereotypical tropes that Barnes and Preston discuss, little attention has been given to disability representation that specifically navigates grief within new communication media or digital media in anti-ableist ways.<sup>67</sup> What has gained attention is how the internet and social media platforms can also be sites that perpetuate similar stereotypes. Katie Ellis and Mike Kent suggest that “the web 2.0 has been developed in and by the same social world that routinely disables people with disability” and that the “inaccessibility of the offline world has been duplicated online, especially in social networking sites.”<sup>68</sup> Further, Ellis writes, “technology typically follows a three-step process to becoming more accessible to people with disability. First, technology begins as being relatively accessible, then, as it becomes more widely adopted by the general population, it begins to be designed in ways that exclude people with disability, before finally being retrofitted to allow access by this group.”<sup>69</sup> The problem with the digital media landscape is further problematic for representation because digital media may

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<sup>66</sup> Jeffrey Preston, *The Fantasy of Disability: Images of Loss in Popular Culture*, (London: Routledge, 2017), 142.

<sup>67</sup> J.L. Schatz and Amber E. George, *The Image of Disability: Essays on Media Representations* (Jefferson: McFarland & Company, Inc., Publishers, 2018); Jacob Johanssen and Diana Garrisi, *Disability, Media, and Representations: Other Bodies*, (London: Routledge, 2020).

<sup>68</sup> Katie Ellis and Mike Kent *Disability and New Media* (New York: Routledge, 2011), qtd. in Jacob Johanssen and Diana Garrisi, *Disability, Media, and Representations: Other Bodies*, (London: Routledge, 2020).

<sup>69</sup> Katie Ellis, *Disability and Digital Television Cultures: Representation, Access, and Reception* (New York: Routledge, 2011), 11.

“contribute to the self-empowerment of excluded and silenced bodies, [and] they may equally open up spaces of discrimination, threats, hatred, trolling and silencing online.”<sup>70</sup> Although the digital media landscape can both encompass sites of empowerment and discrimination, little attention has been paid to the ways disability activists themselves are utilizing these spaces to re-theorize what it means to be disabled in popular culture’s view by subverting expectations and stereotypes historically assigned to them, especially when it comes to discussing emotions such as grief.

Disability activists who are championing and utilizing the digital media landscape, I argue, operate within the postcolonial term “third space,” opening up discussion on “in-between spaces that are created at virtual and material intersections.” When applied to disability discourses, these third space sites and intermedial practices seem to be transforming disability discourses more broadly.<sup>71</sup> Intermedial practices in this context refer to how representation is being created both among online and offline spaces—further expanding on the third space’s liminal quality.<sup>72</sup> The third space, further, is often utilized by historically marginalized voices, while simultaneously working as “innovative sites of theoretical production” that can “broaden our (academic) understanding of social discourse.”<sup>73</sup> For instance, when I discuss digital media, such as the Digital Visibility Project (DVP), as an intermedial connective site as well as other places where disability activism is being enacted by people with disabilities, such as on Instagram, I am framing these investigations as “public third spaces” that purposefully seek and center marginalized voices. These sites, as Samira Rajabi theorizes, are a “digital space [that]

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<sup>70</sup>Johanssen and Garrisi, *Disability, Media, and Representations*, 8.

<sup>71</sup> Adela C. Licona, *Zines in Third Space: Radical Cooperation and Borderlands Rhetoric* (Albany: State University of New York Press, 2012), 4.

<sup>72</sup> Ela Przybylo, “Rainbow Mary and the Perceived Threat of LGBTQ+ Bodies in Poland,” *Studies in Russian, Eurasian and Central European New Media*, 2021, 112; Klaus Bruhn Jensen, “Intermediality” *The International Encyclopedia of Communication Theory and Philosophy*, 2016, 1.

<sup>73</sup> *Ibid.*, 6.

encourages negotiative mediation that transcends time and is ever changeable, never fixed,” allowing space for renegotiating one’s own identity.<sup>74</sup> Part of renegotiating one’s identity at these sites, in relation to disability, grief, and the trauma an individual may hold – especially in relation to racism or queerphobia – is the community-building, collective action that occurs on social media platforms, blog sites, podcasts, and other forms of intermedial autoethnographic texts.

In the following chapters I will look to the differences between mainstream disability representation and public third spaces that act as sites for grassroots activism by and for people with disabilities. Chapter 2 will take readers through how mainstream television and movies often portray disability and grief in problematic, ableist ways by looking at *House*’s episode “Spin” and *American Horror Story*’s fourth season “Freak Show.” In Chapter 3, I present two disabled content creators—Alex Darcy and Shelby Lynch—to discuss how they utilize their individual platforms to navigate their grief and insidious trauma. In Chapter 4, I move towards collective disability communities, focusing on the Disability Visibility Project (DVP), founded by Alice Wong, as a case study to analyze how a collective community can critically mourn and grieve their insidious trauma in anti-ableist ways. My study suggests that having conversations around grief, insidious trauma, and disability representation, like ordinary people have begun to do on social media and blog sites, is creating nuanced and robust representative models that will continue to inform and transform meanings of disability as well as disability studies and trauma theory’s relationship to each other, creating relatable sites of identification for ordinary disabled folks, like myself.

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<sup>74</sup> Samira Rajabi, “Losing Someone Like Us,” in *Disability, Media, and Representation: Other Bodies* (New York: Routledge Press, 2020), 64.

## CHAPTER II: THE NEED FOR NUANCED DISABILITY REPRESENTATION

### Trigger Warning

In the following chapter, the section *American Horror Story (AHS)* “Freak Show” and **Ableist Grief Models** includes a discussion of traumatic sexual violence and body dismemberment.

Beginning in 2007, Anita Altman and Issac Zablocki founded the ReelAbilities Film Festival to present films “by, about and for people with disabilities.”<sup>75</sup> Altman and Zablocki realized that film and mainstream portrayals of disability have been and continued to be riddled with ableist stereotypes and tropes, so they desired to promote “awareness and appreciation of the lives, stories and artistic expressions of people with disabilities.”<sup>76</sup> Each screening includes discussions and other programs created to celebrate the diversity within film and representation. When I discovered the ReelAbilities Film Festival through social media, I was thrilled to learn some people were creating a site to promote anti-ableist films written, created, and produced by people with disabilities that I, and many others living with a disability, would never have otherwise been exposed to. When perusing their film directory that lists all the movies that they have displayed throughout the last fifteen years, I was distraught by how many films created by the disability community have been created that are not circulated within mainstream avenues.

In this chapter, I will first situate my understanding of the mainstream and how it will be used throughout the next few chapters. I argue that nuanced, anti-ableist disability representation in film does exist, however, not often within the American mainstream. Instead, the disability representation within the American mainstream is often convoluted with contradictory, ableist stereotypes that misrepresent the reality of lived experiences of disability for many individuals. Following on this, I will look at two ableist disability representations that exist within the American mainstream. The first will be focused on the desexualization that occurs within an

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<sup>75</sup> “About Us” *ReelAbilities Film Festival*, <https://reelabilities.org/about-us/>.

<sup>76</sup> *Ibid.*

episode from the medical drama *House*. I chose *House* because the popular medical drama often conflates disability representation with ableist stereotypes, and the show often reflects the disbelief, tension, and gaps in care that people with disabilities face in medical institutions in real life. The second disability representation I will look at will be focused on pity and monstrosity stereotypes that are touched on within *American Horror Story*'s fourth season "Freak Show." I chose this season of *American Horror Story* to contrast the fantastical, supernatural elements in the disability representation to the realistic medical drama of *House*. I believe the mainstream representation of "Freak Show," even if fantastical in nature, cultivates an audience's ableist perception of disability, and those perceptions shape real-world interactions beyond watching the show.

### **Mainstream and Representation**

Mainstream are "the social and cultural spaces where the native majority feels at home" and are closely tied to ideas about assimilation, white supremacy, and cultural dominance.<sup>77</sup> Alison Huber ascribes the term mainstream to various specific cultural contexts:

It is sometimes imagined to be a place (when things "go mainstream" or "cross over into the mainstream"); ... at other times it is used as a marketing synonym for the "mass audience" of popular culture products; frequently it is used as an adjective, attached to a noun to signify some inherent aesthetic trait; you'll hear it used in the place of the word "normal" or "normative;" it can also refer to a socio-economic category used by politicians to refer to the majority of their constituency.<sup>78</sup>

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<sup>77</sup> Richard Alba, Brenden Beck, and Duygu Basaran, "The U.S. Mainstream Expands—Expands" *Journal of Ethnic and Migration Studies*, vol. 44.1, 2018, 99.

<sup>78</sup> Alison Huber, "Mainstream as Metaphor: Imagining Dominant Culture" in *Redefining Mainstream Popular Music* by Sarah Baker, Andy Bennett, and Jodie Taylor (New York: Routledge, 2013), 4-5.

Huber goes on to suggest that mainstream can be “a synonym for hegemony; a social group; the opposite of art, the epitome of ‘straight-ness.’”<sup>79</sup> Her description of mainstream focuses on how mainstream Western ideology has been produced and controlled by white, heterosexual narratives that rely on white supremacy. However, Richard Alba and Victor Nee suggest that the mainstream can be attuned to an ethno-racially stratified society and encompass a myriad of people within the mainstream.<sup>80</sup> Alba, Brendon Beck, and Duygu Basaran expand:

Even if the mainstream is where the dominant majority is found, it need not be exclusive: that is, individuals from outside the white majority can participate in mainstream settings and be accepted there. And the mainstream itself is internally quite diverse, according to the various dimensions, such as social class and region, that are associated with the heterogeneities within the majority population.<sup>81</sup>

Although the mainstream could include participation from various races, social classes, and regions, it often occludes other aspects of identity, such as queer sexual orientation and disability.

When I think about representation within the mainstream, my mind immediately jumps to film and television. Mirosław Przyłipiak analyzes both social blogs and academic papers to find how mainstream movies are understood in the general sense.<sup>82</sup> He suggests that the general Wikipedia definition of mainstream movies, “movies that cost much to make and are created for profit...from major movie companies...the opposite of mainstream movie is art films,” are really focused on production and distribution.<sup>83</sup> Mainstream movies are often contrasted with

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<sup>79</sup> Huber, “Mainstream as Metaphor,” 8.

<sup>80</sup> Richard Alba and Victor Nee, *Remaking the American Mainstream: Assimilation and Contemporary Immigration*, (Cambridge: Harvard University Press, 2003).

<sup>81</sup> Alba, Beck, and Basaran “The U.S. Mainstream Expands,” 101.

<sup>82</sup> Mirosław Przyłipiak, “The Notion of Mainstream Film in Contemporary Cinema,” *Panoptikum*, 2018.

<sup>83</sup> *Ibid*, 17.

independent films, which are “not shown in cinemas, and immediately directed to DVD distribution, or are shown in specialized, local cinemas.”<sup>84</sup> Within academia, however, mainstream is more understood based off of the narrative trajectory of a film instead of a film’s production and distribution.<sup>85</sup> Susan Hayward suggests that Western society mainstream “revolves round the standardized plot of order/disorder/order restored...narrative closure occurs...the continuity of the film is seamless.”<sup>86</sup> So, when I think about many of the films featured within the ReelAbilities Film Festival directory, I presume that many of the films are considered independent and not mainstream. This presumption comes from the fact the many of those films were not circulated, advertised, or distributed widely due to budget and marketing constraints. Secondly, many films that people with disabilities create that are anti-ableist in nature are pushing against Western narrative trajectories, finding that not all narratives need specific closure or to be made for mass entertainment.

Movies like *Best Summer Ever*, *Beeswax*, *Keep the Change*, and many more featured through the ReelAbilities Film Festival, portray disabilities in nuanced, complicated ways that suggest disability representation is being made in the film world.<sup>87</sup> However, anti-ableist representation is not being shared widely or publicly to the degree to get this type of representation—that deconstructs stereotypes— assimilated into the mainstream. Mainstream movies and television shows, readily available to a large portion of Americans, are either shown in theaters or do not require premium subscriptions or renting fees from online streaming

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<sup>84</sup> Ibid.

<sup>85</sup> Ibid.

<sup>86</sup> Susan Hayward, *Cinema Studies. The Key Concepts. Fourth Edition* (London-New York: Routledge, 2013), 118-119.

<sup>87</sup> *Best Summer Ever*, directed by Michael Parks Randa and Lauren Smitelli (Produced by Zeno Mountain Farm), distributed by Freestyle Releasing LLC, 2020; *Beeswax* directed by Andrew Bujalski (Produced by Dia Sokol and Ethan Vogt) distributed by the Cinema Guild, 2009; *Keep the Change* directed by Rachel Israel (Produced by Tangerine Entertainment), 2017.

services. They often exasperate disability stereotypes because those films often occlude people with disabilities in their production.<sup>88</sup>

### ***House* and Desexualizing Disability**

One nuanced, yet problematic representation of disability that exists within mainstream American television, is on the television show *House*, when the titular protagonist suffers a leg injury that causes severe chronic pain. His physical disability is often rendered as solely manageable through House's abuse of Vicodin. House's character is played by nondisabled actor Hugh Laurie. In the episode "Spin," House confronts Mark Warner, his ex-wife's new husband.<sup>89</sup> I focus on the representation of disability in this scene because it is a common ableist example of desexualization occurring within a medical context. Mark is also played by a nondisabled actor, Currie Graham. Mark is paraplegic recovering from acute intermittent porphyria. Mark enters the cafeteria, pushed by his wife Stacey, and House mutters, "yes, she's miserable with Mark because he's not me" and directly says to Mark, "how's your recovery going? Run into the small muscles yet?"<sup>90</sup> Mark retorts, "it's not the size of the muscle, it's where you get to put it."<sup>91</sup> Although Mark was being harassed by House's desexualizing insinuations and remarks, his witty retort briefly destabilizes and inverts the ableist framework within which House framed his question.

Later in the same episode, Mark is at group therapy for people coping with disabilities and reflecting on the insidious trauma they've come to face since developing their disabilities. Mark asserts, "so, when am I going to be done? I need to know because I got plans to make.

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<sup>88</sup> Tom Grater, "Agnieszka Holland Warns That Streaming Could Become 'Big Black Hole' Where Indie Films 'Vanish,'" *Deadline*, 2021, <https://deadline.com/2021/07/agnieszka-holland-streaming-could-become-big-black-hole-indie-films-vanish-cannes-1234788410/>.

<sup>89</sup> Currie Graham, *House*, Season 2, Episode 6, "Spin," directed by Fred Gerber, aired November 15, 2005, on Fox.

<sup>90</sup> *Ibid.*

<sup>91</sup> *Ibid.*

When can I safely book a game of squash? When am I going to stop being angry?”<sup>92</sup> House comes into therapy and continues to tyrannize Mark by discussing his chronic leg pain. I point to this example because audiences are receiving both an ableist representation of disability—assuming Mark cannot satisfy Stacey sexually and the assumption that some disabilities are worse than others (House can walk, which he assumes is better than being in a wheelchair)—and a nuanced anti-ableist representation of coping with disability—Mark processing his anger and grief in an assumed safe environment about losing his ability to walk or do things he previously had been able to. The group therapy session is presented as an anti-ableist resource within the hospital because the hospital recognizes that people who have suffered traumas that have caused their disabilities will desire collective help in their transition to their new desirable lives. This could be read as a move towards Leah Lakshmi Piepzna-Samarasinha’s collective care model that shifts organizations and communities to be ones “where people feel fine if they get sick, cry, have needs...move slower.”<sup>93</sup> Mark’s representation shows on the screen that it is okay to have these feelings of grief when coping with physical and insidious trauma within lived experiences of disability and still believe there is access to a desirable future within his disabled body.<sup>94</sup>

Although the *House* episode shows brief interactions with grief in an anti-ableist light, most of the episode sets up people with disabilities as certain stock characters that perpetuate stereotypes. This is further compounded by the fact both House and Mark are played by nondisabled actors. As many critical disability studies (CDS) scholars have noted, stereotypes inflict irreparable damage, impacting how society understands disability and how disabled

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<sup>92</sup> Ibid.

<sup>93</sup> Leah Lakshmi Piepzna-Samarasinha, *Care Work Dreaming Disability Justice* (Vancouver: Arsenal Pulp Press, 2018), 116.

<sup>94</sup> Kafer, *Feminist, Queer, Crip*, 13.

people understand themselves.<sup>95</sup> Susan Wendell asserts, “stereotypes of disabled people as dependent, morally depraved, superhumanly heroic, asexual, and/or pitiful are still the most common cultural portrayals of people with disabilities.”<sup>96</sup> Stereotypes, when repeated within discourses, create stock characters. Jordynn Jack discusses how repeated narratives of autistic individuals create “stock characters” within autism discourse, enforcing certain stereotypes such as the Refrigerator Mothers, Mother Warriors, and Fixer Fathers.<sup>97</sup> Refrigerator Mothers are described to be cold and uncaring towards their autistic kids, Mother Warriors are advocates for curing their children against all odds, and Fixer Fathers are coping through “fixing” things they can throughout their work and family obligations.<sup>98</sup> These stock characters are gendered stereotypes that help Jack pay attention to power dynamics, asking tough questions like “who is encouraged to participate and who is left out,” which leads to gauging “how those omissions affect scientific knowledge.”<sup>99</sup> The creation of stock characters in relation to other disabilities is apparent throughout media representation, including *House*, and can compound ableist assumptions that may be internalized by viewers, which has the potential to create real barriers of political or social engagement for people with disabilities.

For instance, within *House*, Mark’s character is repeatedly desexualized and is set up to perpetuate the stereotype that people with disabilities are not sexual by drawing on the angelic-innocent stock character. The angelic-innocent stock character typically invalidates any sexual or

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<sup>95</sup> Gillian Lester, “The Aging Workforce and Paid Time Off” (New York: Springer, 2011); Jordynn Jack, *Autism and Gender: From Refrigerator Mothers to Computer Geeks* (Champaign: University of Illinois Press, 2014); Piepzna-Samarasinha, *Care Work*; Mark Priestly, *Disability and the Life Course Perspective: Global Perspectives* (Cambridge: Cambridge University Press, 2001); Melanie Yergeau, *Authoring Autism: On Rhetoric and Neurological Queerness* (Durham: Duke University Press, 2018); Susan Wendell, “The Social Construction of Disability,” 61.

<sup>96</sup> Wendell, “The Social Construction of Disability,” 61.

<sup>97</sup> Jack, *Autism and Gender*, 218.

<sup>98</sup> *Ibid*, 34, 67 158.

<sup>99</sup> *Ibid*, 218.

asexual expression individuals with disabilities may wish to express, such as through themes of forgetting, invisibility, and erasure, which reinforces the stereotype that people with disabilities are “uninterested in sex, or shouldn’t be interest in it,” because of their disability.<sup>100</sup> Thus, people with disabilities are often represented as innocent, infantilized figures who would be taken advantage of if placed in sexual scenarios.<sup>101</sup> Mark, within his nuanced representation, does not fully submit to House’s desexualizing insinuations, instead making witty remarks to indicate that he still desires and leads a successful sex life with his wife Stacey.

Although Mark challenges the imposed label and association with the angelic-innocent stock character, this particular stock character still presents an engaging introduction to how real people are navigating their own grief in relation to their physical and insidious trauma, as the question of sexuality and sexual satisfaction is often utilized in ableist ways. Further, the angelic-innocent stock character is placed in conversation with Kristina Gupta’s system of “compulsory sexuality” that insists that we live in a system that assumes people are sexual, take up sexual identities, or engage in sexual activity while still disallowing “marginalized groups from sexual expression through the process of ‘desexualization’” as a form of social control.<sup>102</sup> Often caretakers and family members subjugate their dependents to desexualized living, in which they maintain all the sexual power over their dependents, for either easy care-taking that is not complicated with sexual or asexual feelings or by the complete eradication, erasure, or suppression of any sexual/asexual expression. Moreover, people with disabilities are often falsely labeled as asexual, so that “claims for the sexual rights of desexualized minority groups”

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<sup>100</sup> Don Kulick and Jens Rydstrom, *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement* (Durham: Duke University Press, 2015), 6.

<sup>101</sup> Ibid.

<sup>102</sup> Ela Przybylo, *Asexual Erotics: Intimate Readings of Compulsory Sexuality* (Columbus: Ohio State Press, 2019), 15; Kristina Gupta, “Compulsory Sexuality: Evaluating an Emerging Concept,” *Journal of Women in Culture and Society* vol. 41.1 1, 2015, 132.

mistakenly target asexuality and endorse compulsory sexuality, as explored by Eunjung Kim.<sup>103</sup> In other words, labeling marginalized groups such as people with disabilities as “‘asexual by default’ [misuses] the term and ‘asexuality’ in the process.”<sup>104</sup> Thus, moving forward in discussing representation and labels, I make the distinction between imposed desexualization and individuals who celebrate their chosen asexuality.

The insidious trauma cultivated by the infantile imagery associated with desexualizing practices and the angelic-innocent stock character brings the relationship between intellectual disabilities to childhood, suggesting that “disabled people, particularly those with intellectual disabilities ... are cast as ‘unfinished adults,’ as Alison Kafer notes in *Feminist, Crip, Queer*.<sup>105</sup> As a case study, Kafer dives into the Pillow Angel Case, or the Ashley Treatment, in which the parents of Ashley, who has static encephalopathy, agreed to controversial medical procedures of hormone-stunting prescriptions along with a bilateral breast bud removal and appendectomy.<sup>106</sup> The purpose of the hormone treatment to stunt Ashley’s growth was to prevent her body developing into a mature female, as “the Treatment was necessary to keep Ashley’s cognitive self and physical self-aligned,” forcing her to become an “eternal child” and be deemed as nonsexual.<sup>107</sup> Although Ashley could not speak or move on her own, Adrienne Asch and Anna Stubblefield write, “there is a long history of experts underestimating the cognitive abilities of people who appear to be profoundly intellectually impaired.”<sup>108</sup> Thus, the eradication of choice in Ashley’s case—which was sensationalized and picked up *NY Times*, *The Guardian*, *CBS News*, and *CNN*, as well as spread all over *YouTube*—became the mainstream representation of

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<sup>103</sup> Eunjung Kim, “Asexuality in Disability Narratives,” *Sexualities* vol. 14.1, 2011, 490.

<sup>104</sup> Przybylo, *Asexual Erotics*, 15.

<sup>105</sup> Kafer, *Feminist, Queer, Crip*, 54.

<sup>106</sup> *Ibid*, 56.

<sup>107</sup> *Ibid*, 49, 53.

<sup>108</sup> *Ibid*, qtd 64.

how families can handle negative affects (feelings of fear, grief, confusion) and sexuality in their daughter's caretaking. This ableist representation that perpetuated mainstream media might suggest that this family—who had to navigate their own grief in relation to their daughter's quadriplegia—may not have had another model (another family or mainstream representation) of how to navigate their daughter's growth and disability in an anti-ableist way, in a way that still granted Ashley the “future possibility of feeling the sensations of her Breasts” that she is entitled to.<sup>109</sup> What would it mean if Ashley's family could see the ethical dilemmas they were facing approached within mainstream media (TV, movies) in anti-ableist ways? Would deciding about the health and wellbeing of their daughter be more informed? More robust?

Although Mark in *House* is a fictional paraplegic character (not quadriplegic) who resists the desexualization that he is still faced with, his representation is not robust enough to argue that he could be an exemplary case in navigating grief in relation to trauma and disability, or to argue that he would even be a sufficient representation of navigating the ethical dilemmas Ashley's case called for. However, Mark does present the beginnings of how attention to grief within his disability experience has the potential of modeling ways to navigate troubling terrain in anti-ableist ways. In reality, there has been little to no input by disability activists or disabled content creators to tease out Mark's significant representation. How the episode and show stand now, audiences could be more susceptible to the ableist messaging within the *House* episode and ignore any attunement to discussing the character's navigation of his negative affects because of how the angelic-innocent stock character is situated within medicalized, traumatic histories of eugenic and biopolitical movements. Particularly, the eugenics movement, in relation to disability, argued that people with disabilities should not reproduce to eliminate the human “gene

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<sup>109</sup> Ibid, 65.

pool of ‘undesirable’ traits,” thus, the movement forced people with disabilities to have sterilization procedures without informed consent.<sup>110</sup>

Although Mark attempts to navigate his anger, his representation is not sufficient to be considered anti-ableist, and as Mark is a white, cis male he only represents a small portion of the disability community. BIPOC, disabled, femme viewers of *House* cannot identify with Mark’s white, cis male identity. Instead, BIPOC, disabled, femme viewers of *House* are forced to disidentify with Mark or “read oneself and one’s own life narrative in a moment, object, or subject [that] is not culturally coded to ‘connect’ with the disidentifying subject.”<sup>111</sup> In other words, viewers seeing this particular episode of *House* who have intersectional marginalized identities would find it necessary to rethink Mark’s representation, regardless of his white, cis male privileged positionality, as a way that creates significant meaning to themselves. Positionality is important to consider within mainstream representation, especially regarding race, since an attempt is made to align Mark’s character with the angelic-innocent stock character. The angelic-innocent stock character is often desexualized and embedded in whiteness, contrasting with other stock characters that emerge within disability, queer, BIPOC discourses and align with hypersexualization and multi-ethnicity (such as the monster, criminal, or sexual addict being associated with BIPOC communities). On a mere rhetorical level, “angels” are associated with the color white, which has a deep, complicated history that plays into biblical and historical racist ideologies.<sup>112</sup> Frantz Fanon discusses the oppression BIPOC individuals face, such as how “the black man is locked in his body” and unable to separate from

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<sup>110</sup> “Involuntary Sterilization of Disabled Americans: An Historical Overview” *Reiter & Walsh, P.C.*, <https://www.abclawcenters.com/blog/2018/11/06/involuntary-sterilization-of-disabled-americans-an-historical-overview/>, 2018.

<sup>111</sup> Muñoz, *Disidentifications*, 12.

<sup>112</sup> Eric Arnesen, “Whiteness and the Historians’ Imagination,” *International Labor and Working-Class History*, Vol. 60, 2001; John M. Kang, “Deconstructing the Ideology of White Aesthetics” *Michigan Journal of Race and Law*, Vol. 2, 1997.

colonial biopolitical regimes, which concretizes the notion that people of color must humanize themselves within multiple layers of subjugation.<sup>113</sup> Fanon’s argument of humanization can be seen for BIPOC individuals with disabilities who must navigate and claim their humanity in face of multiple intersecting oppressions. Moreover, the obsession with counting and keeping track of individuals’ medical histories, records, and sex life contributes to eugenic tendencies of controlling who gets to repopulate and who doesn’t, significantly affecting individuals with disabilities, BIPOC, and queer marginalized communities.<sup>114</sup>

### ***American Horror Story (AHS) “Freak Show” and Ableist Grief Models***

Eugenic practices that have emerged in the American context can also be seen in mainstream disability representation, such as in *American Horror Story (AHS)*. *AHS* is rooted in more fantastical fiction than *House*, but the disability representation cultivated in season four, “Freak Show,” is still ableist and draws on problematic racist histories of exoticization. “Freak Show” does attempt to destigmatize disability representation by focusing on the community building, collective care that exists among the “freaks” centered in the season and the power they gain by reclaiming their public presence.<sup>115</sup> However, the disability representation often perpetuates ableist stereotypes when showing how the individuals or “freaks” with disabilities navigate their grief.<sup>116</sup> Further, in “Freak Show,” unlike the *House* episode discussed above, there are multiple BIPOC, queer, disabled actors/actresses centered to serve as representative models.

It is important to note that freak shows were often sites to reclaim autonomy for people with disabilities, places where instead of hiding away, being ostracized, or being othered,

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<sup>113</sup> Frantz Fanon, *Black Skin, White Masks* (New York: Grove Press, 1967), 307.

<sup>114</sup> Michel, Foucault *History of Sexuality*, (Manhattan: Random House Inc., 1976), 25-26.

<sup>115</sup> Ryan Murphy, *American Horror Story*, Season 4, Episode 1, “Monsters Among Us,” 2014.

<sup>116</sup> *Ibid.*

individuals could be confident and revel in the public's gaze despite being the site for entertainment.<sup>117</sup> Mat Fraser, a disabled actor that plays Paul the Illustrated Seal in *AHS*, says in an interview:

Freak means erratically different person on stage entertaining with their radical difference ... I think what is interesting about me is my personality. Of course, these are different [acknowledging his hands] and they're interesting to look at, and there is nothing wrong with that. I am powerful and awesome. And I have these [showing off his hands]. And I'm a freak. And I am an actor. And I am a freak actor, playing a freak. And it's awesome.<sup>118</sup>

Fraser notes the incredible opportunity he has to play a freak as a disabled actor, and I do not intend to dismiss or diminish the importance of having disabled actors and actresses centered in mainstream television or movies. "Freak Show" centers other disabled actors and actresses such as Jyoti Amge playing Ma Petite, Ben Woolf as Meep, and Rose Siggins as Legless Suzi, among others. However, I do want to call attention to the messaging behind the disability representation within "Freak Show" that perpetuates both histories of colonialism and racism and further falls into the monstrosity/criminality stereotypes that are often assigned to people with disabilities.

American freak shows, circuses, and living exhibitions all are embedded with problematic relationships to exoticism, racism, colonialism, and cultural appropriation where the process of "othering" is pertinent.<sup>119</sup> Jean-François Staszak describes othering as "the act of

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<sup>117</sup> Guy Charles Murrunku Kirkwood, "Performing Freakery: American Freak Shows, Popular Culture and Regimes of Normalisation in the Nineteenth and Twentieth Centuries," *The University of Western Australia*, 2018.

<sup>118</sup> Mat Fraser, "American Horror Story: Freak Show – Interview with Mat Fraser" *YouTube*, 2014, <https://www.youtube.com/watch?v=G2zR0vgESBo>.

<sup>119</sup> Gillian Arrighi, "Circus, Colonialism, and Empire" in *Transnational Geographies of the Modern Circus* (Cambridge: Cambridge University Press, 2021); Lisa Wade, "Colonial Circus: The Case of "Giraffe-Necked Women," *Sociological Images*, 2012, <https://thesocietypages.org/socimages/2012/11/19/colonialism-and-the-circus-the-case-of-the-giraffe-necked-women/>.

making a determination between groups, wherein the dominant group views the non-dominant group in such a way that differentiates, diminishes, or otherwise devalues its members and allows for the perception of ‘Us’ and ‘Them.’”<sup>120</sup> For instance, Angela Bassett, a nondisabled African American woman cast as an intersexed individual within the season, was interviewed about her reaction to getting the part of Desiree Dupree. Bassett says,

you read the stage direction, “African American woman in her 40s, hermaphrodite, three breasts, and a ding-a-ling,” and you’re like, “Oh, my gosh!” You immediately close the pages, and have to walk around and process that for a minute. You’re thinking, “What does that mean? Oh, my gosh! If they thought I was crazy demonic last year, what are they going to think this year?”<sup>121</sup>

Bassett’s reaction to Desiree’s description and character reveals the historical tropes of Black people, Black women in particular, being hypersexualized and exoticized—both within past freak shows, circuses, and living exhibitions, but also within contemporary mainstream television.<sup>122</sup> The perpetuation of centering the Black woman as the exoticized object, in this case, further creates an Us/Them binary that is layered with racist and sexist misunderstandings of lived experiences. Moreover, even though individuals with disabilities have found the site of the freak show as liberating, like Fraser, not *all* individuals have, particularly those living in historical or socio-political climates that are ignorant of different mental and physical abilities. Therefore, othering also had occurred frequently for people with disabilities, who with their

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<sup>120</sup> Jean-François Staszak, “Other/Otherness” *International Encyclopedia of Human Geography*, 2008.

<sup>121</sup> Christina Radish “Angela Bassett Talks American Horror Story: Freak Show, Filming in New Orleans, Her First Reaction to Finding Out her Character, and More,” *Collider*, 2014, <https://collider.com/angela-bassett-american-horror-story-freak-show-interview/>.

<sup>122</sup> Natasha Gordon-Chipembere, *Representation and Black Womanhood: The Legacy of Sarah Bartman* (New York: Palgrave Macmillan, 2011).

physical and intellectual disabilities were displayed as abnormalities for people to view in past freak shows, circuses, and living exhibitions.

The season “Freak Show” follows a fictional company of individuals who are a conglomeration of people with physical and intellectual disabilities—such as Bette and Dot Tattler featured as cojoined twins played by the nondisabled actress Sarah Paulson, Jimmy Darling featured as Lobster Boy who had deformed hands from ectrodactyly played by the nondisabled actor Evan Peters, and Elsa Mars who has amputated legs and prosthetics played by the nondisabled actress Jessica Lange.<sup>123</sup> Othering extends beyond physical and intellectual disabilities to include non-western individuals or non-gender conforming individuals. For instance, managers of these operations often “collected” individuals seen from “uncivilized races,” often from non-western places and put on display for others to view, perpetuating racist and colonial practices in doing so.<sup>124</sup> The company featured in the season also includes non-western individuals who are exoticized—such as Ma Petite played by Jyoti Amge, an Indian actress who has achondroplasia.<sup>125</sup> Freak Shows often displayed non-gender conforming individuals as people who were also “othered”—in the *AHS* season, Desiree Dupree was shown as an intersexed person played by nondisabled actress Angela Bassett and Ethel Darling as the Bearded Lady played by nondisabled actress Kathy Bates.<sup>126</sup> Close analysis of the racial, colonial exoticism, and gender non-conforming othering that is occurring at the site of the Freak Show is beyond the scope of this project, although it is pertinent to mention.<sup>127</sup> I will be focused

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<sup>123</sup> “American Horror Story: Freak Show” *Wikipedia*, 2022, [https://en.wikipedia.org/wiki/American\\_Horror\\_Story:\\_Freak\\_Show](https://en.wikipedia.org/wiki/American_Horror_Story:_Freak_Show).

<sup>124</sup> “Exoticism and Exploitation” in *Flights of Fancy Fashion and Function in Circus Performance*, Cornell University Library Online Exhibitions, 2020, <https://exhibits.library.cornell.edu/flights-of-fancy/feature/exoticism-and-exploitation>.

<sup>125</sup> “American Horror Story: Freak Show.”

<sup>126</sup> *Ibid.*

<sup>127</sup> See Michael M. Chemers, *Staging Stigma: A Critical Examination of the American Freak Show*, (New York: Palgrave MacMillan, 2008); Joshua Gamson, *Freaks Talk Back: Tabloid Talk Shows and Sexual Nonconformity*

particularly on the othering that is occurring towards physical disabilities within the *AHS* season and how the company's reaction to their insidious trauma perpetuates the pity and monstrosity/criminality tropes on mainstream television.

In the United States, freak shows—having been called “human curiosities” in the eighteenth century, and “human oddities” in the nineteenth century—contribute to the image of disability as monstrous.<sup>128</sup> Robert Bogdan suggests that “in horror films the association of evil with disability is even more common... ‘monsters’ are scarred, deformed, disproportionately built, hunched over, exceptionally larger, exceptionally small, deaf, speech impaired, visually impaired, mentally ill or mentally subnormal.”<sup>129</sup> In Bogdan's further research, however, he also notes that “certainly, I found degradation, but I also found fame and fortune. People with disabilities were presented in demeaning ways to promote fear and contempt, but they were also presented in ways that positively enhanced their status.”<sup>130</sup> I am interested in how *Fräulein Elsa's Cabinet of Curiosities* in Jupiter, Florida centered in the season “Freak Show” portrays grief, trauma, and disability in ways that perpetuate the monstrosity/criminality and pity stereotype, while also creating a collective care-oriented space that promotes belonging.

Within the season, Elsa Mars reveals that she is more like her “freaks” than she would like to admit because she has two amputated legs and must wear prosthetics. Elsa has kept her physical disability a secret, by wearing pants or long skirts and dresses, so most people in her company did not know of it. In the fourth episode, “Edward Mordrake: Part 2,” Elsa's backstory comes to light. Even when prompted to divulge her story, Elsa shows resistance. When she

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(Chicago: University of Chicago Press, 1998); Rosemarie Garland-Thomson, *Freakery: Cultural Spectacles of the Extraordinary Body* (New York and London: New York University Press, 1996).

<sup>128</sup> Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (Chicago: The University of Chicago Press, 1988), 55.

<sup>129</sup> *Ibid.*, 6.

<sup>130</sup> *Ibid.*, 7.

discloses her story, she starts by saying, “you trade away your humanity trick by trick. In the end, I wasn’t Elsa. I was nothing.”<sup>131</sup> In a flashback to the 1932 German Weimer Republic, it shows Elsa taking up dominatrix sex work to survive. In a traumatic assault, she became an unwilling participant in a snuff film, where her legs were cut off with a chainsaw. A kind soldier saved her, nursed her to health, and created her prosthetic legs for her. In reflection of the brutal assault, she suggests that her ambition was her downfall, but during the experience when the Watchers held her against her will she was drugged “enough to be powerless. But not enough to forget. Not enough to not understand. Not enough to dull the pain.”<sup>132</sup>

Often discussing how one has come to be disabled can be taboo, as we’ve seen within critical disability scholarship, because there is a fear of perpetuating ableism. For instance, if there is a suggestion a person would be better off if they weren’t disabled—or had to endure the trauma they have—this could be read as an ableist interpretation of disability. Elsa’s disability representation is boldly intertwined with how she navigates her own grief that has come from both the physical trauma to her body and the insidious trauma she has dealt with since becoming a bi-lateral amputee. From the outset, Elsa’s character exudes ableist undertones—from her desire to keep her own disability hidden, to collecting and exoticizing other individuals to be part of her troupe, to clarifying that there was a distinction between herself and her troupe by saying “I am not one of them.”<sup>133</sup> Moreover, the flashback that takes audiences into the origin of her disability is framed in a way that perpetuates the idea that disability makes a person pitiful or live a tragic existence. To begin, the flashback shows Elsa as a powerful woman dominating the men that sought her out. She describes the experience:

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<sup>131</sup> Howard Deutch, *American Horror Story*, Season 4, Episode 4, “Edward Mordrake: Part 2,” October 2014.

<sup>132</sup> *Ibid.*

<sup>133</sup> *Ibid.*

Unable to find work on the stage, starving. But even in that world, I was a star. I was a minette, a French cat. I worked only at the top hotels. But I wasn't like the rest of those whores. I never let my clients touch me, let alone put their filth inside of me. (shouting) I gained a reputation for being the one you went to when you were looking for something... creative.<sup>134</sup>

The power that Elsa wielded came from her able-bodied navigation through the world. After the traumatic assault she became furious and angry with the soldier that nursed her back to health, finding no solace in the fact she had survived or lived. Realizing she had lost her power she says, “He rushed in the minute they left. I will never forgive him for it.”<sup>135</sup> Elsa insinuates she would rather have died than learn to live without her legs and find new ways to survive. Her insisting, “I had the most beautiful legs,” further suggests the removal of her legs was the removal of her chance at a successful career and fulfilling life.<sup>136</sup>

Her telling of the story, her attitude towards her past, and the grief she shows are not productive or anti-ableist representations of disability, grief, and trauma. Instead, her character compels the audience to pity her and the trauma she has endured, instead of recognizing the resilience she encapsulates while navigating her physical and insidious trauma despite repeated personal and career failures. Tobin Sieber notices this trend in disability representation and writes that the presence of pain serves “as a motive force” that justifies “disability oppression.”<sup>137</sup> Alyson Patsavas further writes that in the past pain “(real or assumed) has justified the pity and disqualification of disabled lives.”<sup>138</sup> Elsa’s story and representation of

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<sup>134</sup> Ibid.

<sup>135</sup> Ibid.

<sup>136</sup> Ibid.

<sup>137</sup> Tobin Siebers, “In the Name of Pain” in *Against Health*, (New York: New York University Press, 2010), 184.

<sup>138</sup> Patsavas, “Recovering a Cripistemology of Pain,” 203.

grief, trauma, and disability are falling into the ableist trope of pitying disability because of the pain she endured to receive the disability is framed as ending a desirable life. This moment exemplifies why critical disability scholars are often hesitant to discuss the traumatic origins of disability, since the grief is framed to elicit pity from audiences and downcast disability experiences.

Although in the moments of the flashback and her retelling her traumatic past have ableist undertones, Elsa's reaction to her past and how she actually navigated her trauma and disability attempts to cultivate and create a collective care community that helps her survive. Piepzna-Samarasinha emphasizes this idea of care work that deconstructs the notion that disabled folks are burdens by formulating what it means to live in a system of collective care and healing justice attuned to the intersections of colonization, racism, and ableism.<sup>139</sup> Collective care is when individuals within a disability community can provide care needs to one another, without expecting anything in return.<sup>140</sup> The care given comes out of a place of understanding, belonging, and empathy.<sup>141</sup> Elsa's community, although centering on this idea of collective care, does not recognize the colonial, racist, and ableist constructions that brought their troupe together. However, I think it is important to show that Elsa does work hard in face of her own physical and insidious trauma to create a place where others like herself can belong and access care.

Piepzna-Samarasinha also addresses the fear that people with disabilities have in accessing care, saying "people's fear of accessing care didn't come out of nowhere. It came out of generations and centuries where needed care meant being locked up, losing your human and civil rights, and being subject to abuse."<sup>142</sup> This fear is also spread because the representational

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<sup>139</sup> Piepzna-Samarasinha, *Care Work*, 113.

<sup>140</sup> Ibid.

<sup>141</sup> Ibid.

<sup>142</sup> Ibid, 39.

models readily available within mainstream TV and movies perpetuate negative stereotypes. *AHS*'s "Freak Show" is no different, as the season still perpetuates the idea that if someone needs extra care, they will either be abused or must be used as profit. For instance, when Elsa creates her "family" by going to various institutions where people are locked up, abused, or tossed away, she makes those individuals feel safe with her. In return for Elsa's kindness, the people she carries along with her perform in her Freak Show. The troupe she creates conglomerate like how Tanya Titchkosky and Rod Michalko describe:

Living in the midst of others, at times we experience a sort of 'belongingness,' a sense of belonging in and to a group, a social space, not as someone marginal to this group and space, but as someone integral to them and thus as someone who is valuable. What we conceive to be relevant is now understood as a shared perspective and as relevant to everyone 'in the know.'<sup>143</sup>

The belongingness that Titchkosky and Michalko discuss resists and rejects how disability is framed as "unnatural" or the "bad and the wrong way of being-in-the-world," and that resistance comes out of the collective care that is given within built communities.<sup>144</sup> Similar to how belongingness is formulated in a modern disability community, Elsa's troupe creates an intense bond with one another that enacts this collective care and belongingness. Emily Nussbaum writes that the freak show family was "historically, the one place where people with odd anatomies were glamorized, not hidden away. They could make money, live independently, and find sex and love. The difference between gawking and gazing, fearing and desiring, is not so simple."<sup>145</sup>

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<sup>143</sup> Tanya Titchkosky and Rod Michalko, "The Body as the Problem of Individuality: A Phenomenological Disability Approach" in *Disability and Social Theory New Developments and Directions* by Dan Goodley, Bill Hughes, and Lennard Davis (New York City: Springer, 2012).

<sup>144</sup> *Ibid*, 132.

<sup>145</sup> Emily Nussbaum, "The New Abnormal: The Carnival Logic of 'American Horror Story'" *The New Yorker*, 2014, <https://www.newyorker.com/magazine/2014/12/08/new-abnormal>.

Further, the belongingness that secures people's loyalty to one another, seen within Elsa's troupe, is built because of their collective insidious trauma—such as being outcast or rejected from society. A. Dirk Moses highlights that trauma can be experienced collectively in the “form of structural violence.” The structural violence the troupe has endured suggests that the troupe's deep bond with one another could also be attributed to their shared insidious trauma and having to navigate societal and cultural barriers to belonging. Further, their shared sense of grief, the internalized feelings they must process, are given an outlet as the collective troupe mourns together as well. From the introduction, I made the distinction between grief—internalized feelings—and mourning, which is the externalized actions that occur to show grief. The troupe, I argue, collectively mourns their insidious trauma, but they then channel their mourning process in negative, dangerous outlets that perpetuate the ableist monstrosity-criminality stereotype.

For instance, there is a distinct “them” versus “us” mob mentality that takes over the season. In one of Elsa's famous speeches, she exasperates:

I'll tell you who the monsters are! The people outside this tent! In your town, in all these little towns. Housewives pinched with bitterness, stupefied with boredom as they doze off in front of their laundry detergent commercials, and dream of strange, erotic pleasures. They have no souls. My monsters, the ones you call depraved, they are the beautiful, heroic ones. They offer their oddity to the world. They provide a laugh, or a fright, to people in need of entertainment. Everyone is living the life they chose.<sup>146</sup>

Elsa is targeting the “other” that exists beyond the troupe, or the society that has rejected the troupe, as the site to channel their anger. In fact, the messaging serves to create “collective evocations of the future,” where disability and the societally othered person can be accepted and

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<sup>146</sup> Murphy, “Monsters Among Us.”

integrated into the mainstream.<sup>147</sup> However, instead of Elsa cultivating and sharing an anti-ableist collective evocation of her troupe's future where the traditionally othered can live among people who act monstrous towards them, there is still a push to be separate from the mainstream because of the grief and insidious trauma society has already caused them. Although what she says rings true in many instances, where the people out casting others because of how they look are monstrous, the message she sends her troupe will end up perpetuating the monstrosity-criminality stereotype for people with disabilities—both within the show and the mainstream representations given for audiences watching because of how her troupe takes up her ideas of their collective future.

Although Elsa's company does find some sense of belonging and enact collective care towards one another, their grief and navigation of their insidious trauma are channeled in ableist ways that perpetuate the monstrous-criminal stereotype they have been assigned. For instance, the collective grieving the company goes through transitions from being a collective-care community that promotes belonging to being a site for destructive, criminal, and monstrous activity as they channel the grief from their insidious trauma towards being murderous, rageful, and revengeful. This transition is abrupt within the season, occurring in the first episode, suggesting the next twelve episodes of the season are perpetuating stereotypes more than centering the belongingness the troupe has cultivated. The moment I am referring to is when a police investigator in Jupiter, Florida, arrives at the site of the freak show to question and arrest Bette and Dot Tattler, the conjoined twins. In an act of protection, Jimmy Darling, the Lobster Boy, takes out a knife and slits the investigator's throat, screaming, "Don't call us freaks!"<sup>148</sup> When the investigator drops to the floor, three other members of the troupe rush to help move the

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<sup>147</sup> Kafer, *Feminist, Queer, Crip*, 27.

<sup>148</sup> Murphy, "Monsters Among Us."

body. In a following scene, almost the entire troupe parades in the dark to a secluded part of the woods. Here, they lay the dead investigator in the middle of them, and Jimmy gives this speech:

This lawman was supposed to protect and serve the innocent but instead he judged us guilty before he even set foot into our camp. All we've ever wanted was a place where we could all feel safe and be just the way we are, but no one is gonna hand it to us. We're gonna have to rise up and take it. Don't we deserve to be happy? [*Troupe Screams: Yeah!*] When bad things keep happening to good people, you start to question what is right and what is wrong. Well, I say it's time we make our own right and wrong. I saw, it's wrong for them to treat us like shit and kick us around like the scum of the earth. They want to call us monsters, fine. We'll act like monsters. From this day on, if anyone tries to mess with us, any of us ... they're gonna end up like this pig. Let's show what we can do [*Troupe screams in agreement*]<sup>149</sup>

After Jimmy's speech, the troupe raises machetes and other sharp objects and then the camera zooms out to show the troupe dismembering the investigator's body. Drawing on Michel Foucault, Theo Blackmore and Stephen Lee Hodgkins write, "power circulates through a web of human social relations, connecting and engaging people as both the oppressed and the oppressor, the liberated and the liberator, the ethical and the unethical, the powerful and the powerless."<sup>150</sup> Through expressing his overt anger, Jimmy and the troupe are channeling their feelings of oppression and powerlessness and turning into the oppressor and the powerful, where the ethical lines that once existed no longer do. By giving into the self-fulfilling prophecy that the troupe is full of monstrous individuals, Jimmy and the troupe perpetuates ableist interpretations and

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<sup>149</sup> Evan Peters, "Jimmy Darling" directed by Ryan Murphy, "Monsters Among Us."

<sup>150</sup> Theo Blackmore and Stephen Lee Hodgkins, "Discourses of Disabled Peoples' Organisations: Foucault, Bourdieu, and Future Perspectives" in *Disability and Social Theory New Developments and Directions* (New York: Springer Publishing, 2012).

misunderstandings of disability.<sup>151</sup> Through the act of purposefully giving into monstrous-criminal stereotypes, the creators of *AHS* are calling attention to the stereotype and the harsh reality that lies behind the stereotype. However, even recognizing the satirical nature of the season and ignoring the fantastical/supernatural elements that attempt to distance an audience from the sad truth that ordinary people engage in monstrous activity, the ways in which the troupe collectively mourns (murdering and dismembering an investigator) does not show positive or alternative models on how to navigate insidious trauma and grief, especially when it comes to the intersection of disability, grief, and trauma. Rather, it further insists that audiences pity the troupe as a whole for the injustices they face throughout the season.

## **Conclusion**

Although the two examples of mainstream television representation of disability I've discussed do not encompass all the mainstream disability representations within America, these two case studies are useful to point to the common angelic-innocent, pitiful, and monstrous/criminal stereotypes that are perpetuated when disabled creators are occluded and ignored in the writing, producing, or acting elements of mainstream television. Although at times throughout these two examples anti-ableist navigation of disability experiences are being attempted, such as recognizing the role of grief in *House* or creating a collective care community in *AHS*, ultimately, the resulting show that audiences see are still intertwined with problematic, ableist messaging. Moving forward, I will be looking into disabled content creators and spaces that offer places to navigate grief and insidious trauma openly in an anti-ableist way. In direct contrast to the *House* example, I will be presenting the next chapter with how disabled content creators are navigating their desexualization, hypersexualization, and insidious trauma. In the final chapter, I

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<sup>151</sup> Grant Welstead, Tobias Brambrink, Rudolf Jaenisch "Stereotype Threat and Self-Fulfilling Prophecies" *Jove*, <https://www.jove.com/science-education/11072/stereotype-threat-and-self-fulfilling-prophecies>.

will present how disabled communities are enacting critical mourning as a practice of anti-ableist collective grieving that contrasts with the *AHS* “Freak Show” disability representation. Nuanced representations of disability and grief are gaining traction within the mainstream, not through television or movies, but rather through social media and other intermedial platforms that are run, created, and produced by and for people with disabilities.

### CHAPTER III: CONTENT CREATORS' COLLECTIVE CARE: NAVIGATING GRIEF AND INSIDIOUS TRAUMA

Mona Eltahawy, a disabled, queer of color writer, recently wrote on what it means to pay attention to grief and to grieve amidst the COVID-19 pandemic. She poses the question of what a “grief literate society” would look like, where people would understand and accept differences in grieving styles, “in terms of gender, race, and culture, and they would feel comfortable to talk about their own loss experiences and to ask about the loss of others, instead of avoiding the subject or showing discomfort.”<sup>152</sup> As I explored in Chapter 2, mainstream disability representations often portray topics of grief as uncomfortable or taboo and are intertwined with problematic, ableist messages for audiences to process. In this chapter, I argue that disabled content creators are curating a space through social media sites, using platforms such as Instagram and Tik Tok to reject the taboo of discussing grief openly while modeling ways of navigating their own grief and enacting Eltahawy’s vision for a more grief literate society. Their posts on social media act as autoethnographic texts that offer “heightened self-reflexivity” and “increased focus on emotion.”<sup>153</sup> Looking at how disabled creators use social media platforms to create and share autoethnographic texts, I argue, constitutes a form of grassroots activism effective at shifting disability stereotypes.

In this chapter, I will discuss how disabled content creators are utilizing Instagram and Tik Tok to confront the grief they feel from insidious trauma in ways that deconstruct stereotypical representations of disability, such as desexualization and hypersexualization. I will first discuss social media’s relationship to surveillance and the suppression of marginalized

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<sup>152</sup> Mona Eltahawy, “Some of Us Did Not Die\* On Learning to Talk to my Grief with Vivaldi while reading June Jordan,” *Feminist Giant*, 2021, <https://www.feministgiant.com/p/essay-some-of-us-did-not-die>.

<sup>153</sup> Leon Anderson, “Analytic Autoethnography” *Journal of Contemporary Ethnography* vol. 35.4, 2006, 373.

bodies. I then argue that disabled content creators, aware of this “technological redlining,” have consciously worked to create collective care spaces within social media platforms that connect disabled individuals to a broad coalitional community.<sup>154</sup> I look at two social media activist influencers who have Spinal Muscular Atrophy and are wheelchair users, Alex Darcy and Shelby Lynch. Although their platforms and voices advocate for very similar things—sexual/body positivity, education around ableism, fashion, and diverse representation—each influencer confronts different forms of insidious trauma related to their disability, race, and socioeconomic background. I will argue that race informs how each influencer is perceived on social media by discussing how Darcy is navigating and theorizing her lived experience in comparison to the implications race may have on Lynch’s theory of grassroots activism.

### **Social Media: Connectivity or a Risk?**

Social media use and presence has become a societal norm, so much so that a lack of social media presence has been noted to negatively impact a person’s ability to find a job, grow their business, or even connect with future friends or partners.<sup>155</sup> Daniel Trottier suggests that social media is characterized by “social convergence,” which “refers to the increased social proximity of different life spheres.”<sup>156</sup> He suggests this provokes discomfort because we “maintain different representations of ourselves, and these may clash or directly contradict one another. This discomfort suggests that we live compartmentalized lives, and that we perform

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<sup>154</sup> Safiya Umoja Noble, *Algorithms of Oppression: How Search Engines Reinforce Racism*, (New York: NYU Press, 2018), 1.

<sup>155</sup> Aliah D. Wright, “Lack of Social Media Presence Can Hurt Job Seekers” *SHRM Better Workplaces Better World*, 2015, <https://www.shrm.org/resourcesandtools/hr-topics/technology/pages/lack-of-social-media-presence-can-hurt-job-seekers.aspx>; LaKesha Womack, “Is Your (Lack of) Social Media Strategy Killing Your Business” *Forbes*, 2017, <https://www.forbes.com/sites/forbescoachescouncil/2017/10/06/is-your-lack-of-social-media-strategy-killing-your-business/?sh=45f271755cf4>; Heather Havrilesky, “Is My Absence From Social Media A Red Flag” *The Cut*, 2019, <https://www.thecut.com/2019/02/ask-polly-is-my-absence-from-social-media-a-red-flag.html>.

<sup>156</sup> Daniel Trottier, *Social Media as Surveillance*, (Farnham: Ashgate Publishing, 2012), 11-12.

differently in each context.”<sup>157</sup> Trottier’s observation is that the ever-consuming presence of social media is a cause for celebration, yet the extreme “connectivity” can be “framed as a risk.”<sup>158</sup> For example, social media facilitates a lot of connections between people with disabilities, allowing people to find peers and have meaningful experiences, especially if those individuals have limited movement or social interaction beyond their home-base. Surveillance and data collection from social media can help document disability, which could result in accessibility; further, “insurance companies, schools, and employers require personal data to provide eligibility for accommodations and support.”<sup>159</sup>

However, social media also poses a risk for individuals with disabilities and many other communities, as the facilitation and connectivity that social media creates can attract predators, or individuals looking to exploit others.<sup>160</sup> Focusing on exploitative fears, social media creates platforms that revel in practices of surveillance where there is a “sustained and targeted collection of personal information” that is “pervasive in everyday life.”<sup>161</sup> The disability community often must rely on surveillant technology and social media and cannot easily opt out of its usage because to “live, study, and move around in society” often one must give up their data.<sup>162</sup> Moreover, disability “needs for assistive technology are met by big tech companies,” and “bureaucracies use artificial intelligence and surveillance to deny... support needed to participate in your community and even survive at all.”<sup>163</sup> Further, social media surveillance practices take advantage of “relations between individuals, organizations, and the state” becoming the “driving

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<sup>157</sup> Ibid.

<sup>158</sup> Ibid, 17.

<sup>159</sup> Karen Reilly, “A Primer on Surveillance Issues in the Disability Community” *Team Community*, 2022, <https://www.digitalrights.community/blog/primer-surveillance-in-disability-community>.

<sup>160</sup> Trottier, *Social Media*, 24.

<sup>161</sup> Ibid.

<sup>162</sup> Reilly, “Primer.”

<sup>163</sup> Ibid.

force behind social sorting, the allocation of life chances.”<sup>164</sup> Surveillance from social media can be a way to deny benefits to individuals with disabilities, as insurance companies hire private investigators to monitor social media so that “people must self-censor or risk their ability to pay bills and get medical care.”<sup>165</sup> Karen Reilly provides the example of an ambulatory wheelchair user or a person with an energy-limited chronic illness who cannot post pictures that show moments where they have more energy and less pain because of these fears.<sup>166</sup>

The social sorting facilitated by social media is extraordinarily apparent when we consider how marginalized groups are “sorted” by algorithms within social media.<sup>167</sup> Safiya Umaja Noble writes about how algorithms make “digital decisions [that] reinforce oppressive social relationships and enact new modes of racial profiling.”<sup>168</sup> She argues that within the social media landscape, “technological redlining” occurs, meaning that the Internet and “our everyday uses of technology” has “discrimination embedded in computer code.”<sup>169</sup> Further, algorithms are “serving up deleterious information about people, creating and normalizing structural and systemic isolation, or practicing digital redlining, all of which reinforce oppressive social and economic relations.”<sup>170</sup> The digital redlining, I argue, extends beyond the gender and racial bounds that Noble refers to and also applies to individuals with disabilities, enforcing the negative and ableist representations that are circulated.

Historically, people with disabilities have been cast from the public gaze by surveilling authorities and communities, such as governmental and medical institutions, and understood through stereotypes of monstrosity or uncleanness. For instance, Susan Schweik dives into

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<sup>164</sup> Trottier, *Social Media*, 25.

<sup>165</sup> Reilly, “Primer.”

<sup>166</sup> Ibid.

<sup>167</sup> Noble, *Algorithms*, 1.

<sup>168</sup> Ibid.

<sup>169</sup> Ibid.

<sup>170</sup> Ibid, 10.

historical ugly laws, or “unsightly beggar laws,” that were statutes passed that outlawed the appearance of people with disabilities or deformities in public, prominent in the United States in the 1800s until the 1970s, which disproportionately targeted poor, unhoused, disabled folks.<sup>171</sup> The eugenic desire to hide bodily variance from the public gaze continues into the modern digital age, such as promoting pressured abortions for individuals with disabilities or limiting procreation prospects by desexualizing individuals with disabilities so they do not have access to tools, education, or aide in having sex.<sup>172</sup> Moreover, hiding bodily variance in social media has a reputation for having a maleficent effect on body image, perpetuating ideas of what standards beauty should look like, often occluding bodily variance and representations of disability.<sup>173</sup> Mavis Henriques and Debasis Patnaik write on social media’s effects on beauty perceptions, observing that “social media has had a major impact on the perceptual, affective, cognitive and behavioral aspects of body image by encouraging lean body patterns and delivering anti-obesity messages.”<sup>174</sup> In this regard, social media platforms have been recently utilized as sites of grassroots activism to challenge beauty norms and make visible bodily variance to actively resist the cognitive and perceptual impact that impossible beauty standards convey. For example, the Cute Baby Face filter on Instagram that sculpts one’s face, increases one’s eye size, and adds make up has been picked up by many social media users to promote the caption “social media is

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<sup>171</sup> Susan Schweik, *The Ugly Laws: Disability in Public* (Manhattan: New York University Press, 2010), 142.

<sup>172</sup> Rosemarie Garland-Thomson, “Misfits: A Feminist Materialist Disability Concept” *Hypatia*, vol. 26.3, 2011, 591.

<sup>173</sup> Jasmine Fardouly and Elise Holland, “Social media is not real life: the effect of attaching disclaimer-type labels to idealized social media images on women’s body image and mood” *New Media & Society* vol. 20, 2018, 4311–4328; Scott Fatt, Jasmine Fardouly, Ronald Rapee, “#malefitspo: links between viewing fitspiration posts, muscular-ideal internalisation, appearance comparisons, body satisfaction, and exercise motivation in men” *New Media & Society* vol. 21, 2019, 1311–1325; Mariska Kleemans, Serena Daalmans, Llana Carbaat, Doeschka Anshutz, “Picture perfect: the direct effect of manipulated Instagram photos on body image in adolescent girls” *Media Psychology* vol. 21, 2018, 93–110.

<sup>174</sup> Mavis Henriques and Debasis Patnaik, “Social Media and Its Effects on Beauty” *Cosmetic Science, Cultural Issues, and Creative Developments*, 2020.

fake” and show how they really look when the filter is removed.<sup>175</sup> Movements and usage like this, from marginalized groups or individuals that show off their body variance have started to decrease the pressure to attain idealized body images, such as being built thin or athletic, having clear skin, and having abled-bodied function. Idealized body images that are perpetuated are also difficult on individuals with disabilities because there has traditionally seldom been anti-ableist coverage on mainstream movies and television, such as coverage that does not fetishize disability, partake in inspiration porn narratives, or feed into negative stereotypes.<sup>176</sup> The constant onslaught of misrepresentations of disability, I argue, is a form of insidious trauma that many individuals with disabilities must navigate through. As I discuss in the introduction, insidious trauma “offers a way to think about the repetitive, daily injustices and vulnerabilities” or the “persistent marginalization created by institutional structures that value certain subjectivities over others.”<sup>177</sup>

Insidious trauma cultivated because of ableist and sanist misrepresentations affects both those with physical and intellectual disabilities. Further, social media can both aid in harassment and perpetuate stereotypes, but also be a site where people create supportive communities. For example, Rae Rosen navigates social media and blogs as a mom with bipolar disorder to write about the misrepresentation of her own disorder.<sup>178</sup> She says, “When I search for ‘bipolar mother’ on Google Images, I find a lot of women with their heads in their hands, their crying

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<sup>175</sup> Shoaib Khan, “What is ‘Cute Baby Face Filter’? Why Social Media Users Criticizing It?” *Brunch Virals*, 2020, <https://brunchvirals.com/trending/cute-baby-face-filter/>.

<sup>176</sup> Ashraf Ahadzadeh, Saeed Sharif, Fon Ong, “Self-schema and self-discrepancy mediate the influence of Instagram usage on body image satisfaction among youth” *Computers in Human Behavior* vol. 68, 2017, 8–16; Zoe Brown and Marika Tiggermann, “Attractive celebrity and peer images on Instagram: effect on women’s mood and body image” *Body Image* vol. 19, 2016, 37–43; Katerina Lup, Leora Trub, Lisa Rosenthal, “Instagram #instasad? Exploring associations among Instagram use, depressive symptoms, negative social comparison, and strangers followed” *Cyberpsychology, Behavior, and Social Networking* vol. 18, 2015, 247–252.

<sup>177</sup> Westengard, *Gothic Queer Culture*, 15, 17.

<sup>178</sup> Rae Rosen, “The Power of Finding a Disabled Community Online” *Disability Futures*, 2019, <https://www.howwegettonext.com/the-power-of-finding-a-disabled-community-online/>.

children in the corner.”<sup>179</sup> Rosen desires to change that representation and posts about her own journey as a mother with bipolar disorder. However, people confront her content on social media surrounding her disability and role as a mother, saying things like is it “really true that I’m bipolar *and* a mother” because other followers, too, have been warned not to have children.<sup>180</sup> Rosen has also been subject to harassment with unsolicited statements such as “eat a shotgun.”<sup>181</sup> The aggressions and misrepresentation Rosen face are forms of insidious trauma that she is not shy to address. However, amid confronting her insidious trauma, Rosen recognizes that although social media can facilitate microaggressions and insidious trauma, “social media can function as the support group and family that most of us don’t have or have trouble accessing physically.”<sup>182</sup> She explains that social media is “something I can rely on when I’m feeling great or not so great. No matter the time or day of the week, I can find someone going through something similar to what I’m going through ... This centers me—it helps me be honest about who I am, and about what I can and cannot do every day.”<sup>183</sup> Rosen recognizes that social media can be weaponized as a double-edged sword, however, the benefits that social media usage can produce for Rosen and other disabled content creators suggest that the collective care communities that social media facilitates make the trouble of being vulnerable to the public worth it.

Confronting insidious trauma, such as navigating misrepresentations on TV, movies, and social media, has become a pertinent issue for disability activists in recent years. Instead of allowing digital redlining, which promotes falsified and inaccurate stereotypes to circulate, people with disabilities have begun to speak up and out against the discrimination they feel and

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<sup>179</sup> Ibid.

<sup>180</sup> Ibid.

<sup>181</sup> Ibid.

<sup>182</sup> Ibid.

<sup>183</sup> Ibid.

hear about in day-to-day life. The sheer number of disabled activists and content creators that has emerged is shifting disability discourses among non-disabled audiences. Caroline Casey writes that “the voices of this new generation of disabled influencers ring loud and clear; their ownership of who they are, their rejection of the old stereotypes of what it means to be disabled, and the way they are replacing them with something so humanly compelling, relatable, exciting, informed and real” characterizes the reach of the individuals’ content.<sup>184</sup> Furthermore, the “relatable” and the “real” aspects that Casey mentions play into the fact that disabled content creators who are deconstructing stereotypes do not shy away from having difficult, anti-ableist discussions surrounding grief, such as acknowledging the pain and loss they have experienced from insidious and other forms of trauma.

### **Care Work, Crip Time, Content Creation**

Social media platforms such as Instagram and Tik Tok have become exemplary places to investigate how content creators are using the public third space to subvert and challenge stereotypical representations, allowing BIPOC, queer, and disabled folks to theorize their own lived experience with more accurate and realistic representations. Historically, representation within popular culture of queer, BIPOC, and disabled bodies has been created and produced by people outside the scope of those lived identities.<sup>185</sup> Yet the creation of the types of stereotypical representations that I discussed in Chapter 2 is actively being resisted on the grassroots level through the ordinary everyday practices of queer, BIPOC, and disabled folks utilizing social media platforms to navigate their insidious trauma by both deconstructing preconceived notions

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<sup>184</sup> Caroline Casey, “Is the Social Media Generation Transforming Disability Representation” *Forbes*, 2020, <https://www.forbes.com/sites/carolinecasey/2020/09/14/is-the-social-media-generation-transforming-disability-representation/?sh=14912dd86084>.

<sup>185</sup> Barnes, *Disabling Imagery, and the Media*, 15; Schatz and George, *The Image of Disability*; Johanssen and Garrisi, *Disability, Media, and Representations*; Carolyn Hinds, “Accessibility and the Lack Thereof in the Film Industry” *Disability Visibility Project*, 2021, <https://disabilityvisibilityproject.com/2021/10/13/accessibility-and-the-lack-thereof-in-the-film-industry/>.

that their non-disabled followers may have about their experiences or identity and consciously building communities that are welcoming to the sharing of their experiences. Take for instance Rosen, who is deconstructing stereotypes of mothers with bipolar disorder, and her comments on media presence:

My desire to set an example has helped me move away from people who demeaned me (intentionally or not) and spend more time in a more supportive climate, even if the support is digital. My digital spaces help me feel that I'm protecting myself in an otherwise hostile environment ... The irony is that the digital world feels more real to me than the real world has ever felt—this digital world includes so many of us, and it shows our strengths and helps us deal with our weaknesses. I have found not only friends on Instagram but collaborators as well. <sup>186</sup>

Rosen, and other disabled content creators, recognize the power they have when building their own communities on social media. These communities are more than just mere communication among strangers: they build intense support systems that become essential to the day-to-day life of people with disabilities. When disabled content creators are presenting themselves, their stories, and their opinions on social media, one commonality I have found amongst many of them is their emphasis on how the disability community connects and relates with one another in a distinct way. Disability content creators can have tough, anti-ableist conversations on grief because often these individuals are integrated into a vast community that enacts collective care or care work, making possible interconnection and support to speak about their insidious trauma. Leah Lakshmi Piepzna-Samarasinha describes care work as the inherent connection built between people with disabilities that are aware of access needs.<sup>187</sup> She further explicates:

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<sup>186</sup> Rosen, "Power of Finding."

<sup>187</sup> Piepzna-Samarasinha, *Care Work*, 258.

I mean that when we reach for each other and make the most access possible, it is a radical act of love. When access is centralized at the beginning dream of every action or event, that is radical love. I mean that access is far more to me than a checklist of accessibility needs—though checklists are needed and necessary. I mean that without deep love and care for each other, for our crip bodyminds, an event can have all the fragrance-free soap and interpreters and thirty-six-inch-wide doorways in the world.<sup>188</sup>

I understand care work as radical acts of care that do not make another person feel bad about their accessibility needs, such as needing music lowered, needing more time to rest, or leaning on another for support. Support and radical acts of care can be given digitally as well, as it is not tied to in-person care. This could look like promoting a disabled friend's business, sending an encouraging message on social media, allowing people more time to respond to text messages, or understanding people may ignore a phone call if they need to rest.

Piepzna-Samarasinha describes her vision by imagining care work as a site where “disabled only or ... disabled and non-disabled folks ... still work from a model of solidarity not charity—of showing up for each other in mutual aid and respect.”<sup>189</sup> The mere consideration of solidarity instead of charity pushes against weak and vulnerable narratives that have been circulated on digital media in the past, to instead focus on being and living in a world together.

Care work would further appear as:

shifting our organizations to be ones where people feel fine if they get sick, cry, have needs, start late because the bus broke down, move slower, ones where there's food at meetings, people work from home—and these aren't things we apologize for. It is the way we do the work, which centers disabled-femme-of-color ways of being in the world,

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<sup>188</sup> Ibid, 81.

<sup>189</sup> Ibid, 41.

where many of us have often worked from our sickbeds, our kid beds, or our too-crazy-to-go-out-today beds.<sup>190</sup>

The slowing down Piepzna-Samarasinha adheres to relates to Alison Kafer's concept of "crip time," which is an acknowledgement of the fact that bodies move in different ways, at different paces, and desires different things.<sup>191</sup> Care work involves a conscious push back against hegemonic white ableist and heterosexual narratives of lifespan development, which is a normative approach in psychology to explain how a human develops throughout their lifetime, following age-related averages for large social milestones such as graduating college, getting a job, getting married, having kids, etc.<sup>192</sup> By lessening the pressure of social milestones that are emphasized within modern Western psychology, making room for crip time is essential to giving and receiving care work in a community like Piepzna-Samarasinha imagines.

The flexibility that crip time and care work allow works well within digital communities. Samira Rajabi argues that the third space or "digital space encourages negotiative mediation that transcends time and is ever changeable, never fixed," which allows space for renegotiating one's own identity.<sup>193</sup> Part of renegotiating one's identity in relation to disability and the encompassed insidious trauma that an individual may hold is the coalitional community-building, collective action, collective care work that occurs on social media platforms. Like Rosen's example, this collective care work can be easily seen in Rajabi's anecdote of her Google and Twitter searches after she discovered she had a brain tumor. She writes:

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<sup>190</sup> Ibid, 116.

<sup>191</sup> Kafer, *Feminist, Queer, Crip*, 26.

<sup>192</sup> Iiham Fitrotul Hayat, "What is Lifespan Development" in *Introduction to Psychology*, 2017, <https://courses.lumenlearning.com/wmopen-psychology/chapter/what-is-lifespan-development/>.

<sup>193</sup> Rajabi, "Losing Someone Like Us," 64.

When I saw the results of my search, I saw that I wasn't alone. It is in the stories that were told along-side mine that my story became a collective one. It both belonged to me and belonged to the #btsm community. Moreover, my story became situated in a broader discourse, one in which I railed against the diagnosis of a brain tumour and one in which I watched others make similar political gestures to be seen in their disabled, suffering bodies.<sup>194</sup>

The connection Rajabi felt after finding similar stories and people representing her grief in coming to terms with her diagnosis shows that having this type of representation easily within reach and having a known collective care model and care work ingrained in those models, are essential to learning and reorienting herself and her internal biases in anti-ableist ways. Further, the empowerment felt in finding others who share similar embodied experiences gives agency back to individuals with disabilities to tell their stories and experiences in ways that do not need to be censored or hidden from the public gaze, as has been historically imposed within our society. In the next two sections, I present two disabled content creators who have built expansive digital communities that promote anti-ableist models on how to navigate insidious trauma. Both content creators' platforms facilitate connection between their followers and provide a space for disabled followers to enact care toward one another that adheres to crip time.

### **Alex Darcy: Navigating Desexualization**

Instagram influencer Alex Darcy (username @wheelchair\_rapunzel) is a white writer, model, creator, and disability advocate who centers her lived experience to deconstruct stereotypes, especially those that are desexualizing in nature, by often vlogging and posting material that navigates both positive and negative affects within her day-to-day life. Darcy lives

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<sup>194</sup> Ibid, 70.

with Spinal Muscular Atrophy and uses a wheelchair. On her Instagram, Darcy is often met with insidious trauma in the form of infantilizing microaggressions and has been removed from TikTok repeatedly due to those reports. In this section, I will explore how Darcy theorizes her lived experiences using social media and how she navigates her grief and insidious trauma whilst building a collective-care digital community that enacts care work.

As a person with white privilege, Darcy experiences certain and specific forms of ableism on her social media accounts that must be understood in relation to the angelic-innocent stock character and the accompanying desexualization that goes along with it. As outlined in Chapter 2, the angelic-innocent stereotype often invalidates any sexual or asexual expression individuals with disabilities have with the assumption that they shouldn't be having those experiences or feelings because of their child-like innocence. Desexualization, or the "ongoing process of creating distance between sexuality and people with disabilities" often involves having "sexual assistance and access to social settings and communications ... prohibited."<sup>195</sup> Further, white privilege relates to the angelic-innocent stereotype because of historical white supremacist connotations between purity, whiteness, and childhood. Dorothy Roberts writes, "The powerful Western image of childhood innocence does not seem to benefit Black children. Black children are born guilty. The new bio-underclass constitutes nothing but a menace to society—criminals, crackheads, and welfare cheats waiting to happen."<sup>196</sup> Further, Robin Bernstein writes, "white children became constructed as tender angels while black children were labeled as unfeeling, non-innocent nonchildren."<sup>197</sup> As Roberts and Bernstein suggest, there is a historical proclivity to

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<sup>195</sup> Kim, "Asexuality in Disability Narratives," 490.

<sup>196</sup> Dorothy Roberts, *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (New York: Vintage Books, 1997), 42.

<sup>197</sup> Robin Bernstein, *Racial Innocence: Performing American Childhood from Slavery to Civil Rights* (New York: New York University Press, 2011), 30.

associate whiteness with innocence and moral superiority, and Blackness with animalism and morally deficiency. Darcy is often treated as a child because of her disability, but her desexualization is also exasperated because her whiteness is grounded in a racialized, historical past dependent on white supremacy that suggests she must have child-like innocent demeanor.

Additionally, desexualization and compulsory sexuality both relate to hypersexualization, which is “the branding of some groups—most especially gay men and racialized groups—as excessively sexual... and in need of ‘population management.’”<sup>198</sup> As I will present in the next few pages, the relationship between compulsory sexuality, desexualization, and hypersexualization show “uneven racial histories” behind narratives and stock characters to enact forms of social control.<sup>199</sup> Ianna Hawkins Owen writes on historical stereotypes and suggests that whiteness expresses “asexuality as ideal,” in which white individuals struggle and triumph against their sexual desires, expressing “a form of innocence, moral control, and restraint.”<sup>200</sup> In contrast, Black people “have often been positioned as hypersexual so as to justify enslavement, lynching, and other instruments of racism.”<sup>201</sup> Thus, when taking into consideration a racial intersection for people with disabilities, the angelic-innocent stock character represented within popular culture is often solely associated with white narratives. Darcy is among those white narratives that must face and push against the ableist, insidious trauma associated with the angelic innocent stereotype she receives. In the next section, I will present Shelby Lynch, who is a Black similarly positioned disabled content creator who must face ableist, insidious trauma that is centered around her hypersexualization.

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<sup>198</sup> Przybylo, *Asexual Erotics*, 16.

<sup>199</sup> Ibid.

<sup>200</sup> Ianna Hawkins Owen, “On the Racialization of Asexuality,” in *Asexualities: Feminist and Queer Perspectives*, ed. KJ Cerankowski and M. Milks (New York: Routledge, 2014), 125.

<sup>201</sup> Przybylo, *Asexual Erotics*, 16.

On Darcy’s Instagram story from September 28, 2021, she posts a selfie that shows tears streaking her cheeks.<sup>202</sup> Her caption says, “allow yourself to grieve.” Another Instagram story captured on September 9, 2021, includes a selfie that shows the top half of her forehead. She captions it, “crying and having a panic attack weee.”<sup>203</sup> Both of these examples of her vlogging sessions represent times where she enacts her own form of disability mentorship and is transparent about the grief she is dealing with—the first post addressing the grief she felt over aggressive comments on her account, the second post addressing the frustration and sorrow she felt with a new medical update.<sup>204</sup> Recalling Judith Halberstam’s work on the art of failing, Darcy is also dismantling visions of what success means by showing her community the ways she is “failing, losing, forgetting, unmaking...” by providing a transparent look into how she navigates her insidious trauma.<sup>205</sup> To address her feelings, both positive and negative, consistently on her account, creates a robust representative model for her followers who also have disabilities to navigate their own experiences in anti-ableist ways and for her nondisabled followers to gain deeper understandings of an individual’s lived experience with disability.

As an example of Darcy processing her positive affects (confidence and happiness), she posted a selfie on May 11, 2018. In the post, Darcy is caressing her hair and touching her face in an unabashed flirty way. The caption of her post says, “Disability misconception: people with disabilities are angelic & innocent. I mean, I can pretend like I’ve never gotten blacked out & made out with more than one guy in a night [shrug emoji, tongue out emoji].”<sup>206</sup> In a casual, joking tone, Darcy is advocating for a new imagined future, “positioning ‘crip’ as a desired and

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<sup>202</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, Sept. 28). Allow Yourself to Grieve [Story]. *Instagram*.

<sup>203</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, Sept. 9). Panic Attack [Story]. *Instagram*.

<sup>204</sup> Piepzna-Samarasinha, *Care Work*, 258.

<sup>205</sup> Judith Halberstam, *The Queer Art of Failure* (Durham: Duke University Press, 2011), 2.

<sup>206</sup> Alex Darcy [@wheelchair\_rapunzel]. (2018, May 11). *Disability Misconception* [Photo]. *Instagram*. [https://www.instagram.com/p/BipdoOIBCiY/?utm\\_medium=copy\\_link](https://www.instagram.com/p/BipdoOIBCiY/?utm_medium=copy_link).

desirable location regardless of one's own embodiment," one where she is not othered or fetishized because of her disability, but is being integrated and incorporated in social activities that other peers her age are engaging in.<sup>207</sup> She challenges the angelic-innocent trope her because she directly is calling out the misconception that people with disabilities are often considered to be angelic, sweet, and desexualized. Further, her post and caption work together to show her followers that she does not identify with that trope, but rather pushes against it completely, providing an example for how other disabled followers can break that specific stereotype. Moreover, Darcy's interactions with both positive and negative affects deepens her relatability and representation to her followers.

One of Darcy's main themes throughout her advocacy work is fighting for representation in the mainstream that will deconstruct the angelic-innocent stock character she had traditionally been tied to, and she often vlogs about her desire to become an actress to do that work in professional ways, such as creating a Netflix Series. One example of how Darcy responds and deconstructs the angelic-innocent stereotype and the ableism she faces is a post from early October 2021. Within this post she responds to an aggressive comment that reads, "Please stop. It's like watching a child being exploited. Is not sexy. Is disturbing. It's not about equality. It's about accepting you're different and disgusting to look like this."<sup>208</sup> Darcy responds with a post demanding more representation saying she "will shout from the rooftops that disabled bodies are valid" and expresses those comments like these are the reasons "why I am here and do what I do" to "reflect the ableism disabled people have to endure on a daily basis."<sup>209</sup>

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<sup>207</sup> Kafer, "Unsafe Disclosures," 13.

<sup>208</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, October 16). *Disabled Bodies are Beautiful* [Photo]. *Instagram*. <https://www.instagram.com/p/CVF7MSorPam/>.

<sup>209</sup> Ibid.

In another image, posted on June 3, 2021, Darcy is in a modest white lingerie piece looking away from the camera, capturing the majority of her chair in the frame.<sup>210</sup> Darcy is purposefully blurring the private/public line within her sexuality expression by bringing lingerie, which is typically confined to the secrecy of a bedroom, into the public gaze. In the next series of photos, within the same post, there is a close-up to her back, showing a long scar that traces the center of her spine. In this image, she is subverting what Schweik discusses as the history of ugly laws, where poor people with disabilities had been traditionally cast from certain public spaces, by not allowing public discourse to deter her body being seen in intermedial public contexts.<sup>211</sup> Her caption says:

It hasn't always been easy to find beauty in my disabled body. #savagexambassador to look at my disabled curves with grace and not disdain. To appreciate the function my body does have and savor those moments instead of focusing on the times I feel like I'm living in a broken body. To know my body is worthy of intimacy, pleasure and touch. To unlearn ableism and unpack the internalized ableism that tells me my body is ugly, broken, and disgusting. Lingerie is a huge part of my body image journey. It's helped me find confidence in my imperfections. In my disabledness.<sup>212</sup>

Not only is Darcy here continuing to assert her desirability, but there is a layer of discussion about who gets to decide what is desirable and what is not. Don Kulick and Jens Rydstrom write, “unsurprisingly, this hierarchy of desirability is linked to, and in important senses is determined by popular culture and conventional norms of attractiveness.”<sup>213</sup> Darcy is navigating previous

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<sup>210</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, June 3). *Beauty in My Disabled Body* [Photo]. *Instagram*. <https://www.instagram.com/p/CPq26QHJ4Pf/>.

<sup>211</sup> Schweik, *The Ugly Laws*, 170.

<sup>212</sup> Darcy, *Beauty in My Disabled Body*.

<sup>213</sup> Kulick and Rydstrom, *Loneliness and Its Opposite*, 215.

negative affects (feelings of grief or sorrow over her body) and the internalized ableism that she is still fighting because of her insidious trauma that suggest what she can or cannot do in her body. Further, through navigating her grief on social media, Darcy is enacting what Rajabi refers to as meaning-making through “digital media platforms that afford users an opportunity to play with the constructedness of socially constituted identities in ways that produce new meanings, build on existing meanings and possibly transgress boundaries of what it means to materially live in a disabled body.”<sup>214</sup> By asserting her sexuality as a lingerie ambassador, Darcy is creating a space that suggests forms of sexuality are healthy within the public gaze, which is fundamental when we think of how reluctance to explore insidious trauma can affect the daily lived experience for individuals with disabilities who are watching or seeking models to navigate those experiences, as this reluctance can reinforce isolating practices that privatize pain and suffering, drawing on histories of controlling what bodies and affects are allowed in public spaces or not.

Additional to her activism for body and sexual positivity, Darcy discusses and shares her own experiences within her body through poetry. She shares often about the insidious trauma she faces or just the grief she navigates through. She posted this poem on her Instagram story at the beginning of December in 2021. She writes:

Attractive young women scrub me  
I feel the water trickling down the  
scar engraved down my spine that  
runs for miles down my back  
Kind of like the road I am running  
down

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<sup>214</sup> Rajabi, “Losing Someone Like Us,” 57.

In my mind to be anywhere but  
here.

To feel the water and the warmth  
Of the room hug me like a cozy  
blanket without anybody else  
touching me<sup>215</sup>

Darcy is relaying the intimacy she feels with her caretakers as they give her a shower or bath, but she is showing her resistance to that intimacy as well. Her caretakers know the “scar” that traces her back very well, and Darcy alludes to the scar as a metaphor for her own life’s journey. In this moment she captures, she desires to be anywhere but in this intimate moment with her caretaker. There seems to be a desire for solitude, away from the comfort her caretakers typically give, to self-soothe and self-comfort. The self-soothing that appears in this poem theorizes how she navigates moments that are common among people with disabilities. The desire to be away, but knowing she must remain, and how she handles those moments is to write and express her feelings and desires for another future. Her writing recalls a portion of what it means to provide care work. Piepzna-Samarasinha asks, “How do we handle the realities of our bodies and minds that need what they need when they need it? What does it mean when I can’t support you in the ways you’re supporting me?”<sup>216</sup> One aspect of care work that Darcy promotes is the unfazed, deep love and support her care givers grant her. However, another side of care work suggests knowing when to give an individual space so they can process, self sooth, find solitude whenever possible.

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<sup>215</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, Dec. 3). Poem [Story]. *Instagram*.

<sup>216</sup> Piepzna-Samarasinha, *Care Work*, 57.

Although it is not always possible to gain the solitude she desires, as she suggests in her poem, the act of writing and sharing her creativity to her followers are again showing ways in which she navigates her day-to-day feelings, trauma, and experiences. Darcy, through her representation, pushes against the insistence that she must present a performative version of herself to prove her worth in her disabled body – such as resisting becoming inspiration porn. Additionally, Darcy does lean into this idea of collective-care and ethics – often posting images or stories with her mother or caretakers.<sup>217</sup> Her platform archives the sites of joy in her life, whether they spawn from her family, boyfriends, or friends. By marking her lived experience with live commentary and experience, Darcy fights and creates more nuanced representation for her followers on social media.

Her nuanced representation can be seen as a grassroots meaning-making movement where she has extraordinary influence and reach based on her personal experience navigating the world in a transparent, anti-ableist light, allowing her to construct a collective community around her embodied experience. Darcy's 154K following, as of 2022, suggests that she has found a community of people who seek the same representation that she is trying to create. For instance, Instagram user @musiciangirl13 comments, "I recently got a central line in my neck/chest and omg it has damaged my self-image terribly. Yes, there's days I've been good and gotten past it but it's hard. Disabled bodies matter."<sup>218</sup> In the same post, @annakathrynvd comments, "Dope scar. I have a similar one down my back from 2 spinal fusions" and @rabbidfaerie writes,

You are stunning ... I am recovering from cancer and learning to live with my new leg, and I know it's absolutely nothing compared to what so many others have to deal with,

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<sup>217</sup> Ibid, 116.

<sup>218</sup> @musiciangirl13 on Alex Darcy [@wheelchair\_rapunzel]. (2018, May 11). *Disability Misconception* [Comment]. *Instagram*. [https://www.instagram.com/p/BipdoOIBCiY/?utm\\_medium=copy\\_link](https://www.instagram.com/p/BipdoOIBCiY/?utm_medium=copy_link).

but it has been tough to unlearn ableism as you said, and love what I can still do ... thank you for being a role model to everyone who needs it [heart emoji].<sup>219</sup>

The other comments from followers who may or may not have a disability often include heart eye emojis, fire emojis, and other comments such as you are beautiful, stunning, go get it girl, etc. The mere exposure that Darcy's posts is getting and the interaction among followers is deconstructing the weight behind desexualizing practices, allowing for a huge population of people like Instagram users @musiciangirl13, @annakathrynvd, and @rabbidfaerie to embrace their desirability within their disabled bodies.

Often disability advocates and influencers are mistaken as “inspiration porn,” which I have introduced in Chapter 1. Stella Young defines inspiration porn as the process of objectifying “one group of people for the benefit of another group of people” such as “objectifying disabled people for the benefit of nondisabled people” in order to inspire you or make you think “however bad my life is, it could be worse. I could be that person.”<sup>220</sup> Darcy, her followers, and almost all other individuals with disabilities who have intermedial media presence, must battle against becoming the object of admiration, for the sake of nondisabled persons to feel better. Although many comments—such as “you are so inspiring,” “wow I wish I could be that confident if I were you,” or even “you are doing amazing things in life” (referring to mundane life activities)—are often meant in a kind way, these are microaggressions from “well-intentioned people” that compound to create insidious trauma for individuals with disabilities to live through.<sup>221</sup> Derald Wing Sue argues that the most impactful insidious trauma comes from microaggressions of people who “believe in their own morality, and experience

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<sup>219</sup> Ibid, @annakathrynvd and @rabbidfaerie comment.

<sup>220</sup> Young, “I’m Not Your Inspiration.”

<sup>221</sup> Westengard, *Gothic Queer Culture*, 14.

themselves as fair-minded and decent people who never consciously discriminate.”<sup>222</sup> Moreover, by asserting her content in the face of these micro-aggressive influences, Darcy is deciding “how to position [herself], [her] body and [her] stories in [her] broader world.”<sup>223</sup> While simultaneously battling against the microaggressions within society—and popular culture—and the ideas of inspiration porn and objectification by followers, Darcy does an outstanding job of creating a transparent page that addresses these problems and makes her process of coping, navigating, and managing her disability real and desirable.

Darcy faces ableist, insidious trauma on whatever platform she uses, however, Tik Tok has notoriously taken down Darcy’s account repeatedly. In one instance in late November, it was completely banned and removed. Darcy wrote on Instagram the reasoning for Tik Tok’s ban and removal of her account. She says that it was banned because users were reporting Darcy for content that went against Tik Tok community standards, such as “illegal drug and substance use,” “minor safety,” and “nudity and sexual activity.”<sup>224</sup> Her followers on Instagram were outraged and responded with comments of support and similar experiences, and many people reposted her post to their own stories. I argue that the socialization of Darcy’s outrage/frustration with Tik Tok in this Instagram post created a movement with ripple effects towards recognizing that Tik Tok’s review of reported posts are ableist in nature. For one, Darcy is of age to drink and does post herself drinking alcohol, and there is never any mention of illegal drugs or substances in her materials. Darcy is above the legal drinking age and is not a minor. The reports of minor safety made against her are infantilizing as they perpetuate the stereotype that because she is disabled, she does not have agency or control. Lastly, the reports on her nudity and sexual

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<sup>222</sup> Ibid, qtd. 14.

<sup>223</sup> Rajabi, “Losing Someone Like Us,” 71.

<sup>224</sup> Alex Darcy [@wheelchair\_rapunzel]. (2021, June 3). *Tik Tok Account Banned* [Photo]. *Instagram*. <https://www.instagram.com/p/CW4A0sGJsYK/>.

activity are unfounded when compared to the other existing Tik Toks of abled-bodied people wearing or acting as lingerie ambassadors. Thus, it appears to be people reporting Darcy based on ableist and infantilizing assumptions, restricting her as a disabled creator.

Infantilization is a particularly dangerous tool used against people with disabilities under the claims of “protecting” them. Melanie argues that “infantilizing constructions have served as rationale for innumerable abuses, including forced sterilization, institutionalization, and euthanasia.”<sup>225</sup> Through being read as a “child,” the conflation of whiteness with innocence and disability with ableist presumptions of underdevelopment also come out. Discussing transgender children, Jules Gill-Peterson writes:

I agree that the child is a dehumanized social form, the product of historical and political processes of infantilization ‘designed to control various populations’ through sexual and racial difference, rather than to index meaningful age differences. As [Paul] Amar points out, one of the most pernicious effects of the production of children through infantilization is “a failure to recognize children as agents,” to render their lives politically informal—effectively unintelligible to adults.<sup>226</sup>

Through infantilization and being read as a child by social media users, Darcy is thus effectively being demoted to a space that is considered less fully human, underdeveloped, and pre-sexual. The dehumanization and lack of agency given to individuals with disabilities over constructing their own identity is due to an explicit type of governance over their bodily autonomy.<sup>227</sup> Highly problematic bioethicists, such as Joseph Fletcher and Peter Singer, who both contributed to eugenic and biopolitical movements, have argued that persons with severe cognitive disabilities

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<sup>225</sup> Yergeau, *Authoring Autism*, 190.

<sup>226</sup> Jules Gill-Peterson, *Histories of the Transgender Child*, (Minneapolis: University of Minnesota Press, 2018), 10.

<sup>227</sup> Kulick and Rydstrom, *Loneliness and Its Opposite*, 6.

are nonhumans or “nonpersons [that] lack moral status and human rights.”<sup>228</sup> The eugenics movement, further, portrayed people with disabilities as threats to the human race who must be “eliminated through sexually segregated institutionalization, involuntary sterilization, or euthanasia.”<sup>229</sup> The history of disabled people as infantilized and child-like is thus a long and well-established one that is clearly visible in the commentary on Darcy’s posts as well as in the shutting down of her Tik Tok account.

### **Shelby Lynch: Navigating Hypersexualization**

Like Darcy, Shelby Lynch (username @shelbykinsxo) has Spinal Muscular Atrophy and uses her social media platforms to advocate for disability representation. Lynch is a BIPOC social media activist, model, and influencer. Her platform focus is centered on educating her followers on ableist experiences she faces by discussing her insidious trauma openly. Lynch is invested in the fashion industry and creates a lot of content about new fashion trends, opinions on fashion and disability, and disability representation within the fashion world. While using Tik Tok as her preferred platform. Lynch, unlike Darcy, has never had her account removed or banned from the platform. But there are other problems Lynch confronts using Tik Tok as her main platform. For instance, Lynch navigates through being portrayed as inspiration porn, receiving aggressive hypersexualized comments about her body, and being insulted by remarks that align her to animality.

Although Tik Tok has attempted to centralize other disabled content creators and influencers, like Lynch herself, the platform treats Lynch with another form of ableism, and that is using her and her content as inspiration porn. Tik Tok published a creator spotlight on the

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<sup>228</sup> Stephen Drake and Diane Coleman, “Fact Sheet on Peter Singer” *Independent Living Institute*, 1999, [www.independentliving.org/docs5/singer.html](http://www.independentliving.org/docs5/singer.html)

<sup>229</sup> “Eugenics Archive,” Eugenics, [eugenicsarchive.ca/discover/tree/5233c3ac5c2ec50000000086](http://eugenicsarchive.ca/discover/tree/5233c3ac5c2ec50000000086).

creator, [username @shelbykinsxo]. In the spotlight, the article highlights how Lynch is shifting conversations around fashion and beauty. In the interview framing, Tik Tok approaches Lynch's content, voice, and goals as inspiration porn. In the beginning blurb, Tik Tok writes:

Shelby posts engaging and educational videos on what it is like to live with a disability. She doesn't shy away from tricky questions, and regularly offers advice about what her followers can do to support the disabled community and tackle ableism - **inspiring us all in the process!** From providing advice on how you can support Disability Pride Month to how to raise awareness about Spinal Muscular Atrophy, Shelby's aim is to educate the TikTok community and break down misconceptions around disability. She's recently taken her activism one step further and launched a petition to advocate for children to be educated on disability in schools and has been keeping her followers regularly updated on how she has been getting on. What a woman and **what an inspiration!** [emphasis added]<sup>230</sup>

Inspiration porn, as I outlined above drawing on Young, suggests that these types of narratives or portrayals are created to make non-disabled people feel better about themselves.<sup>231</sup> Lynch is aware of the fact that Tik Tok is spinning her story in this way. She created a video captioned “No I’m not inspirational for existing [laughing emoji] #disabilitytiktok #mylife #ableism.”<sup>232</sup> However, Lynch also believes that any coverage is better than none, so she takes the opportunity after her interview to create this video with that caption to use her platform as a reflective archive and track how she has responded to the insidious trauma at various points in her life. As

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<sup>230</sup> “Tik Tok Creator Spotlight @shelbykinsxo” *Tik Tok*, 2021, <https://newsroom.tiktok.com/en-gb/tiktok-creator-spotlight-shelbykinsxo>.

<sup>231</sup> Young, “I’m Not Your Inspiration.”

<sup>232</sup> Shelby Lynch [@shelbykinsxo]. (2021, November 15). *No, I'm Not Inspirational for Existing* [Video]. *Tik Tok* [https://www.tiktok.com/@shelbykinsxo/video/7030904060144291077?is\\_copy\\_url=1&is\\_from\\_webapp=v1](https://www.tiktok.com/@shelbykinsxo/video/7030904060144291077?is_copy_url=1&is_from_webapp=v1)

she is not afraid to address the grief in her life, in this video she splices together many other videos she has made and has a closed-captioned narration of her reflection. It says:

In high school boys used to pick on me quite a bit. One time a boy asked me really loudly in a lesson, “how do you get a bath?” Which was super embarrassing. Another boy in school referred to me as the “R” slur. That damaged my confidence. I wish I was more prepared for how ignorant people can be towards disability. Just so I could prepare myself more for the backlash I receive...when I was younger, I was aware I was disabled, but I never felt different to anyone else. Then I got older and realized that the rest of the world wasn’t as accepting of me. Because they are not used to seeing disabled people.<sup>233</sup>

In the same video, Lynch calls out the other names and things that were said about her or towards her including, “Piggy,” “You shouldn’t have children,” “Shark Teeth,” “Why are you still hot,” and “Voldemort.”<sup>234</sup> The bully name-calling and insinuations about her fertility or ability to be a mother are harmful and have haunted Lynch throughout her adulthood. The name calling is multifaceted trauma because it refers to multiple intersecting aspects of her identity. While the “you shouldn’t have children” desexualizes her, the animal references draw on histories of negative stereotypical images of Black people that emphasize criminality or immorality, and the “why are you still hot” hones into the hypersexualization of her body.<sup>235</sup>

As she mentions, people are not as understanding as she hoped they would be in the world. For instance, there are two moments I am referring to. The first one is when she says “that damaged my confidence” talking about the hurtful names people were calling her. The second suggests, “Then I got older and realized that the rest of the world wasn’t as accepting of me” as a

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<sup>233</sup> Ibid.

<sup>234</sup> Ibid.

<sup>235</sup> Jan Nederveen Pieterse, *White on Black, Images of Africa and Blacks in Western Popular Culture* (New Haven: Yale University Press, 1992).

response to a comment she received that reads “ugly af [laughing emoji].” One of the main ideas that she is presenting is the fact that she should not be considered inspirational for existing in her body. The microaggressions and bullying Lynch has faced have been the driving forces behind her platform as she focuses on “educating” young people about how to interact with a person with disabilities as she makes her presence known and other people with disabilities more present within the mainstream.

Lynch’s navigation through her own insidious trauma does differ from Darcy. Some of this has to do with the type of microaggressions, bullying, and reports that each influencer receives. Although Lynch does face a few desexualizing comments that she has created content on, she for the most part must handle *hypersexualized* comments. Hypersexualization like mentioned previously is the branding of some groups as excessively sexual.<sup>236</sup> Black people, in particular, have been stereotyped as hypersexual throughout the American eugenics movement as racist theories have developed in the past to “justify the enslavement of Africans,” to modern racial discrimination practices.<sup>237</sup> Further, hypersexualization has been used to justify the “rape of Black women, as well as the more commonly cited lynching of Black men.”<sup>238</sup> Importantly, desexualization and hypersexualization often go hand in hand, as “nonsexuality, hypersexuality, and sexual ‘perversions’” had traditionally been used as methods of social control.<sup>239</sup> Kristina Gupta, in her theorization of compulsory sexuality, suggests that “a socially marginalized group may be viewed as hypersexual or nonsexual, or as both at the same time” such as Black women and people with disabilities.<sup>240</sup> Moreover, Owen suggests that the compulsory sexuality between

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<sup>236</sup> Mikki Kendall, *Hood Feminism: Notes from the Women That a Movement Forgot* (New York: Viking, 2020), 96.

<sup>237</sup> Roberts, *Killing the Black Body*, 112.

<sup>238</sup> *Ibid*, 58.

<sup>239</sup> Gupta, “Compulsory Sexuality,” 141.

<sup>240</sup> *Ibid*, 141.

racess are distinct from each other—as mentioned earlier—whiteness is often aligned with asexuality and purity, while Black people are often aligned with hypersexuality and immorality, both of which are ideas perpetuated that reinforce the “white, abled-bodied, heteropatriarchal nation-state.”<sup>241</sup>

One example of a response to a desexualized remark is when she created a witty video using Lizzo’s song *Rumor*. Her closed captioning is, “Rumor has it disabled people have sex,” and then the beat drops to her nodding her head, smiling, and giggling. Her caption writes, “Omg I know the shock #ableism.”<sup>242</sup> As an example of a microaggression towards Lynch that focused on her hypersexualization, a user commented on a post, “You’re hot for a disabled person.”<sup>243</sup> Lynch, in her reaction video, rolls her eyes to indicate that obviously being disabled does not mean she cannot look hot, feel hot, or be hot as a person. Her caption is “Story of Our Lives.”<sup>244</sup> In another video, Lynch says, “when ableism is built into society ... you use humour and trends to educate the ables on disability through your social media platforms.”<sup>245</sup> Thus, Lynch is taking the microaggressions she continually receives and responding to them in reaction videos. These videos are oriented towards educating the public about misconceptions that are often received and perceived about her and disabilities in general. Additionally, Lynch’s favorite hashtag is #ableism, which links users to many other disability advocates and content creators who are doing similar work to deconstruct the ableism they come in contact with in their everyday lives. When we recall Owen’s writing on how whiteness is often aligned with asexuality, it is not

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<sup>241</sup> Owen, “On the Racialization,” 125; Przybylo, *Asexual Erotics*, 16.

<sup>242</sup> Shelby Lynch [@shelbykinsxo]. (2021, November 11). *Rumor* [Video]. *Tik Tok*  
[https://www.tiktok.com/@shelbykinsxo/video/7029389739924999429?is\\_copy\\_url=1&is\\_from\\_webapp=v1](https://www.tiktok.com/@shelbykinsxo/video/7029389739924999429?is_copy_url=1&is_from_webapp=v1)

<sup>243</sup> Shelby Lynch [@shelbykinsxo]. (2021, September 15). *You’re Hot* [Video]. *Tik Tok*  
[https://www.tiktok.com/@shelbykinsxo/video/7008202796474387717?is\\_copy\\_url=1&is\\_from\\_webapp=v1](https://www.tiktok.com/@shelbykinsxo/video/7008202796474387717?is_copy_url=1&is_from_webapp=v1)

<sup>244</sup> Ibid.

<sup>245</sup> Shelby Lynch [@shelbykinsxo]. (2021, September 21). *Humor* [Video]. *Tik Tok*  
[https://www.tiktok.com/@shelbykinsxo/video/7010774951040961798?is\\_copy\\_url=1&is\\_from\\_webapp=v1](https://www.tiktok.com/@shelbykinsxo/video/7010774951040961798?is_copy_url=1&is_from_webapp=v1)

surprising that Lynch navigates insidious trauma that has more to do with hypersexuality because of the various forms of institutional racism at play.<sup>246</sup> Lynch does not get reported for “minor safety” even though she is the same age and has the same disability as Darcy. Nor does Lynch get reported for “nudity and sexual activity” even though she, like Darcy, is a lingerie ambassador for Savage X Fenty. Although it is wonderful that Lynch’s representation and media presence is able to be circulated more freely because she is not reported for ableist, desexualizing understandings of disability, the distinct comparison between Darcy and Lynch goes to show that understandings of race and sexuality are still conflated with deeply problematic associations and stereotypes within the public third space, despite all the effort of disabled content creators to break down those barriers.

Besides Lynch’s content being displayed as inspiration porn by Tik Tok, attempting to break rigid hypersexualized associations, and combatting ableism from commenters, her advocacy for representation is strong. She creates her platform in a way that shows off her vivacious personality through showcasing her trendsetting fashion, multi-colored long hair, and hobbies. In a pinned Tik Tok video created on November 10, 2021, captioned “Dear @mollymaehague this my application to be a model for @prettylittlething,” she announces:

Here are the reasons you need more disabled people as models. There’s such a lack of representation of disabled models because we are literally everywhere. I feel like it’s so important for little girls and boys that are disabled who want to get into the industry to have someone to look up to and I would love to be that person. Also, there’s such a lack of like disabled bodies in the media anyway because disabled people love to buy clothes, so why would you not hire more disabled models? ... As you can see, I am wearing

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<sup>246</sup> Owen, “On the Racialization,” qtd. in Przybylo, *Asexual Erotics*, 16.

Pretty Little Thing right now, I'm wearing the Stassie dress that just came in and it's so cute. And I love it so much ... I think it's so important to have more disabled representation because as I said, disabled people are literally everywhere, going all aspects of life. We are the biggest minority, and we also like to spend money on clothes.<sup>247</sup>

Lynch is witty and calls attention to the obvious – disabled individuals are everywhere, and they need to wear and buy clothes. Her deduction thus is: why wouldn't they hire disabled models if they have clientele who are disabled? Lynch is carving representation quite literally into the fashion industry, calling out ableism within capitalist markets and the current limitations of fashion. By envisioning and becoming a model represented by Zebedee Talent located in the UK, Lynch's intermedial presence shifts viewers' understanding of disability and expands notions of what imagined futures people with disabilities can have.<sup>248</sup> Kafer writes, "How one understands disability in the present determines how one imagines disability in the future; one's assumptions about the experience of disability create one's conception of a better future."<sup>249</sup> Lynch is focused on how she is portrayed and represented in the present through her proactive videos, which call out the ableism she encounters day-to-day. By doing so, Lynch's platform works well to also call attention to the grief she has experienced in anti-ableist ways by giving her followers insight into her pain, resisting trauma porn or inspiration porn tropes.

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<sup>247</sup> Shelby Lynch [@shelbykinsxo]. (2021, November 10). *Dear @mollymaehague* [Video]. *Tik Tok* [https://www.tiktok.com/@shelbykinsxo/video/7028998810936282374?is\\_copy\\_url=1&is\\_from\\_webapp=v1](https://www.tiktok.com/@shelbykinsxo/video/7028998810936282374?is_copy_url=1&is_from_webapp=v1)

<sup>248</sup> "Who We Are," Zebedee Management, December 30, 2021, <https://www.zebedeemanagement.co.uk/copy-of-who-we-are>.

<sup>249</sup> Kafer, *Feminist, Queer, Crip*, 2.

## Conclusion

By breaking away from the angelic-innocent character, resisting hypersexualization, creating robust representation in new communicative media, and navigating grief in anti-ableist ways, Darcy and Lynch create realistic and robust models of facing insidious trauma for followers. Darcy and Lynch have successfully created spaces that critique mainstream representation of people with disabilities by pointing out the need for nuance, complexity, and variety in what appears in mainstream media. However, Darcy and Lynch's accounts are not the only grassroots activist social media accounts out there – they are merely two in a broad community of creators. Alice Wong runs both a blog site and Instagram account for the Disability Visibility Project, Gabe Adams-Wheatley manages his own Instagram and TikTok account discussing his queer life living as a bilateral amputee, and Selma Blair documents her multiple sclerosis journey on major news outlets and social media. These activists, among many others, are enacting models of representation that pay attention to grief and address the complexities that are often omitted in other linear grief models. In the next chapter, I will explore how grassroots theorizing creates spaces that diversify representation and encourage collective mourning by looking at the Disability Visibility Project (DVP), which spans across a website/blogsite, podcast, book, and social media platforms.

## CHAPTER IV: THE DISABILITY VISIBILITY PROJECT (DVP): INTERMEDIALITY AND COLLECTIVE GRIEVING

As I write, I am living through the COVID-19 pandemic wherein Americans have deeply distorted understandings of each other and what our communities need. The coronavirus disease (COVID-19) “is an infectious disease caused by the SARS-CoV-2 virus” which results in moderate to severe respiratory illness.<sup>250</sup> According to the World Health Organization, “older people and those with underlying medical conditions like cardiovascular disease, diabetes, chronic respiratory disease, or cancer are more likely to develop serious illness ... or die at any age.”<sup>251</sup> Tom Shakespeare, Florence Ndagire, and Queen E. Seketi write on how people with disabilities are differentially affected by the COVID-19 pandemic.<sup>252</sup> They say the effect on disability communities is greater because “the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social impacts of efforts to mitigate the pandemic.”<sup>253</sup> Thus, large percentages of the disability community are radically grieving from the COVID-19 pandemic that goes beyond the loss of life—but reaches into the fear of losing one’s own life, losing medical assistance or support, and even losing the freedom to connect and socialize as they please.

Further, the COVID-19 pandemic has radically altered our experience of grief for society in general.<sup>254</sup> Non-marginalized communities have had to cope with grief, loss, and changes since the COVID-19 pandemic has begun just like disability communities—as the disease has

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<sup>250</sup> “Coronavirus disease (COVID-19),” *World Health Organization*, 2022, [https://www.who.int/health-topics/coronavirus#tab=tab\\_1](https://www.who.int/health-topics/coronavirus#tab=tab_1).

<sup>251</sup> *Ibid.*

<sup>252</sup> Tom Shakespeare, Florence Ndagire, and Queen E. Seketi, “Triple Jeopardy: Disabled People and the COVID-19 pandemic” *The Lancet*, vol. 397.10282, 2021, 1331.

<sup>253</sup> *Ibid.*

<sup>254</sup> Johnathan Ishoy, “Coping with Grief and Loss – Mourning the Changes since COVID-19” *Purdue University*, 2022, <https://www.purdue.edu/caps/covid-19/coping-with-grief.html>.

affected and killed within nearly all populations, ages, bodies, and families.<sup>255</sup> However, mass death in our society has altered our grieving and mourning practices. Before, a person's life would be celebrated after their death with in-person parades, grandiose funerals, or long obituary posts.<sup>256</sup> Now, life celebrations and mourning practices occur via Zoom funerals, virtual memorials, or with small groups of people who are masking.<sup>257</sup> Although some virtual mourning practices can increase the accessibility for certain individuals to attend a mourning ceremony and grieve a lost one, there is a fundamental change to how we mourn in-person with others that are changing our social dynamics and connections. The overwhelming amount of deaths within the pandemic has also overburdened funeral homes, where sites had no choice but to cremate bodies instead of hosting casket burials amid the rising death toll.<sup>258</sup> The mass death, according to Hannah R. Stevens, Yoo Jung Oh, and Laramie D. Taylor, have perpetuated desensitization practices where people are displaying a "blunted" emotional response over time to images and stories of COVID-19 related deaths.<sup>259</sup> The desensitization to mass death is a privileged position to be in, as many individuals within the disability community do not have the privilege of being desensitized to the maleficent or deathly effects COVID-19 can have on their disabled bodies.<sup>260</sup>

Some people do not acknowledge or completely ignore the health crises the COVID-19 pandemic poses to the disabled, older adult, and immunocompromised communities. The

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<sup>255</sup> Ibid.

<sup>256</sup> John DiConsiglio, "New Mourning: How COVID is Altering the Way We Grieve," *GWTODAY*, 2020, <https://gwtoday.gwu.edu/new-mourning-how-covid-altering-way-we-grieve>.

<sup>257</sup> Ibid.

<sup>258</sup> Christopher J. Brooks, "Funeral Home Staff Overwhelmed by Waves of COVID-19 Deaths" *CBS News*, 2021, <https://www.cbsnews.com/news/covid-deaths-funeral-homes-overwhelmed/>.

<sup>259</sup> Hannah R. Stevens, Yoo Jung Oh, and Laramie D. Taylor, "Desensitization to Fear-Inducing COVID-19 Health News on Twitter: Observational Study," *JMIR Publications Advancing Digital Health & Open Science*, vol. 1.1, 2021.

<sup>260</sup> Emma Bubola, "As COVID rules lift, high-risk people feel 'our life and our freedom are not as important,'" *The Seattle Times*, 2022, <https://www.nytimes.com/live/2022/02/22/world/covid-19-tests-cases-vaccine#our-life-and-our-freedom-are-not-as-important-high-risk-people-in-england-react-to-the-rules-lifting>.

continual disregard given to marginalized, threatened communities at this time suggests that most Americans shy away from facing, discussing, and navigating grief as a collective—or the “ugly” that exists within the world.<sup>261</sup> Mia Mingus writes that disabled femmes must “move toward the ugly,” and further explains:

Not just the ugly in ourselves, but the people and communities that are ugly, undesirable, unwanted, disposable, hidden, displaced. This is the only way that we will ever create a femme-ness that can hold physically disabled folks, dark skinned people, trans and gender non-conforming folks, poor and working class folks, HIV positive folks, people living in the global south and so many more of us who are the freaks, monsters, criminals, villains of our fairytales, movies, news stories, neighborhoods and world. This is our work as femmes of color: to take the notion of beauty (and most importantly the value placed upon it) and dismantle it (challenge it), not just in gender, but wherever it is being used to harm people, to exclude people, to shame people; as a justification for violence, colonization and genocide.

By ignoring the pandemic as a public health issue, by not openly acknowledging the “ugly” truths of our current situation and the grief our current experiences have created, we are perpetuating political ostracization that continues to marginalize the marginalized. This makes what should be a collective effort into an individual issue.<sup>262</sup>

Disability activists have been strong advocates throughout the entire pandemic, calling attention to the hypocrisy and eugenic practices that America has continued to enact in the past

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<sup>261</sup> Mia Mingus, “Moving Toward the Ugly: A Politic Beyond Desirability” *Femmes of Color Symposium* Keynote Speech, Oakland, 2011, <https://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability/>.

<sup>262</sup> P. Sol Hart, Sedona Chinn, and Stuart Soroka, “Politicization in COVID-19 News Coverage,” *Science Communication*, Vol. 42.5, 2020.

few years towards the ill, elderly, immunocompromised, and disabled populations as institutions and politicians push towards “getting back to normal.”<sup>263</sup> The disability community is not a univocal population, so there are people within the disability community who see the benefits of abolishing mask mandates and returning to their sense of normalcy. For example, parents with children on the autism spectrum have argued for more flexible mask mandates, since masks can exasperate sensitivity issues.<sup>264</sup> Further, masks can be an obstacle for individuals within the Deaf and Hard-of-Hearing community as face masks take away the ability to see lip-movement and facial expressions, which affect the Deaf and Hard-of-Hearing community’s verbal communication.<sup>265</sup> The masks, in these contexts and others, have been argued to foster inequitable learning environments for the reasons cited above.<sup>266</sup> However, many disability advocates recognize that masking, although inaccessible accommodations for some, should be adhered by the greater public to reduce the spread of the COVID-19 virus and ultimate death toll. For instance, Adam Hubrig is an English professor at Sam Houston State University who has autism and other disabilities and writes:

This messaging—meant to encourage a return to normal and apparently meant to comfort nondisabled people—is the real sting of this constant refrain of “people with comorbidities” rhetoric. I have been told, almost daily since the earliest stages of this pandemic, that it’s only *people like me* that are dying, that *people like me* are somehow a completely acceptable sacrifice for “the economy” and a “return to normal.” What should

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<sup>263</sup> Adam Hubrig, “Disabled Deaths Are Not Your ‘Encouraging News’” *Disability Visibility Project*, 2022, <https://disabilityvisibilityproject.com/2022/01/26/disabled-deaths-are-not-your-encouraging-news/>.

<sup>264</sup> “The Challenge of Face Masks,” *Organization for Autism Research*, 2020, <https://researchautism.org/the-challenge-of-face-masks/>.

<sup>265</sup> Lindsay Saltsman, “How COVID-19 Impacts the Deaf & Hard-of-Hearing Community,” *Health Hive*, 2020, <https://hive.rochesterregional.org/2020/10/covid-impact-on-deaf-community>.

<sup>266</sup> Julia H. Kaufman and Melissa Kay Diliberti, “Divergent and Inequitable Teaching and Learning Pathways During (and Perhaps Beyond) the Pandemic,” *Rand Cooperation*, 2021.

be read as a profound failure of national policy to protect the most vulnerable among us is being repackaged as “encouraging news.”<sup>267</sup>

The desperation and frustration apparent within Hubrig’s writing shares sentiment with many other disability advocates, writers, and content creators.<sup>268</sup> Having historically been institutionalized, marginalized, and not taken seriously, most of the disabled community of America is angry.<sup>269</sup> In the last chapter, I discussed online disabled activism on social media as a site for grassroots activism which acts as a liminal location for people with disabilities to create and theorize their lived experiences and how they face insidious trauma. I focused on how individual disabled content creators navigate their insidious trauma. In this chapter, I will focus on how the collective interacts with the public third space—such as how groups of people with disabilities are forming in the third public space to navigate collective trauma, form communities, and critically mourn.

I will be discussing how the Disability Visibility Project’s (DVP) intermedial nature facilitates disabled content creators’ paratextual community advocacy work. I will first introduce intermediality and how it affects disability representation within the DVP. I will then introduce and expand upon Sam Durrant’s model of critical mourning to suggest that the content disabled activists share, the community that is being built, and the ways in which representation is curated through the DVP, encourage a form of critical mourning. I will be paying particular attention to the intersections between critical mourning, collective care, and crip time, using works written

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<sup>267</sup> Ibid.

<sup>268</sup> Marisa Kabas, “Disabled Americans Feel Abandoned by CDC. Now, CDC is Desperate to Make Amends,” *Rolling Stone*, 2022, [https://www.rollingstone.com/politics/politics-news/covid-cdc-disability-comorbidity-anger-1282759/?sub\\_action=logged\\_in](https://www.rollingstone.com/politics/politics-news/covid-cdc-disability-comorbidity-anger-1282759/?sub_action=logged_in); Abigail Abrams, “‘This is Really Life or Death.’ For People with Disabilities, Coronavirus is Making It Harder Than Ever to Receive Care,” *Time*, 2020, <https://time.com/5826098/coronavirus-people-with-disabilities/>.

<sup>269</sup> Matthew Green and April Dembosky, “‘So Angry, So Scared’: California COVID-19 Vaccine Rollout Change Leaves Disabled People Behind, Say Advocates,” *KQED*, 2021, <https://www.kqed.org/news/11857538/so-angry-so-sad-so-scared-disability-advocates-say-states-new-vaccine-rollout-plan-leaves-them-behind>.

and posted or published through the DVP. I will then refer to how disabled content creators within the DVP are shifting grief models by analyzing the collective grieving that the DVP facilitates and promotes. I end by expressing how this particular project acts as a model for future community advocacy projects that seek to challenge problematic disability representations.

### **Intermediality, Paratext, and the Disability Visibility Project (DVP)**

The DVP is an online community that is dedicated to centering disability media and culture and collects stories and content created by and for people with disabilities. The DVP is significant because the stories the project collects brings nuance to disability representation, as disabled experiences vary between individuals—even individuals with similar disabilities. Further, the DVP aims to make safe spaces for other disabled individuals to share their own experiences and stories. The DVP is intermedial in nature, meaning the project suggests an attunement to the ways various mediums blur online and offline boundaries.<sup>270</sup> DVP is housed on a central website that operates as a blog site, where disabled narratives can be published on the website as essays, reports, or blog posts, and as an oral archive—such as sharing disabled narratives through StoryCorps, podcasts, and videos—while also creating intercultural communities on various social media platforms such as Instagram [@disability\_visibility] and Twitter [@DisVisibility]. Additionally, Alice Wong, the founder and director of DVP, is a disabled activist, writer, media maker, consultant and editor who has spinal muscular atrophy. Wong is known for her activism for access and representation for people with disabilities. As the founder of DVP, she has published two anthologies as an addition to the paratextual community the project encompasses. The DVP works to introduce main ideas that are important to the

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<sup>270</sup> Przybylo, “Rainbow Mary,” 112.

disability community, such as collective-care and crip time. The anthologies also include themes of mourning which notice the difficult intersections between grief and mourning, disability, and insidious trauma, and what it means to represent these heavy terms.

The DVP works to introduce, explain, and expand upon these terms through their intermedial presence. Klaus Bruhn Jensen writes, “intermediality represents the combination of separate material vehicles of representation, as exemplified by the use of print, electronic, and digital platforms in a communication campaign.”<sup>271</sup> Further, intermedial practices can take the form of feminist and queer protest, such as when Ela Przybylo writes on Polish trauma in regard to homophobia and transphobia, suggesting that intermediality embodies “action and the fluid movement of protest symbology between online and offline public spaces.”<sup>272</sup> When analyzing the DVP’s reach into the disability community, discussing the intermedial nature of the project will help trace how individuals’ stories that discuss grief are transforming into a form of public mourning that essentially is a form of grassroots activism—having anti-ableist messages being represented, socialized, consumed, and disidentified with both online and offline.<sup>273</sup>

This is essential when we also discuss how disability advocates navigate insidious trauma within intermedial platforms, because “trauma does not originate in the bodyminds of the individuals or populations who live with trauma, but rather in the social structures that unequally distribute life changes and resources toward a livable life. Trauma is more likely to reach those who are marginalized.”<sup>274</sup> Importantly, the DVP works to break the hegemonic hold white narratives have had within popular disability discourse by centering grief attuned to traumatic discrimination voiced by BIPOC, queer, and disabled folks. Angela Carter suggests, “if we want

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<sup>271</sup> Jensen, “Intermediality,” 1.

<sup>272</sup> Przybylo, “Rainbow Mary,” 112, 109.

<sup>273</sup> Muñoz, *Disidentifications*.

<sup>274</sup> Carter, “When Silence Said Everything.”

to better the lives of traumatized people, we need to focus our efforts on changing the social structures and cultural ideologies surrounding trauma and its healing processes.”<sup>275</sup> I believe the DVP, as an intermedial platform focusing on disabled marginalized voices, is doing work to change social structures and combat harmful cultural ideologies surrounding trauma by focusing on collective mourning practices that channel grief in anti-ableist ways.

The DVP writes, “the Disability Visibility Project is an online community dedicated to creating, sharing, and amplifying disability media and culture” and further “Believes that disabled narratives matter and that they belong to us... Builds online spaces for people to share and connect.”<sup>276</sup> The website serves to be the main host, of which hyperlinks to StoryCorps, Twitter chats, various campaigns—such as #CriptheVote or #AccessIsLove—and are used to connect the DVP to other active sites where community members are connecting with one another.<sup>277</sup> The construction and intermediality of DVP is important for the paratextual community advocacy work that is occurring within the project space. Gérard Genette defines the paratext of a literary work or project as the things that reinforce or accompany the main text, “like an author’s name, a title, a preface, illustrations” that “one does not always know if one should consider they belong to the text or not,” but their existence is to “present” the text, and their presence affects the reception and consumption of that text in the world.<sup>278</sup> When we think about the DVP, the intermedial nature of the project relies on the paratext to function. The paratext for the DVP specifically would be the diverse number of authors—who provide bios—the links shared openly throughout the various involved platforms, or even the images and

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<sup>275</sup> Ibid.

<sup>276</sup> Ibid, “About,” <https://disabilityvisibilityproject.com/about/>.

<sup>277</sup> Ibid.

<sup>278</sup> Gérard Genette and Marie Maclean, “Introduction to the Paratext” *New Literary History*, vol. 22.2, 1991, 261.

advertisements for community events that occur in person or via zoom. For the DVP, moreover, the paratext functions in a way that builds an activist community that ties these activist movements back to the DVP. Activists, writers, politicians, content creators featured and shared on the DVP are therefore all a part of the paratextual community advocacy work that the DVP facilitates.

An example of the paratextual community advocacy work that occurs within the DVP involves recent writings, tweets, blogs, and podcasts about the COVID-19 pandemic. As of January 2022, at the top of the website is a huge link to the page High-Risk Pandemic Stories: A Syllabus.<sup>279</sup> The site is a conglomeration of various texts written by many disabled individuals collected in one spot. The site proclaims:

Disabled, fat, older, poor, immunocompromised, and chronically ill folks have been oracles well before this global public health disaster and continue to this day as institutions and leaders treat marginalized communities as disposable. With the Disability Visibility Project, I feel a keen urgency to publish as many pieces about the pandemic because our perspectives and warnings are not heeded ... I resent the implication that we have to prove our value and reveal our traumas in order to be seen as human and worthy of 'care.'<sup>280</sup>

The page itself links the intermedial projects that discuss living and grieving in a pandemic-filled world as BIPOC, queer, disabled folks—and how to navigate the grief as well. There are connections to social media posts on Twitter, collections of stories and blogs made on DVP, other sources such as “The Access Issue” for *Bitch Media*, DVP Interviews, DVP Podcast

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<sup>279</sup> “High-Risk Pandemic Stories: A Syllabus” *Disability Visibility Project*, 2022, <https://disabilityvisibilityproject.com/2022/01/09/high-risk-pandemic-stories-a-syllabus/>.

<sup>280</sup> *Ibid.*

episodes, and articles written both by Alice Wong and other disability advocates. This main page with the hyperlinks attached functions to provide a collective, coalitional approach to protest the injustices made by people or institutions in regard to the COVID-19 pandemic. In reality, the page is enacting Margaret Price’s vision of coalitional futures within disability politics: “an attempt to signal a belief in potentiality and flexibility, an effort to occupy a more ‘contestatory’ space that merges activist and academic work” and further build coalitions across disability categories.<sup>281</sup>

One post hyperlinked I find intriguing—both because of its contestatory nature, but also because of the supportive framework it creates—is the thread that Kaayln, a queer, disabled artist, scientist, altruist, and activist who we know through their twitter handle @rollwthepunches and nickname Hell on Wheels, had written entitled “What the Disabled Community Offered the World this Past Year.”<sup>282</sup> I’ve included some of the things they’ve mentioned below:

- New members of the disability and chronic illness community widely known as ‘long haulers.’ We are here and were always here.
- Honest, raw conversations about death or hospitalization.
- Tips, commiserations and resources to navigate healthcare and insurance.
- Dark humor; relief knowing it could be worse.
- Infinite coping strategies and realistic tools for incapacitating isolation, depression, anxiety, and knowing the system will not protect you.
- Hospital and ER survival guides! (both in the fun way AND literal way)
- Tips on how to best support a sick loved one in your life.
- Often giving lifesaving instructions on using an IV pump, insulin, feeding tubes, oxygen, central lines, catheters, etc. for either yourself or a loved one bc Home Care was canceled, denied, unsafe, not set up yet, or the edu was just skipped altogether in the hospital crises.
- Resources, links, psycho-ed, numbers, etc. for dealing w/ trauma alone. So. Much. Trauma.<sup>283</sup>

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<sup>281</sup> Margaret Price, “The Bodymind Problem and the Possibilities of Pain” *Hypatia*, vol. 30.1, 2015, 270.

<sup>282</sup> Kaayln [@rollwthepunches], “What the Disabled Community Offered the World This Past Year,” 2021, <https://twitter.com/rollwthepunches/status/1370211503207559177>.

<sup>283</sup> Ibid.

Although many points within the thread attempt to create a light-hearted tone showing the dark humor they mention, the specific points centered on grief I've selected are pointed to how the disabled community has embraced and welcomed the non-disabled community to their reality and grasp of the world. Further, having this Twitter thread attached to the DVP increases the paratextual community advocacy that the DVP is trying to convey about the COVID-19 pandemic—such as stressing the importance of listening to COVID-19 safety guidelines for the sake of keeping the disabled and immunocompromised safe. Moreover, the rawness needed in discussing death, grief, and medical institutionalization has always been extraordinarily important topics that are breached by grassroots activists such as Kaayln in ways that are readily accessible in mainstream culture and promoted by sites and disabled communities like DVP.

### **Disabled Content Creators and Critical Mourning**

Since the DVP is building a community to discuss grief openly, it is important to discuss the intricacies of the representation of grief and mourning. As I discussed in the introduction, grief and mourning have traditionally been analyzed separately. Grief is associated closely with internalized feelings, such as the sadness or loneliness one may feel.<sup>284</sup> On the other hand, the process of mourning has been recognized to be the externalized actions that people do to show their grief.<sup>285</sup> What hasn't received much attention is how grief and mourning interact, especially when it comes to the new digital age and how new media communications alter our understandings of grief and our processes of mourning. I propose that the DVP exemplifies a site where grieving and mourning can occur simultaneously and encourages collective consciousness/collective mourning that subverts expectations of the mourning process. For

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<sup>284</sup> Poinier "Grief and Grieving."

<sup>285</sup> Stephenson, *Death, Grief, and Mourning*.

instance, a person with disabilities who shares a blog post discussing their insidious trauma could use the creative process of writing to grieve and process those internalized feelings. At the same time, uploading and circulating those same posts into a community is an act of mourning that cultivates a critical consciousness by unveiling insidious trauma.

My line of inquiry expands upon Andi Schwartz' work on online subcultures and how the digital space is disrupting traditional processes for mourning. Schwartz suggests that a site that allows for trauma to be narrated and heard—without objectification or further traumatization—is “online femme mourning,” such as Twitter, which “encompasses a social critique, and employs (and encourages) selfies and other behavior typically considered incongruent with the affects of death.”<sup>286</sup> Disrupting traditional mourning processes deemed fit by westernized white societies to account for other contexts, such as posting selfies alongside a grieving blog instead of wearing black and keeping a sophisticated front, may be an act of critical mourning as well. The upsetting of expectations through talking or sharing may become just as powerful as not speaking to alter the temporality of grief and process of mourning if silence is expected. Like Schwartz's analysis of bringing ugliness and digital media to the forefront with the mourning process, I contend that when it comes to disability contexts on the DVP platform, a similar mourning process is being implemented where disability activists and writers are upsetting societal expectations by attuning to grief in their content, as speaking of grief in disability contexts have been traditionally taboo.

Further pushing towards upsetting expectations, I critique Sam Durrant's theory of critical mourning.<sup>287</sup> Durrant explains critical mourning as “a mourning that works to undo not simply the idea of the sovereign subject” but sovereignty itself, property relations, and the human assumption of sovereignty over nature” towards a more shared consciousness of

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<sup>286</sup> Schwartz, “Put on All Your Make-Up and Cry,” 79.

<sup>287</sup> Durrant, “Undoing Sovereignty,” 94.

mourning.<sup>288</sup> The collective consciousness of mourning is the aspect of his theory that I have attached to and apply to disability community contexts. However, Durrant refers to critical mourning to embody substitution and abstraction—or the refusal to talk about one’s trauma—as a form of slowing down to avoid the perpetuation of trauma porn or objectification when processing grief.<sup>289</sup> Within this refusal is where the collective consciousness is found. He writes, “the very corporeality of the testifiers becomes their testimony; grief takes on material weight that, precisely because it remains un verbalized, resists abstraction and thus instrumentalization.”<sup>290</sup> Durrant suggests the weight of the traumatized individual’s silence is embodied and that corporeality itself resists being turned into a trauma porn subject ready to be objectified. Durrant is suggesting that to force a traumatized individual to divulge their story defeats the purpose of salvaging the witness from further trauma. To instead refuse to speak, in this context, may suggest a more powerful resistance to being objectified. In fact, refusal to speak purposefully pushes against the temporal process of grief expected by society.

I agree with Durrant’s assessment that to critically mourn means to purposefully upset the temporal order of divulging trauma—as in give the opposite response to what certain onlookers are desiring. For example, Carter writes, “as an audience, they seem to want or even need a call and response. Audiences demand a particular kind of trauma narrative, trauma performance, wherein trauma is presented as devastating chaos that is ultimately overcome.”<sup>291</sup> On the other hand, when the expectation is that marginalized BIPOC, disabled, or queer individuals would remain silent, I argue that to critically mourn would be to speak up instead of remaining silent.

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<sup>288</sup> Ibid, 94.

<sup>289</sup> Ibid, 104.

<sup>290</sup> Ibid.

<sup>291</sup> Carter, “When Silence Said Everything.”

David Eng and Sinhee Han make visible the politics of loss and mourning when it comes to racialized communities.<sup>292</sup> I argue that Eng and Han’s focus on assimilation in their work is a useful contribution to critical mourning seen in disability communities like the DVP. In dialogue with Freudian concepts, Eng and Han suggest:

Freud’s theory of melancholia provides a provocative model to consider how processes of assimilation work in this country and how the depression that characterizes so much of our contemporary culture at the turn of this century might be thought about in relation to particularly marked social groups. In the United States today, assimilation into mainstream culture for people of color still means adopting a set of dominant norms and ideals—whiteness, heterosexuality, middle-class family values—often foreclosed to them. The loss of these norms ... a series of failed and unresolved integrations.<sup>293</sup>

Eng and Han’s premise of assimilation—that suggests particular social groups must enact certain heteronormative and economic standards to pass within the mainstream—apply to the socio-political barriers often presented to individuals with disabilities as well. Further, Eng’s and Han’s focus on the collective over the individual is purposeful to form “intellectual, clinical, and political coalitions.”<sup>294</sup> I argue, by focusing on the collective, there is a push against assimilation into the mainstream, to instead tread new paths of inclusion that don’t adhere to heteronormative, able-bodied narratives. Thus, the way I see critical mourning being used within the DVP suggests that the writers, activists, and content creators who are discussing grief openly are not trying to assimilate their experiences, but rather show the variety of experiences that do exist in

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<sup>292</sup> David Eng, and Shinhee Han, “A Dialogue on Racial Melancholia” in *Loss the Politics of Mourning* by David Eng, David Kazanjian, and Judith Butler, (Los Angeles: University of California Press, 2003).

<sup>293</sup> Ibid, 344.

<sup>294</sup> Ibid, 344.

the world. By doing so, the DVP as a collective becomes critical mourners for ableist, insidious trauma—their mourning, acting in a way to call attention to their lived experiences.

### **Collective-Care and Critical Mourning within the DVP**

To dive more deeply into what it means to have an intermedial project encompass my particular use of critical mourning, I will look at the paratextual community advocacy work that the DVP has through its anthology’s visionary whole, website construction, and social media reach. The DVP started off as a website in 2014. The stories collected and shared within the online community were so successful that two print anthologies were created to discuss some stories originally online in 2020. I start with the anthology *Disability Visibility: First-Person Stories from the Twenty-First Century* because Alice Wong, founder of DVP and editor of the collection, selected the stories as representative models that discuss major theorization that are occurring on the grassroots level. I first introduce how the anthology is broken into specific sections and then discuss a collective-care example introduced in A.H. Reaume’s story “Why My Novel is Dedicated to My Disabled Friend Maddy,” as an example of the advocacy work that is occurring through the anthology.<sup>295</sup>

I contend that, within the anthology, we are specifically being exposed to more theorization on collective-care, temporality, and critical mourning when it comes to grief—and the selected stories showcased within the anthology are just the starting point for people more curious about learning more of the disability experience. The anthology, a physical book, also has elements of digitalization as the accessible e-book version being sold online. The physical or virtual copy, nonetheless, both become sites where recorded stories are being told in ways that

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<sup>295</sup> A.H. Reaume, “Why My Novel is Dedicated to My Disabled Friend Maddy,” in *Disability Visibility First-Person Stories from the Twenty-First Century* by Alice Wong, 2020.

implement Wong’s vision of “visibility” subverting the historical marginalization and invisibility of BIPOC, queer, and disabled folks.

The book is broken into four parts: Being, Becoming, Doing, and Connecting. The stories I have selected analyze and discuss grief and are part of the latter half of the book, the sections on “Doing” and “Connecting.” It seems Wong purposefully put the handling of grief in these sections because each story that grieves is theorizing ways to enact action or connect with others that perpetuate the sense of a collective critical mourning. The start of the anthology grants authority to BIPOC, queer, and disabled voices by showing unapologetic disabled joy, or the ways in which people have learned to live “being” and “becoming” with their insidious trauma. The “Doing” and “Connecting” sections, moreover, become more concrete in their call-to-action for readers that go together with the collective-care models that are becoming more prominent within grassroots activist communities.

The first story in the section “Doing” is from A.H. Reaume, who writes about how her deep connection to her friend Maddy began from bonding over having similar brain injuries, and having a connection built from the pain and loss that they’ve both experienced.<sup>296</sup> Reaume writes:

There were often tears, but there was also so much understanding, love, and care extended between us. I felt seen in ways I hadn’t felt seen since my injury. Maddy would take all the hurt parts of me and just hold them. She wouldn’t try, like everyone else, to force me to make sense or order out of them until I was ready. She knew what it was like to lose. She also knew what it was like to come back—but in a different body. A brain injury is a particularly hard injury to have because it changes who you are in ways that

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<sup>296</sup> Ibid.

other injuries don't, since it affects how you think, act, and respond. It's hard to talk about that loss and grief with people who have never experienced it."<sup>297</sup>

Reaume is commenting on the collective care and care work that her friend and herself employ towards one another. Reaume had gained Maddy's editing services, while Maddy, who was seeking work, now found an accommodating and flexible job. Part of this collective care modeled friendship she had stumbled into was finding solidarity with a person who could discuss loss and grief in an anti-ableist way, where she could be honest about how she was feeling. Reaume admits that she was "facing ableism in a lot of areas of my life on top of grieving all the things that my injury had taken from me," and that she "often [felt] dragged down by the struggle. Or you don't have the emotional energy to work on anything difficult."<sup>298</sup> Going beyond the care that Maddy provided, Reaume also writes that the connection between them is:

a kind of love that I hadn't known existed before my disability. It's fierce and patient and tender and rare. It's what disabled people give one another because we wish the able-bodied world had given it to us. It's tinged with grief and pain—and also with defiance. It's gentle and it's incredibly kind."<sup>299</sup>

This grief-tinged care and love Reaume describes is a beautiful description of the kind of care work that Piepzna-Samarasinha discusses.<sup>300</sup> Moreover, Reaume is using her story to share what Shayda Kafai suggests: "we tell our stories as a way to speak for our bodyminds. With these stories we create new routes and new maps back to ourselves."<sup>301</sup> In "finding" her way to herself beyond the loss her brain injury has inflicted, Reaume concludes her writing by suggesting that

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<sup>297</sup> Ibid, 199.

<sup>298</sup> Ibid.

<sup>299</sup> Ibid, 200.

<sup>300</sup> Piepzna-Samarasinha, *Care Work*.

<sup>301</sup> Kafai, *Crip Kinship*, 71.

her story is “complex” and that her disability is “always present and painful” but laced with powerful disabled interdependence.<sup>302</sup> By refusing to eliminate or eradicate the grief within her story, Reaume is continuing to build robust representative models for readers that show it’s okay to be vulnerable and feel not okay, thus, showing these feelings can still be shown and still resist ableist stereotypes or tropes. Moreover, her writing enacts a call-to-action for the readers to adopt into a collective consciousness that is aware of the overwhelming ableism in the world, but also of the ways in which ordinary people can break down those barriers.

### **Crip Time and Critical Mourning within the DVP**

When discussing grief, one theme prominent in past scholarship is the focus on temporality.<sup>303</sup> Often, scholars point to a person’s sense of lost or disoriented time when grieving. The rejection of linear time when one grieves is powerfully aligned with disability scholarship’s idea of crip time. Alison Kafer defines crip time as involving “an awareness that disabled people might need more time to accomplish something or to arrive somewhere.”<sup>304</sup> Thus, temporality of a person grieving and crip time rejects linear, constrictive timelines that are societally constructed. Further, when we look at digital spaces, such as the DVP, grief and mourning are occurring simultaneously, pushing more against linear timelines. Margaret Price, writing on crip spacetime, describes the intersection between the space and time a person inhabits and suggests each person’s spacetime is unique and is constantly fluctuating depending on their day-to-day encounters with the world.<sup>305</sup> Carter expands upon Price and suggests there is

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<sup>302</sup> Ibid, 205.

<sup>303</sup> Constantin Mehmel, “Grief, Disorientation, and Futurity,” 2021; Katherine Kenny, Alex Broom, Emma Kirby, “In One’s Own Time: Contesting the Temporality and Linearity of Bereavement,” *Health: Interdisciplinary Journal for the Social Study of Health and Medicine*, vol. 23.1, 2017; Dan P. Mcadams, “The Problem of Narrative Coherence” *Journal of Constructivist Psychology*, vol. 19.2, 2006; Paul Ricoeur, *Time and Narrative Volume 3* (Chicago: The University of Chicago Press, 1990).

<sup>304</sup> Kafer, *Feminist, Queer, Crip*, 26.

<sup>305</sup> Price, “Toward a Theory of Crip Spacetime.”

room to also discuss trauma spacetime that “illuminates the normative assumptions and regulatory mechanisms placed upon bodyminds,” as a person living with crip spacetime may not be able to disengage from trauma spacetime.<sup>306</sup> Carter’s suggestion here directly connects critical disability lenses to critical trauma studies, which is useful to keep in mind in how these intersections inform mourning practices. In another story within the DVP anthology, Ellen Samuels writes:

Crip time is time travel. Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings ... But we who occupy the bodies of crip time know that we are never linear, and we rage silently—or not so silently—at the calm straightforwardness of those who live in the sheltered space of normative time.<sup>307</sup>

There is a suggestion here that adhering to crip time can make disorienting grief more palatable, or the more cliché saying, being okay with not being okay—just like in Reaume’s writing. Being forced to live in compulsory heteronormative, sexual, and able-bodied spaces that encourage the linear progress forward creates little to no space to find alternative ways to connect to others. Further, a connection to the surrounding world in this linear fashion is strained when time does not feel or work that way in chronically ill and disabled bodies. Further, Samuels refers to her own young age and how her chronic pain and illness have placed her oddly in disjunction with her own bodily ability and closely tied to others more advanced in age. In her interactions with elderly people, Samuels is raw and honest about her grief about having a

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<sup>306</sup> Carter, “When Silence Said Everything.”

<sup>307</sup> Ellen Samuels, “Six Ways of Looking at Crip Time,” in *Disability Visibility First-Person Stories from the Twenty-First Century* by Alice Wong, 2020, 242-243.

numerically young-aged body but feeling anything but. She exasperates after micro-aggressive comments of her being in a water aerobics class:

I hate them when, after demanding my bodily narrative, they give me their own: how they've finally had to give up cross-country skiing at age sixty-two, how frustrating it is they can't go hiking anymore. I hate them for their decades of proper health, for their unconscious privilege, for the fact that only in older age are they contending with not being able to hike or bike or knit or whatever it is they're talking about as they move in their little companionable knots around the pool. I know that I'm being unfair. I know that I know nothing about their lives, what they may have lost. So, I keep my rage inside. I keep my grief inside.<sup>308</sup>

Samuels admits here that she understands it is unfair to judge another's body or story, and to do so is ableism in action. Despite feeling all the rage, anger, and grief about her own situation, Ellen channels her rage into her story, to share publicly in a way that does not harm anyone she's interacted with. The significance here, however, is that Samuels admits publicly that she does feel this way sometimes, and that is a fact that is often overlooked or written out of narratives that are easily accessible within popular culture. There is a fear of being ageist or ableist within these feelings. However, Samuels shows us that once a person admits to having these raw feelings in moments of grief, they can still act in anti-ableist ways. Even if that means hiding their own grief and reactions to insidious trauma momentarily and sharing later in more helpful ways.

Samuels is further theorizing that "Crip time is grief time. It is a time of loss and of the crushing undertow that accompanies loss."<sup>309</sup> This suggests that people who experience and

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<sup>308</sup> Ibid, 243.

<sup>309</sup> Ibid, 244.

embody crip time may have fruitful wisdom when it comes to grieving and mourning. I posit that since crip time and time for grieving challenge linearity, there is potential for overlap between the two processes of grief and mourning, such as the temporal challenge that grief and mourning can occur together but work on two separate spheres or worlds—meaning if an individual shows their grief through writing, the posting of the same writing could be part of the mourning, or vice versa. Samuels continues to write and refer to the Freudian terms “normal mourning” that refers to mourning that comes to a typical end without any intervention and “melancholia” which is the illness of mourning that has no end, where the bodymind refuses to let go of the “lost object” and “deforms itself in the process.”<sup>310</sup> Freud’s understanding of melancholia is often aligned with today’s medical understanding of prolonged grief disorder.<sup>311</sup> However, the distinction between normal mourning and melancholia becomes deeply problematic when the grief that is being actively mourned is structural in nature—such as grief stemming from intergenerational and insidious trauma people with disabilities face. When it comes to anti-ableist grieving about one’s own disability and trauma, Samuels further proves that both can co-exist in anti-ableist means. In reflection, she says:

What I have found much harder to let go is the memory of my healthier self. With each new symptom, each new impairment, I grieve again for the lost time, the lost years that are now not yet to come. This is not to say that I wish for a cure—not exactly. I wish to be both myself and not-myself, a state of paradoxical longing that I think every person with chronic pain occupies at some point or another. I wish for time to split and allow two paths for my life and that I could move back and forth between them at will.<sup>312</sup>

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<sup>310</sup> Ibid, 244; Sigmund Freud, *Mourning and Melancholia* (London: The Hogarth Press, 1918), 255.

<sup>311</sup> Alexander H. Jordan and Brett T. Litz, “Prolonged Grief Disorder: Diagnostic, Assessment, and Treatment Considerations” *Professional Psychology Research and Practice*, vol. 45.3, 2014, 180-187.

<sup>312</sup> Ibid, 244.

With long histories of eugenic discrimination and intergenerational and insidious trauma, people with disabilities are publicly sharing avenues and representational models to handle grief. This is seen in Samuels’ writing, where there is a dichotomy that exists in relation to disability that needs to be discussed and talked about—and the more that it is, the more representational models are created for others to disidentify with. More representational models emerging that discuss disability, insidious trauma, and grief have become apparent during the COVID-19 pandemic that emerged in the United States in 2020, in which the disability community is still fighting to be seen and heard, especially amid the Omicron variant that spread rapidly at the beginning of 2022.<sup>313</sup> The wisdom from disabled people on grief has proved to be substantial within these times and has been collected by intermedial disabled communities, such as the DVP. On the DVP website, we are connected to a myriad of advising voices that champion themselves on subverting expectations of what it means to grieve and critically mourn. These voices build various categories of text that create a living, breathing, and changing space to interact and react to the political, social, and economic structures that they are held against.

### **Models of Grief within the DVP**

The COVID-19 pandemic has proved that disabled lives are intricately tied to the political/relational systems that have infrastructurally suppressed their wisdom, advice, and brilliance. For instance, the pandemic has shown that models of grief created by people with disabilities are often only paid attention to for the sake of improving non-disabled lives. I would like to highlight now how the DVP centralizes and diversifies voices on their website through their blog in other matters of grief, which though they are not localized on the COVID-19 pandemic still provide fruitful insight on what it means to collectively grieve and how to handle

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<sup>313</sup> “Omicron Variant in the United States” *Centers for Disease Control and Prevention*, 2021, <https://www.cdc.gov/coronavirus/2019-ncov/variants/omicron-variant.html>.

the intergenerational and insidious trauma experienced in day-to-day life as a BIPOC, queer, disabled individual in America.

Each of the blog posts on DVP that I discuss here also are actively forming their own theories on how to handle grief in anti-ableist ways, whether that appears as advice, opinion, or representational model for other people through story. In Allison Masangkay's "We Must Reimagine Ourselves," blog post on the DVP website, she discusses her chronic pain and fatigue and her handling of the depression and grief, which she has faced throughout her life.<sup>314</sup> When her partner died by suicide, Masangkay discusses the emotional toll and aftermath of her grief. She writes:

A week after A\* took her life, I bought two donuts and ate them by myself. It was the best way I could honor my lost love, as our relationship largely remained a secret. The world doesn't approve of two queer brown femmes publicly in love. Licking the last of the chocolate glaze off my fingers, she didn't feel too far away. I drove to the closest park to greet the trees before it was supposed to rain. No more than 10 seconds before the first raindrops fell, a murder of crows circled around me as I cried and cried and cried... "Am I the only one who jumped up in the air as a kid and then, like, never came down? Like, I was floating and just had my legs swinging." I wait for a response from my college classmates. I have a Budweiser can in my right hand, hovering over my two previous ones. We've agreed to wash out my grief with alcohol on the last night of our final spring quarter together.<sup>315</sup>

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<sup>314</sup> Allison Masangkay, "We Must Reimagine Ourselves," *Disability Visibility Project*, 2020, <https://disabilityvisibilityproject.com/2020/07/19/we-must-reimagine-ourselves/>.

<sup>315</sup> Ibid.

Masangkay shares the vulnerability she felt in the loss of her partner and expresses how processing her grief needed to be private as well, because her love had to be private. The buying and eating of donuts in remembrance is Masangkay's way to critically mourn, to slow down and reflect on her relationship with her partner. The combination of Masangkay's disability and the trauma she's endured, the temporal shift to slow down resembles crip time, where "crip time bends the clock to meet disabled bodies and minds."<sup>316</sup> This is also seen when she describes her experience in the park where a murder of crows surrounded her and she cried continuously—readers lose linear temporality in these moments of her story, however, they don't lose the impact of the grief she is expressing. Further, when she does express grief with a group of trusted friends, Masangkay expresses her grief through a metaphorical dream where temporality is again shifting between the past and present. Significantly, immediately after her loss, her grief remains privatized between herself and a close group of friends. Years later, her grief is being shared through the blog post openly and publicly, which simultaneously archives the pain, again pushing against our notions of time—as the blog post is written in first person—placing readers directly in those moments with her. The shift between what has been private to being public does not diminish her grief. However, the process of sharing her grief theorizes ways for others to handle despairing moments, especially when Masangkay actively reflects on her story. She writes:

As I see it, the "real work" is not in my ability to work more, experience less bodily pain, or even create; rather, it's in my belief of a version of myself that freely exists outside of white supremacist systems and narratives.<sup>317</sup>

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<sup>316</sup> Kafer, *Feminist, Queer, Crip*, 27.

<sup>317</sup> *Ibid.*

Masangkay writes on her futurity, how she is actively “imagining and manifesting a better future, beyond the fucked up medical-industrial complex, through my art.”<sup>318</sup> She has found an outlet to channel her own grief, that goes beyond the experiences she has felt within her own body. This reminds me of Kafai’s manifestation of collective futures where “revolutions begin with rest, with time to think, feel, and create our way into dreaming new realities.”<sup>319</sup> The purposeful slowing-down, altering temporal reality in ways to create and imagine oneself working with grief, within one’s own body, is one way into crip-liberation.

Masangkay is not the only guest blogger on the DVP to discuss grief. Both Rachel Litchman and Alana Saltz blog on their handling of disability, trauma, and grief that has emerged from these intersections. Litchman writes on her experience with being homeless with a disability and Saltz writes on the failure of Cognitive-Behavioral Therapy (CBT) and the detrimental impact it has had on her disabled life. Both women share the grief they have endured from institutional failures that have perpetuated the ableism and insidious trauma in their lives. Litchman expresses:

Later, because my parents refused to believe the trauma I had endured, self-harm became my only way to cope. The nights I spent screaming at my parents to stop hurting me, to get their hands off of me, were evidence of my being “crazy.” My father’s intrusions into my bedroom, to monitor and watch me, when I had no clothes on, and asked him to go away, justified sexual abuse in the name of what he called looking out for my personal “safety.” ... it’s imperative that policymakers, healthcare professionals, and homeless services systems be aware of these issues faced by disabled youth, so they do not merely push traumatized youth through the same abusive systems in an attempt to “fix” them.

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<sup>318</sup> Ibid; “About” *Allison Masangkay*, 2022, <https://www.allisonmasangkay.com/>.

<sup>319</sup> Kafai, *Crip Kinship*, 165.

This awareness can help make our homeless services systems better at responding to youth who experience mental and physical health challenges by providing them with the support, care, and freedom from harm that we all deserve.<sup>320</sup>

Litchman draws on her personal experience with being homeless to create and theorize the changes that need to occur to prevent and help other individuals that may end up in similar situations. By using her voice, her story, and her experience, Litchman’s blog rejects the medical model of disability, the “curative” model we have seen to the detriment of other representations within popular culture, and instead situates her story alongside the infrastructural and political laws and systems that facilitated the insidious trauma she’s had to face as a houseless youth. Here, Litchman suggests that it is nearly impossible to separate houseless individuals with disabilities from the policies implemented by the government and the healthcare network. Moreover, Litchman goes beyond just blogging about her thoughts, as she currently serves on the Youth Advisory Board at the National Runaway Safeline and works on the Youth Action Board with Homeless Services Consortium of Dane County.<sup>321</sup>

Saltz is another individual who is using her lived experience to reject and challenge popular culture’s insistence on the medicalized model of disability, resisting cures for her own disability. With a history of being not believed for her chronic pain, Saltz has been in and out of medical institutionalizations and psychiatrist offices, all of which told her that her thoughts were the problem—being psychosomatic in nature—and not the pain she was feeling.<sup>322</sup> One harmful

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<sup>320</sup> Rachel Litchman, “Reflecting on my experiences as a homeless youth with disabilities” *Disability Visibility Project*, 2021, <https://disabilityvisibilityproject.com/2021/11/14/reflecting-on-my-experiences-as-a-homeless-youth-with-disabilities/>.

<sup>321</sup> Ibid.

<sup>322</sup> Alana Saltz, “How CBT Harmed Me: The Interview that the NY Times Erased” *Disability Visibility Project*, 2021, <https://disabilityvisibilityproject.com/2021/11/11/how-cbt-harmed-me-the-interview-that-the-new-york-times-erased/>.

encounter she has was when she was interviewed by *The New York Times* on the effects of Cognitive-Behavioral Therapy (CBT), in which she was honest. She says:

CBT as a modality is based around gaslighting. It's all about telling a patient that the world is safe, bad feelings are temporary, and that pain (emotional or physical) is a "faulty or unhelpful" distortion of thinking. That's literally in CBT's definition on the APA website. But how do they determine that someone's thinking is "faulty or unhelpful"? From the first session, therapists told me my way of thinking was the problem, not the medical conditions I couldn't control or things like systemic injustices, financial struggles, trauma, and discrimination.<sup>323</sup>

Saltz's voice was later erased from the *New York Times* article, which decided to go with an article that further supported CBT instead of centering on how CBT can be harmful. Saltz writes about the negative affects she feels, "the anger, fear, grief, and depression always come back because the pain, the source of those feelings, never stops."<sup>324</sup> How CBT has made her pain invalid has inspired Saltz to blog about her experiences, and she writes that "I want there to be more awareness and research around new modalities that have the ability to acknowledge pain and oppression without making someone feel invalidated. I think therapy might have really helped me if it had been more validating and supportive instead of gaslighting and dismissive."<sup>325</sup> Further, Saltz theorizes that what has helped her to manage the pain she's felt is the collective-care and solidarity she has found in her chronically ill friends.

That's one of the most helpful things that came out of me connecting with the chronic illness community. Realizing I wasn't doing anything wrong. It's a systemic issue, not a

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<sup>323</sup> Ibid.

<sup>324</sup> Ibid.

<sup>325</sup> Ibid.

personal failure to find the right doctors or express my symptoms correctly...What I will personally recommend are patient advocates and organizations for specific conditions [like Suffering the Silence and Hyp-Access]. I've also found chronic illness support groups to be invaluable. The better organizations have doctor recommendations or lists. You can also often find patient advocates who offer care consults.<sup>326</sup>

The crip kinship that Saltz found online signifies what Kafai refers to as the “crip-centric liberated zones” that are made and connected to disabled communities through computers and phones.<sup>327</sup> Crip-centric liberated zones refer to sites where individuals with disabilities do not have to fight to be recognized as human, their civil rights are granted freely, and there is no fear of stigmatization, bias, or discrimination.<sup>328</sup> Saltz is liberated from the disbelief of her chronic pain and disabilities through the connections she makes with other people who are in similar positions as herself. There is also a liberation of finding helpful resources and the generosity and love that is given as she shares those resources publicly in her blog post. The stories Masangkay, Litchman, and Saltz share are their individual stories that show how they have navigated their insidious trauma and grief. However, since their stories are connected and shared through the DVP, their stories are also not just merely individual, but function as part of a bigger picture network that centers people with disabilities critically mourning their insidious trauma, by speaking up about the injustices they have faced, in anti-ableist ways.

### **The DVP and Collective Grieving**

The DVP not only serves as a place to discuss individually felt grief but also a place to theorize collective grief the disability community has felt and collectively mourn. As a practice

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<sup>326</sup> Ibid.

<sup>327</sup> Kafai, *Crip Kinship*, 117.

<sup>328</sup> Ibid.

of collective critical mourning, for instance, the DVP has organized events such as the Bay Area Day of Mourning to “remember and mourn the deaths of disabled people at the hands of their parents, caregivers, or care providers or by law enforcement and other authorities.”<sup>329</sup> At organized events such as these, intermedial in nature as the event creation and spaces were held on and offline, there are programmed speakers that discuss grief and what to do with that grief. For instance, La Mesha Irizarry speaks at the 2015 event in the California Bay Area in person, “So as we mourn today, worldwide tomorrow, we must advocate outside the box, outside of non-profit turf wars, outside of the grant cycles, outside of popular movement and work inside all of these systems worldwide.”<sup>330</sup> Alice Wong is another speaker at this event, who talks about the murders of Ben, Max, and Olivia Clarence who were murdered by their mother for having the same disability as Wong—spinal muscular atrophy.<sup>331</sup> In her speech, Wong speaks directly to the murdered children to say:

Yes, you needed total help with your personal care. Yes, your muscles were going to continually become weaker over time. Yes, most people considered you vulnerable and “wasting away.” But you know what? I bet you also knew how to have fun, enjoy life, and dream big. I wish that people didn’t think that you were trapped in your body, powerless and filled with suffering. I wish that the three of you lived until you were old enough to use a computer so we could connect. I wish my disabled friends and I could have welcomed you to this funky global crip tribe and mentor you in whatever ways you

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<sup>329</sup> Alice Wong “Bay Area Day of Mourning: Program Information and List of Names” *Disability Visibility Project*, 2015, <https://disabilityvisibilityproject.com/2015/02/28/bay-area-day-of-mourning-program-information-and-list-of-names/>.

<sup>330</sup> La Mesha Irizarry “Bay Area Day of Mourning: La Mesha Irizarry” *Disability Visibility Project*, 2015, <https://disabilityvisibilityproject.com/2015/02/28/bay-area-day-of-mourning-lamesha/>.

<sup>331</sup> Alice Wong “Bay Area Day of Mourning: Alice Wong” *Disability Visibility Project*, 2015, <https://disabilityvisibilityproject.com/2015/02/28/bay-area-day-of-mourning-alice-wong/>.

wanted. As a fellow disabled kindred spirit, please know this: Even in death, you are not alone. You are valued. You are remembered. You are loved.<sup>332</sup>

Wong avoids the inspiration porn tropes in her words, avoids the suggestion that if they could have lived, they would have overcome and thrived in their bodies. Instead, Wong focuses on the fact that if they had lived, they would have learned to cope and manage their disability, to dream, and to imagine anti-ableist futures along with many other disabled activists. Wong also suggests the connectivity between people with disabilities is essential to survival, suggesting that the collective critical mourning she is enacting was essential to their survival. This is important: as I've noted with Samira Rajabi's case, she built connections online after discovering her brain tumor, Digital media facilitates content creation from people with disabilities to share their story and also be heard and mourned for with others when they do, in turn, share their story as well.<sup>333</sup>

Further, DVP has allowed disabled writers, content creators, and experts to share and relate to one another on an intense level. Insidious trauma for people with disabilities comes in "relational terms" where "trauma does not happen in isolation. Trauma connects us ... trauma reminds us of our deep interconnectedness, our interdependence."<sup>334</sup> The call for collective voice and collective action speaks to the intermedial protest that the DVP has already been and continues to encompass. Further, from this event, the DVP has come up with an "action plan" to channel the grief the collective may be feeling. The website writes:

What you can do:

- Raise awareness by being proactive and believing survivors of abuse, ask what they want you to do to help, and then support them.
- Push for improved documentation (data collection, statistics at the local, state and federal level) of violence toward people w/ disabilities by law enforcement including deaths, beatings and harassment.

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<sup>332</sup> Ibid.

<sup>333</sup> Rajabi, "Losing Someone Like Us."

<sup>334</sup> Carter, "When Silence Said Everything."

- Advocate for a centralized database of children and adults with disabilities killed, tortured or neglected by their adult caregivers/parents/care providers.
- Join a task force creating a “Know your Disabled Rights” workshop.
- If you are on Facebook, join the Healing Circle for the Soul, which is a Bay Area support group for people who have lost a Loved One to violent crime.
- Learn more about this issue of the denial of family and removal of children through history, whether we are talking about the Gypsy Laws in medieval Europe, the mass removal of American Indian/Alaska Native children to boarding schools in the 20th century, or the issue of disability and denial of parenting today.
- Sign up to urge disability community agencies to push for changes to the law and policy in California. There is a sign-up sheet for those who are interested in this project.<sup>335</sup>

The focus on action here is grounded in histories of pointed activism that the disability community generates.<sup>336</sup> Here, the DVP advocates for macro and micro-leveled actions that individuals who feel affected by can do. These range from speaking up and sharing their own story—such as with the DVP—to protesting local and federal governmental structures. Even within the macro level protests, the bullet point list gives specific things for people to fight for, such as documentation of abuse or learning the law to become knowledgeable about one’s own rights, or even signing petitions. There is an advocacy to join a Healing Circle, which grounds the list provided by the DVP with blooming healing justice efforts that are attempting to focus on the aftermath of violence and violent crime. Within all these points, there is an underlying resistance to sitting with one’s grief and sorrow—that pushes frantically towards action. It is seen within the list above and within the DVP platform itself—the advocacy for a more action-based approach to channeling one’s grief that is anti-ableist because it accounts for various approaches and timelines to processing grief, while also acknowledging not all grief must be action-oriented or productive. Their main tagline surrounding the Bay Area Day of Mourning is,

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<sup>335</sup> Wong “Program Information and List of Names.”

<sup>336</sup> Richard K. Scotch, “Politics and Policy in the History of the Disability Rights Movement” *The Milbank Quarterly*, vol. 67.2, 1989.

“Mourn for the dead. Fight like Hell for the Living.”<sup>337</sup> The temporality of “doing now” on a platform as powerful as DVP hints at the reach that the disabled community is making. The pressure and advocacy occurring on this platform may seem to be contradictory to crip time—however, these advocate movements are occurring alongside crip time—where individuals with disabilities “corporeal presence and absence” are being accounted for.<sup>338</sup> Further, this urgency and desire to do something is part of the critical mourning that comes out of a collective consciousness cultivated by the intermedial project of disability activists.

## Conclusion

What would it look like for our society to continue to listen, adhere, and see representational models of grief that are enacted by BIPOC, queer, disabled people? The knowledge and wisdom being shared through everyday practices is turning into survival guides for not only the disabled community, but for everyone else to listen. The conversation regarding grief, trauma, and how people can critically mourn as a collective critiques ongoing medical conversation that suggests some people get to live and some must die because of their abilities or inabilities. The DVP is a project that acts as a model for future community advocacy work—especially work focused on challenging problematic disability representation and politics. The presence of disabled content creators, who as critical mourners, build coalitional communities to do justice work, is the road to which disability and trauma theory is heading. I want to point to part of Piepzna-Samarasinha’s poem that she wrote for the Disability Visibility anthology:

We have what we always have had, and more.

We know how to mourn

to pray

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<sup>337</sup> Wong, “Program Information and List of Names.”

<sup>338</sup> Kafer, *Feminist, Queer, Crip*, 3.

to persist  
to find resistance in the smallest of spaces  
to find each other and make homes, alone and together  
to lay down in the middle of the road and keen with grief and rage and block traffic  
to crip innovate  
to do some shit that no one says is possible  
to do something wild and unexpected under the radar  
to keep going.”<sup>339</sup>

The acknowledgement of the grief, pain, and mourning that takes place within the disability community produces creative, anti-ableist avenues to protest misrepresentation. Like Piepzna-Samarasinha suggests here, the collective disability community has been facing insidious and collective trauma and in doing so has crippled what resiliency and advocacy looks like. The work disability advocates have been doing, moreover, has now become more visible and present because of collective, intermedial platforms like the DVP. By specifically focusing on individuals who do share their insidious trauma and grief on public platforms—challenging the taboo of speaking of grief openly in mainstream tv and movies in doing so—critical mourning pushes the traditional public/private divide and what that suggests about how to critically mourn and process grief. Further, when grassroots activists are on intermedial platforms purposefully expressing how they have handled the grief and encompassing the pain and loss they’ve experienced, agency is given back to people with disabilities and power is given to their stories.

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<sup>339</sup> Leah Lakshmi Piepzna-Samarasinha, “Still Dreaming Wild Disability Justice at the End of the World” in *Disability Visibility First-Person Stories from the Twenty-First Century* by Alice Wong, 2020, 327.

## CHAPTER V: CONCLUSION

Power is given to people with disabilities on social media and other intermedial platforms, especially when grief is made transparent. The resulting robust representation from people with disabilities' grassroots activism within these digital sites is beginning to influence the mainstream. The content I've analyzed from Alex Darcy and Shelby Lynch in Chapter 3 shows more nuanced representations within social media platforms in terms of sexuality and disability than the character Mark Warner could provide in an episode of *House*. The content from writers, creators, and professionals I've looked at in Chapter 4 also continues to show more diverse and realistic representation for people with disabilities that contrasts the pitiful, monstrous/criminality stereotypes centered in *American Horror Story's* "Freak Show." I conclude my thesis with a few expanding thoughts: What does it mean to witness disability advocacy attuned to grief and insidious trauma on social media and intermedial platforms as a disabled person? As an abled bodied person? What impact do witnesses have on grieving models? What are further avenues of inquiry for the conjunction of disability studies and trauma theory?

Witnesses to the content from disabled creators are provided with concrete advice on how to improve their interactions with the disability community, to enact care work and reduce the perpetuation of micro aggressive comments and insidious trauma. Disabled witnesses, on the other hand, are invited to participate in remaking understandings of disability and in the formation of rich online communities as sites of collective care. The care work we have seen throughout this thesis from disabled content creators cultivates collective care models that emphasize mentorship.<sup>340</sup> Sharing content on social media and intermedial platforms is shifting

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<sup>340</sup> Piepzna-Samarasinha, *Care Work*, 258.

conversations that were previously held in trauma theory when it comes to witnessing. Dori Laub has discussed the importance of testimony by suggesting testimony helps the traumatized individual organize their pain into meaningful linguistic patterns, but an important part of testimony is the witness or listener.<sup>341</sup> The listener, who “bears witness” to another’s trauma is often characterized as a silent presence because the listener must simultaneously encourage the traumatized to share but not push too far to emotionally strain the individual.<sup>342</sup> However, bearing witness to a person you know or are having a face-to-face conversation with is different from bearing witness to content from social media or other intermedial platforms. Jenna A. Altomonte, for instance, has analyzed the impact of witnessing violence or reliving trauma online and traces how that technology is shifting the way trauma is “realized, recognized, and represented.”<sup>343</sup> The media’s changing landscape offers different affordances that facilitate the communication of grief differently, such as how “technological innovation participates in reimagining the deceased” by affecting commemoration and memorialization practices.<sup>344</sup>

When looking at bearing witness through new technology like social media platforms, the silent presence of a witness does not transform or change discourses, or even grant comfort to the traumatized. Rather, the content disabled activists are creating via social media, attuned to grief and insidious trauma, pushes its witnesses to scrupulously analyze their interactions with the disabled people in their own lives—whether that be a passerby or a close family member/friend—and unashamedly adjust if they find moments or biases that perpetuate insidious traumatic cycles for people with disabilities. Moreover, the content from disabled activists is also

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<sup>341</sup> Laub, “Bearing Witness,” 57.

<sup>342</sup> Ibid.

<sup>343</sup> Jenna A. Altomonte, “Witnessing Violence, (Re)Living Trauma: Online Performance Interventions in the Digital Age” *Ohio University*, 2017, 227.

<sup>344</sup> Ibid, 2.

creating robust, representative models that allow witnesses with disabilities to see how others are navigating grief in anti-ableist ways. To encourage action from witnesses, disability activists are providing mentorship through their content. For example, Piepzna-Samarasinha centers on the idea of healing justice as a framework alongside crip mentorship or modeling.<sup>345</sup> She calls herself and others who have cared for her as partaking in “disability doulaship.”<sup>346</sup> A doula is “*a trained professional who provides continuous physical, emotional and informational support to a mother before, during and shortly after childbirth to help her achieve the healthiest, most satisfying experience possible.*”<sup>347</sup> Piepzna-Samarasinha is referring specifically to the mentoring aspect that doulas provide expecting and new mothers and parents. Here, Piepzna-Samarasinha recognizes “every person who has trusted me with the honor of supporting them through their journey and those who have supported me through the same.”<sup>348</sup> The interconnected network Piepzna-Samarasinha recognizes also has helped her interact with an ableist world. For instance, Piepzna-Samarasinha discusses how she navigates negative affects like shame, and although she still grapples with and grieves having these emotions, the collective care she receives creates a sense of “wealth” through “these small spaces away from shame, where it is okay to have a disabled bodymind.”<sup>349</sup> To incorporate mentorship within the materials she creates, Piepzna-Samarasinha communicates with the witnesses to her work ways in which they can improve interactions with other people with disabilities by attuning to their needs and enacting the care work we have seen throughout this thesis. Although much of Piepzna-Samarasinha’s work is text-based, through her published poetry and books, she also has a strong social media following

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<sup>345</sup> Ibid.

<sup>346</sup> Ibid.

<sup>347</sup> “What is a doula?” Dona International, 2022, <https://www.dona.org/what-is-a-doula/>.

<sup>348</sup> Piepzna-Samarasinha, *Care Work*, 258.

<sup>349</sup> Ibid, 272.

on Twitter and Instagram. On her Twitter (@thelipsx) she tweets on disability justice, preventing microaggressions, reflecting questions, and interacts with other disability activists by retweeting, sharing, or responding to their content.<sup>350</sup> It is the site of her Twitter where she breaks down her text-based arguments found in her academic writing and remediates her core beliefs into 140-character snippets, which results in her mentorship possibly reaching further than her academic writing's influence.

Further, the healing justice approach to Piepzna-Samarasinha's work centers "crip ideas of what illness and disability are, as well as honoring disabled and sick and mad people's autonomy and wisdom, and centralizing accessibility in a broad sense."<sup>351</sup> Her work and social media presence, alongside the other content creators I have presented—Alex Darcy, Shelby Lynch, and the authors within the Disability Visibility Project (DVP)—are showing alternative ways to embrace the grief, messiness, and reality of disabled, queer, BIPOC experiences. Embracing the messiness of grief pushes against medicalized grieving models that have been perpetuated through cycles of psychological and psychiatric care that encourage linear, productive grieving.<sup>352</sup> Moreover, these medicalized grief models can be problematic, as I've noted before, as they often paint grief as part of a coping and overcoming process which limits people with disabilities' ability to grieve openly without perpetuating tropes and narratives of them as weak and burdensome.

Piepzna-Samarasinha and other disability activists' approach to grief, on the other hand, expands our notions of what grief could or ought to look like. Piepzna-Samarasinha continues:

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<sup>350</sup> Leah Lakshmi Piepzna-Samarasinha, Twitter @thelipsx, 2022, [https://twitter.com/thelipsx?ref\\_src=twsrc%5Egoogle%7Ctwcamp%5Eserp%7Ctwgr%5Eauthor](https://twitter.com/thelipsx?ref_src=twsrc%5Egoogle%7Ctwcamp%5Eserp%7Ctwgr%5Eauthor).

<sup>351</sup> Ibid, 111.

<sup>352</sup> Such as Kübler-Ross and Kessler, *On Grief and Grieving*; Dennis Klass, Phyllis R. Silverman, and Steven L. Nickman, *Continuing Bonds: New Understandings of Grief* (New York: Routledge, 1996); William Worden, *Grief Counseling and Grief Therapy*; Therese Rando, *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers* (Champaign: Research Press, 2000).

What if more survivors—and the therapists and healing spaces available to us—had a Mad, cripp idea of healing, one that was not about cure but about increasing possibility, about learning, about trying to love all our survivor madness, and about shifting our communities to ones where crazy was really okay? What if there were models for long-term grief? Where we had more space in our jobs and homes where it was okay to grieve—like long-term lots of paid grief time off? What would it be like if our communities really, really believed that grief was sacred and valuable, a source of life-giving knowledge, instead of a pain in the ass? What if bad survivors were good survivors? What if all survivors were beautiful in our mess? ... even more dangerous, I want to venture: What if some things aren't fixable? What if some things really never will be the same—and that might not be great, but it might be okay?"<sup>353</sup>

Piepzna-Samarasinha's framing here has strong implications for the way that representation of grief and who people grieve with can fundamentally change the relationship they have to healing—not aiming for a curative or overcoming narrative but rather finding the solidarity and community to support these aims.

As I wrote this thesis, sites of investigation for further study have become apparent. For one, the implications of witnessing insidious trauma within digital media is a question I am interested in further exploring. How does witnessing trauma on digital platforms affect the witnesses? What are the implications of randomly coming across content expressing trauma? What are the witnesses' responsibilities? Can one be held accountable for being an active witness if they did not consent to consume the material? Further, it will be necessary to continue putting disability scholarship in conversation with trauma theory to create more pluralistic models that

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<sup>353</sup> Piepzna-Samarasinha, *Care Work*, 252.

are attuned to navigating disability-related trauma in anti-ableist ways. How are intergenerational cycles of trauma—attuned to historical eugenic practices—affecting families navigating disability contexts in the modern age? Can digital media and shifts in representational models break intergenerational cycles? How do emerging awareness/advocacy practices from people with disabilities continue to shift disability representation? Concepts of testimony and future investigations of bearing witness in the digital age are important to keep in mind as further theorization of how disability communities are navigating their grief within these intermedial spaces come around.

Analyzing how people with disabilities are creating, making, and building these collective care communities is an essential move to explicate how grief is being modeled deeply with nuances on the grassroots level. At the beginning of the thesis, I introduced Mona Eltahawy’s vision for a grief literate society, in which she asks what a society would look like if we comfortably discussed and accepted differences in grieving styles that were attuned to gender, race, and culture.<sup>354</sup> After taking a closer look at the content creation being made by people with disabilities, Eltahawy’s vision of a grief literate society is indeed emerging through social media and other intermedial platforms. The grassroots activism occurring at these sites are not showing discomfort or avoiding topics of loss, grief, or pain, but rather showing ways witnesses can navigate loss by openly discussing grief and mourning practices. Lastly, the collective care within disability communities that have emerged, and will continue to emerge, is transforming disability representation in the mainstream by using social media and other intermedial platforms to disrupt ableist stereotypes and narratives. In doing so, disability communities are also showing ways to grieve as a collective and to critically mourn injustices

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<sup>354</sup> Eltahawy, “Some of Us Did Not Die.”

and insidious trauma people with disabilities have endured. By putting grief, insidious trauma, and disability representation in conversation, this thesis informs and transforms disability studies and trauma theory's relationship to one another and highlights relatable sites of identification for ordinary disabled folks.

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