
A dissertation presented to
the faculty of
the Scripps College of Communication of Ohio University

In partial fulfillment
of the requirements for the degree
Doctor of Philosophy

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August 2017
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This dissertation titled

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Abstract

PARSLOE, SARAH M., Ph.D., August 2017, Communication Studies


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People with disabilities have long been under-represented and misrepresented in mainstream media, and have sought strategies to contest discourses of difference that frame disability as a pitiable tragedy, a burden, or a source of inspiration used to make non-disabled people feel better about their own lives. With the advent of the internet and the increasingly participatory character of the media landscape, people with disabilities are now more able to generate and circulate a counter-narrative—one which draws on the social model of disability to highlight the ways in which stigmatizing and oppressive responses to different bodies create and perpetuate marginalization.

However, the disability community is far from monolithic. In addition, the line between “chronic illness” and “disability” remains blurry. Thus, as individuals engage in self-advocacy and collective/connective action by publicizing their stories, they draw from varied discourses of difference that preserve or resist medicalization. Similarly, advocates organize to pursue potentially conflicting goals. The resulting tensions of representation and organization are particularly apparent in the case of The Mighty, a for-profit media company that publishes stories submitted by people with disabilities, chronic illnesses, and mental health conditions. This site has become an increasingly popular resource for some members of the disability community. At the same time, it has also
become a site of contention and has received criticism from disability activists who protested its publishing practices via the hashtag initiative, #crippingthemighty.

For this dissertation project, The Mighty served as a context to explore how public performances of self-advocacy in digital spaces link to connective/collaborative action. Taking a constructivist approach to grounded theory (Charmaz, 2006), I analyzed interviews with Mighty staff members (14 participants), Mighty contributors (29 participants), and #crippingthemighty activists (2 participants) and conducted a textual analysis of 213 Mighty articles and 22 #crippingthemighty blog posts. In Chapter 4, I explored how individuals engage in sense-making processes (re)construct both individual and collective identities in ways that reflect varied discourses of difference and multiple forms of problematic integration (PI; Babrow, 1992). In Chapter 5, I conceptualized the nature of refracted self-advocacy, collective self-advocacy, allyship, and collective action. I also provide a typology of collective goals that animate advocacy and activism. In Chapter 6, I build on Giddens’ (1979) structuration theory and Ashcraft’s (2001, 2006) description of paradoxical hybrid forms to consider how Mighty staff members communicate in ways that constitute and manage three sets of dialectical tensions. Chapter 7 offers an analysis of #crippingthemighty, describing disability activists’ response to tensions and ableist structures apparent on the The Mighty, their conceptions of allyship, appropriation, and dialogue (Bakhtin, 1981; Buber, 2010), and their use of Twitter to engage in cyberactivism. Finally, Chapter 8 offers theoretical and practical implications, limitations and directions for future research, and some personal reflections of the nature of academic allyship.
Dedication

I dedicate this dissertation project to my participants. Thank you for sharing your time, your work, and your stories.
Acknowledgments

All that I have accomplished in my life, I have done with help from allies. Allies taught me the skills I needed to reach for my goals; they recognized my own potential when I could not see it myself; they celebrated with me in moments of triumph and held me in moments of despair; and, most importantly, they asked me to pause mid-sprint to look around at the beautiful, ephemeral, poignant details of a life well-lived. I have many allies to thank, but I mention just a few of them here.

To my advisor, Dr. Austin Babrow: you have convinced yourself that you were merely a spectator in this dissertation process, but that is far from the truth. I have been learning from you since the first time I met with you in Lasher Hall. I came to Ohio University because of that meeting—because your passionate curiosity reverberated with my own, and because your genuine interest in my work helped me to believe that it was work with doing. You have advised me throughout these four years, often without knowing it. You have shown me what it means to be a rigorous scholar, an engaged mentor, and a humble, ethical, kind human being. Thank you for being my first co-author. Thank you for spending time with me each week on the phone and in your office, thinking together about the developing outline for this dissertation. Those were some of the most gratifying intellectual conversations of my graduate career. Thank you for never doubting me, even when I faltered. Earning your respect is one of my most cherished accomplishments, because I respect you more than I can say.

To my first advisor at Ohio University, Dr. JW Smith: some of my fondest memories from graduate school will be from times spent with you in laundromats, diners,
and Buffalo Wild Wings. Thank you for being my comedic relief and my confidant. I hope that you will visit me in Florida so that we can share a fancy meal (my turn to treat!), drink wine, and put our feet in the sand.

To my thesis advisor and continual mentor, Dr. Patricia Geist-Martin: you are the person who introduced me to health communication, qualitative research, and feminist scholarship. You helped me to imagine my capacity to become a teacher-scholar. From you, I have learned what it means to enact the vulnerable, emotional, mutually-validating labor of love that is feminist mentorship. Thank you for always being there to provide advice and to celebrate achievements. I am grateful for our continued friendship, and I look forward to our future collaborations.

To my professors at Ohio University and at San Diego State University: thank you for providing me with your support and your academic expertise. I would like to acknowledge the remaining members of my dissertation committee, Dr. Brittany Peterson, Dr. Stephanie Tikkanen, and Dr. Risa Whitson, for their guidance and advice regarding this dissertation project. Thanks especially to Stephanie for including me in your work with the Sturge-Weber Foundation, for opening up your home to me when I was struggling, and for gifting me with lucky toffee (it worked!). Thanks also to Dr. Charee Thompson for inviting me to work on the crying wolf project. Your interest in why people doubt and are doubted in healthcare contexts has informed this dissertation project, and I am excited to work with you as we continue to develop this line of research. I would also like to acknowledge Dr. Beck, Dr. Chawla, Dr. Harter, and Dr. Rawlins for teaching me about the nature of qualitative research, interpretive theory,
narrative, dialogue, and health organizing. Your scholarship has infused my own, and your guidance helped me to move from confusion to clarity. Thanks also to my academic auntie, Dr. Laura Ellingson. I hope to emulate your generous, optimistic spirit. Finally, thank you to my undergraduate mentor, Dr. Cochece-Davis, who encouraged me to apply to my very first academic conference and who fueled my grad school aspirations.

To my cohort members, Lanie Presswood, Kristen Okamoto, Steve Granelli, Sean Gleason, Sidi Becar-Meyara, and Nicole Eugene—we made it! Thanks especially to Nicole for being a steadfast friend, even when I did not always return the favor. You are the most tenacious person I know. I’d also like to acknowledge my writing buddies, Rebekah and Hanan. I’m very proud of your successes, and I wish you the best of luck as you push forward.

To my friends: thank you for filling my life with laughter. I am especially grateful for my roommate, Kelly Choyke (and her cat, Captain). Thank you for the farm walks, for nights with boxed wine and (discounted) fancy cheese, for impromptu dance parties, and for always reminding me that I am worthy of friendship. Thanks also to my townie friend, Dr. Suzanne Pennington, for encouraging my inner goofball and for reminding me how beautiful Southeast Ohio really is. Thank you to all of the long-distance friends who supported me from afar and welcomed me back, especially the San Diego Beer Club, the “enginerds,” Christi Sheehan, and Cynthia Dagenais. Finally, thank you to my first grad school friend, Melissa Lucas. You were the best Europe travel companion, TAG teammate, and brunching partner. I am so grateful for the continued connection we’ve shared while contending with the (un)expected challenges of academic life.
To Mom, Dad, and Doug: your love sustained me throughout this grad school journey. Mom—the first Dr. Parsloe—as I have grown into an adult I have become even more aware of how important it was for me to see your success as a competent, respected, professional woman. Watching you has given me the strength to pursue my own ambitions. I could be strong because I knew that you would be there when I felt inadequate—when I needed a cup of tea and a cuddle on the couch. Dad, you are the mooring I anchor myself to in the midst of a storm. Your calm, logical approach to problems grounds me in moments of frantic uncertainty. Thank you for always being ready to listen, and for telling me that you are proud of me. Broski, my twin—our lives began at the same time, but have taken us down such different paths. I am so proud of the progress we have made.

To all of my aunts and uncles: you have been the witnesses to each milestone of my life—each dance recital, concert, play, and award ceremony. Those moments were meaningful to me because you were included in them. Thanks especially to Uncle Mark, Aunt Karen, and Aunt Jane; you were sources of inspiration and comfort during this dissertation process.

To Grandma and Grandpa Libassi: I am grateful for every phone call and every hug we share. Grandma, from you comes my love of literature, writing, and teaching. I cherish the one fuzzy memory I have of being carried into your English classroom as a toddler. Grandpa, from you I have inherited a cheesy, buoyant sense of humor. It carries me through tough times, and helps me to recognize the good in other people.
To Kevin, my partner and my best friend. We have endured four long years living on different sides of the country. Thank you for never making me feel guilty for pursuing this PhD, despite how difficult it has been to be apart. Thank you for sharing so many wonderful adventures with me. Thank you for giving me cuddles, fresh-cut pineapple, fuzzy blankets, and your unwavering confidence in my ability. Even the worst days were infinitely better because they ended with a phone call from you. I can’t wait to start this new chapter of my life with you by my side.
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Chapter 1: Introduction

I don’t care [about] the color of your skin, or your religion, or if you have a disability or not. I want you to feel like you’re a part of my community because feeling like you belong can change someone’s life (personal communication, T. Yu, December 8, 2015).

For 27-year-old Taiwanese-American Tiffany Yu, becoming disabled was a traumatic experience. On November 29th, 1997, a car accident took her father’s life and left 9-year-old Tiffany with brachial plexus palsy—severe nerve damage to her right arm. In my interview with Tiffany, she described the personal pain linked to her disability story: “my personal story to me is more than just loss of the ability to use my arm; it’s the . . . shattering disruption of my own identity of self . . . and also how I view family.”

Growing up with a disability, Tiffany internalized feelings of self-pity and developed low self-esteem. However, her self-concept shifted during her time at college, where she connected with other members of the disability community on her campus and formed the student club, Diversability. Through her involvement with Diversability, Tiffany became more comfortable sharing and owning her personal story and began to view herself as a disability advocate.

Diversability eventually disbanded once Tiffany graduated college. Just as she was “itching to get back involved” in 2014, Tiffany received an email from an unknown man:

I read about your work and your journey is very inspiring. . . . I would definitely like to help you build Diversability. Even if I’m not public about my disability yet I can still contribute to the community. I think it would be great to use media to spread awareness and educate.
Just a few days later, Tiffany received a Twitter message from another man interested in Diversability’s work. “I’m like ‘I think this is a sign,”’ Tiffany told me, “a sign that there’s more work to be done, and a sign that there are . . . millennials who are excited about what’s going on in the disability space or [are] looking for some type of belonging.”

Tiffany subsequently re-launched Diversability as a “movement to rebrand disability through the power of community” (Diversability, 2016). She wanted to “connect, showcase, and empower people of all abilities doing amazing things.” Tiffany envisioned a space that would inject disability into the diversity conversation, unite a fragmented disability community, welcome allies, and celebrate disability pride. Initially launched from Tiffany’s home base in New York City, loosely connected Diversability hubs have popped up in Los Angeles, San Francisco, Washington, D.C., and Montgomery, Alabama. While Diversability does host on-the-ground events, at its heart it is a network of interlinked social media channels acting to connect community members, coordinate Twitter chats, and amplify disability bloggers’ voices through shares, likes, and re-tweets. During our interview, Tiffany described her ultimate goal of creating a “faceless movement similar to Black Lives Matter or Giving Tuesday.” “I see Diversability as the disability advocate,” she explained, “and I just happen to be a part of it.”

“Genuine solidarity is recognizing that while all of our struggles are absolutely not the same, they are all interconnected” (personal communication, L. Brown,
November 4, 2015). For 23-year-old Lydia Brown, a genderqueer, east Asian, autistic\(^1\) activist who was adopted from China by a white American couple, engaging in advocacy work means recognizing intersecting, layered categories of privilege and marginalization. As Lydia notes, “disabled people are both straight and queer, are both cisgender and transgender, are white and are of color, etcetera.” During our interview, Lydia described how encounters with racism, ableism, and heterosexism made them\(^2\) more conscious of their membership in multiple marginalized communities, shaping the ethos of intersectional social justice that drives their advocacy work. Lydia recalled how the terror of narrowly escaping a sexual predator on the streets of Washington, D.C. rendered them temporarily nonverbal. When Lydia attempted to report the incident the following day, police officers assumed that they would need a Mandarin interpreter (despite the fact that Lydia had grown up in America and spoke only English) and harangued Lydia for not reporting the attack sooner. Lydia also told me about how others used their diagnosis to discredit aspects of their identity, explaining that “so many of us are told ‘oh your gender identity isn’t real it’s just a symptom because you’re autistic.’” Facing multiple forms of marginalization, activists like Lydia develop resilience by forming connections. Speaking with me over Skype, Lydia eloquently described the “power of disability solidarity”:

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\(^1\) There is some debate in the disability community about the use of people-first language (as in a person with autism) and identify-first language (as in autistic person). People-first language acknowledges that people should not be solely defined by their condition, and emphasize their humanity. Identity-first language acknowledges that a disability can be a source of pride and may constitute a cultural category. Cultural norms regarding the use of people-first vs identity-first language vary between specific types of disability (as in Down syndrome or cerebral palsy) and also may be a source of contention within communities. For instance, while some within the autism community prefer people-first language, autistic activists tend to prefer identity-first language because they view autism as an important, valuable aspect of who they are.

\(^2\) Lydia’s preferred gender pronoun
We live with internalized ableism and the fear of associating with each other because . . . we only get to be around each other if we’re all there for therapy; we’re all there because our parents are in the other room complaining about what a burden it is to raise us. And so . . . for those of us who become politicized . . . knowing and being around other disabled people becomes incredibly important, becomes crucial for not just survival, but the possibility of being able to thrive.

The connections necessary for disability solidarity are often forged online. During our time together, Lydia spoke of how reading essays posted by autistic bloggers helped them to develop their own autistic identity and to connect to the wider autism community. These connections fueled their initial foray into advocacy. As Lydia explained, “other autistic people introduced me to the neurodiversity movement, and the neurodiversity movement introduced me to the disability rights movement. Disability rights work introduced me to radical disability justice work.” Now a prominent blogger, co-founder of the Washington Metro Disabled Students Collective (WMDSC), co-president of TASH New England, chairperson of the Massachusetts Developmental Disabilities Council, and an executive board member of the Autism Women’s Network, Lydia works to reject the pathologization of disabled people, to legitimate self-diagnosed individuals’ knowledge of their own bodies, and to enact policies that facilitate inclusion and prevent state violence and other forms of abuse.

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3 A movement, popularized by autistic advocates, driven by the idea that variation in cognitive function should be valued and respected
4 TASH is a disability advocacy organization that promotes inclusion and social justice for people with disabilities. TASH used to stand for The Association for Persons with Severe Handicaps. However, they organization discontinued use of the acronym in 1995, noting that it no longer reflected the organization’s mission. Instead, it has retained the name TASH because it is widely recognized (About TASH, 2016) https://tash.org/about/
5 A self-advocacy organization founded and run by autistic women
Conceptualizing Self-Advocacy

As stories like Lydia’s and Tiffany’s illustrate, the internet has become an increasingly important tool for linking, inspiring, and empowering self-advocates. I define self-advocate as an empowered individual who acts to shape the tangible and discursive resources associated with their condition. Researchers have suggested that a self-advocate identity emerges from a two-part process: “(a) integration of disability positively into one’s sense of self and oneself into the disability community and (b) expansion to include an increasing variety of disabilities, other diverse communities struggling for equal rights, and a spiritual sense of oneness” (Caldwell, 2011, p. 315). Similarly, researchers have suggested that the activity of self-advocacy involves four dimensions: (1) knowledge of self (strengths, preferences, goals, dreams, interests, learning style, support needs, accommodation needs, characteristics of one’s disability, and responsibilities), (2) knowledge of rights (personal rights, community rights, human service rights, consumer rights, educational rights, steps to redress violations, steps to advocate for change, and knowledge of resources), (3) communication, and (4) leadership (connecting with and advocating for a group of similar others) (Test, Fowler, Wood, Brewer, & Eddy, 2005; Test, Fowler, Brewer, & Wood, 2005). As a communication scholar, I emphasize the central role of communication in the self-advocacy process. Redefined with this emphasis in mind, self-advocacy can be understood as a set of communicative activities that constitute an individual’s self-advocate identity, their sense that they are entitled to particular rights and resources, and their perception that they have
agency in securing those rights and resources. Communication researchers, then, must attend to how these forms of “knowledge” are discursively constructed and enacted.

Further, self-advocacy can be understood as a set of communicative activities through which individuals act to pursue their private interests (Brashers, Haas, Klingle, & Neidig, 2000). For instance, self-advocates may communicate to defend or obtain informational resources (i.e., information about the nature of their diagnosis), tangible resources (i.e., funding for research, accessibility accommodations), or relational resources (i.e. emotional or appraisal support, understanding, acceptance). As a communication researcher, I am interested in understanding how discourses interact with material challenges to shape self-advocates’ goals and the communicative strategies they employ.

Finally, it is often difficult to separate self-advocacy from wider efforts toward advocacy and activism. For instance, Test et al.’s (2005) four dimensions of self-advocacy includes leadership, which inherently shifts the focus from the individual to the collective. Brashers et al. (2000) found that the persuasive self-advocacy strategies used by individual AIDS patients paralleled strategies used to accomplish collective AIDS activism. In addition, those who engage in self-advocacy develop “a collective identity, providing an essential foundation for grassroots activism” (Tilley, 2013, p. 470). This collective identity is often the product of biosociality—shared somatic identities that strengthen social connections (Dubriwny, 2013). Biosocial communities form around efforts to raise awareness and funds and to develop “life strategies” that answer the complex ethical questions tied to how one should live with a particular condition
(Dubriwny, 2013). Additionally, members of biosocial communities act to reject stigmatizing depictions, criticize medical knowledge (Parsloe & Babrow, 2015), and demand political action (Lupton, 2013). Given the unclear link between individual and collective advocacy processes, communication scholarship would benefit from further interrogating the relationship between self-advocacy and more concerted efforts toward advocacy and activism.

**Self-Advocacy and Collective Action**

The communicative labor of self-advocacy is often linked to the organizing processes inherent to *collective action*. Flanagin, Stohl, and Bimber (2006) define collective action as communicative practices that cross the boundary between the private and public realms, reframing private interests as public goods. They explain that “collective action is communicative insofar as it entails efforts by people to cross boundaries by expressing or acting on an individual (i.e., private) interest in a way that is observable to others (i.e., public)” (Flanagin et al., 2006, p. 32). By publicly engaging in self-advocacy, individuals potentially lay the groundwork for participating in, or developing, a collective action organization.

Collective action organizations provide an infrastructure for coordination, offering both the “resources to overcome obstacles to collective action” and “a context for people’s attachments to collective goals” (Flanagin et al., 2006, p. 32). Flanagin et al. (2006) situate collective action organizations along two axes, developing the four quadrants of a collective action space. The first axis, the mode of interaction, explores how people within the organization interact with each other. One end of the continuum
denotes organizations that encourage a high degree of personal interaction. The other end of the interaction mode axis is populated by organization forms that foster impersonal interaction, where individuals remain largely unknown to each other. The second axis, the mode of engagement, outlines the ways in which individual members are able to contribute to the organization. Organizations operating in the entrepreneurial mode encourage to autonomous individuals to direct their own participation. In contrast, organizations operating in the institutional mode develop clear-cut job descriptions.

Traditional advocacy organizations and non-profits, such as Lydia’s Washington Metro Disabled Students Collective, might be characterized as collective action organizations. However, social media provides individuals with the ability to transform their private interests into public concerns in much less structured ways (for instance, Tiffany’s vision of Diversability as a social movement akin to #Blacklivesmatter). Self-advocates may view their individual self-advocacy activities (for instance, publishing a blog post) as a way of participating in a loosely networked collection of advocacy activities. Recognizing this, new media scholars have theorized about how digital spaces facilitate *connective action*.

**Self-Advocacy and Connective Action in Digital Spaces**

Connective action has been defined as instances in which “participants engage with issues largely on individual terms by finding common ground in easy-to-personalize action frames that allow for diverse understandings of common problems to be shared broadly through digital media networks” (Bennett, Segerberg, & Walker, 2014, p. 233). Essentially, connective action involves developing a self-organizing network (Caraway,
2016). This network is energized by the twin logics of *peer production* and *self-motivated sharing*. Peer production involves “the production, curation, and dynamic integration of various types of information content and other resources” (Bennett et al., 2014, p. 234). For instance, individual self-advocates may produce materials by writing blog posts, taking pictures, creating videos, or designing symbols or memes. They may curate resources by creating hashtags or blogrolls. Finally, self-advocates can engage in dynamic integration by cross-posting to various social media platforms, linking several audiences. Similarly, self-motivated sharing involves distributing resources across multiple networks, such as through the processes of (re)tweeting on Twitter or liking and sharing on Facebook. Bennett et al. (2014) refer to these digital affordances as “stitching mechanisms,” noting that they sew together multiple networks in ways that facilitate the rapid expansion of connective movements. For instance, researchers who study health social movements (HSMs) have noted the key role social media plays in facilitating health activism, particularly as patients seek to be active participants in developing their own health resources (Zoller, 2005). Patient organizations’ websites make use of social media to form information pathways that connect visitors to platforms where health information is crowdsourced from individual patients. In doing so, they develop digital spaces that frame patient knowledge as a valuable counterpart to expert medical knowledge (Vicari & Cappai, 2016). Clearly, digital spaces provide important contexts for investigating the link between self-advocacy and collective/connective action, as well as the tensions inherent to transforming private interests into a public agenda for
advocacy/activism. The publishing company, *The Mighty*, provides one such digital space.

**The Mighty: A Case Study of Digital Self-Advocacy and Collective/Connective Action**

As internet-based news sites have turned to blogs and Twitter to generate disability-related stories, self-advocates’ perspectives have begun to infiltrate mainstream media. This phenomenon is especially evident on the digital publishing platform, *The Mighty*. Modeled after sites that aspire to inspire (for instance, *Upworthy* and *Love What Matters*), *The Mighty* was founded specifically to showcase stories written by those impacted by disability, chronic illness, and mental health challenges. The media company embraces a content aggregation format; it gathers much of its material from bloggers and from readers who submit articles and who comment on questions posed to the company’s Facebook communities. Thus, *The Mighty* provides contributors with a highly visible platform from which they can publicly engage in self-advocacy. By forming connections online, self-advocates cultivate networked communities with/through which they can contest ableist discourses, amplify (counter)-narratives to reframe societal norms, and lobby for political and material resources. In doing so, they shift from engaging in self-advocacy to participating in collective/connective action.

For this dissertation project, I used *The Mighty* as a case study to investigate the complexities of engaging in digital self-advocacy in the context of disability. More specifically, I explored the ways in which the public performance of self-advocacy in digital spaces links to connective/collective action. I considered how *Mighty* contributors
developed a self-advocate and collective identities, elected particular goals for their advocacy and/or activism, and made use of new media to connect with others in pursuit of these goals.

However, the disability community is far from monolithic. A second purpose of this dissertation project was to consider the tensions associated with cross-condition organizing. Self-advocates face the challenge of deciding who they can/should connect with. Both Tiffany and Lydia attempt to connect their work to a very broad disability community, aiming for inclusivity and intersectional solidarity. However, an individual’s experience of disability can vary greatly depending on a number of factors, including the person’s level of impairment, whether an individual was born with the condition or became disabled later in life, the degree to which the condition is “visible,” the social and tangible resources available to the person (especially those tied to their ethnicity, race, class, and other aspects of their positionality), the amount of stigma attached to their diagnosis, and the level of public awareness about, and medical knowledge of, their condition. These variations impact the ways in which individuals understand their disability identity and, in turn, prioritize goals for self-advocacy. Even within condition-specific communities, political concerns (i.e. whether to use people-first versus identity-first terminology) can fragment solidarity. Fault lines develop as advocates pursue potentially conflicting goals, such as the desire to demand acceptance and encourage disability pride vs. the desire to pursue treatments and cures—a desired that appears to
devalue disabled bodies. Inevitably, then, self-advocates’ communicative labor privileges particular interests, potentially producing tensions within the disability community. Further, self-advocates navigate additional tensions tied to the advocacy work carried out by parents and non-disabled individuals. Often, they work to resist their stories’ co-optation even as they seek to connect with would-be allies. This dissertation, then, explores how digital spaces like The Mighty provide opportunities for both self-advocacy and collective/connective action, even as they amplify tensions tied to these communicative activities.

The following chapter defines disability in relation to chronic illness, explores the communicative construction of health and the functions of health narratives, and discusses the (dis)empowering potential of narratives in constructing discourses of difference, particularly via traditional and social media. In addition, I provide an overview of The Mighty and an argument for its relevance as a site of study. I conclude by outlining the research questions that guided this dissertation project.

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This tension is particularly clear in the autism community, where some members of the autism community vehemently oppose the “cure movement” and frame cure-focused research as a form of eugenics. Similarly, individuals who embrace deaf culture sometimes ostracize those who elect to receive a cochlear implant.
Chapter 2: Rationale

As the previous chapter suggested, engaging in digital self-advocacy involves navigating numerous tensions. Before self-advocates can grapple with these challenges, however, they must address a key definitional challenge: what, exactly, does it mean to identify as disabled?

Defining Disability

The Americans with Disabilities Act (ADA) defines a disability as “(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individuals; (b) a record of such an impairment; or (c) being regarded as having such an impairment” (Americans with Disabilities Act, 1990, para. 1). In comparison, chronic illnesses are defined as “illnesses that do not go away by themselves within six months, that cannot reliably be cured, and that will not kill the patient any time soon” (Wendell, 2001, p. 20). As of the 2010 census, about 56.7 million Americans, or 19 percent of the total population, lived with a disability (Brault, 2012). According to the Centers for Disease Control, 117 million Americans, or about half of the adult population, reported having one or more chronic health conditions in 2012 (CDC, 2012).

Given that many chronic illnesses are disabling in their impact, the line between disability and chronic illness remains blurry. For instance, the United States Census Bureau included conditions like cancer, diabetes, and atherosclerosis in its criteria for having a physical disability (Brault, 2012). In grappling with this categorization challenge, Wendell (2001) proposed two alternative categories: the “healthy disabled”?

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7 This definition is contested; see the following explanation of the social model of disability.
and the “unhealthy disabled.” Emblematic depictions of disability portray the healthy
disabled, defined as “people whose physical conditions and functional limitations are
relatively stable and predictable for the foreseeable future” (Wendell, 2001, p. 19).
Individuals who are deaf, blind, who have a limb difference, or who have a
developmental or cognitive disability would fit into this category. In contrast, those who
experience disabling chronic illnesses might be categorized as the unhealthy disabled.
These individuals often face a unique challenge in that they experience fluctuating
periods of illness. Because those with chronic illnesses may only intermittently
experience themselves as impaired during times when their condition flares up, they may
be less likely to consistently embrace a disabled identity (Wendell, 2001). Despite these
distinctions, both those with disabilities and those with chronic illnesses are linked by
their experience of embodied difference, or the sense that their bodies deviate from a
socially-constructed conception of “normal” (Cardillo, 2010; Harter & Rawlins, 2011).
Both those with disabilities and those with chronic illnesses draw on multiple
D/discourses to determine what being different means.

Increasingly, movements for disability rights have embraced the social model of
disability, which differentiates between disability and impairment. Whereas impairment
denotes “the medically defined condition of a person’s body/mind,” (Wendell, 2001, p.
22), disability refers to the ways in which society oppresses the impaired body through
ableist practices that contribute to individuals’ social exclusion (Shakespeare, 2013). As
Wendell (1996) explained, “The social response to and treatment of biological
differences constructs disability from biological reality, determining both the nature and
the severity of the disability” (p. 42). The social model of disability enables members of the disability community and their allies to reframe difference as a source of pride. In doing so, they participate in the communicative constitution of their ontological health.

**Social Constructionism and the Communicative Constitution of Health**

As the previous sections suggest, I embrace a social constructionist approach to health. I recognize that the ways in which we assign meaning to the biological realities of disability and chronic illness are mediated by cultural and social processes that define “normalcy” and “deviance,” shaping the ways in which these physical realities are interpreted and experienced (Lupton, 2012; Sharf & Vanderford, 2003). Operating from this social constructionist perspective, Zook (1994) defined the field of health communication as “the study of personal and sociocultural symbol usage for the purpose of developing, maintaining, and adapting ontological health” (p. 367). He describes ontological health as the “meaningful (i.e., authentic) embodiment of biological, psychological, and social experience” (p. 364). Communication, then, plays a constitutive role in that it is the means by which we pursue the “authentic integration” of these three realms (Cardillo, 2010; Zook, 1994). Those who are born into bodies which are biologically atypical, or those who experience the biographical rupture of disabling injury or chronic illness later in life, confront the psychological challenge of cultivating a positive self-concept. In facing this challenge, individuals draw on various discourses of difference.

**Discourses of difference.** Throughout this dissertation project, I use the term “embodied difference” to refer to experiences of living in atypical bodies impacted by
disability or chronic illness. Communication scholar, Allen (2011), used the term “difference” to refer to a variety of social identities. I adopt the disability-specific rationalization for using this term, as articulated by Wendell (1996):

Difference is a more general concept than either ‘Otherness’ or stigmatization, both of which are forms of difference. Difference is also more value-neutral than either stigmatization or ‘Otherness,’ and it is possible therefore possible and necessary to ask whether a particular kind of difference is good as or better than ‘normality.’ (p. 66)

Both healthy disabled and unhealthy disabled individuals share the common goal of countering disempowering discourses of difference. Lupton (2012) defines discourse as “a coherent way of describing and categorizing the social and physical worlds” (p. 2). She notes that “all discourses are textual, or expressed in texts, inter-textual, drawing upon other texts and their discourse to achieve meaning, and contextual, embedded in historical, political, and cultural settings” (p. 2). Speaking specifically about discourses of difference, Cardillo (2010) recognizes that “difference is neither fixed nor primarily a trait of the individual; rather, individuals or groups are differentiated and set apart through a complex web of intrapersonal, interpersonal, and cultural communicative processes” (p. 526). Thus, what counts as difference, and what difference means, changes across time and space.

The discourse of difference as devaluation links difference with stigmatization (Cardillo, 2010). Individuals with visible disabilities inhabit “marked” bodies, rendering them identifiable members of a stigmatized group (Smith, 2011). Those with invisible disabilities, capable of passing as “normal,” occupy a discrediable position where failed attempts at hiding their disabled status expose them to the threat of stigmatization.
(Goffman, 1963). In either case, biomedical diagnoses label individuals, branding them as “Other” (Smith, 2011). The unhealthy disabled face the added threat of blame, where others suspect them of being responsible for their own ill health (Smith, 2011; Wendell, 2010). Influenced by the discourse of difference as devaluation, people with disabilities and chronic illnesses adopt the role of “passively suffering victim” and internalize the idea that they are ugly, inferior, and shameful (Cardillo, 2010). Additionally, ontological health for those with disabilities and chronic illnesses is threatened by the discourse of *difference as hard reality* (Cardillo, 2010). Framed in this way, difference is an inevitable source of suffering, limitation, and alienation. Influenced by the discourse of difference as hard reality, people with disabilities and chronic illnesses view themselves as burdens and attempt to accommodate their “abnormal self to society’s taken-for-granted attitudes, rules, prejudices” (Cardillo, 2010, p. 534). As the core to the master narrative of biomedicine, these discourses of difference situate disability as an individual, technical problem and direct advocacy efforts towards finding treatments and cures. This master narrative becomes particularly problematic when cures and treatments cannot be found; biomedicine fails both itself and those seeking a way to “fix” a disability.

In response to these discourses of difference, people with disabilities and chronic illnesses have developed and circulated counter-narratives which reflect empowering discourses of difference. For instance, some individuals have embraced the discourse of *difference integrated*. This discourse re-constructs difference as “an integral part of self and life” (Cardillo, 2010, p. 534), reclaiming difference as a natural aspect of human variation and reframing “symptoms” as potential strengths (Parsloe, 2015). By engaging
the discourse of difference integrated, individuals with disabilities can come to accept their differences and/or embrace these differences as a source of pride. For instance, those with developmental and cognitive disabilities, especially members of the autism community, have enacted the discourse of difference integrated via the concepts of neurodiversity and neurodivergence. The term “neurodiversity” acknowledges that the range of human neurological experience is infinitely diverse. The term is often represented by a rainbow infinity symbol. Proponents of the Neurodiversity Movement demand equity for neurodivergent people whose atypicalities require accommodation. They emphasize the value of cognitive difference, articulating the idea that neurodivergence provides laudably unique perspectives that challenge “normal” or neurotypical viewpoints (Armstrong, 2010; Cascio, 2012; Parsloe, 2015). Informed by the discourse of difference integrated, individuals with disabilities invoke the metaphors of disability as culture and disability as community to cultivate a body-positive collective identity (Coopman, 2003). Similarly, some individuals with disabilities have endorsed the discourse of difference as oppression. Viewed through this lens, difference is framed as a source of discrimination, mistreatment, and injustice (Cardillo, 2010), validating the disability rights movement. Alternative discourses of difference have infused and energized the People First Movement, where individual self-advocates mobilized for collective action to place disability rights issues on the public agenda (Beart, 2005; Goodley, 2005; Skelton & Moore, 1999; Tilley, 2013). Self-advocates have begun to form self-advocacy organizations, such as the Autistic Self-Advocacy Network (ASAN), adopting the slogan, “nothing about us, without us” (ASAN, 2016). By rallying behind
the social model of disability and invoking the metaphor of *disability as politics* (Coopman, 2003), individuals organize to assert equality and demand inclusion, accessibility, and social justice. Each of these discourses are embedded in the personal narratives individuals develop as they attempt to explain their experience of disability.

**Narratives of embodied difference.** Narratives shape identities, relationships, and organizations. Through the process of narration, we organize the jumbled details of our lived experiences into coherent plots situated in time and space, driven by motives, and populated by characters. We develop a sense of self that integrates memories of the past with expectations for the future (Thorp, 2006). In the process, we can exercise narrative agency, or “the ability to construct narratives given the constraints inevitably placed on storytellers” (Tye-Williams & Krone, 2015, p. 7). Because narratives are not fixed, but are continuously reconstructed and recreated, individuals can exercise agency in developing and sharing stories that both persuade others and construct an empowered sense of self (Tye-Williams & Krone, 2015; White & Epston, 1990).

However, narrative agency is constrained in that narratives are always developed and enacted in and through our relationships with others, making narration a collaborative, audience-dependent endeavor (Montgomery, 2006; Tye-Williams & Krone, 2015). Often individuals seek validation from others as they attempt to author alternative self-narratives; they affirm an emerging self-concept by enlisting the support of a witnessing audience (Harter & Rawlins, 2011; White & Epston, 1990). Narrative agency is also constrained in that stories are inevitably shaped by political and ideological forces. Personal narratives often reflect “tellable story forms” (Montgomery,
culturally-sanctioned master narratives that reflect and reinforce dominant beliefs, value systems, and modes of practice (Harter, Japp, & Beck, 2005; Thorp, 2006; White & Epston, 1990). When master narratives reinforce hegemony and invalidate lived experiences, they can marginalize and oppress. However, individuals can exploit the “tensions, fissures, and gaps” (Harter et al., 2005, p. 24) present in contested master narratives, excavating subjugated knowledges to critique dominant, unitary knowledge (White & Epston, 1990). In doing so, they develop counter-narratives: “stories/narratives that splinter widely accepted truths about people, cultures, and institutions as well as the value of those institutions and the knowledge produced by and within those cultural institutions” (Mutua, 2008, p. 132).

Health communication researchers have applied narrative theory to understand how people, institutions, and cultures assign meaning to experiences of illness and disability. Sharf and Vanderford (2003) identified several functions of health-related narratives. Many of these functions are individual in nature. For instance, narratives serve a sense-making function in that they help individuals to retrospectively interpret events tied to their experience of embodied difference. Similarly, narratives assist individuals in making health-related decisions. Additionally, by exerting narrative agency, individuals can regain a sense of control in the midst of loss, uncertainty, and stigmatization (Sharf & Vanderford, 2003). In doing so, they (re)negotiate their self-concept and (re)configure their relational roles in the face of new or changing impairments.

Personal narratives also serve collective purposes. They “solidify health-based communities with common visions and social agendas” (Sharf & Vanderford, 2003, p.
They can be used to generate awareness of various conditions, and to drive advocacy and activism geared toward raising funds and changing policies (Harter, Broderick, Venable, & Quinlan, 2013). Thus, personal narratives “function as powerful tools in efforts to enact both social understanding and political recognition” (Harter, Japp, & Beck, 2005, p. 24). These narratives both shape and are shaped by the public agendas of collective advocacy and activism. In some cases, private interests and public agendas reflect the master narrative of biomedicine, which positions those with disabilities and chronic illnesses as the abject, deviant Other (Lupton, 2012). The master narrative of biomedicine supports a mechanistic approach to health that justifies pursuit of technological solutions. In other instances, counter-narratives emerge as self-advocates seek to “take back the illness or disability narrative from those who have framed the experience for them” (Cardillo, 2010, p. 529). In either case, these narratives gain influence as they are told publicly spaces, especially via traditional and social media.

**Disability and (Mis)Representation**

Traditional media outlets typically cater to a non-disabled audience, appealing to the majority. As a result, the products of traditional media outlets often create and reinforce stereotypical portrayals of individuals with disabilities. Popular depictions of disability draw on the master narrative of biomedicine, activating the metaphor of disability as medical problem (Coopman, 2003). Framed in this way, difference is a source of individual deficit and malfunction that must be “fixed,” or at least treated in some way that brings the individual closer to “normal” functioning (Shakespeare, 2013). Consequently, people with disabilities are socially devalued as helpless, pitiable victims.
who are globally incapacitated (Chew, 2008; Fine & Asch, 1988; Haller, 2000; Wendell, 2001; Zola, 1993). The resulting mandate to overcome disability-related difference undercuts activists’ attempts to accept disability, or to view it as an alternative form of embodiment worthy of pride (Linton, 1998).

Additionally, people with disabilities may be portrayed as “supercrrips,” where they are deemed remarkable for simply living a “normal” life despite having a disability (Haller, 2000). In a similar vein, disability activist, Stella Young (2014), identified the media’s tendency to produce “inspiration porn” images which objectify disabled people for the benefit of nondisabled people. Recently, disability activist, R. Larkin Taylor-Parker (2015) developed the Inspiration Porn Resolution, urging producers of media messages to avoid the following themes:

- **Participation Trophies:** Is what the disabled person did more ‘special’ than their non-disabled counterpart? The story cannot be newsworthy simply because a disabled person participated. Example: a person voted Homecoming Queen, becoming a runway model or joining a sports team.

- **Able-Bodied Heroes:** Did somebody do something nice for a person with a disability? Is your article written to praise that person for doing a ‘good deed’ even if the disabled recipient did or did not consent?

- **People as Props:** Are you writing about things done to or for a disabled person rather than focusing on what the disabled person does?
- Gawking without Talking: Does the disabled person have a ‘speaking’ part (even if the individual does not communicate through conventional speech)? Are their opinions or feelings about the described events taken into account?
- SuperParent: Are you praising a special parent, caregiver, coach, or teacher of a special child? Is the story centered on the non-disabled person’s achievements and ‘sacrifices’ while the disabled person’s role and value in the relationship overlooked? Is the disabled person in these stories a passive recipient of such ‘generosity’ and ‘benevolence’? (para. 9)

These traditional media tropes potentially stigmatize individuals with disabilities. Stigma has been defined as “a socialized, simplified, standardized image of the disgrace of a particular social group” (Smith, 2011, p. 455) which denotes that the group’s members are worthy of devaluation (loss of status) and discrimination (extensive social distancing) (Smith & Hipper, 2010). The resulting ableism deters individuals from developing an empowered disability identity, undercutting their efforts towards advocacy and activism.

Stigma and ableism thrive in conditions that perpetuate communicative inequality, where people with disabilities have “unequal access to sites of discourse, discursive processes, and discursive articulations” (Dutta, 2015, p. 12). However, with the advent of the internet, geographically-dispersed individuals hampered by mobility and communicative impairments gained the ability to participate in, generate, and shape discourses of difference. Further, digital media have facilitated the rise of an alternative
press—growing numbers of publications created by and for people with disabilities (Haller, 2010).

The internet facilitates “e-empowerment” (Amichai-Hamburger, Mcenna, & Tal, 2008). On a personal level, individuals with disabilities develop communicative self-efficacy by engaging anonymously online, minimizing social anxiety (Amichai-Hamburger et al., 2008). On an interpersonal level, the internet provides individuals with greater control over their self-presentation, allowing them the ability to disclose or withhold information about their disability (Amichai-Hamburger et al., 2008). Essentially, computer-mediated communication (CMC) facilitates self-advocacy. Social media, in particular, have provided those with disabilities and chronic illnesses with avenues through which to share their individual experiences and perspectives by enabling a more participatory media culture (Lupton, 2012). As Ellis and Goggin (2015) explain, “with the affordances of user-generated content, users are able to become more active in the production of media messages” (p. 123). Through social media, people with disabilities can contest the stereotypical narratives perpetuated by traditional media outlets. However, in doing so, they may encounter several dilemmas of representation.

**Dilemmas of Representation**

Disability rights movements have primarily been driven by those who fit squarely in the “healthy disabled” category. These self-advocates are less likely to perceive their condition as a threat to their physical health, making it easier for them to reject a biomedical model of disability and distance themselves from the concept of illness. However, individuals with chronic illnesses (for example, chronic Lyme disease,
fibromyalgia, and multiple sclerosis), or the “unhealthy disabled,” are increasingly participating in the disability rights movement and embracing the social model of disability. Yet, the embodied experience of chronic illness draws attention to the biological realities of impairment, potentially threatening the notion of disability pride. Lupton (2013) seconds Shakespeare’s (2013) observation that, quite separately from confronting ableism, those with disabilities must deal with everyday inconveniences, minor discomfort, and, in some cases, intense pain. Understandably, these embodied experiences may cause individuals to wish for a life free from the physical challenges linked to their disability. For the unhealthy disabled, the threat of persistent health issues highlights the limitations of the social model of disability. Wendell (2001) aptly articulated this point. She wrote:

Because fear of disability contributes to the social stigma of being disabled, it is one of the goals of disability politics to replace fear with the understanding that disability can be a valuable difference . . . The question is, does this goal make sense in relation to disabling chronic illnesses? . . . compare “Thank God I’m not disabled” with “Thank God I’m healthy,” and you see the difficulty of applying disability pride to a chronic illness. (Wendell, 2001, p. 31)

Clearly, the contested boundary between disability and chronic illness creates a thorny rhetorical challenge for disability self-advocates as they organize to resist misrepresentation and control contested discourses of difference.

Troubling the distinction between disability and chronic illness draws attention to the potential benefits and drawbacks of both a biomedical and social model of disability, and in turn complicates an otherwise binary distinction between stigmatizing, ableist discourses and empowering ones. In their efforts to curb forms of “inspiration porn” and center disabled perspectives, radical activists may inadvertently alienate potential non-
disabled allies. Further, in their zeal to reframe embodied difference as valuable, addressing disabling societal attitudes, radical activists may undercut advocacy efforts aimed toward addressing physical impairments. This challenge becomes particularly apparent in communities for conditions characterized by a spectrum (e.g., autism, cerebral palsy, Dup15q syndrome), where individuals may experience drastically different degrees of impairment. In addition, expecting that those with disabilities and chronic illnesses embrace either the biomedical or social model of disability ignores the fact that individual and collective disability identities continually shift across space and time. Particular physical or interactional contexts may render either the corporeal aspects of impairment or the sociocultural dimensions of disability more salient. In turn, these shifting foci for activism and advocacy evoke various discourses of embodied difference.

As individuals and collectivities navigate between various discursive constructions of embodied difference, they may encounter the challenges of problematic integration. Problematic integration (PI) theory (Babrow, 1992; 2001; Babrow, Kasch, & Ford, 1998; Babrow & Matthias, 2009; Parsloe & Babrow, 2015) posits that individuals make probabilistic assessments about the likelihood that various circumstances will come to pass, and well as evaluative assessments about how desirable or undesirable those circumstances are. Both probabilistic and evaluative assessments are (re)constructed through communication; discourses reinforce or reframe our perceptions. When probabilistic and evaluative orientations are misaligned, individuals experience various integrative dilemmas. These include uncertainty, divergence, impossibility, ambiguity, and ambivalence.
The term “ambivalence,” when it refers to situations in which alternatives are perceived to be similarly valued and mutually exclusive (Babrow, 1992), is particularly useful for this project. For instance, self-advocates may wish for society to cease viewing embodied difference as burdensome and undesirable while also wishing that their bodies were “normal.” They may hope to eliminate inspiration porn news stories that praise disabled individuals for accomplishing mundane tasks, but also hope for avenues through which they might illustrate that people with disabilities are capable of living a “normal” life. As a result, self-advocates, and their allies, may experience irresolvable dilemmas tied to issues of (mis)representation. Indeed, PI theory notes that integrative dilemmas often do not disappear, but morph into new forms as d/Discourses center on alternative foci (Parsloe & Babrow, 2015). These dilemmas of representation persist as individual self-advocates connect in digital spaces.

**Collecting/Connecting in Digital Spaces**

Digital spaces, including social media sites like Twitter and blogging platforms like *The Mighty*, can serve as framing devices that transform crowds of individual self-advocates into networked publics (Papacharissi, 2016). By allowing geographically dispersed individuals to connect, the internet enables self-advocates to form online (biosocial) communities, defined as “temporary, voluntary, intentional connection/disconnection of individuals to a social agglomeration, which is fundamentally and essentially based on a common interest or issue” (Maireder, & Schwarzenegger, 2012, p. 181). In some cases, these online communities develop a unified, collective identity supportive of collective action. For instance, the SIDE model
suggests that online communities form strong in-group ties through the process of de-individuation, where the norms and shared characteristics of the group become more salient than any unique aspects of an individual’s identity (Postmes, Spears, & Lea, 1998). This outcome is produced via deindividuation, “a basic propensity for collective action (based on suggestibility and imitation) stimulated by anonymity in the crowd, resulting in a concomitant loss of awareness of individual identity” (Postmes et al., 1998, p. 694).

In other cases, online (biosocial) communities are more heterogeneous. Rather than forming around a collective identity, they form around the affective pull of a particular topic, such as disability rights. Papacharissi (2016) refers to these online communities as affective publics, or “networked publics that are mobilized and connected, identified, and potentially disconnected through expressions of sentiment” (p. 311). By cultivating and sustaining an affective climate, digital spaces also cultivate and sustain affective publics. While affective publics may not support the more structured organization of collective action, they can support connective action. As Papacharissi (2016) explains, “connective action practices permit people to express interest in or allegiance to issues without having to enter into complex negotiation of personal versus collective politics” (p. 314). Thus, in cultivating opportunities to engage in individual connective action practices, digital spaces may provide opportunities to establish a broader disability community despite divisive tensions.

Essentially, the internet enhances individuals’ ability to develop the kind of collective identity that facilitates collective action. However, the unifying force provided
by a collective disability identity is continually challenged by individual differences in the embodied experience of disability. Self-advocates may instead become members of an affective public, electing to participate in the more loosely coordinated activities of connective action. *The Mighty* provides a unique digital space in which to study the public performance of self-advocacy, and its potential to stimulate both collective and connective action.

**An Overview of The Mighty**

In 2009, Mike Porath and his wife received difficult news: their two-year-old daughter had been diagnosed with Dup15q syndrome—a rare genetic disorder that produces an irregular pattern of characteristics, often including autism and epilepsy (Dup15q Alliance, 2016). Facing the uncertainty of a rare condition with an unpredictable trajectory, Porath struggled to regain a sense of agency:

> I remember feeling small and hollow, a powerless husband and father. Whether it was a futile attempt to comfort my wife or a way for me to make sense of it all, I told her that we were going to do something good with this. (Porath, 2014, para. 2)

Harnessing this drive to do “something good,” Porath became a board member for the Dup15q Alliance. As the non-profit’s fundraising chair, Porath was acutely aware of the challenges associated with raising awareness and generating funding for a condition that only impacts 1,200 families worldwide. How could he connect with a larger network to organize and potentially augment advocacy? Simultaneously, Porath confronted the limitations of health websites. While these sites provided valuable medical information, they did not capture the details of the day-to-day experiences of life with a disability—the kinds of details he and his wife craved as they sought to understand Dup15q syndrome.

Organizational structure of The Mighty. Founded in spring of 2014, The Mighty is a digital publishing company that aims to provide a narrative alternative to the “black-and-white text and medical information and studies and reports. . . you find at health sites” (personal communication, M. Porath, November 5, 2015). Its tagline, “We face disability, disease and mental illness together,” reflects Porath’s vision of creating a broad, cross-condition community united by its members’ desire to combat stigma and to cultivate “strength and joy and courage” (personal communication, M. Porath, November 5, 2015) in response to a variety of challenges. Leveraging his vision to become “the world’s largest community around diseases, disabilities, chronic health conditions” (personal communication, M. Porath, November 5, 2015), Porath wooed venture capitalists intrigued by the site’s ability to attract advertisers. These initial funds allowed the fledgling company to develop its website and hire an initial editorial team. In addition, The Mighty’s staff established strategic alliances with non-profit organizations. By cultivating these relationships, The Mighty extended its reach by developing new audiences for its stories; non-profits could circulate Mighty articles among their members. Above and beyond this reach, non-profit partnerships provided an additional opportunity
for advocacy; Porath hoped that he could support non-profit partners by raising awareness through sharing their constituents’ stories, advertising their events and services, and raising funds through generating and donating advertising revenue.

*The Mighty* rapidly expanded during its first two years. By the company’s second anniversary, it had ballooned to include 2,400 contributors, 100 million total readers, 300 non-profit partners, and 20 full-time employees (Griffo, 2016). By the time this dissertation project was completed nearly one year later, these numbers had increased to 6,300 contributors and 150 million readers. The company’s Twitter handle boasted 37.6 thousand followers and its main Facebook page had garnered approximately 775,000 likes. The site had covered stories about more than 150 distinct conditions, from Addison’s disease to Williams syndrome. Its main page featured regularly-updated stories about a mixture of conditions. It also included links to specific featured topics, including news, parenting, autism, Down syndrome, anxiety, and depression. In addition, *The Mighty’s* staff developed topic-specific Facebook pages, including Autism on The Mighty, Down Syndrome on The Mighty, Rare Disease on The Mighty, Chronic Illness on The Mighty, Mental Health on The Mighty, Epilepsy on The Mighty, and Disability on The Mighty, to cater to key target audiences.

As the name, “The Mighty,” suggests, the site’s ostensible aim is to empower individuals living with disabilities and chronic illnesses. While *The Mighty* publishes news stories written by its staff, its central purpose is to provide a platform for “Real people. Real stories.” To that end, *The Mighty* team developed multiple avenues for individuals to directly participate in shaping the site’s content. Initially, Porath and his
team reached out to bloggers who were already writing about their chronic illness or disability-related experiences. Framing the company as a video hosting/blogging service, they offered potential contributors the opportunity to reach a wider audience (Terms and Conditions, 2016). In essence, writers volunteered their stories in exchange for increased visibility. As *The Mighty* gained prominence, the editorial board began to receive more and more unsolicited articles submitted via the site’s “submit a story” link, even from writers who had never previously engaged in self-advocacy work or blogging.

Clearly, the organization’s for-profit structure both facilitated Porath’s aspiration to create a massive media company and provided the organization and its contributors with increasing power to engage in advocacy work. Yet, this structure also infused *The Mighty* with the profit-focused logic of managerialism, encouraging the company to transform contributors’ stories into “products” that appeal to mainstream audiences. Thus, the company faced tensions tied to the need to both give voice to contributors and satisfy potential readers. Establishing non-profit partnerships also posed potential challenges for *The Mighty*. Partnering with a non-profit also meant endorsing both its approach to advocacy and its framing of disability, chronic illness, or mental illness. In some cases, establishing non-profit partnerships might alienate potential community members. For instance, Autism Speaks, arguably the most influential non-profit organization addressing autism spectrum disorders, has been disparaged by a large segment of the autism community for its use of fear-based rhetoric.⁸ Should *The Mighty*

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⁸ See this Medium article by Kirsten Schultz (2016) which compiles articles and blog posts outlining autistic activists’ issues with Autism Speaks: [https://medium.com/@KirstenSchultz/a-roundup-of-posts-against-autism-speaks-5dbf7f8cfc6](https://medium.com/@KirstenSchultz/a-roundup-of-posts-against-autism-speaks-5dbf7f8cfc6)
publicly link itself to such a powerful, yet controversial, organization? As *The Mighty* gained more widespread influence, these decisions became more consequential to the way in which the organization (dis)empowered self-advocates in their pursuit of various self-advocacy goals.

**Why study *The Mighty***?

“To empower a group is to legitimize its story of who its members are; to silence a group (or person) is to refuse to hear or accept its story” (Harter et al., 2005, p. 23). By providing a platform for (certain) stories, *The Mighty* allows (selective) individuals to engage in the public performance of self-advocacy. In doing so, the company develops the organizing framework for connective/collective action. However, *The Mighty’s* organizers must navigate tensions linked to its for-profit structure, as well as dilemmas of representation inherent to the disability community. Both of these issues have inspired resistance from disability activists. For this dissertation project, I investigated how *The Mighty* functions to enable and constrain digital self-advocacy at three levels: (a) the level of contributors, (b) the level of the organization, and (c) the level of detractors.

**The level of contributors.** Unlike many disability-related sites, which tend to focus on a single condition, *The Mighty* covers stories about a wide range of disabilities and chronic illnesses. Investigating this cross-condition format allowed me to interrogate the unsettled boundary between disability and chronic illness. In addition, studying *The Mighty* allowed me to theorize about how contributors write to develop individual and collective identities, and to engage in various forms of self-advocacy and collective/connective action.
*The Mighty* frames itself as both a news site and a blog-hosting platform, functioning as a hybrid of both traditional and social media. As such, it is a fascinating site for understanding how individuals make use of online platforms to publicly perform self-advocacy. *The Mighty* lends contributors significant power to render marginalized experiences visible. What purpose does this visibility serve? For some self-advocates, making one’s story visible on *The Mighty* may represent an opportunity for personal empowerment. Writers may exercise narrative agency to develop an empowered disability identity in the face of identity threats, including biographical disruption, uncertainty, and stigmatization. In writing, contributors engage in a sense-making activity that lends them a sense of control over chaotic, painful, and oppressive circumstances. By making these personal narratives visible, writers may hope for both validation and for the opportunity to “pay it forward” by helping similar others.

More than this, however, some writers may leverage the visibility afforded to them by writing for *The Mighty* to link their self-advocacy efforts to collective goals. In some cases, they may aim to participate in traditional advocacy work. Advocacy involves working within the existing medical and political system, accepting biomedical expertise and embracing education-based strategies (Brown et al., 2004; Zoller, 2005). This kind of communicative labor aligns with *The Mighty’s* goal of raising awareness and funds by partnering with non-profit organizations. Often, it draws on a biomedical narrative to direct resources towards finding treatments and cures. In some cases, advocacy work is inspired by the recognition that existing medical resources are inadequately accessible or unfairly distributed. For instance, health access movements pursue healthcare and
insurance reform, while constituency-based health social movements (HSMs) are designed to “address health inequality and health inequity based on race, ethnicity, gender, class and/or sexuality differences” (Brown et al., 2004, p. 53).

In contrast, some contributors may eschew traditional advocacy in favor of activism. Activism involves acting to challenge medical knowledge, working from outside the system to demand recognition of lived experience and lay expertise (Brown et al., 2004; Zoller, 2005). For instance, embodied health movements (EHM) are driven by patients who “simultaneously challenge and collaborate with science” (Brown et al., 2004, p. 56), demanding that medical professionals recognize them as active partners in the process of conducting research. In addition, they may lobby to shape funding agendas, change existing law, or instate new laws (Keefe, Lane, & Swarts, 2006). Additionally, activists may organize to control the terms of discourse and shape normative understandings of disability and illness (Brown et al., 2004, Zoller, 2005). In doing so, contributors “challenge the ways in which particular conditions have been represented by others” (Lupton, 2012, p. 135). While contributors to The Mighty may equally frame themselves as (self-)advocates, the goals of their advocacy may be quite different. Indeed, some of these goals may exists in tension with each other, producing a challenge for the site’s staff as they select the stories that will shape a developing organizational narrative.

**The level of the organization.** At the level of the organization, I was interested in studying The Mighty’s unique potentialities and challenges as both a digital space and a for-profit company.
**The Mighty as a digital space.** *The Mighty* represents an organizationally-enabled format (Bennet & Segerber, 2013), melding the logics of both collective and connective action. As Caraway (2016) explains, organizationally-enabled networks “utilize social media platforms – both commercial and custom – to aid individuals in developing their own sense of community. These same platforms are used to develop ties with supporters and organizations from other communities and social movements” (p. 910). Studying *The Mighty* provides a way of exploring how this hybrid organizational structure (Ashcraft, 2001, 2006) might amplify advocacy efforts. Additionally, it provides an opportunity to explore the limitations of this organizational structure. For instance, not all stories are published by *The Mighty*; writers’ contributions are filtered through the company’s editorial process. *The Mighty* mobilizes an organizational narrative (Mumby, 1987) that (de)legitimizes particular realities and privileges specific stakeholders, including readers, non-profit partners, and advertisers. Over the course of this dissertation project, I consider how *The Mighty* (re)designed its digital infrastructure in ways that created or responded to the tensions that it faced as a for-profit company.

**The Mighty as a company.** Although *The Mighty* frames itself as a site for democratic participation, it faces the inevitable tensions and contradictions produced by the gap between participatory ideologies and the practical demands of organizing (Harter, 2004). Harter (2004) seconds Stohl and Cheney’s (2001) contention that “democratic dilemmas arise from: (a) structure (i.e., the architecture of participation); (b) agency (i.e., the efficacy of participation); (c) identity (i.e., the character of participation); and (d) power (i.e., the direction of participation)” (p. 95). As a result, *The Mighty’s* staff must
negotiate several tensions tied to its for-profit structure, its attempt to appeal to both able-bodied and disabled writers and readers, and its decision to include stories about a broad range of conditions.

First, *The Mighty* must manage the tension between the company’s need to turn a profit and its desire to empower contributors. In her research on autobiographies penned by those with disabilities and chronic illnesses, Cardillo (2010) noted that writers’ words are shaped by anticipated reactions from an audience and by the “demands of editors and publishers, who are interested in stories that are understandable, interesting, and meaningful to readers” (p. 530). Operating in a capitalist, neoliberal system, *The Mighty*'s editors select and promote stories that are likely to resonate with consumers. Driven by metrics of success such as Facebook likes, re-tweets, and site traffic, *The Mighty*'s staff may incidentally perpetuate traditional media tropes that are familiar to mainstream audiences. In addition, because *The Mighty* has partnered with non-profits and hopes to attract advertisers, it must consider these stakeholders’ interests as part of its editorial process.

In addition, because the site speaks to both parents and people with disabilities, *The Mighty*'s editors face tensions regarding issues of representation. Using the correct terminology is a particularly thorny subject in the disability community. For instance, while the term “special needs” is embraced as appropriate by many parents and members of the non-disabled population, it is viewed as a demoralizing marker of marginalization
by many members of the disability community. Indeed, Haller (2010) noted that “much media coverage of disability issues often does not include language that reflects current usage within the community” (p. 52). Additionally, because the site publishes stories written by both self-advocates and others, it raises questions about who owns a story and what aspects of that story should be told in a public forum. For instance, by drawing heavily from content generated by “mommy bloggers,” *The Mighty* legitimates parent perspectives while potentially violating the self-advocacy mandate, “nothing about us, without us.”

Finally, by publishing stories on both chronic illness and disability (the unhealthy disabled and the healthy disabled), *The Mighty* confronts the challenge of juxtaposing perspectives drawn from both the biomedical model and the social model of disability. As a result, *The Mighty* is a digital space where contested discourses of difference collide. This dissertation project was designed to explore the communicative processes *Mighty* staff members engaged in to organize amid this collision, especially in response to vocal detractors.

**The level of detractors.** *The Mighty’s* meteoric rise to prominence has not been without criticism. Its articles have instigated public backlash from disability activists, providing a useful context to study disability cyberactivism and connective action (Parsloe & Holton, 2017). Disability cyberactivism has been particularly effective on

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9 The National Center on Disability and Journalism (2017) recommends against using the term “special needs” in its Disability Language Style Guide, stating that “the word ‘special’ in relationship to those living with disabilities is now widely considered offensive because it euphemistically stigmatizes that which is different”
Twitter; as Haller (2010) explained, the capacity to re-tweet or re-circulate content “means that a disability topic can get the notice of not just disability topics followers but journalists, who are looking for sources, story ideas, or more information on a topic” (p. 14). Below, I outline two critical incidents that reflect activists’ use of social media—especially Twitter—to protest perceived misrepresentation.

In May of 2015, The Mighty published a story entitled “My Daughter Wants to Choose Heaven over the hospital” (Moon, 2015). In it, contributor Michelle Moon detailed a conversation she had with her four-year-old daughter, Julianna, about whether or not she would like to continue going to the hospital to treat complications from Charcot-Marie-Tooth Disease, a neurodegenerative condition. In October 2015, the story was taken up by CNN and People Magazine. The articles frustrated disability activists Emily Wolinsky and Laura Halvorson. In response, they founded Dear Julianna, a hashtag and Tumblr campaign that encouraged individuals with a neuromuscular disorder (NMD) to write encouraging open letters addressed to Julianna. Through this campaign, contributors hoped to highlight the potentially harmful impact of framing NMDs as terminal illnesses instead of as disabilities (Wong, 2016).

Similarly, in December of 2015, The Mighty published “Meltdown Bingo,” an article in which an autistic mother outlined a Bingo card cataloguing all the ways in which her autistic son’s meltdowns negatively affected her (Neumeier, 2015). The article received widespread condemnation from the disability community, whose members protested what they viewed as the author’s disregard for her son’s experience of suffering. The Mighty retracted the story, issued an apology, and solicited feedback. In
response, disability activist and founder of StoryCorp’s Disability Visibility Project, Alice Wong, developed the Twitter campaign, #crippingthemighty. Using this hashtag, Wong and other disability activists sought to reshape *The Mighty*’s editorial and organizational practices.

Both #dearjulianna and #crippingthemighty demonstrate how counter-narratives emerge and proliferate as self-advocates organize to control contested discourses of difference. More specifically, they illustrate how social media offers new opportunities for self-advocates to engage in collective/connective action, particularly as they act to resist perceived ableism. As part of this dissertation project, I aimed to add to a growing body of research (Zdrodowska, 2017; Ryan & Julian, 2017; Burke & Crow, 2017) on disability cyberactivism.

**Summary and Research Questions**

In summary, as a rapidly growing, highly visible platform for stories about disability and chronic illness, *The Mighty* is a rich site for studying how self-advocates exercise narrative agency online to shape contested discourses of difference. The traditional media perpetuate stigmatizing, ableist discourses. This ableism has both relational and material consequences. It infuses policies and shapes physical structures, rendering both resources and spaces inaccessible to those with disabilities. However, by cultivating a participatory structure and fusing traditional and social media, *The Mighty* develops a digital space for self-advocates to resist ableism and circulate empowering discourses of difference. In performing self-advocacy publicly, they transform their private interests into public concerns. At the same time, *The Mighty*’s organizational
narrative shapes and filters participation, potentially constraining the self-advocacy and connective/collective action in ways that perpetuate marginalization. As a result, counter-narratives have emerged on Twitter as self-advocates organize to critique the company.

Using *The Mighty* as the context for this dissertation project, I addressed three sets of research questions:

RQ1: At the contributor level:
   a. How do contributors (re)construct individual and collective identities via *The Mighty*?
   b. What discourses of difference are taken up by contributor’s narratives?
   c. What goals are contributors’ narratives designed to serve?

RQ2: At the organizational level: How do *The Mighty* staff members communicatively constitute opportunities for both self-advocacy and collective/connective action, even as they amplify tensions tied to these communicative activities?

RQ3: At the detractor level:
   d. What tensions of organization and representation are communicated through detractors’ protests of *The Mighty*?
   e. How do detractors organize via social media to engage in collective/connective action?

In the following chapter, I outline my methodological approach to answering these questions.
Chapter 3: Methodology

A central feature of conducting qualitative research is engaging in reflexivity; it requires acknowledging that the observations in our research have been filtered through our own perspectives. Before starting this project, my dissertation committee encouraged me to interrogate my own relationship to this topic and to my potential participants. This is an especially important step for me, given that I am a non-disabled researcher writing about issues impacting the disability community—a community whose stories have often been appropriated and exploited. I am particularly concerned with finding ways to speak with my participants as an ally, rather than speaking for them. An initial step in this direction involved reflecting on my own perceptions of embodied difference, and on their source. This exercise in self-reflection drew my attention to a curious silence in my own family.

All my life, I have known that my Uncle Mark was born with some sort of “condition.” Yet, we’ve never really talked directly about it. This dissertation project begins with a phone call I’ve always wanted to have; a phone call that allowed me to write about the unrecognized inspiration for my own research while also acknowledging Mark’s story. By sharing the outcome of my writing with him, I could speak with my uncle in a refracted way about how much he means to me (Parsloe, 2017). This is the secondary purpose of my research; while I hope to contribute to our understanding of how self-advocacy links to connective/collective action in digital spaces, I also think of my work as a means by which I can validate marginalized stories. For this, my dissertation, I write a love letter to Uncle Mark.
Growing Up with (In)Visible Difference

“I always go back and forth with my friend,” Uncle Mark tells me. “He asks me how I can believe in God when God made me like this.” Uncle Mark can’t see how I cringe when he says this—I’ve called him from California, several time zones away from where he lives on Long Island, New York. I know his friend doesn’t intend to be mean, but his comment still seems like such a hurtful thing to say. Yet, I wonder how many times Uncle Mark has heard (or wondered) something similar.

“God blessed me with the wonderfully supportive family I have,” he continues, “Another family might have had me institutionalized.” It’s hard for me to imagine that Uncle Mark might actually have been institutionalized for his differences. To me, he has always simply been “Mark”: my Godfather; the man who loves Elvis, chicken parmesan, and sharp-looking cars; the uncle who gave me a miniature pink Cadillac for Christmas and made my brother feverishly jealous. My family members never really talk about the fact that Uncle Mark looks a bit different—not because we are uncomfortable, but simply because we don’t often see him as different. No one treated Mark differently from his other four siblings. When teenaged Mark was caught skipping school in the family car, his mother exclaimed “Thank God, he’s normal” even as his father condemned him to the shame of riding the bus to school.

Although I have been close with my uncle my whole life, I only learned the actual name of his condition when I started talking with him about my dissertation. Uncle Mark was born with Apert syndrome. Caused by a genetic mutation, Apert syndrome only affects an estimated 1 in 65,000 to 88,000 newborns (Apert Syndrome, 2016). People
with Apert syndrome are born with craniosynostosis, a premature fusion of certain skull bones that can impede brain growth without surgery. It produces characteristic facial features such as wideset eyes with shallow eye sockets (Uncle Mark, master of the couch nap, often falls asleep with his eyes half-closed). Apert syndrome also causes syndactyly, where a person’s fingers and toes are fused. In the 1960s, when Uncle Mark was born, few doctors would have been able to predict how he would fare. Surgeons separated the fused bones in his skull and fashioned three functioning fingers per hand from the joints and tissue he was born with. At age 24, Mark grew tired of clomping around in Frankenstinian orthotic shoes. He laid out a plan for his doctor; he thought that removing a protruding bone might flatten his foot. “Yeah,” his doctor replied, “I think you’re right.”

It wasn’t until I was much older that I realized that Uncle Mark might have had a difficult time growing up. Despite the fact that Mark had no developmental challenges, school officials tried to place him in a separate school. He was bullied by peers, and strangers stared openly as they wondered about Mark’s appearance. Even now, restaurant waiters sometimes direct their comments to Mark’s wife instead of to him, assuming incompetence.

Music was the vehicle through which Uncle Mark connected with others. As a teenager, he became the drummer for a neighborhood garage band. Sitting behind his drum kit banging out backbeats, Mark watched audience members’ skeptical looks morph into appreciative head-nods. He once played Wipeout for an audience of questionable-looking bikers at King James Pub. As Mark walked into the place, he thought “Oh man,
we’re not going to get out of here alive.” By the end of the song, both Mark and the bikers recognized that they had misjudged one another.

“Do you think of yourself as disabled?” I ask Uncle Mark.

“Not really,” he replies, “There isn’t much that I can’t do.”

I’ve never really associated Uncle Mark with the term “disabled” either. It wasn’t until my cousin was diagnosed with autism at 18 months that I became interested in understanding communication in the context of disability. As I worked with my cousin as his full-time babysitter, I became interested in how my family collaborated with his therapist to create an environment in which he could thrive. As a result, during my very first graduate seminar in health communication, I decided to interview parents of children on the spectrum and the therapists they worked with. In the process, I read Amy Harmon’s (2012) *New York Times* article, “Autistic and Seeking a Place in an Adult World.” The story contained a cursory mention of “neurodiversity,” hyperlinked to a second article: “Neurodiversity forever; The Disability Movement Turns to Brains” (Harmon, 2004). “As psychiatrists and neurologists uncover an ever-wider variety of brain wiring,” Harmon (2004) wrote, “the norm, many agree, may increasingly be deviance” (para. 6). I had been focusing on how parents and therapists partner in helping a child function “normally,” yet here was a new civil rights movement that exploded my concept of normalcy. Intrigued, I turned to the disability studies literature to learn more. I read Nancy Bagatell’s (2007) article in *Disability & Society*, entitled “Orchestrating Voices: Autism, Identity, and the Power of Discourses.” In it, she follows one young man for nine months as he struggles to reconcile the empowered autistic identity he developed
through his participation in an online community with the physical and social challenges he encounters in his offline life.

Bagatell’s work inspired me switch my research focus to consider the autistic perspective: how do these individuals develop and maintain resilience while living in a world that continually rejects them? For my thesis research, I read online forums created by people who identify as autistic, and interviewed individuals about their experiences. I met autistic people who were proud of their place on the spectrum, and examined the discursive strategies they used to reclaim a stigmatized identity (Parsloe, 2015). I met a man with autism who told me of his suicidal ideations and shared diary entries detailing the devastation wrought by unsupportive parents and internalized ableism (Parsloe, 2017). I interviewed self-advocates and parent advocates who started various organizations designed to foster acceptance, accessibility, and inclusion. In the process, I learned about the social model of disability, and I started to think more deeply about the (dis)empowering impact of various discourses of difference.

My academic work gave me a new appreciation for my Uncle Mark. Although I’d never viewed him as physically impaired, I had begun to recognize that, all his life, Mark had resisted the disabling impact of others’ lowered expectations. When I learned the term “Apert syndrome,” I looked it up on The Mighty. I read the solitary entry, entitled, “To the Little Girl with Apert Syndrome Who Feels Like She’s All Alone.” “I speak to the girl who grew up living a life of struggles, doubt and judgment,” college sophomore, Vivi Zhang (2016), had written, “Who didn’t think she would go far in life because no one properly welcomed how she looked compared to the others around her. Don’t give
up. Because one day, you will find happiness. One day, you will find confidence just being yourself” (para. 5).

I was born into a typical, if rather petite, body. I live in a built environment that matches my physical needs (though I sometimes require a foot stool and a tailor). The only irritating comments I receive about my appearance are short jokes—easily dispatched with an eye roll, a good-natured laugh, or a quick retort. Interviewing people with disabilities and reading about their experiences has made me more cognizant of my own privileges, and of the pervasiveness of ableism. I recognize that, at this point, I cannot speak directly to what it is like to navigate the world in an atypical body. However, as someone who enjoys the privileges of being non-disabled, neurotypical, white, highly educated, and relatively “normal” looking, I feel called to be an ally to those who are marginalized because of their embodied differences. As a qualitative researcher, I have the opportunity to amplify my participants’ voices, even as I share my own imperfect understanding. By detailing the communicative strategies tied to digital self-advocacy, by outlining the tensions inherent in efforts toward advocacy and activism, and by interrogating sites like The Mighty, I aim to illuminate and critique narratives that perpetuate marginalization. Below, I outline my approach to data collection and my methodological approach to this project.

**Data Collection**

In keeping with a social constructivist conception of health communication, I adopt an interpretive definition of theory. An interpretive theorist aims to develop a rich understanding of the phenomena of study, and “assumes emergent, multiple realities;
indeterminancy; facts and values as linked; truth as provisional; and social life as processual” (Charmaz, 2006, p. 126). With these aims and assumptions in mind, I utilized qualitative methods to conduct this dissertation research. My goal was to collect data that was rich, suitable for the context of study, and sufficient to capture “as full a picture of the topic as possible within the parameters” of this dissertation project (Charmaz, 2006, p. 18). The following sections describe my approach to gathering interview and text-based data.

**Intensive interviews.** Charmaz (2006) defined intensive interviews as conversations that “permit in-depth exploration of a particular topic or experience” and ask the interviewee to “reflect upon his or her experiences in ways that seldom occur in everyday life” (p.25). These kinds of interviews are valuable in that they elicit stories that “give shape to human experience in terms of actors, intentions, context, and actions” (Lindlof & Taylor, 2010, p. 174). For this project, I wanted to elicit stories about the decision to write an article for *The Mighty*, about interactions with contributors and co-workers that shaped *The Mighty’s* organizing practices, and about experiences of repulsion that inspired participation in #crippingthemighty. To that end, I conducted semi-structured interviews with several types of participants, including (a) *Mighty* staff members, (b) *Mighty* contributors, and (c) #crippingthemighty activists. All interviewees were emailed or provided with a physical copy of the consent form prior to scheduling an interview, and were given an opportunity to ask questions about the project before starting an interview. All interviews were either audio-recorded or were conducted via a chat service that provided a ready-made written record of the conversation.
Mighty staff members. Given that some of my research questions address organizing processes that communicatively constitute The Mighty, it was necessary to interview the organization’s staff members. This project began with an initial interview with the company’s founder, Mike Porath, conducted via Skype for a previous project. In this interview, I asked questions such as “Can you tell me the origin story for your organization? How did the organization come to be?”; “Why did you decide to develop an advocacy organization? Was there a moment when you knew you needed to form this organization? If so, what flipped the switch?”; and “Tell me about some memorable conversations that inspired you to develop this organization. Who did you talk with and what did they tell you?” These questions are primarily “experience questions,” designed to prompt participants to “tell a story in a highly personal, first-person voice” (Lindlof & Taylor, 2011, p. 206). The goal for this interview was to elicit the founder’s initial motivation for starting the site, his vision for its future, and his sense of the company’s day-to-day operations (see Appendix A for interview guide).

After securing a letter of approval from Porath to conduct further research (see Appendix B), and after receiving authorization from Ohio University’s Institutional Review Board, I traveled to Burbank, California, and spent two full working days at The Mighty’s headquarters. This trip allowed me to interview the majority of the company’s staff. In these interviews, I asked narrative-based experience questions, such as “Would you tell me about your personal connection to disability, chronic illness, mental health conditions, or rare diseases? What inspires your work with The Mighty?” and “Tell me the story of how you came to work at The Mighty” to explore the motivations that guided
staff members’ work. I also asked questions like “Would you describe yourself as an advocate? In your own words, define what it means to be an advocate” to elicit participants’ understanding of the nature of this communicative process. Over the course of my data collection process, this last question served as a data-referencing question (Tracy, 2013), providing an opportunity to compare previously-proffered definitions of advocacy with new participants’ perceptions of this activity. In addition, this semi-structured interview guided evolved to incorporate *in vivo* language questions (Tracy, 2013) that follow-up on new terms, like search engine optimization (SEO) and “hub pages,” that appeared to be key to *The Mighty’s* daily operations and future visions (see Appendix C for interview guide).

Before arriving at the office, I sent all staff members a link to a scheduling service that allowed them to anonymously sign up for an interview timeslot. I interviewed several members of *The Mighty’s* editorial staff, including: (1) the editor-in-chief, (2) the senior editor, (3) the chronic illness editor, (4) the mental health editor, and (5) a contributing editor (responsible for editing contributions across topics). I also interviewed a video producer, responsible for transforming written articles into visual stories and for preparing contributors to host question-and-answer sessions via Facebook live. Additionally, I interviewed staff members who are responsible for designing and building the site’s features, including (1) the vice president of product and (2) the head of growth. All interviews were conducted privately, either in Mike Porath’s office or in the company’s closet-like board room (affectionately nicknamed “Narnia”). I was also able to conduct an ethnographic interview with Porath, gathering information about the
company’s latest projects and about how the company had responded to #crippingthemighty, which had occurred a little more than one month after our initial interview. Porath subsequently wrote an article, published on Linkedin, which described my visit and outlining his vision for the company in detail. I have included this article in my textual analysis. It functions as a type of elicited text—a text generated in response to a researcher’s request (Charmaz, 2006).

While on-site, I wrote field notes to capture staff members’ interpersonal dynamics and snippets of their conversations, sketched the physical layout of the office, and documented prominent artifacts such as a collage of letters and pictures from contributors featured on the breakroom’s bulletin board.

To account for staff members who telecommute or who were not able to meet with me during my visit, I conducted several additional interviews remotely. I connected with several participants by phone, including (1) another contributing editor, (2) the community manager, responsible for moderating the company’s Facebook pages and comments left on Mighty articles, and (3) the director of community partnerships, responsible for establishing, and developing resources for, the non-profit partnerships. Finally, I conducted interviews via Skype with the disability editor and with the news editor. I have included a list of participants’ job titles in Appendix D, but I have elected to share demographic information separately to avoid compromising confidentiality and identifiability. I have used pseudonyms to refer to all Mighty staff participants, except for Mike Porath, in the body of my analysis. In some cases, I have used a participant’s job title, but have not linked the title with a pseudonym. This strategy allowed me to provide
additional context for some quotes (for instance, quoting the news editor to discuss the site’s approach to news coverage), but also to preserve participants’ confidentiality as much as possible.

All totaled, I interviewed 14 *Mighty* staff members, including 5 men and 9 women. The staff was relatively young; my participants ranged in age from 23 to 47, with an average age of 31. Most staff members self-identified as white/Caucasian (10 participants); one identified as Asian-American, one identified as Mexican-American, one identified as Indian, and one identified as being of mixed ethnicity. Five of my 14 participants identified as having either a disability or chronic illness. One identified as having a mental health condition. Staff members had been working at *The Mighty* for between 3 months and the full two years of its existence. On average, they had spent 11 months with the company. Interviews ranged between 40 and 126 minutes, and were 72 minutes long on average. I used two transcription services, Scribie and Go Transcript, to transcribe all interviews. However, I also listened to the audio-recorded transcripts myself to begin the data analysis process and to check the transcriptions for accuracy. This dataset totaled 353 single-spaced pages of transcription.

**Mighty contributors.** *Mighty* contributors were recruited via an emailed invitation (see Appendix E). I primarily contacted contributors who were included on the Excel spreadsheet of contact information provided to me by *The Mighty’s* staff. They attempted to construct a sample of contributors that would include both people with disabilities and chronic illness, and would include people who have written frequently for the site and people who have only published one or two articles. This spreadsheet
included 189 potential interviewees; 109 had self-identified as having a chronic illness, 49 self-identified as having a disability, and the remaining 31 associated themselves with specific conditions. I emailed participants from the list in batches of 15 using the blind carbon copy function in Outlook, sending out new calls for participants every two to three days to avoid being overwhelmed with responses. Over time, I found that I was getting responses most frequently from people with chronic illnesses, chronic pain conditions, and rare conditions. I used articles that I had already gathered to find contributors with physical and neurodevelopmental disabilities, reaching out to them through information about their personal blogs included in their Mighty bio.

I used a semi-structured interview guide to generate conversation, adjusting prompts to make them appropriate for specific participants and to focus on themes that had emerged during, or had been missing from, previous interviews. I echoed some questions from my interviews with staff members, especially asking contributors to describe what they saw as The Mighty’s purpose and to define the nature of advocacy and describe their sense of themselves as an advocate. These overlapping questions provided opportunities to identify convergences and divergences in the ways in which Mighty staff members and contributors viewed the site and their purpose(s) for writing. Additionally, I asked contributors to define terms like “disability” and “chronic illness,” eliciting answers that indicated which discourses of difference Mighty contributors were drawing from to construct their identities. Additionally, questions directed contributors to consider what motivated them to write publicly about their experiences and how they had settled on The Mighty as an outlet for their story (see Appendix F for interview guide).
I interviewed one participant in person. Most interviews were conducted via Skype or Google Hangout, phone, and through the chat features of platforms such as Facebook and Google chat, allowing me to reach geographically dispersed contributors while also adjusting to individuals’ technological preferences and physical abilities. Four participants emailed responses to my interview guide, an option that allowed me to include them in the study despite time constraints, difficulties with scheduling across time zones, and social anxiety. At the same time, these methods of data collection limited my ability to attend to my participants’ physical, embodied realities, an unfortunate limitation given that this study is concerned with discourses of difference and the interplay of physical impairment and disabling social forces (Markham, 2005).

In total, I conducted 30 interviews with 29 participants. Participants included four men, one person who responds to all gender pronouns, and 24 women. They ranged in age from 21 to 59, with an average age of 36. The majority (21 participants) self-identified as white/Caucasian. Three participants identified as mixed race, two identified as Asian (Pacific Islander; Filipino), two identified as Latinx, and one identified as African-American. More than half (17 participants) were employed, self-employed, or had part-time jobs. Ten participants were unemployed or were currently seeking disability. One participant was retired, and one was a full-time student. Most (21 participants) identified as upper or middle class, while six identified as “lower income” “dependent on others” or “in poverty.” Two participants declined to respond to this question. At the time that they were interviewed, these participants had published between one and 18 articles on The Mighty, writing 6 on average (however,
approximately half of the participants had published 3 or fewer articles). Eleven participants self-identified as having a disability, and 17 had a chronic illness. I also included one participant who did not have a condition herself, but who wrote a book to capture her experiences as a daughter and sibling to family members with the same rare genetic condition. See Appendix G for information about participants’ conditions.

Interviews lasted between 29 and 109 minutes, with an average length of one hour. The transcribed data filled 465 single-spaced pages. I refer to participants using pseudonyms, unless participants expressed comfort with remaining identifiable.

#Crippingthemighty activists. I also secured two interviews with prominent disability activists who interacted with #crippingthemighty. I spoke with:

(a) Alice Wong: Alice Wong initiated the #crippingthemighty hashtag, and has created several important initiatives in the disability community. Here is a brief description of her work, taken from the Disability Visibility Project’s (n.d.) “About” page:

Alice Wong is a San Francisco-based degenerate tv watcher, cat lover, and coffee drinker. She is the Founder and Project Coordinator for the Disability Visibility Project™ (DVP), a community partnership with StoryCorps and an online community dedicated to recording, amplifying, and sharing disability stories and culture created in 2014. Alice is a co-partner in #CripTheVote, a nonpartisan online movement activating and engaging disabled people on policies and practices important to the disability community. . . . Alice’s areas of interest are accessible healthcare for people w/ disabilities, Medicaid policies and programs, storytelling, and social media. She has a Masters in sociology and worked at the University of California, San Francisco as a Staff Research Associate for over 15 years. During that time she conducted qualitative research and authored online curricula for the Community Living Policy Center, a Rehabilitation Research and Training Center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research and the Administration for Community Living. From 2013-2015
Alice served as a member of the National Council on Disability, an appointment by President Barack Obama. (para 6-8)

(b) Meriah Nichols: Meriah Nichols crafted several key blog posts in response to #crippingthemighty. She operates her own blog, Meriah Nichols: A Disability Blog with A Little Moxie. She also launched an online disability-related publication, Two Thirds of the Planet. Additionally, Nichols created the #365dayswithdisability project, an “Instagram-based photo project that seeks to normalize disability, one gloriously mundane photo at a time” (Nichols, n.d., para. 1). She has a traumatic brain injury, PTSD, and bi-polar disorder, but the main disability she identifies with is being deaf. She also has a young daughter with Down syndrome. Nichols has been a driving force in transforming the way parents write about children with disabilities, especially in the Down syndrome community. The bio on her personal blog reads: “I’m a deaf teacher, artist, activist and mom to 3 (one with Down syndrome).”

Interview questions overlapped significantly with questions asked to Mighty contributors, focusing on similarities and differences linked to participations conceptualization of advocacy, their motivation to make their stories public, their sense of belonging to a collectivity, and their perceptions of The Mighty’s purpose. I also asked questions designed to elicit the motivation behind, and the perceived impact of, #crippingthemighty, including “Not everyone who has a disability/chronic condition actively participates in movements like this. What made participating important to you?”; We are now nearly a year since the #crippingthemighty movement. What impact, if any, do you think that this initiative made?”; and “If you were to stand back and critique this
movement, what might be some of its challenges?” I also posed hypothetical questions (Tracy, 2013) about what an improved version of *The Mighty* would look like (see Appendix H for interview guide).

Both Alice Wong and Meriah Nichols consented to remaining identifiable in this research. I refer to them by their first and last names because I switch between citing quotes from our interviews and quotes from their published work. I distinguish between these two sources of data by included years and page numbers associated with any published work. My interview with Alice Wong was conducted via Skype, lasted for 68 minutes, and generated 18 pages of single-spaced transcription. My interview with Meriah Nichols was conducted via Facebook chat, lasted for approximately one hour, and generated nine pages of comments.

**Textual analysis.** Much of my data collection involved gathering extant texts—texts that were not generated in response to any requests from me (Charmaz, 2006). As Lindlof and Taylor (2011) explained, documents or texts are useful forms of data in that they are rich sources of information, are typically widely available on internet-enabled platforms, and are nonreactive—they are the relatively enduring and unchanging products that have “come into being at the end of a lively social process or as the result of deliberative and/or creative thought process by an individual” (p. 237). Given that texts are forms of discourse generated from shared conventions and assumptions, researchers can “compare the style, contents, direction, and presentation of material to a larger discourse of which the text is a part” (Charmaz, 2006, p. 35). I followed Charmaz’ (2006) recommendation to analyze texts by comparing their structure with their content, thus
attending to the ways in which *Mighty* articles and #crippingthemighty blog posts have been structured in ways that pursue individual and collective goals tied to the text’s content. For instance, I have considered what it means for both contributors and #crippingthemighty activists to structure their articles as open letters.

For this project, various texts provided a sense of the larger discourse(s) of disability as (re)constructed on *The Mighty* and in response to *The Mighty*. This project required analysis of two key sources of text-based data: *Mighty* articles and #crippingthemighty blog posts. Analyzing *Mighty* articles provided me with a means to explore what discourses contributors drew from to both engage in identity (co-)constructing and to select and express collective goals for advocacy and activism. I collected my sample of *Mighty* articles during a one month period between May 27, 2016 and June 27, 2016. Until June 17th, I collected all articles authored by a person with a chronic illness or disability. However, I began to recognize that I was collecting many more articles about chronic illness than disability, and that the topics covered in these chronic illness articles appeared redundant. From June 17th through the 27th, I focused on collecting only articles written by authors who had disabilities. I collected a total of 213 articles. Appendix I offers a list of all conditions included in this dataset. *The Mighty*’s editor-in-chief also gave me access to the Google document that staff members used to store past monthly blogging prompts. Analyzing this document provided additional insight into how *Mighty* contributors generate articles in response to these topical and formal recommendations.
In addition, I followed several of The Mighty’s Facebook pages, including their main page, Disability on The Mighty, Chronic Illness on The Mighty, and Rare Disease on The Mighty. Doing so allowed me to passively observe new articles as they were posted to the company’s social media feeds. Encountering new Mighty articles via Facebook pushed me to critique, alter, and expand upon my initial theorizing by exposing me to articles that were structured differently and addressed different topics. In this way, following The Mighty on Facebook discouraged a premature closure of inquiry.

I collected a second corpus of text-based data to capture prominent responses to #crippingthemighty. By both Googling “Crippingthemighty” and “Meltdown Bingo” and by collecting materials that had been shared via the Twitter hashtag, I gathered blog posts and articles addressing the controversy. In addition, I followed Alice Wong’s Facebook page, Disability Visibility, to keep up with any additional developments. In this way, I learned about an article that Wong wrote to capture disability activists’ responses to the hashtag one year later. I was also alerted to a brief resurgence of the hashtag at the beginning of April of 2017, when disability activists discovered The Mighty’s non-profit partnership with the controversial organization, Autism Speaks. Finally, in the process of monitoring The Mighty’s website, I realized that the company had hired a disabled editor, Twilah Hiari, who then disappeared from the site’s “Our Team” page. I located her blog post about why she resigned, and asked Hiari for permission to include it in this dissertation. The final #crippingthemighty dataset included a total of 22 articles and blog posts (see Appendix J).
Data Analysis: Grounded Theory

I have utilized Charmaz’ (2006) constructivist approach to grounded theory, informed by tenets proposed by Glaser and Strauss (1967), to conduct an analysis of the data enumerated above. Certainly, narrative thematic analysis might have been a helpful approach for this project. Indeed, Riessman (2008) outlines how thematic narrative analysis could be used to interrogate “how individual’s stories of resistance actually generate collective action in social movements” (p. 73). However, I preferred to use a grounded theory approach to this project for several reasons. First, thematic narrative analysis typically begins with a strong theoretical framework. While theoretical ideas about stigma, social construction, collective and connective action, as well as theoretical frameworks such as PI theory, structuration theory, and the communicative constitution of organizations perspective provide “sensitizing concepts” (Charmaz, 2006, p. 17) for this project, I wanted to allow the data to suggest which theories I ultimately attended to. Indeed, Charmaz conceptualized grounded theories as “products of emergent processes that occur through interaction” (p. 178). This approach captures my dynamic, flexible approach to theorizing, and also recognizes that both data and analysis are co-constructed by the researcher and study participants.

Second, grounded theory was an appropriate methodology for this study because, rather than being interested in the form of individual narratives, I was more concerned about the goals of these narratives and the ways in which self-advocates communicate to achieve them. Grounded theory, particularly as outlined by Charmaz (2006), is concerned with the particular activities that communicative labor accomplishes. Additionally,
whereas thematic narrative analysis is concerned with explicating individual cases, grounded theory seeks to “generate inductively a set of stable concepts that can be used to theorize across cases” (p. 74). My goal was to develop a more general sense of the discourses that infuse self-advocates’ narratives and their attendant goals, especially paying attention to tensions produced by conflicting narratives.

Finally, whereas thematic narrative analysis attempts to preserve the structure of a narrative (Reissman, 2008), grounded theory involves fracturing the data in order to reassemble it to support developing theoretical categories. Again, this satisfied my desire to theorize across cases. In addition, this approach made it easier for me to integrate insights from list-style articles and other forms of data which did not reflect the traditional narrative format. The following sections offer a more detailed description of my analytic procedures.

**Analytic procedures.** “Coding” refers to the analytic activities necessary to begin “weaving two major threads in the fabric of grounded theory: generalizable theoretical statements that transcend specific times and places and contextual analyses of actions and events” (Charmaz, 2006, p. 46). To begin this weaving process, I first loaded all of my data files into the data management software, NVivo. I created four NVivo project files to correspond to each segment of my larger data corpus, including (a) *Mighty* articles, (b) *Mighty* contributors, (c) *Mighty* staff members, and (d) *Mighty* detractors. Using this software and creating four files enabled me to better navigate my unwieldy dataset, and also allowed me to attend closely to the communicative processes characteristic of each of these sub-contexts. Within each file, I created folders of codes that appeared to connect...
across contexts (for example, data from contributors that connected to what staff members had told me). I then collected these data excerpts into a single file and uploaded that file into the associated context (for example, moving data from the contributors file into the staff members file), re-coding it to explore connections between each of my four smaller datasets.

I began my coding process by engaging in initial coding, using both line-by-line and incident-by-incident coding. These approaches to coding attend to Glaser’s (1978) recommendation to create codes using gerunds, capturing the processes that participants are engaging in. For example, in initial codes included phrases like “balancing divides in the community” and “withdrawing from The Mighty.” Additionally, initial coding involved developing in vivo codes that reflected culturally significant words and phrases (Olson, 2011), including “insider shorthand terms specific to a particular group that reflect their perspective” (Charmaz, 2006, p. 55). For instance, I recorded the use of terms like “zebra,” “spoonie,” and “Crohnie” which referred to specific sub-groups on the site. Additionally, I recorded the metaphors that participants used to describe their experiences, aware that these metaphors reflected and perpetuated particular understandings of embodied difference. All transcripts and articles were coded in full during this initial coding stage. Thorough initial coding allowed me to identify and fill apparent gaps in my dataset to flesh out concepts that were of increasing theoretical interest.

During a second stage of focused coding, I began to group initial codes together by comparing data to data. I also began to compare new data to emergent concepts,
changing or deepening my understanding of those concepts in the process. As I gained a clearer sense of the dataset as a whole, I began to eliminate or rephrase initial codes that no longer appeared to capture the nature of participants’ activities, experiences, and motives. At this stage, I also began to identify related processes tied to larger segments of data, such as participants’ anecdotes. For instance, I generated focused codes such as “re-narrating the past,” “constructing a ‘new normal,’” and “re-imagining the future.” At this point, I began generating my version of advanced analytic memos (Charmaz, 2006). These were not as detailed as Charmaz (2006) recommends; rather, I began constructing alternative outlines for the ways in which emergent focused codes might fit together.

In a third stage of coding, described by Strauss and Corbin (1990) as “axial coding,” I began to identify the sub-components and facets of larger theoretical categories. In practice, this involved both generating broader themes in which to situate seemingly related focused codes (for example, situating “re-narrating the past,” “constructing a ‘new normal’” and “re-imagining the future” under the larger category, “revising a non-disabled self”) and exploring the subcomponents of a larger category (for example, breaking down “protesting oppression” into “protesting inaccessible healthcare,” “protesting ableist representations,” and “protesting institutionalized ableism”).

I also engaged in a fourth and final stage of coding: theoretical coding. As Charmaz (2006) explained, theoretical coding incorporates pre-existing theory in a way that may “help you tell an analytic story that has coherence. Hence, these codes not only conceptualize how your substantive code are related, but also move your analytic story in
a theoretical direction” (p. 63). While some sensitizing concepts had informed my thinking all along, I only began to incorporate pre-existing theory explicitly after writing initial drafts of each analysis chapter. During the revision process, I added references to various theories throughout my analysis, creating a bricolage of more generalizable theoretical assertions and more grounded, context-driven observations. Additionally, after I had written all four of my analysis chapters, I returned to each chapter to add a summary and discussion. In these segments, I engaged in more sustained theorizing to frame my observations using terms like “problematic integration,” “structuration,” and “paradoxical hybrid forms.” While this account of my analysis process suggests a linear structure, the reality was purposefully messy and recursive in ways that reflect the true spirit of grounded theory.

**Cultivating the emergent spirit of grounded theory.** To successfully construct a grounded theory, rather than a thematic analysis, researchers must incorporate three key processes to ensure that codes and theoretical categories truly emerge from immersion in the data, rather than from the application of existing frameworks. First, grounded theorists enact the constant comparative method. This method directs ethnographers “(1) to compare data with data from the beginning of the research, not after all the data are collected, (2) to compare data with emerging categories, (3) to demonstrate relations between concepts and categories” (Charmaz, 2006, p. 23). I have aimed to satisfy these tenets of constant comparative method in several ways. First, collecting a corpus of *Mighty* articles prior to conducting interviews allowed me to begin initial and focused coding while still gathering new data. This allowed me to compare data to data from the
outset, a process that I continued through analysis of each sub-set of my full dataset in turn. Similarly, I collected each set of interviews consecutively, starting first with collecting all staff member interviews, then all contributor interviews, then the two detractor interviews. This meant that I was transcribing and analyzing one set of data while collecting another, allowing me to compare the new data with emerging categories. Additionally, as previously described, I read new scholarly materials across the course of my analysis and writing process, allowing me to compare newly-encountered theoretical concepts with newly analyzed data.

Second, true grounded theories make use of theoretical sampling. Charmaz (2006) defines theoretical sampling as the process of “seeking pertinent data to develop your emergent theory” in order to “elaborate and refine the categories” (p. 96). The Mighty’s site provided a useful means to engage in theoretical sampling. For instance, when I identified the emergent category, “writing open letters,” which later became an aspect of “refracted self-advocacy,” I needed a way to elaborate on the specific purposes that these open letters were crafted to achieve. I turned to the search bar on the company’s website, plugging in the phrases “to the” and “to my” to generate additional examples of open letters. Additionally, as I described when outlining my methods, I purposefully sampled more articles and interviews written by people with disabilities once I recognized that my developing dataset was oversaturated with chronic illness-related data.

Finally, true grounded theories strive for theoretical saturation, or the point when “gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories” (Charmaz, 2006, p. 113). As outlined in
the description of my methods, I followed several of The Mighty’s Facebook pages and Alice Wong’s Disability Visibility Facebook page. Doing so provided me with a means to continually observe new content published by The Mighty and published by disability activists. This provided one means to check for theoretical saturation; I knew that my emergent categories were well-developed when the new content present on my Facebook feed resonated with my theoretical framework without offering any additional insights. Additionally, as I continued to analyze articles and interviews collected in each of my four sub-sets, I found that my initial codes were becoming increasingly redundant. Utilizing the constant comparative method, engaging in theoretical sampling, and pursuing theoretical saturation enhanced the rigor of this qualitative project.

**Pursuing quality in qualitative research.** To craft a qualitative project worthy of my participants, I have attended to the eight “big tent” criteria for excellent qualitative research proposed by Tracy (2010). She contends that quality qualitative projects have (a) worthy topic, (b) rich rigor, (c) sincerity, (d) credibility, (e) resonance, (f) significant contribution, (g) ethics, and (h) meaningful coherence. While I believe that the worth of this general topic of this project is self-apparent, I have constructed my study rationale developing a clear argument for why The Mighty provides a particularly worthy case study. In addition, I have outlined my approach to collecting an appropriately large corpus of data that samples a variety of key perspectives, allowing me to thoroughly support my claims and to provide the “complexity of abundance” and “bountifully supplied, generous, and unstinting” descriptions and explanations characteristic of richly rigorous projects (Tracy, 2010, p. 841).
Tracy (2010) defines sincere research as “research that is marked by honesty and transparency about the researcher’s biases, goals, and foibles as well as about how these played a role in the methods, joys, and mistakes of the research” (p. 841). While I have engaged in some self-reflexivity in the narrative describing how interactions with my uncle and cousin inspired this research, I conclude this dissertation project with more personal descriptions that capture that challenges I faced in developing this dissertation and that nature of academic advocacy.

Credibility refers to the “trustworthiness, verisimilitude, and plausibility of the research findings” (Tracy, 2001, p. 842), accomplished through engaging in thick description (Geertz, 1973) and cultivating multivocality. While my fieldwork was minimal for this study, I have attempted to offer thick accounts of my participants’ experiences by weaving interview responses together with the detailed descriptions available in Mighty articles and #crippingthemighty blog posts. In addition to cultivating multivocality by including data from numerous participants, I also made an effort to place participants’ ideological assumptions in contrast with each other: I contrast medicalized understandings of disability with social ones, and offer accounts of #crippingthemighty from the perspectives of both Mighty staff members and detractors. Additionally, credible research includes soliciting members’ feedback and reflections on the developing project. While I have not shared the entire dissertation with my participants, I shared pieces of it with one contributor who offered feedback on previous drafts. Additionally, I intend to send the completed dissertation to all participants who expressed interest in receiving it, as well as an executive summary of findings. Receiving responses from participants will
inform the future work of refining and parsing ideas. These aspects of credibility are also key components of my stance regarding ethical research. I approached all participants with transparent descriptions of my intentions, and respectfully considered contradictory viewpoints.

Research is resonant when it is able to “meaningfully reverberate and affect an audience” (Tracey, 2010, p. 845). I have attempted to generate as complete an accounting of the processes of identity (re)construction and the nature and goals of self-advocacy and collective action as possible, hopefully developing a final piece that speaks to multiple experiences of chronic illness and disability. While I have acted as the conductor for this data symphony, much of its aesthetic merit stems from the strikingly insightful and evocative ways in participants described their own experiences.

Finally, Tracey (2010) asserts that good qualitative research offers significant contributions and is presented in a coherent way. My analysis chapters both build on theory and offer new directions for inquiry related to four topics that logically stem from my research questions. First, Chapter 4 explores the ways in which Mighty contributors (re)construct the disability and chronic illness identities on the site, integrating various discourses of difference into their narratives and positioning themselves as members of narrow or broad biosocial collectivities. Second, Chapter 5 considers how contributors use the site to engage in refracted self-advocacy, collective self-advocacy, and collective/connective action, illustrating how they act on individual and collective goals informed by their individual and collective identities. Third, Chapter 6 explores how The Mighty’s staff members develop a platform that supports and shapes the aforementioned
activities, attending to key tensions that shape their organizing processes. Fourth, Chapter 7 acknowledges criticisms from #crippingthemighty activists, linking their criticisms to The Mighty’s organizational tensions and illustrating how this form of cyberactivism worked to structurate The Mighty. Finally, Chapter 8 provides a conclusion that summarizes theoretical implications, limitations, and future directions, while also offering significant practical contributions.
Chapter 4: Chronic Illness, Disability, and Identity (Re)construction on *The Mighty*

The experience of living in a physically or cognitively different body poses a variety of identity challenges. For individuals who are born with a disability, identity (re)construction involves constructing a sense of self in relation to a non-disabled majority, and others with disabilities, across the course of a lifetime. Alternatively, people who become suddenly disabled via an accident or through acute illness experience a tumultuous period of identity crisis in which they must revise a previously non-disabled self. However, *Mighty* contributors often fell into a third, intermediate category: they had finally received an accurate diagnosis after experiencing long periods of being undiagnosed, self-diagnosed, misdiagnosed, or underdiagnosed.

This chapter incorporates insights from *Mighty* articles and from interviews with contributors to explore the processes of (re)constructing an identity in response to these experiences of difference. First, I consider how *Mighty* contributors engage in three interlinked sensemaking process to revise a non-disabled self in the wake of diagnosis. Second, I problematize these sensemaking processes by exploring how sources of diagnostic, physical, and social flux disrupt individuals’ ability to create and integrate probabilistic and evaluative orientations. Third, by attending to the metaphors used in *Mighty* articles, I describe how contributors draw from various discourses of difference to evaluate their identities as people with chronic conditions or disabilities. In addition, I outline how individuals began to see themselves as members of biosocial communities, positioning themselves along a spectrum of relatively narrow to broad collective identities.
Sense-Making and Diagnosis: Revising a Non-Disabled Self

We had no idea what we were up against. Then the doctor came through the door and uttered the words, “Addison’s disease.” As he began explaining this unfamiliar illness, my head was buzzing with both thoughts of relief and thoughts of fear. Relief because the drought of not knowing was finally over — we had a diagnosis and a plan. Fear because he was throwing around phrases like “steroid treatment” and “life-threatening.” (McKnight, 2016, para. 2)

This excerpt, taken from a Mighty article entitled, “When My Doctor Gave Me a Lifetime Diagnosis at 17,” captures the fraught moment of finally receiving a diagnosis. A diagnostic label is both a sense-making tool and a medicalized narrative—it transforms a smattering of biomedical data points into a meaningful constellation; it lends a sense of coherence to chaotic or seemingly inexplicable physical experiences; it structures future action by suggesting a set of next steps. Katie Jo Ramsey (2016), a woman with adrenal insufficiency, explained the paradoxical desire to receive “abnormal” test result, writing that “the undiagnosed but very sick know normal test results are often the worst news to receive. Abnormal or positive test results mean answers, mean help and mean life can get better than the hell you are living” (para. 7). Additionally, a diagnosis can serve as a form of validation, confirming a patient’s knowledge of their own body—particularly when claims of pain or other invisible challenges have been previously discounted by others. Thus, receiving a diagnosis initiates and directs three interlinked sense-making processes that assist individuals in developing a disability or illness identity: (a) re-narrating the past, (b) constructing “new normals” (Harter, 2013), and (c) re-imagining the future.

Re-narrating the past. First, Mighty contributors described the process of re-narrating the past. For example, I interviewed several autistic adults who had only recently been diagnosed. They described the profound experience of “finally
understanding that everyone didn’t see, hear or smell the world the way I did.” James described how this realization caused him to reevaluate his interpersonal experiences, explaining:

You think everyone experiences the world that way. So, some of my responses were defensive because I thought, maybe I am just being picked on. I come to find out that the people honestly were making observations [and] did not experience the world the way that I did which is why they had questions. So, when that demarcation came for me, it’s when I realized, “Okay, I’m in another category of people who, even though you cannot see, there are some profound things that can be disabling for us.”

Autism provides a particularly interesting case for studying the process of re-narrating the past. The “symptoms” of the condition are closely intertwined with the way in which autistic individuals approach interpersonal interactions, sometimes resulting in negative responses like bullying and other forms of ostracism that shape the autistic person’s self-conception. For example, DG described the sense-making process of recognizing her own behaviors as coping mechanisms linked to sensory overload, and her increasing ability to “really piece it together—to tell what’s ‘my condition’ and what’s ‘me.’” Subsequently, she began to re-narrate a flawed sense of self, gradually “realizing that most of [her] ‘failures’ were a direct result of ADD and autism, that it was much more about the outside world basically speaking the wrong language to [her].” Interestingly, receiving an autism diagnosis did not have such a transformative impact on Sakari, who had already found ways to accept her quirky interpersonal style. In contrast, she had struggled for years with an undiagnosed auditory processing disorder. Receiving this diagnosis caused her to re-narrate past experiences as a college student and employee, and also to re-narrate her
traumatizing experiences with the mental health system. She described her response to
diagnosis in this way:

I was relieved first because it legitimized my lifelong perceptions that I really just
can’t hear in certain environments, mostly those with background noise, rooms with
poor acoustics. Getting through college was hell . . . I managed to get my degree
and that’s great, but the worst thing that came out of it is for the years that followed
I experienced some mood challenges, I experienced some depression, I experienced
lots of anxiety due to sensory overload. And those experiences were completely
mischaracterized by psychologists, psychiatrists, therapists, anybody—you name
it. And I knew I was just seeking help because I knew I was having problems with
communication in my workplaces and they just threw drugs at me and told me to
do things that didn’t work. When I said, “this isn’t working,” they said I wasn’t
trying hard enough. When I got the diagnosis, it was like, “oh my god,” I couldn’t
continue trying all this cognitive behavioral therapy, all these drugs, all this crap. It
would never work because I’m just not wired like that. It was an enormous relief;
it was really validating.

Sakari’s comments capture an additional facet of re-narrating the past. Diagnosis
provided individuals with vindication in cases where their reported experiences had been
previously disregarded. Sakari’s account draws attention to the fact that diagnoses do not
reflect purely objective evaluations of scientific facts. They also reflect a patient’s
rhetorical skill in arguing their case (Segal, 2007), persuading healthcare professionals to
take their intuition seriously by presenting their condition in ways that are coded as credible
and “doctorable” (Buetow & Mintoff, 2010; Ellington & Wiebe, 1999; Heritage, 2009).
This is particularly true in cases where receiving a diagnosis is more difficult, such as when
a condition is rare, when there is little measurable physical evidence (e.g., autism,
fibromyalgia, mental health conditions), and when there are medically unexplained
physical symptoms (MUPS; Aamland, Werner, & Malterud, 2013). Further, the ability to
pursue a diagnosis assumes a certain level of financial, linguistic, and educational privilege.
Some individuals may be unable to afford to pursue diagnosis—especially when initial
attempts fail. Additionally, people who belong to marginalized groups (e.g., people of color, women, people of lower socioeconomic status), contend with systemic prejudices that make it more challenging for them to persuade healthcare providers to take their complaints seriously (Mik-Meyer, 2011). Thus, as Ramsey (2016) explained, “the fear of not getting answers and being judged as a complainer or drug-seeker can keep [individuals] from pursuing medical care” (para. 13).

Several Mighty contributors shared stories of receiving vindication after long periods of invalidation. For instance, Cindy had experienced a lifetime of being doubted and misunderstood by medical professionals. While she had been hospitalized at two years old after becoming mysteriously ill and losing her hair and eyelashes, she did not receive a diagnosis of psoriatic arthritis until she was nearly 50 years old. Her lifelong pursuit of diagnosis was riddled with stories of invalidation. For example, at age 27 she sought medical treatment after experiencing intense pain in her chest and stomach. “My doctor told my husband there was nothing wrong with me and that I probably needed a psychiatrist, because I was always looking for things to be wrong with me,” Cindy recounted, “And within a couple of weeks from that, I made my husband take me to a hospital in the middle of the night. I had 65 gallstones.” In her early 40s, Cindy waited eight months and drove several hours to see a specialist in Toronto. She shared the devastating impact of this encounter with me:

We went into his office. He didn’t even look up at me and he had my records in front of him, and he said, ‘Well I can tell you right now, the only thing that’s wrong with you is you’re fat and lazy.” . . . And that crushed me. My husband was furious, but that crushed me. And that drove me underground again for a very long period of time.
Maurine described a similar experience of being continually doubted by medical professionals. She defined her condition as a “fat disorder that causes the inflammation of the fat cells in the body, increasing limb size while decreasing mobility and function of soft systems like the lymphatics.” Maurine “went through the ringer with physicians telling [her she] was eating too much and not exercising, pushing [her] toward bariatric surgery.” Clearly, these repeated experiences of invalidation negatively impacted these women’s self-concept. Cindy explained that “psychologically, it has a really hard effect on me not knowing. . . . It erodes your self-confidence, people questioning you all the time.” In contrast, receiving a diagnosis caused individuals to re-narrate past healthcare experiences as mistreatment and trauma, giving them added confidence to advocate for themselves in future healthcare encounters and to share their experiences publicly.

**Constructing a “new normal.”** Second, receiving a diagnosis initiated the sense-making process of *constructing a “new normal.”* This process involved redefining oneself in response to changes in physical or cognitive ability. For example, Eleanor emphasized the challenge of acknowledging physical limitations linked to her rare chronic pain condition, ankylosing spondylitis, stating, “I’m experiencing a huge shift in how I define myself, because I used to define myself as healthy, active, grab the world by the horns and do everything. And now, it’s the complete opposite.” Alicia, who promotes disability health as a public health professional and also has a chronic health condition, identified several ways in which people respond to this “huge shift.” “You’ve [got] one camp of people who say, ‘Oh my God, your life is over as you know it,’” she explained. “And then you get this other camp of people that are like, ‘No, you go get ‘em, girl. You can do what
you want, how you want it, the same way you’ve always been.” She positioned herself in the middle of these two camps, noting that, “neither one of those is really the reality. To me, it’s a very normal life.”

Many Mighty participants adopted this middle-ground approach, frequently repeating the duel refrain of “it’s OK” and “I’m OK” to express acceptance of their new normal. For example, Juliana Tamayo (2016) wrote of accepting a new normal with gastroparesis:

I made peace with myself . . . I am now another “me.” But still me. . . . I may be better at dealing with my disease, but I don’t need to hold hope for a cure or a miracle. All I need is an “It’s OK.” It’s OK to be sad sometimes. It’s OK to cry and get frustrated. It’s OK to stay in bed. It’s OK to not be able to hold food down. It’s OK because I’m OK and at the end of the day I’m better now than I was before.

Similarly, Jo spoke of coming to terms with her life as a person with fibromyalgia and additional health complications:

I’ve had to accept that I’m not always going to do what I want to do or live in a way that I want to live and that it’s OK. . . . You have to start giving yourself an OK. It’s OK to not get out of bed today. It’s OK to order pizza . . . I realized you can’t have what you want all the time, but if you look at your life and identify the things that you did get, it’s OK.

Interestingly, much of Jo’s ability to be “OK” with her physical condition, as well as her children’s diagnoses of autism and ADHD, was linked to her ability to attach a sense of purpose to these experiences. She framed these conditions as evolutionary missteps—attempts to improve the human genome that did not work out. As she explained, “I had to find a silver lining. There had to be a reason for what’s happening to me and a reason that I could accept—not just some big mystery, but something black and white.” Locating this sense of purpose provided a logical sensemaking framework Jo’s new normal, invoking
the plotline of a “quest narrative” (Frank, 2013) that protected her from the sense that the world is unpredictable, senseless, and inexplicably difficult.

**Re-imagining the future.** Relatedly, *Mighty* contributors engaged in the sensemaking process of *re-imagining the future*. Receiving a diagnosis disrupts previous notions of what life will be like, as captured in Noelle Chelli Lopez’s (2016) response to receiving a reflex sympathetic dystrophy diagnosis:

> Questions and thoughts spiraled in my brain like an unyielding vortex of panic. ‘Can this be cured?’ ‘Will I get worse?’ ‘I have to finish college!’ ‘You’re going to put needles in my spine?!!?’ ‘Will I be living with this much pain *forever*?’ (para. 6)

Diagnosis involved, “letting go of dreams” and recognizing “I’m probably not going to earn that black belt in taekwondo. I’m not sure if I’ll make it back to the hiking trails I love. . . . But [these dreams] aren’t my only path to happiness” (Meadowlark, 2016, para. 7). As this quote suggests, part of re-imagining the future involved locating an alternative source of hope. Rather than hoping to achieve unattainable goals or experience a medical miracle, *Mighty* contributors adjusted their future expectations to hope for different, more achievable, accomplishments. For example, Delaney Mowers (2016), a college student with chronic pain and dysautonomia, wrote about the gradual process of “re-examining hope” after recognizing that she likely would never be cured of her conditions:

> Acceptance of chronic pain came slowly, which left me somewhere between hope and acceptance. . . . I believed hope had failed me and I had no more use for it. . . . After a while, however, a spark of something I couldn’t identify at first began to flicker. . . . I felt like I fully participated more in all the relationships in my life. I noticed the wind in the trees and the excitement of my dog as I walked through my neighborhood much more than I used to. The pain still insisted on blanketing every particle of my life, but now the pain passed between those particles rather than over them.
Eventually, I realized I felt so much more alive only because I had found hope again. This hope was different than the hope I had held before, and it was much more subtle. . . . This hope told me I could find contentment despite the pain. It said I could learn to function without feeling like I was straining against an immutable force. It helped me to believe maybe I could find a way to make some of my dreams and goals for my life come true despite the pain. (para. 6-7) 

Mowers re-imagines a future that is not contingent on achievement as defined by her previous, non-disabled self. Instead, her future is one in which contentment—tied to mindfully experiencing the pleasant details of daily experience—might be possible.

**Sense-Making and Problematic Integration: Revising an Unstable Identity**

Mower’s orderly narration suggests that moving from hope through despair to a re-imagined future is a plottable, linear sense-making process. The reality, however, is far messier. While a diagnosis lends a sense of coherence to the embodied experience of physical and cognitive difference, receiving a diagnosis also creates new forms of chaos. A diagnosis occasions complex decisions about treatments and therapies. It demands that an individual revise their sense of themselves as “able-bodied,” recognizing assumptions of ability that had permeated images of a past, present, and future self. Post-diagnosis, individuals must reposition themselves in relation to an imagined “normal,” sometimes reframing or rejecting the very idea of “normalcy.” Diagnosis also affixes an individual with a potentially stigmatizing label. For instance, autistic activist, Lydia, outlined some of the “safety considerations” self-diagnosed individuals grapple with in deciding whether to document their condition, such as, “If I have this on paper could I be profiled? Could I be put in a data base that’s used for widespread discrimination? Could an employer find this out about me?”
In her article examining autobiographies written by people with disabilities and chronic illnesses, Cardillo (2010) described participants’ “shifting reconstructions of a different self” (p. 539). She noted that ways in which individuals narrated their experiences were shaped by three interconnected influences: (a) the embodied, material reality of their condition, (b) exposure to condition-related communication from peers, friends, family members, and healthcare providers, and (c) self-talk. Cardillo further noted that these influences are situated in a broader sociocultural milieu. Individuals internalize or push back against artistic, literary, and journalistic depictions of difference, and live within or resist physical and social structures imposed by economic, political, religious, and educational institutions. This process of continual self-construction invokes the concept of the “body without organs”—an embodied identity that is “fluid and shifting rather than static, and forever in the process of being made and remade, an assemblage of relations with their bodies, including non-human phenomena, which is constantly changing as it comes into contact with others” (Lupton, 2012, p. 22). The following analysis expands Cardillo’s insights to highlight the ways in which orderly sensemaking processes are disrupted as individuals revise selves in (a) diagnostic, (b) physical, and (c) social flux.

**Revising a self in diagnostic flux.** Mighty contributors continuously revised an unstable identity in response to diagnostic flux. Clearly, remaining undiagnosed contributes to problematic integration in the form of uncertainty. Individuals and their healthcare providers continually consider and discard potential diagnoses, making it challenging for a patient to form either probabilistic or evaluative orientations toward
their unlabeled condition. For example, Jayson received his diagnosis of a rare blood
disorder at age 24, after undergoing gene sequencing. “Before that I didn’t have a
confirmed diagnosis,” he explained. “It’s difficult to live in that space as well, especially
if you’re undiagnosed because you don’t have a definitive answer on anything. Doctors
don’t know, you don’t know. That’s a difficult place to be.”

Individuals also experienced diagnostic flux when they were misdiagnosed. For
example, in her Mighty article entitled, “My 31-year Journey to a Babesiosis Diagnosis,”
Wendy Simpson (2016) recounted, “I had been diagnosed with fibromyalgia in my late
30s and that was fine for a few years, but it didn’t explain why I felt like I was dying and
why I would sometimes sleep for a month.” Simpson’s case represents a misdiagnosis—a
mistake that not only prevents an individual from making informed decisions and
accessing effective treatments, but also prevents them from situating themselves in
relation to others with the same condition. In his Mighty article entitled, “The Legacy of
my Brother-in-Law’s Misdiagnosis and Rare Disease Battle,” Carlos Labrada (2017)
emphasized this point: “Misdiagnosis hurts patients, families, and those fighting the same
battle. They all miss the opportunity to belong. Not to be lost alone” (para. 8).

Other Mighty contributors described being underdiagnosed; a single diagnosis did
not completely capture their experience. These contributors described continually
receiving additional diagnoses, each one requiring tweaks to both their treatment
regimens and their self-concept. For example, when I asked Cindy if there was anything
else that she would like to tell me about her experience, she replied, “what I have learned
over the years is, when you’re diagnosed with one autoimmune disease, you’re always
going to be diagnosed with more. So, a big part of my life has been running back and forth between doctors and hospitals.”

The experience of being misdiagnosed or underdiagnosed was often linked to being doubted and discounted over time. For example, Cindy noted that her initial diagnosis of fibromyalgia prevented her from receiving necessary additional diagnoses because of the way this condition was trivialized by medical professionals. She explained, “back then [approximately 20 years ago], it was considered a psychiatric issue. So, once you’ve got fibromyalgia tacked on your forehead, nobody listens to you anymore. You could break your bone and nobody would listen to you.”

Cindy’s description of her experience highlights an additional source of diagnostic flux—both popular perceptions of diagnostic categories and their clinical definitions change over time. For instance, diagnoses like fibromyalgia may become more or less contested in medical communities, in turn impacting how seriously individuals labeled with such conditions are taken by both healthcare professionals and the lay public. Further, the ways in which such diagnoses are defined frame what it means to live the condition. For example, Sakari discussed how definitions of her auditory processing disorder did not capture the complexities of her actual experience. Educational websites described her condition as a “learning disability,” whereas she perceived of it as “an auditory disability with implications for learning.” “Those aren’t identical,” she explained:

I can learn perfectly well with other mediums, I’m just really limited as to how much information I retain through my auditory senses. . . . This [definition] is just restricted to “this as a learning disability” . . . If a person’s life is only their
learning endeavors, I suppose that’s true, but I don’t know about any person where that’s the case.

This example does not illustrate a form of diagnostic flux per se—it simply reflects a gap between biomedical and embodied knowledge, reflecting the power biomedical institutions have in shaping the meaning ascribed to diagnostic categories. However, it also points to the ways in which shifting diagnostic descriptions can disrupt sense-making. For instance, my own research (Parsloe & Babrow, 2015) has considered the forms of problematic integration that arose as individuals who identified as “Aspies” responded to the 2013 revision of the Diagnostic and Statistical Manual (DSM V), which removed Asperger’s syndrome as a diagnostic category and revised the criteria for diagnosing an autism spectrum disorder. This event disrupted individuals’ probabilistic and evaluation orientations, causing members of the autism community to both wonder if their diagnosis was valid and to reconsider the cultural significance of identifying as an Aspie\textsuperscript{10} versus as autistic or as a person with autism. These experiences of a self in diagnostic flux are further complicated by experiences of a self in physical flux.

Revising a self in physical flux. Mighty contributors described revising a self in physical flux, trying to make sense of continually changing bodies situated in various physical environments. For people with degenerative conditions, physical flux meant recognizing that their current abilities would deteriorate. For example, Jayson defined

\textsuperscript{10}Interestingly, some autistic activists have begun rejecting the term “Aspie,” recognizing that this label suggests a hierarchy within the autism community that undercuts efforts toward spectrum-wide solidarity (personal communication, L. X. Z. Brown, March 3, 2017).
himself as “able bodied disabled,” recognizing that his current capacity to advocate by running half marathons would not last.

In some cases, physical flux was linked to identifiable events. For instance, Jo described her anger and frustration when, just as she had reached the point of “moving forward and accepting that [she] wasn’t going to get better and [she] was going to have to be on high doses of pain medication with muscle relaxants,” she discovered that a treatment for her fibromyalgia had permanently damaged her heart. “I’m trying to deal with the stuff I already have,” she explained, “and it just steals more of my faith.”

Similarly, Ariel Henley (2016) wrote about coping with physical flux that resulted from a series of surgeries to address craniofacial differences caused by Crouzon syndrome:

> The surgeries to advance my mid-face and my skull were performed periodically as I grew . . . Each surgery changed my appearance, sometimes so drastically I refused to look into the mirror for weeks because I was afraid of what I would see staring back. (para. 7)

Alternatively, physical flux captures the unpredictable nature of the conditions themselves, or of a condition’s response to treatment. For example, Kate Eastman (2016) wrote about her fluctuating experiences with chronic fatigue syndrome and myalgic encephalomyelitis, explaining, “What I couldn’t do three years ago, I can do now. What I struggled with last week is now a different battle this week. What you saw in a bad month or a day isn’t the whole story” (para. 4). This form of physical flux complicated efforts to re-imagine the future. Ellison Bartone (2016b) articulated this challenge in her description of life with malignant multiple sclerosis: “It’s hard to plan when you have no idea how you will feel at any given moment. It’s easy to feel lost when life is full of constant questions with few answers” (para. 8).
Further, physical flux presented challenges in presenting a self to others. In her *Mighty* article, “‘Did the Surgery Work?’ Is a Complicated Question When You’re Chronically Ill,” Nikki Bhumaram-Gilbert (2016) explained:

> Some days it feels as if we tackle one problem just to find that another has either popped up or stopped responding to the medication regimen. . . . So, am I better after the surgery? I’m better and worse. . . . More often than not, when I try to answer the “Are you feeling better?” question, I feel as if I’m not allowed to deteriorate or even plateau, that the answer has to be a binary “yes” or “no” because any other answer is, for some reason, uncomfortable. (para. 4-7)

Similarly, experiencing continual physical flux disrupts the ability construct a new normal. The challenge of “knowing” a continually changing body complicates decisions to present physical observations to healthcare providers. Bartone’s (2016a) musings reflect this challenge:

> If I tell the doctor about a new symptom, what will he think? Will he think I’m a hypochondriac, or oversensitive? Or maybe I am just tired of telling doctors everything. There’s always something. But it’s also possible that the new symptom is serious. (para. 6)

These comments underscore the ways in which the experience of physical flux creates self-presentational dilemmas; contributors balanced the desire to vent against the reality of others’ limited ability to understand, and balanced the need to receive medical treatment against the fear of being seen as a “difficult” patient.

Even in cases where individuals’ corporeal characteristics remained stable, they experienced their bodies in relation to evolving assistive technologies and the (in)accessible features of a changing physical environment. *Mighty* contributors frequently explored how their use of mobility aids and other assistive technologies compelled them to revise their sense of self. Chloe Tear (2016) described how, initially,
using a wheelchair as a teenager felt like “a loss of identity”: “I no longer was referred to as ‘Chloe.’ I was ‘the girl who uses a wheelchair’ . . . I felt like I’d just figured who I was, only to have it pulled out from under me” (para. 8). Alternatively, Gabrielle Cole (2016) depicted the ways in which use of a wheelchair was both empowering and disempowering. She wrote:

I feel absolved from the looming responsibility of walking around and looking able-bodied. In a wheelchair, I can focus on what I’m doing, where I’m going, or something else instead of the fact that I am in an excess of pain. I become less approachable in some ways, and more so in others. Fewer people ask me what’s wrong, for fear of getting an answer they won’t like. However, using a wheelchair can make one seem powerless in the eyes of society. (para. 9)

Kevin Enners (2016) described his relationship with his “Rumbler,” a modified recumbent trike that allowed him to participate in road races and embrace the idea that he was “born a runner” (para. 1). He describes this mobility aid as an “equalizer,” allowing him to “rebuild [his] self-esteem and rehabilitate [his] self-worth” (para. 2). In contrast, he describes the “anxiety” people with mobility challenges feel “when you cannot go places too narrow for your power chair, and you watch your friends leave—or worse—carry you through” (para. 2).

Enner’s description highlights the interaction between bodies and (in)accessible physical environments, underscoring this aspect of physical flux. Even when environments have been designed with the capacity to accommodate different bodies, their accessible features may remain inaccessible in practice. For example, Kat Macfarlane (2016) noted that, even though her workplace has two bathrooms equipped for disabled use, these spaces were unpredictably usurped by non-disabled individuals:
I’ve waited to use one while people inside did everything from brush their teeth, gargle, clip their nails, and even use a curling iron. . . . All of this activity would go down while I waited outside, propped up against the bathroom wall, one hand on a cane, gritting my teeth and praying that the fool inside would hurry up. (para. 25)

Similarly, transportation services that should enable different bodies may instead contribute to the sense of self as impaired. Katarina Showalter (2016) recounted experiences of being randomly refused service by Uber drivers, and even by paratransit drivers who decided that she had “too many problems” and that she was “too much of a liability.” “Every time I leave my house I take a gamble,” (para. 5) she wrote.

In these cases, technically accessible physical environments remain in a state of flux because others who interact with these environments structurate them through their ignorance and prejudice. Structuration is concerned with the ways in which social actors preserve or transform the character of structures through the ways in which they interact with existing rules and resources, in turn maintaining or altering the social systems in which they are embedded (Giddens, 1979). Thus, in the example above, individuals render resources available to people with disabilities less accessible by not using them in the ways they were intended, ultimately (re)producing systemic ableism. Athena Stevens’ (2016) writings illustrate structuration as it occurs at a macro-level, tracing how policies enacted in response to a changing sociopolitical environment rendered London’s physical environment (in)accessible:

With London hosting the 2012 Paralympics . . . it seemed as if London was opening up to those of us with disabilities. . . . And then, [austerity] cuts to disability services started happening. Wheelchairs paid for by the government were taken away by the same party who issued them . . . The current government has been so aggressive in cutting the rights and programs meant to aide those of us with disabilities that the country has come under investigation by the United
Nations for human rights violations. And now, Brexit. Most people don’t realize hundreds of regulations and laws go into making a country more accessible. . . . And most of that legislation comes from EU regulations. Meaning when the U.K. leaves the EU in two years, I have no idea what rights I will have as a person with a disability. (para. 3-6)

This example draws attention to how forms of physical flux intersect with a third category of flux: social flux.

**Revising a self in social flux.** *Mighty* contributors also revised their sense of self in response to a changing sociocultural landscape. In some cases, social flux captures the more gradual evolution of self across a person’s lifetime. For instance, individuals may receive more or less social support from friends, family members, and others over time—especially if they connect with a biosocial community in which their embodied differences are understood and accepted. Additionally, social flux may refer to recurrent, day-to-day presentational and privacy management challenges, as in disclosing a condition to strangers, to dates, and to potential employers. Changes in mainstream discourses, economic, governmental, and educational policies, medical information and related treatment/therapy protocols, and assistive technology also contribute to long- and short-term social flux, reinforcing or ameliorating (self-)stigma and (internalized) ableism.

In some cases, *Mighty* contributors wrote about how initially supportive social contexts became toxic, reducing their sense of self-worth. For instance, Becks Moulton (2016) wrote of meeting a romantic partner who initially accepted her for who she was, “disability (cerebral palsy) ‘warts’ and all” (para. 3). Over time, however, he began to exploit her disability to perpetrate physical and emotional violence. In her *Mighty* article
entitled, “Why I’m Talking About Domestic Violence as a Woman with a Disability,”

Moulton documented her trauma:

I was punched, dragged out of my wheelchair by the hair and neglected in every way possible. He would lock me out of the house if he was in a bad mood. He removed the phones and money cards from my reach. He even disengaged my wheelchair to prevent me from asking for help and leaving him. Like many people in my situation, I believed I deserved it. I also believed I was not worthy of anyone else’s love. Who would want to take me on with a child and a disability?

Moulton’s testimony captures both the dark side of social flux and how it operates within a single relationship.

Other contributors explained how their self-concept fluctuated across the course of a lifetime. For example, Cedar explained how his perceptions of cerebral palsy and his own identity had “evolved”:

When I was a young kid, my folks told me I was the best, and as the only child, who was I to disagree with them? But in fourth grade I changed schools . . . and then I began looking around and realizing I was so different. Then I alternated between being angry with my speech and coordination and being in denial of it. . . . In the last eight years, I’ve been more vocal: I post a lot on Facebook. I speak a lot. I’ve gotten to saying, “I have a disability, we all are disabled in one way or another because there’s always things that each of us can’t do, that we want to.” . . . That was a crucial part of owning my story and coming out as a disabled person.

Cedar’s identity shifted both when he began to situate himself in comparison to typical peers, and when he received validation from his social media network in the process of “coming out” as a disabled person. Mandy described a similar childhood experience, recounting the frustration of learning that having ocular albinism made her unable to complete tasks, like coloring, that came easily to her peers. This frustration turned to shame when she was retained in a pre-first program for children with behavioral issues. She explained that she was put in this program because,
I would cry and have a little temper tantrum . . . I wouldn’t get why I couldn’t be normal. And nobody really explained it, it’s just like ‘all your friends are going to the first grade and you’re not.’ It’s kind of screwed me up in the long run because it made me like a year older than all my classmates throughout my whole schooling career, and also killed my self-esteem. That was kind of a big issue, because I would try to hide my disability.

Eventually, however, Mandy met her partner, Bryan. Bryan has cerebral palsy, and was connected to a network of self-advocates. He “tricked” Mandy into talking about her own disability as part of a self-advocate conference. This initial foray into self-advocacy inspired Mandy to find outlets for her writing, eventually leading her to stumble on The Mighty. “Ever since I started writing for The Mighty,” Mandy explained, “it kind of helped my confidence boost a little bit, because it’s like, ‘Hey, at least I know I’m not alone in all this.’ People are actually paying attention.”

Mandy’s story illustrates how finding supportive social systems, both in “real life” and online via platforms like The Mighty, can facilitate development of an empowered sense of self. For instance, #crippingthemighty founder, Alice Wong, emphasized the transformative impact of meeting and learning about other activists. Alice Wong was born with a form of neuromuscular disability called spinal muscular atrophy. She shared a particularly clear description of how she became “politcized”:

My entire life I knew I was different. I moved differently, people treated me differently. . . . I probably really wanted to just to blend in with the crowd and not really identify as disabled, even though it’s obvious. It wasn’t until I became a little politicized during my college years. I’d read about disability studies and then I read about the Independent Living Rights Movement at Berkeley. . . . I moved out to the San Francisco Bay Area where I am now and that’s really where I believe I really encountered the disability community. I’ve met so many amazing people that just really motivate me and they showed me around, they gave me tips. But they were generous with their time and their friendship and I just felt

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11 Pseudonym
such a kinship with a lot of these folks. Later on, my other real involvement with the disability community was really online. . . . Growing up, I didn’t really have any role models. I always felt somewhat ashamed. I feel so privileged to be a part of many different disability communities.

Meriah Nichols, a prominent blogger and #crippingthemighty participant who is deaf, and has a traumatic brain injury (TBI), post-traumatic stress disorder (PTSD), and bipolar disorder, described a similar experience of self-transformation. She explained:

I had been raised to ‘overcome’ my disability and really downplay it and try to ‘pass’ as non-disabled. When I started working at Berkeley, I met all of these incredibly cool, strong, intelligent people with disabilities. It was hugely empowering and eye-opening. I had never seen anything like it. That was my turning point.

Mandy, Alice Wong, and Meriah Nichols each discussed their initial desire to hide their condition and blend in with “typical” society. These sentiments illustrate Goffman’s (1963) notion of passing, where individuals with “spoiled” or stigmatized identities attempt to blend in to the “typical” population. In contrast, some Mighty contributors described coming out as disabled or chronically ill, claiming embodied difference as a source of pride, a justification for support, or both.

For some individuals, passing is not a viable option—they are so visibly ill or disabled that they cannot convincingly perform an able-bodied identity. Additionally, an individual’s ability to pass is linked to the experience of physical flux—corporeal changes may cause individuals to become more or less visibly ill/disabled over time, or interactions with (in)accessible physical environments may highlight or downplay an individual’s impairments.

To the degree that individuals can decide to pass/come out, their decision is shaped by the experience of social flux. For instance, individuals may shift between
passing and coming out depending on the social context, or may become generally more or less comfortable with being “out” as a result of accumulated social experiences.

Additionally, the stigmatizing discourses that “spoil” certain identities and encourage passing, as well as what social performances “count” as passing, are socially-constructed and also in flux. For example, Athena Stevens (2016) wrote about new notions of “passing” in relation to the “lucky cripple” (a disabled person who is attractive, relatively mobile and self-sufficient, educated, and employed/financially stable). She explained:

By “passing,” I mean society views it as more OK to be disabled now, as long as you’re not “too disabled.” As long as you are inspirational / good looking / don’t need too much to fit into the rest of our lives, the world at least pays lip service to the idea that disabled people should have their basic human rights protected. But if you drool, if you don’t look good on camera, if we need to put in a lot of work and make a lot of changes to help you, then your needs can be negated. (para. 3)

Steven’s description highlights how the notion of “passing” has shifted over time as society becomes more accepting of disability—so long as the disabled person can perform a certain degree of privilege.

Contributors frequently debated the benefits and drawbacks of passing. For example, Bartone (2016a) outlined the tension between desiring to avoid stigma while also needing support, explaining that individuals with chronic illness “want to be treated the same as everyone else, but if we share, or share too much, we risk losing that. But if we keep quiet about our health issues, we risk others misunderstanding what we can and can’t do.” Mandy especially emphasized the challenge of “coming out” in the context of a job interview, explaining “I don’t really tell [potential employers] because they’ll kind of put me on a shelf . . . I fight that urge where it’s like, ‘Should I be a self-advocate or should I keep my mouth shut?’” In her article, “Why I’m Coming out of the Asperger’s
Closet,” Kelly Searsmith (2016) described her reluctance to come out to co-workers who already recognized “a distasteful difference” in her social behaviors:

If I gave that kind of person a label to explain it, would it render me more palatable to them? Or would they believe instead that there is some kind of medication to help me conform, or therapy that could fix me? (para. 11)

In Searsmith’s case, coming out to disapproving co-workers might undermine efforts she had made to “understand [her]self as someone with Asperger’s, to accept that Asperger’s is a form of autism, and even to acknowledge that it may put [her] at a disadvantage in certain contexts, despite [her] intelligence, ability, and confidence” (para. 13).

Mighty contributors also confronted passing/coming out dilemmas when deciding to write publicly about their experiences. Jayson talked with me about how writing for The Mighty required him to claim aspects of his condition—and of his identity as a rare disease advocate—that he had not previously shared with friends and family. He explained:

[My family] know that [my condition] affects me differently, but I think they have a level of expectation as who they see me as their sibling, as their brother, and who I am as a rare disease patient. That they don’t allow and make room for that to exists in this space. With writing these articles, some of them are clearly over their head and they’re like, “You’ve been doing this and you’ve been working with these people and this is what stuff you’re doing? Because we don’t see it.”

In response to these dilemmas of passing versus coming out, some Mighty contributors engaged in strategic labeling.12 For instance, Cindy rationalized her use of the term “chronic illness” versus “disability,” noting that when people hear the term, “disabled,” “they automatically imagine that you’re in a wheelchair or you’re missing a

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12See research on label and stigma management, such as Meisenbach, 2010; Smith & Hipper, 2010
“limb.” In contrast, “people are becoming more aware that ‘chronically ill’ can be many things . . . whereas they still have a very distorted view of what ‘disabled’ means.” Cindy also strategically used the term “autoimmune disease,” rather than “psoriatic arthritis,” to avoid “the eye roll of, ‘Oh, well, everyone has arthritis,’ because they don’t understand.” Similarly, Emily explained her use a particular technical term for her condition. “Many of the people that have it prefer . . . ‘sympathetic dystrophy’ because it encompasses the disease as a whole,” she explained. “When you say, ‘complex regional pain syndrome,’ it pinpoints the area of aggravated pain—for example, my knee—but it doesn’t address the rest of the systemic issues.”

Strategically labeling their conditions allowed *Mighty* contributors to shape others’ ability to understand the nature of their experiences and, to a certain extent, control responses their disclosures. Additionally, strategic labelling is responsive to social flux—it allows individuals to tailor their self-presentation to reflect the knowledge, assumptions, and expectations held by specific interlocutors. For example, Rose explained that she shifted between using “chronically ill” or “disabled” “depending on the type of person . . . or the kind of conversation.” She clarified:

If I’m talking to my family, a lot of times I’ll use “disabled,” but if I’m talking to maybe a stranger or a person I don’t know that well, I’ll use “chronically ill.” . . . I feel like maybe “disabled” is a little bit more personal, at least to me. So when I’m talking to my family I can be like, “I’m disabled, I’m sad about it or [it] keeps me from doing this.”

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13 Note that this description of “disabled” is in line with discourses of difference as devaluated or as hard reality (Cardillo, 2010), framing disability as a source of personal limitation.
However, strategic labeling as described by these participants typically had the effect of preserving others’ notions of disability as shameful limitation, hampering efforts to “come out” proudly as disabled and to reclaim terms like “disability” and “crip” in the process. Alternatively, individuals who had become “politicized” through learning about disability culture and the concept of internalized ableism eschewed this approach. For instance, Adelle described herself as a “crippled punk-rock asshole.” She explained:

I’m kind of in everybody’s face. I’ve grown up essentially apologizing for my own existence. Particularly as a woman, we’re taught to be small. And now it’s getting to the point where I’ve realized that I’ve done nothing, like this isn’t wrong, I shouldn’t apologize for it. I can take up space, that’s more than fine. I’m rather vocal about that now.

Her description highlights how her identity as a woman intersects with her identity as a disabled person, acknowledging that both groups have been historically oppressed by socially-constructed systems of power. The self-presentational challenges caused by social flux were even more apparent for individuals who identify with intersecting marginalized identities, and also for those who occupy liminal spaces.

**Acknowledging liminality and intersectionality.** _Mighty_ contributors sometimes described how their corporeal characteristics made them “a mixture between two worlds” or left them “caught in the middle of two worlds.” These descriptions capture a sense of *liminality*—of existing in the ambiguous space between two clear-cut identity categories. Often, this sense of occupying a liminal space was tied to experiencing some physical impairment, but not complete disability. For example, Adelle described how her experience of cerebral palsy left her, “too disabled to deal with the able-bodied community, and not disabled enough to deal with the disabled community.”

Similarly, Tina spoke about the identity challenges of being DeafBlind. She noted that
she sometimes faced stigma from members of the Deaf community—both because low or impaired vision makes it more difficult for her to communicate via American Sign Language, and because her ability to hear in one-on-one situations had allowed her to be raised orally and to have some hearing friends. Tina also described members of the DeafBlind community who grow up Deaf, but slowly become blind as well: “They get frustrated because, they live [in] the [Deaf] world and now they’re getting slowly pushed out.” Similarly, Charlie Tarantola (2016b) identifies as blind, but has some vision. He explained, “I live in the space many people with a disability live in — I am somewhere in between a non-disabled person and what people assume a disabled person is” (para. 7).

Stephanea McCoy (2016) further described the social “reality” of “living with low vision in the sighted and non-sighted worlds,” writing that “sighted people can’t comprehend why a person who appears to see uses a white cane, and on the other end of the spectrum, blind people can take offense to people who aren’t totally blind being referred to as such” (para. 8). In several cases, contributors equated this experience of liminality to other identity categories that defy socially-constructed binaries. For example, Tarantola compared his status as a person with a visual impairment to his experience as a trans man “at the crossroads of gender.” Adelle explained that as “somebody that’s pan-sexual and/or bisexual, I’m not straight enough to date somebody or I’m not gay enough to date someone.”

As Adelle’s description of her sexuality suggests, occupying a liminal space in a binary world can incur social sanctions. For instance, in her Mighty article entitled, “I Can Walk, But That Doesn’t Mean I Don’t Need a Wheelchair,” Rebecca Giddings
(2016) noted that “society really struggles to understand part-time wheelchair use. . . .

According to society, I can walk, so I shouldn’t have to use one. So maybe I should stay at home where I can manage” (para. 4). Her description highlights insights that inform the social model of disability—the idea that cultural expectations about who is “qualified” to make use of mobility devices disable people by discouraging them from participating in society in ways made possible by these and other accommodations.

Similarly, Jenn Penny (2016) wrote about the shame and embarrassment she feels when she uses the accessible bathroom stall so that she can maneuver a body that is “unstable,” but does not yet require a full-time mobility aid. She asked readers to imagine “drinking a glass of water on your lawn on a hot day:”

There is someone walking by on the sidewalk and they stop and say, “You know there are other people who need that water more than you, right?” Would you feel shame, even though you know you shouldn’t and you know you need that water, too? This is how I feel when I exit an accessible stall only to be glared and scoffed at, and stared down by other people waiting in line who are of the mindset that only visibly disabled people can use that stall. (para. 6)

Social sanctions were also faced by individuals who experienced intersecting marginalized identities. Rather than being positioned “between worlds,” individuals found themselves in multiple worlds simultaneously. Discussions of intersectionality often focus on race, gender, sexuality and class. Certainly, these categories intersected with contributors’ experiences of disability. For example, Adelle described how, while she was proud to “have a membership card” in three marginalized identity categories—queer, Jewish, and disabled—her disabled identity was not embraced in the other two communities. “In queer spaces there’s no accessibility,” she explained, “Then when it comes to Judaism, some people want to treat me as though I’m a mitzvah project, as
opposed to a person, because I am disabled.” She recognized that, even in other social movements designed to pursue social justice, activist initiatives remained inaccessible and ableism remained unacknowledged.

Beyond intersections of race, gender, sexuality, and class, the identity challenges associated with intersectionality also applied to people who had multiple disabilities. For instance, as a self-advocate whose mitochondrial disease (mito) necessitates visible markers of disability—as in a “wheelchair loaded with pumps, medicine, and tube feeds” (para. 5)—Lydia Wayman (2016) surprises people when she describes herself as autistic. She writes:

Mito might be what you see, but it’s not who I am. If I were to stop the pumps and disconnect the lines, you wouldn’t see mito. Autism is different. It’s a part of every thought and feeling and experience. That’s why I focus on autism in advocacy. I don’t care if you understand the medications I take, but I hope by knowing who I am, how I see the world, and why I’m different, others will take a step toward accepting the differences in all people. (para. 8)

Clearly, while Wayman acknowledges that both mito and autism diagnoses apply to her, she evaluates and identifies with each quite differently. In doing so, she invokes alternative discourses of difference.

Evaluating the Self: Invoking Discourses of Difference.

The above analysis explores the sensemaking processes that Mighty contributors engaged in as they constructed their identities as individuals with disabilities and chronic illnesses. It also highlights the ways in which these sensemaking processes are continually interrupted by diagnostic, physical, and social flux. However, an additional important aspect of identity construction involving evaluating the self the process of communicating to attach meaning to embodied difference in (dis)empowering ways. This
aspect of identity construction reflects the ways in which individuals are embedded in a “lifeworld,” the “conglomeration of discourses and beliefs that people accumulate through everyday experiences and activities” (Lupton, 2012, p. 86). Evaluating the self involves invoking discourses of difference, including discourses of (a) difference as devaluation, (b) difference as hard reality, (c) difference integrated, and (d) difference oppressed, to narrate the experience of disability/chronic illness. In the following sections, I explore how Mighty contributors’ use of various metaphors reflect this process.

**Difference as devaluation.** Mighty contributors who drew on discourses of difference as devaluation endorsed the biomedical model’s focus on fixing malfunctioning bodies, viewing themselves as ugly, inferior, and shameful (Cardillo, 2010). Their articles contained metaphors of (a) destruction and (b) brokenness, positioning “normalcy” as an unattainable goal.

Mighty contributors used metaphors of destruction to frame their condition as a source of both physical and spiritual violence. Jennie Smales (2016) wrote of being “pulverized by a Hulk-type monster,” (para. 8), while Ashley Creveling (2016) described a community of people with chronic illnesses whose “bodies have waged war against our every fibers” (para. 2). Writers spoke of their condition as a weapon, describing “staring down the barrel of a diagnosis gun” (Lawrence, 2016, para. 13) and facing “a ticking time bomb that implodes me, physically, mentally, emotionally and financially” (Blanca, 2016, para. 4). Kim Tocker (2016) focused especially on how truly “getting” her diagnosis of systemic scleroderma destroyed her sense of self. She compared her initial
experience of using a mobility scooter to watching her cat, Otis, leap onto her half-completed jigsaw puzzle. She described how the “pieces of who I used to be, everything about what I could physically do, and all the hard work I’ve put into working hard at achieving myself as a mother, wife and successful therapist seemed to disconnect and scatter” (para. 8).

Naturally, metaphors that described the destructive nature of diagnosis were linked with metaphors that described the body as “broken,” including being “broken from the get-go” (Philips, 2016, para. 11) and breaking down over time. Bhumarom-Gilbert (2016) crafted an especially illustrative extended metaphor of her body as an unreliable car. She wrote:

Think of our bodies like your old, hand-me-down, beloved car, the one most of us have going into an adult or financially independent life. You’re tight on cash and just starting your career or a graduate education five states away from family. You ride around in your aging car, forever aware of the accumulating mileage and its fragile machinery. One thing breaks down, you get it fixed, sending a prayer to the car gods that the other weird sound you keep hearing is nothing because you can’t afford it . . . Eventually, too soon, something does break and you’re forced to empty your bank account (which is synonymous to the infinitesimally tiny store of energy the chronically ill maintain). You feel like you’re in this perpetual game of catch-up between your bank account and car, but you keep fixing it because it’s essential and because you love it. That car is me. (para. 8-9)

Notably, Bhumarom-Gilbert still “loves” her car/body, despite its lemon status. In contrast, Hannah Philips (2016) claimed that “it is only when I die that I will be free from all illness and disease. When I leave this earth, my body will be at it’s [sic] purest.” (para. 9). This is a very clear expression of the idea that a chronically ill or disabled body is devalued—the best option for “unfixable” bodies is death, where all bodies are “pure” again. Indeed, writers who invoked metaphors of brokenness typically positioned their
bodies as “less than” an imagined “normal.” “I feel like my body is a failure,” Bartone (2016) explained. “I feel exhausted, always, from trying to be stronger than I feel, from trying to have a “normal” role in society” (para. 10).

It is important to observe that nearly all the Mighty writers who invoked discourses of devaluation identified as chronically ill—what Wendell (2001) would call the “unhealthy disabled.” Indeed, Bartone (2016) even positioned her experience as abnormal in comparison to other types of illness, explaining, “If you have a “normal” illness, you see a doctor, get treatment and get better. Normal illness has a beginning, middle and end that chronic illness doesn’t have” (para. 6). Her observation suggests that chronic illness is devalued even in relation to “normal illness” because it resists the orderly framework of the “restitution narrative” (Frank, 2013). Instead, individuals envisioned themselves trapped in a “chaos narrative” (Frank, 2013) that resists the social mandate to “get well”—a narrative framework that sometimes persisted when individuals invoked the discourse of difference as hard reality.

**Difference as hard reality.** Relatedly, Mighty contributors invoked the discourse of difference as hard reality to frame their conditions as inevitable sources of suffering, limitation, and alienation (Cardillo, 2010). They invoked metaphors that framed their condition as a (a) burden and (b) hijacker. These metaphors suggest the lack of order and agency inherent to a chaos narrative. However, Mighty writers reasserted some agency in their use of metaphors to frame themselves as fighters, warriors, and superheroes. Cardillo’s (2010) typology situates this metaphor under the difference integrated category, suggesting that characterizations of self as being a strong, resilient survivor
count as “integration.” Yet, while fighter metaphors allowed writers to reclaim a sense of control and affirm their self-worth, they required these writers to distance themselves from their “burdensome” bodies.

*Mighty* writers frequently use metaphors to describe the burden of their condition. They described their symptoms as “weight,” “heavy fog,” “wind,” and “shadows”—concepts that allowed them to express the idea that others might be only partially capable of observing the nature of their difficulties. Metaphors of burden were typically linked to feeling punished. For example, Smales (2016) talked of being “desperate to get out of it and take a step forward into the sunlight,” but being “shackled here in the grim darkness” (para. 2). Similarly, Tiffany Early (2016) described chronic illness as a “life sentence without parole” (para. 8). Alternatively, Brittany Rogers (2016) wrote of chronic illness as “a job with a boss who doesn’t care what else is going on, who gives you no breaks or time off. A job that is literally 24/7 and you hate, but can never quit” (para. 6). Most of these metaphors of burden were written by people who identified as chronically ill, even in cases where the condition is usually labeled as a disability. For example, Elizabeth Terry (2016) wrote about narcolepsy as a chronic illness, equating it to an “iceberg” that saddled her with the “cold, lonely, and heavy weight” of continually trying not to appear “sick” (para. 2).

*Mighty* contributors also equated their conditions to hijackers, using metaphors that suggested that they had been kidnapped or were being held hostage by a body that refused to allow them any sense of control. They described their lives as rollercoasters; they were passive bodies strapped unwillingly into seats, hurtling down an unpredictable
track. Similarly, Allison Dunne (2016) equated her chronic pain to a bus driver, elaborating:

The bus driver calls all the shots — left turn, right, run the light. For years my bus was just barreling through the city, not caring about what was in its path. My pain was out of control and I was simply along for the ride. (para. 1)

However, after her healthcare provider advised her to “take back the bus,” Dunne extended her metaphor to reassert her agency. She wrote:

I knew, though, at some point this fictitious bus was going to crash, hard. You end up riding the bus for so long that you start to ask yourself if you ever want to get off, if you could even imagine a future for yourself anymore. That’s when it becomes vitally important to push past the fear and plan a way to fight back against the chronic pain that has taken over your life. (para. 4)

Dunne’s revision takes up the idea of being a fighter—a metaphor embraced by Mighty contributors who viewed themselves as locked in battle with their condition. Contributors referred to themselves as “warriors,” “superheroes,” and boxers who continuously don their gloves and step into the ring “with an opponent that never tires or weakens” (Parker, 2016a, para. 12). In her article, “The 4 Superpowers of a Crohn’s Disease Warrior,” Becki Parker (2016b) explained:

Chronic illness warriors are a part of a real-life league of superheroes. . . . Sometimes it feels like I’m fighting a villain lurking in the shadows. The vicious “Immuno-Miscreeant” plots its takedown of my positive outlook, strong will and unwavering courage. But we never let this menace take us down. (para. 2)

Similar metaphors related to fighting a battle have been noted in research on the discourses surrounding cancer (Harrington, 2013; Laranjeira, 2012; Songtag, 1978). As the authors of this research have noted, metaphors which emphasize individual, personal strength (here framed in ableist terms that glorify physical prowess) may become
oppressive. In the context of cancer, the idea of “losing the fight” and dying from the disease implies that an individual simply did not fight strongly or bravely enough. In the context of chronic illness and disability, “losing the fight” might involve admitting to having physical weaknesses or experiencing mental health challenges—a framing that further stigmatizes these experiences in ways that jeopardize an individual’s ability to seek help. Several writers recognized this potential flaw in the fighter metaphor, attempting to redefine strength in more inclusive ways. They emphasized that “strength isn’t determined by your inability or ability to ask for help” (Urquhart, 2016, para. 8), that being able to recognize and admit limitations “means you’re strong and courageous” (Wagner, 2016, para. 5), and that “giving yourself over to feel takes strength” (Petersil, 2016, para. 7). Maddie Petersil critiqued the notion that strength might have a single definition, pushing beyond the strong/weak dichotomy to redefine strength as a complex and evolving spectrum. She wrote:

> Each person displays their strength differently. And beyond that, strength evolves . . . our strength lives on some sort of spectrum — never a spectrum of less to more, but simply a spectrum of here to there, neither that “here” nor that “there” being either better or worse. It’s highly personal. There is no one way to define “strength,” just as there is no one way to define “normal.” (para. 2)

Alternatively, Victoria Churchill (2016) offered a less combative alternative to the fighter metaphor by describing chronic illness as a game of Monopoly with chronic illness as the opponent. This altered metaphor retains the adversarial relationship between the individual and their condition, but allows for several important recognitions. First, this metaphor acknowledges the role of Chance/chance, acknowledging that some aspects of a person’s experience will always remain outside of their control. Second, Churchill
discusses her medical “Properties” (“prescriptions, equipment, treatment, appointments, tests;” para. 10), noting their expense. Her description hints at the notion that a person’s ability to “win” is also tied to their material assets—their financial privilege and their access to good healthcare. Finally, Churchill discusses the Community Chest: “These cards are my people — those that empathize and offer support in any way. It means I’m not playing the game entirely alone” (para. 11). This is a particularly important aspect of her game metaphor; it moves beyond an individualized notion of strength to recognize the importance of having access to a supportive social network. However, while the game metaphor resolves some of the issues of the fighter metaphor by recognizing these complexities, it still suggests that an individual should always try to “beat” their opponent—a mandate to “overcome” that has long troubled disability self-advocates (e.g., Linton, 1998) who seek to accept and embrace embodied differences.

While writers who expressed discourses of difference as hard reality sought ways to re-affirm their self-worth, they spoke of attaining success in life despite their condition. Churchill (2016) ended her article by concluding that “I have decided, life goes on despite the game. And I live in spite of my opponent” (para. 14). Similarly, contributors claimed that their diagnosis did not define them, asserting that they had their diagnosis—not the other way around. Such descriptions reinforce Cartesian dualism; contributors envisioned themselves as separate from their chronically ill or disabled bodies. Additionally, the sentiment of being committed to fighting/winning against a chronic condition remains in line with Parson’s (1975) conceptualization of the “sick role.” The sick role activates a set of social expectations that, in part, require that
individuals view their “abnormal” bodies as undesirable, cooperate with healthcare professionals and accept their technical expertise, and take an active role in pursuing health (as in a “normal” body).

As contributors moved toward discourses of difference integrated, they began to push back against this biomedical framework. For instance, in her article about being fat-shamed while also living with epilepsy, Rachel Sutter (2016) first envisioned “living a full life despite [her] disabilities” (para. 18). However, she subsequently described herself as “a warrior who is overcoming the stigma of being a disabled person” (para. 19). This is a subtle, but important, shift in focus—instead of framing epilepsy or fat as her adversary, Rachel instead pivots toward combatting society’s stigmatizing responses to her “deviant” body. Similarly, Jesse James (2016) pushes back against both the mandate to keep fighting, and the idea of succeeding despite. They explained:

We can do everything “right,” but the outcome doesn’t change. When that happens, we learn to live with [our conditions], until we don’t. . . . We live our lives not in spite of our illness, but rather knowing it is now an integrated part. This doesn’t mean we failed or we weren’t doing the same things to help ourselves as someone else — we likely were. It just means they didn’t work. (para. 10)

Amy, a woman who had nearly 30 surgeries in the process of trying to reconstruct her digestive tract after it “exploded,” described how the uncertainty of dealing with a medically complex, unique condition eventually caused her to shift from fighting to be healed to accepting her current body as-is. She explained, “my anatomy doesn't have a road map or like real protocol.” As a result, doctors could only give vague advice about

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14 This contributor identifies as genderqueer in their Mighty bio.
what she should try, and uncertain predictions about whether and when it would work. For example, her trauma caused her to have a fistula—a hole in her abdomen that leaked food and fluids. Doctors told her that the fistula might heal if she didn’t drink more than a “few sips here or there,” but could not quantify the amount of liquid she could have or estimate how long she would be required to live in a state of thirst. Faced with radical uncertainty, Amy decided to relinquish the fight. She recounted the dramatic scene when she stole a water bottle from her mother and ran out of a store and into the parking lot:

I’m like, “I don’t fucking care anymore, I’m going to drink this whole fucking water bottle.” It was so dramatic, and I drank the whole thing. It all came out [of] the fistula that I didn’t remember at that moment, because in that moment I had to make an impulsive decision: “Okay, do I want to half live numbly with the hope that things will get better? Or do I want to just accept that this is my physical circumstance, but I’m not going to give up my life and my happiness to do it?”

Amy’s story mirrors Jane’s observations about the uncertain and uncontrollable nature of chronic illness, where “you can’t stop it. You didn’t start it. You don’t really know why it happens, but you’re in the throes of it.” “It’s not about fixing it,” Jane concludes, “it’s about emotionally getting through it.” This focus on accepting and emotionally getting through draws on the discourse of difference integrated.

**Difference integrated, difference empowered.** The discourse of difference integrated positions difference as an “integral part of self and life,” where it is “accepted, embraced, normalized, or valued” (Cardillo, 2010, p. 534). Findings from my analysis suggest that, while individuals may accept life with a condition, they did not necessarily embrace or value it. For example, *Mighty* contributors who use journey metaphors to describe their condition accepted that their condition would be a permanent part of their lives, but sometimes retained the sense of being condemned to a devalued existence. For
this reason, I suggest adding the category, *difference empowered*, to Cardillo’s taxonomy of discourses. Individuals who invoked the discourse of difference empowered moved toward embracing their condition. They expressed metaphors of partnership, personifying their conditions as team members and friends. They also used metaphors to explain different ways of being in the world. Writers who invoked the discourse of difference empowered normalized difference, and wrote about how their lives had value *because of*, rather than *in spite of*, their experiences as a person with a chronic illness or disability.

As noted above, some *Mighty* contributors described their experiences using journey metaphors—a metaphor that has been widely noted in research on communication about cancer (Gill & Babrow, 2007; Harrington, 2012). Journey metaphors free individuals from the mandate to “fight” their condition, allowing them to simply live with, and potentially accept, their condition. In some cases, *Mighty* contributors journey metaphors participated in the discourse of difference as hard reality by emphasizing the burdensome nature of their journey. Christy Bloemendaal (2016) explained that, instead of living in a “Disney princess story,” her reality was more like the “original, dark and frightening tales by the brothers Grimm” in which the “heroine” is a woman who “was once full of life,” but is now “weighed down” by multiple chronic illnesses (para. 2-3). Similarly, Bhumarom-Gilbert (2016) described chronic illness as a “long family road trip with lots of restroom stops and detours made for gawking at small-town curiosities along the way without any of the fun [emphasis added]” (Bhumarom-Gilbert, 2016, para. 4). These metaphors emphasize the sense of being forced to endure a journey that is annoyingly pointless at best, terrifying and demoralizing at worst.
In contrast, Robin Dix (2016) described traveling “this road of chronic illness with fibromyalgia and hypothyroidism in my backpack,” writing: “My map for this journey is prayer and good books. My sustenance are the friendships I make along the way. I have been strengthened and challenged in ways I never could have anticipated” (para. 9). Here, the journey metaphor describes a rewarding experience, where the potential challenges of the journey are mitigated by receiving various forms of support along the way. Some writers shifted even further toward embracing their journey, recasting the journey as an “interesting,” “exciting,” and “beautiful” adventure. Sarah Nuxoll (2016) referred to her life with cystic fibrosis as a “choose-your-own-happy-adventure book,” praising the ways in which her condition had caused her to live in a more mindful way. Amy described her exploded stomach” as a “beautiful detour”—a twist in her life path that lead her to discover art and to create her autobiographical play. She told me about how she created her own therapeutic writing regimen as she tried to recover from several sources of physical and psychological trauma. She discovered Joseph Campbell’s (1949) work about the hero’s journey archetype and used it to frame her journey toward physical and spiritual health:

Every day I gave myself a warrior’s training based on some kind of sign I saw in nature, like, “May 28th. Warrior symbol lightning bolt because I was strong today when this happened.” Or, “Warrior symbol for June 6th. A spider’s web because I learned that connection is important.” I did this for years and my journal entries, they’re beautiful because I’m literally writing hero’s stories in my room to survive—thousands of pages.

Amy’s embodies the character of the “warrior,” but does not describe herself as being at war with her own body. Rather, she focuses on the concept of “training,” using the
scaffolding provided by a “quest narrative” (Frank, 2013) as a tool for authoring a more resilient self.

In a similar vein, Mighty contributors used metaphors of partnership, personifying their condition to describe the twin experiences of working with and learning from. For example, Michelle Joseph (2016) framed the experience of chronic illness as her body’s attempt to write her a “love letter,” one that encourages her to slow down and be grateful for each moment. Similarly, Tracy Coval (2016) penned “A Letter to My Body About Our Life with Chronic Pain,” writing, “I’m willing to be a team with you. Thank you for the life lessons you have taught me and pushing me to the max. I know you are teaching me to be the best that I can be” (para. 7). Of course, contributors didn’t always have such cordial relationships with their personified conditions. For instance, Jennifer Bolton (2016) spoke of naming the Ehler’s-Danlos syndrome that impacted her family:

We call it ED with an S instead of pronouncing each letter as an acronym, because EDs is our invisible friend. He travels with us 24 hours a day. He is intrusive, rude, obnoxious, and a big bully that stops us from living life. (para. 4)

While EDs is clearly an unsavory character, speaking of “him” in this way was part of Bolton’s ability to locate the humorous aspects of her experiences, e.g., “I sat down and my hip dislocated. I was bummed” (para. 1).

Mighty contributors also used metaphors to explain different ways of being in the world. This was especially common among autistic writers. DG described why this form of expression was well-suited to her “geniuses,” explaining, “I love writing in analogies, metaphors, and allegories because one thing that a lot of auties do well, I think, is see the
bigger patterns.” She used metaphor to explain the experience of managing sensory overload while trying to navigate communication challenges and confusing social norms:

Imagine having Chrome, Firefox, IE, Edge, Opera, and Safari all open at the same time, all running at least thirty tabs, some of which are the same but rendered differently or in odd languages, and somewhere there’s six different songs playing at the same time – good luck finding them to shut them down—and on top of that, you’re trying to write something in one of the browsers, run it through a filter on another one, because if you just let it fly, no one will ever understand that you’re trying to say…and somehow you have to focus on one or two at a time to try to get things done enough that no one starves to death or dies of a dirty diaper. AND THEN imagine that things OUTSIDE of the browsers in your head are also trying to get your attention all at once, but they’re all using words that sound like the ones you know, but they mean something different.

In a powerful poem published on *The Mighty*, Spenser Stephen Roberts (2016) described himself as a “third seat bassoonist in the symphony of society,” writing: “I play my three notes and then retreat to a safe distance, watching, waiting to see if I am going to be accepted or if I have brought the music to a crashing halt and a scolding is imminent” (para. 6). While these metaphors focus on the challenges of navigating a neurotypical world as an autistic person, other metaphors reassert the value of these differences. For example, James quoted a metaphor that compared the autistic mind to a stereo with a frayed wire: although it sometimes produces static-y white noise, it is also capable of playing beautiful music.

*Mighty* writers who invoked discourses of difference integrated and difference empowered normalized the idea of both facing challenges and being different. In their articles, they expressed sentiments like “I am not any more broken than anyone else; some of my shortcomings might just be more visible than others” (Parks-Williams, 2016, para. 2) and “I face some of the same challenges, I just deal with them on a different
scale” (Spence, 2016, para. 1). While these quotes reframe struggle as a universal, “normal” human experience, they still associate difference with struggle.

Contributors who expressed these sentiments also spoke of being better people because of, rather than in spite of, their struggle. For example, Michaela O’Connor (2016) emphasized that she would “give almost anything to end the pain.” At the same time, she noted that she would “never give up the person I have become as a result of my pain,” clarifying:

Perfection does not come from success, approval or lack of pain and struggle. It comes from living your life to the best of your ability under the circumstances you are given and loving the life you have. (para. 4)

Contributors wrote about skills gained through their struggles. For instance, Casey McBain (2016) described how “lifelong patients” can bring valuable skills to the workplace. She explained how being ill had pushed her to become a more effective communicator; she had learned to be flexible and to adapt to negative feedback, to negotiate and compromise as a member of a healthcare team, and to be assertive enough to “insist that although tests do not always show it, I know when something is wrong” (para. 5).

In contrast, some contributors disrupted the link between difference and struggle, engaging in the process of what Cedar and I dubbed “flipping challenges into opportunities.” Cedar, who speaks with a speech impediment, described how he had learned to view his disability as one of his “greatest gifts” because it allowed him to be “unique in the world,” allowing him to connect with audience in an especially powerful way as a motivational speaker. Cedar spoke of “embodying the disability in an
empowering way where it almost has flipped to an ability now. I mean get paid to use the same voice that was a profound limitation to speak to audiences.” Other contributors similarly recognized the unique potentials tied to their differences. For example, Henley (2016) wrote about how appearing physically different allows her to know that she is “surrounded by people that truly love me because of who I am and not what I look like, and it’s wonderful. . . . I do not feel wrong. Most days I don’t even feel different” para. 24). Laura Walsh-Abbot (2016) described her physical disability as an “asset” for parenting her daughter, explaining:

Because of me, she understands empathy, and stands up for others who are classified as “less than,” insisting they deserve equal opportunities. She’s an advocate.

Because of me, she’s bright, funny, and smart. She’s learned to face obstacles that seem insurmountable with bravery and determination. She’s learned her worth isn’t tied up in how she looks or what she can do, but rather who she is as a person. (para. 10-11)

The general sentiment of difference empowered might be summed up in Tina’s hilarious response to our conversation about conforming to non-disabled expectations of normalcy: “I tried to be normal once, it was the worst two minutes of my life.” Contributors like Tina began to acknowledge the disciplining function of “normalcy,” invoking the discourse of difference as oppression/oppressed.

**Difference as oppression/difference oppressed.** Cardillo (2010) suggested that discourses that frame difference as oppression identify “society’s attitudes about difference as source of unjust treatment” and frame difference as a “civil rights issue” (p. 534). While I agree with Cardillo’s definition, the phrase “difference as oppression” suggests that “difference” is the source of oppression. I prefer the phrase, “difference
oppressed,” which better captures the idea that people with disabilities and chronic conditions are oppressed by ableist responses to their embodied differences—not necessarily by the differences themselves. As Wendell (1996) explained, the process of “othering” allows us to view members of a group as the “objects of our experience” and “see them primarily as symbolic of something else—usually, but not always, something we reject and fear” (p. 60). She observes that people with disabilities and chronic illnesses become “the ‘Others’ that society would like to forget” (p. 63) because identifying with them requires non-disabled individuals to recognize Western medicine’s ability to control and correct “imperfect” bodies. Mighty contributors who invoked the discourse of difference oppressed used metaphors of “otherness” to demonstrate societal exclusion. In addition, they critiqued the socially-constructed nature of “normalcy” and the pathologization of difference. In turn, they began to identify with a larger biosocial community—a marginalized culture with latent political power.

Metaphors of “otherness” depicted the “othering” impact of prejudice, illustrating oppression. For example, Athena Stevens (2016) invoked the metaphor of being on an “inhospitable planet,” comparing her life to Mark Watney’s experience in the movie, “The Martian.” She explained: “Nothing is built for me, there is no infrastructure for my basic needs, and I have to live a life that no one else has ever attempted” (para. 4). Similarly, Juana Ortiz (2016) used the concept of being an “alien”15 to describe her schooling experiences growing up with cerebral palsy in the Dominican Republic:

15 This metaphor is also used by segments of the autism community. For example, there is a prominent online community for people on the autism spectrum named “Wrong Planet,” which uses an alien with a magnifying glass as its logo (see http://wrongplanet.net/)
I remained sitting in my chair, like an outsider, while my classmates played. I didn’t want to fall and hurt myself, but I was also afraid I would not be welcome. . . I wanted to be let out of the box, but aliens are never asked to join the human race. (para. 9)

Rather than being excluded from “the human race,” some contributors described being compelled to join it. For example, Autonomously Autistic (2016) described the physical and mental exhaustion of trying to “pass” as neurotypical. They explained how, as a child, parents, teachers, and peers had continually forced them to endure the nauseating sensory overload of bright light, loud noises, and confusing nonverbal cues without “stimming” (calming, repetitive physical movements) or other compensatory tactics (such as wearing sunglasses, headphones, or hats). They subverted the common puzzle piece symbol used by some (typically non-autistic) advocacy groups, explaining, “The modern social world is not build for us—but we are expected to fit into it like a puzzle piece. I am not puzzle. I am human, an Aspie. I’m not like you and shouldn’t have to be” (para. 26-27). In his poem, Roberts (2016) wrote of being expected to conform to the seemingly irrational norms of neurotypical society, rather than being allowed to enjoy the orderly logic of trains—a topic that held special interest for him. He wrote:

I wonder why your words are so important, I wonder why the fork goes on the right. I wonder why you want to shake my hands, see my eyes. These things are arbitrary things. Not like Watt’s steam engine, not like pipes, and condensers, and metal stresses. Trains are real. Trains are concrete.

Manners are just more rules, and what are rules, words and what are words, sounds.

Social conventions. Mass hallucinations. Subject to change and flux and, God help me, fashion. Different from country to country, heck, from town to town. All strains on some theme for social groupings.

Not for me.
But I want to please you. I want to fit in. I want to learn. I want to love and to be loved… and so I study. I think. I memorize. I adapt. (Yes, we can do that.) I take lessons. I do therapy. I train. (para. 23-28)

Contributors who invoked the discourse of difference oppressed pushed back against the mandate to conform to “normal” society, asking “We’ve accepted the way we are, this is our life, why can’t you accept it? . . . You’re trying to fix us to fit into your world—why do we have to change?” (Tina). Cole (2016) observed that being asked the “seemingly innocuous” question, “Wouldn’t you rather not be disabled?” translates to being asked, “Wouldn’t you rather be more like me? More normal?” She answers “no” to both questions, concluding that “normalcy is a construction that enforces the idea that I’m even disabled in the first place” (p. 8) These Mighty contributors embraced the social model of disability, troubling the notion that being “fixed” or “cured” might always be either necessary or desirable. For example, Adelle noted that focusing on a cure “gets into the realm of eugenics,” and asked, “why are we fixing us versus fixing you? . . . Why fix us, as opposed to fixing the society that we live in?”

These quotes suggest an awareness of how systems of power discipline and punish “deviant” bodies, a la Foucault (1977). Invoking the discourse of difference oppressed encouraged politicization; individuals equated their struggle to that of other marginalized groups and recognized their agency to resist marginalization. For example, Brianna Beck (2016), a woman with dwarfism, framed herself as an “advocate for a marginalized group,” and explained: “My condition has challenged me and empowered me to seek justice for those that are seen as “less,” whether it is because of their race, socio-economic status, ability, religion, gender or sexual orientation” (para. 7). As this
quote suggests, the discourse of difference oppressed encourages individuals to move beyond their individual experiences to both identify with their own biosocial community and to position themselves in solidarity with other marginalized groups. In the following sections, I explore how such intra- and cross-condition collective identities develop.

**Biosocial Communities: Developing Collective Identities**

Collective identity describes imagined as well as concrete communities, involves an act of perception and construction as well as the discovery of preexisting bonds, interests, and boundaries. It is fluid and relational, emerging out of interaction with a number of different audiences (bystanders, allies, opponents, news media, state authorities), rather than fixed. It channels words and actions, enabling some deeds but delegitimating others. It provided categories by which individuals divide up make sense of the world. (Poletta & Jasper, 2011, p. 298)

Poletta and Jasper’s (2011) definition of collective identity emphasizes the ways in which communication (de)constructs collectivities, facilitating (dis)identification with others. While *Mighty* contributors wrote about their own experiences, they often wrote to, or on behalf of, people who shared those experiences. In doing so, they positioned themselves in relation to a biosocial community, adopting a collective identity that recognized an “us” distinct from “them”—non-disabled, “neurotypical” “normies.” Some writers adopted a relatively narrow collective identity, identifying with others who shared their specific condition. However, as individuals identified broader themes present in their shared experiences, they began to situate themselves within a broader, cross-condition collective.

**Narrow collective identities.** *Mighty* contributors frequently invoked nicknames to position themselves in relation to a condition-specific biosocial community, adopting a narrow collective identity. For example, contributors referred to themselves as crohnies
(Crohn’s disease), lymies (Lyme disease), endo sisters (endometriosis), and heart friends (congenital heart defects). Narrow collective identities associated with chronic illnesses, or conditions that fit more clearly in the “unhealthy disabled” category (Wendell, 2001), frequently invoked discourses of difference as hard reality by adding the term “warrior” after a condition name, such as “Von Hippel-Lindau Syndrome warrior” and “myotis warrior.” These collective identities were defined by very specific, shared experiences of struggle. For example, Carolina explained, “I feel like I’m part of a community, because I know I’m not out there suffering by myself.”

Carolina’s comments highlight the idea that becoming part of community was closely tied to the desire to receive and provide social support. Interestingly, Rose noted that her family felt uncomfortable with the fact that she identified herself as a member of community because “it sounds like I’m just accepting this and I’m not going to fight it anymore.” Her comments acknowledge the fact that people who have not experienced a chronic condition are unsettled by its unpredictable, irresolvable nature; they invoke a “fight” metaphor that assumes the ability to “beat” the condition and construct a tidy restitution narrative. In doing so, family members and other non-disabled others cling to the myth of control, protecting themselves from the interpersonal spread of PI (Babrow, 1992). In contrast, Carolina invokes the discourse of difference integrated, explaining:

I can’t spend more years of my life being angry about where I am . . . All signs point to it’s probably not ever going to go away. So, I don’t have to like it, I don’t have to embrace it and make myself only my disease or illness . . . but I do have to learn to live with it. And if I want a happy life, then that means I got to change my thinking. And I have met so many people who’ve been so influential in giving me advice and support and just talking to me in ways that my normal support system can’t.
Carolina’s community provides strategies for “living with,” offering tailored support based on their understanding of “what it’s like to live sick every single day of your life.”

People who identified with narrow collective identities sought such support from others with their specific diagnosis. For example, Maurine emphasized that she identified “more specifically as a patient with the advanced stage of the disease (there is a drastic difference in impact of lipedema on the quality of life of stage 1/2 women and 3/4 women).” Her clarification emphasizes the especially narrow nature of this collective identity, where individuals sought to connect with people who closely matched their level of impairment. Shared experiences allowed members of these biosocial communities to provide tailored social support in response to struggles. As Maurine explained:

These literally are women like me; we can talk about anything and even the most embarrassing elements of living with advanced lipedema (finding underwear that fits us or toileting). We celebrate the small victories with each other and we hold each other up when we struggle. I think we all know eventually the disease will take us, but until then we at least know we’re not alone.

People who identified as disabled also positioned themselves in relation to narrow, condition-specific collective identities. For example, *Mighty* writers referred to themselves as Autistic, Auties, and Aspies, and made use of the Twitter hashtag, #actuallyautistic, to claim legitimate membership to the autism community. As noted earlier, the term “Aspie” denotes an even more specific segment of the autism community, connecting individual who were more likely to experience autism in a similar way (while potentially marginalizing others who have been labeled “low
functioning”\textsuperscript{16}). This example highlights the challenge of forming a narrow collective identity even within a specific condition, particularly if that condition manifests as a spectrum of ability (as in Down syndrome and cerebral palsy). DG explored this challenge as she described her own position within the autism community:

The funny thing about auties is that, for all that we all have this common diagnosis, the way it presents for each of us is maybe more unique than fingerprints. Some people can’t be touched no matter what while others require constant contact with a trusted person. We all know we don’t speak the same language as the “other people,” but that doesn’t mean we all speak the same language as each other. We’re a community in that we all recognize that we need space in this world.

Her comments highlight the idea that even developing a collective identity tied to a single condition may require a broader narrative framework.

Biosocial communities linked to disabilities, particularly those that more clearly fit into the “healthy disabled” (Wendell, 2001) category, were more likely to embrace the discourses of difference empowered and difference oppressed, conceptualizing their conditions as cultural groups or as extended family networks. Deaf culture is a quintessential example of this. Sakari, who was diagnosed with both autism and an auditory processing disorder, discussed identifying with biosocial communities who understood and accepted her way of being in the world:

I really identified with the way a lot of the Asperger’s folks thought. I’ve always been a little more rational than I have been emotional. . . . I also actually really identified with the Deaf community even though I’m not deaf. I found a lot of kinship there and I found a lot of support and kindness.

\textsuperscript{16} “Functional” phrasing has been rejected by some autistic activists, who assert that it either sediments assumptions that some individuals are more “broken” and should be institutionalized, while others should be expected to “pass” as neurotypical.
As people like Sakari began to identify shared cross-condition experiences, they developed even broader collective identities.

**Broad collective identities.** “I see myself as a part of several communities. I’m part of the community of people who have spondyloarthritis . . . Then on a wider range, I see myself as part of the chronic disease community.” Eleanor’s statement captures Mighty contributors’ tendency to vacillate between identifying with a narrow condition and adopting a broader collective identity. Individuals who fell more clearly into the “unhealthy disabled” category constructed biosocial communities defined by shared physical and relational challenges, as well as challenges linked to making treatment decisions and managing healthcare encounters. Some, like Eleanor, adopted the broad terms “chronic disease” or “chronic illness,” rallying around the nickname, “spoonie.”

This term derives from a virally popular blog post written by Christine Miserandino (2003), which shared a story about explaining her limited energy stores to a friend using a handful of spoons. The resulting “spoon theory” even has its own Wikipedia entry (2017), which defines it as:

> a disability metaphor used to explain the reduced amount of energy available for activities of daily living and productive tasks that may result from disability or chronic illness. Spoons are a tangible unit of measurement used to track how much energy a person has throughout a given day. (para. 1)

*Mighty* contributors used “spoonie” phrases like “I’ve run out of spoons” or “I don’t have enough spoons” to describe the experience of managing limited energy. The concept of

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17 *Mighty* contributors also wrote articles that critiqued spoon theory, noting that the theory suggests that people with chronic conditions have predictable amount of energy that they can manage strategically (see Smales, 2016).
“spoonie” highlights the physical realities of life with a chronic illness, but also implicates how the physical experience of having limited energy impacted social experiences—such as having to ration energy spent enacting the roles of “employee,” “parent,” “spouse,” “friend,” etc. The term “spoonie” focuses attention on the ways in which “the pace of life is a factor in the social construction of disability” (Wendell, 1996, p. 37). Wendell (1996) highlighted the idea that, as pace of modern life increases, “fewer people can meet expectations of ‘normal’ performance” (p. 37)

Similarly, some contributors embraced the term “invisible illness” because it provided a clearer picture of both the physical and social nature of their experience, specifying the unique relational and credibility challenges associated with looking good while feeling terrible. Indeed, there is a whole collection of stories on The Mighty written about the experience of having a stranger leave a nasty Post-it-note on their windshield accusing them of taking an accessible parking spot that they didn’t truly need.

Likewise, individuals with rare conditions situated themselves in relation to a broader rare community, invoking the phrase “alone we are rare, but together we are strong.” They adopted the nickname, “zebra.” Again, this term for the rare disease community is so common that it warrants its own Wikipedia entry (2017), which defines “zebra” as “shorthand for the aphorism coined in the late 1940s by Dr. Theodore Woodward, professor at the University of Maryland School of Medicine, who instructed his medical interns: ‘When you hear hoofbeats, think of horses not zebras’” (para. 1). This nickname acknowledges a collective identity based not just on the shared physical realities of being ill, but also on the shared experiences of having few medical resources
and on the shared challenge of confronting ignorance in both lay and medical circles. For example, many zebras experience periods of being un-, mis-, or underdiagnosed, and were written off by healthcare professionals who were unfamiliar with their rare condition. As Alexandra Kaye (2016) explained, “we zebras have to constantly defend ourselves and our diagnoses to new doctors” (para. 3).

Similarly, some contributors positioned themselves in relation to a broad disability community. For example, Sakari described embracing a “pan disability level,” where she connected herself with people across conditions because, as she explained, “while their experiences and limitations are very different than mine, I’m really moved by the challenges they face.” Additionally, Sakari described the potential power of forming cross-condition partnerships, providing several examples to illustrate the importance of solidarity:

[My friend is] paralyzed from the waist down, and I can go shopping with him. If I get confused, he doesn’t. But I can help him into his car; I can drive. . . . That’s where the partnership I think can really liberate lots of people with disabilities from the kind of restrictions that some of us experience. . . . [My friend with epilepsy and neurological impairments] can’t write very well, but she’s really delighted that I can. While I can’t speak from an epileptic perspective, if she ever asked me to write something or say something, her voice is as important as mine. I think it’d really be great if more people with different disabilities would recognize the common challenges that we face from broader society and utilize one another’s strengths to make a stronger community and allow each other to navigate more fully.

Sakari’s comments acknowledge the very real physical and cognitive impairments associated with various disabilities, but also focus on challenges “from broader society” that impose further “restrictions” on people with disabilities. For Sakari, both forms of challenge provide a basis for collective identity. My interview with prominent disability
activist, Alice Wong, provided a clearer picture of how people with disabilities might begin to situate themselves in relation to a broader biosocial community. She explored her own process of “finding” her community, first explaining her initial acceptance of an individualized, medicalized understanding of disability:

Growing up you absorb a lot able-bodied values about disability. Also for me as a physically disabled person it was very “medical model.” So, I did think about it very much as something that was wrong with me and my body. Obviously, as a kid I saw a lot of doctors, I had various treatments. A lot of things that I thought were just on the individual level.

Learning about disability history and culture with and through other people altered Alice Wong’s self-concept, allowing her to reimagine disability in “a much larger, more nuanced sense.” She described disability as “not always something that is part of my body,” but instead “a political and cultural identity. . . a protected class with rights and legal protections . . . a larger class marked by difference.” This understanding of disability explains why some members of the disability community have rejected “person first” language, which suggests that the person is distinct from their condition, to adopt “identity first” language, speaking of themselves as a “disabled person” to emphasize their identification with a collectivity. Further, Alice Wong explained that people with disabilities may not adopt this collective identity because their history—a defining feature of a biosocial community—remains untold or inaccessible. She elaborated:

There’s a lot of people with disabilities that don’t feel any sense of pride. . . . They see themselves, they see the way they navigate the world, but they don’t see how we all created this culture that’s really important and really meaningful. I think that’s where ableism plays in where it’s very difficult for our people to recognize and embrace our history and culture. I think as more people actually discover their own history and culture and that connection with a larger group, a long line of history of decades of people all over the world doing this stuff, that’s
when you start realizing, “Wow, I am just a small part of this. And I’m part of something bigger.”

Alice Wong’s comments compliment Caldwell’s (2011) research on how leaders of the self-advocacy movement developed a self-advocate identity. He found “connections to the self-advocacy movement fostered integration of difference within their identity, providing self-advocates with a whole new way of defining themselves” (p. 321). Further, Caldwell noted that connections to the larger movement fostered a sense of interdependency—a commitment to supporting other people with disabilities. These findings, along with Alice Wong’s comments, highlight the idea that the ability to access a shared history, and the ability to situate one’s own story as a continuation of that history, is a key component of developing a collective identity—particularly one that moves beyond biological realities to acknowledge the “social” (communal, cultural, political) dimensions of a biosocial community. Social media have created digital spaces in which marginalized histories can be told and invisible or silenced experiences can be articulated. For example, Alice created the Disability Visibility Project—a collection of disability-related blog posts, interviews with disability activists, and oral histories recorded in partnership with StoryCorp.18 In addition, social media provides mechanisms for connecting otherwise isolated individuals. Consequentially, digital spaces facilitate the development of collective identities.

**Collective identities in digital spaces.** Mighty contributors frequently spoke about how social media had facilitated their connection with a larger community. They

18 See https://disabilityvisibilityproject.com/; https://storycorps.org/
recognized that the internet provides an “amazing way to find people” who are geographically isolated, who are less physically mobile, and/or whose social anxiety or alternative communication needs (e.g., people who are nonverbal or who have apraxia of speech) render face-to-face interactions more difficult. As DG, an autistic woman explained, “the internet is where [the autism community] will get the most done because there, we are protected and safe and can still interact and show our solidarity.”

Contributors often initially turned to the internet to learn more about their own condition. In the process, they stumbled upon online support groups and blogs, as well as individuals’ personal social media profiles. Natalie described how engaging with a digital network of endo sisters caused her to shift from feeling “very isolated” to feeling part of both a narrow endometriosis community and a broad chronic illness community. She explained:

My struggles with endometriosis were just getting really bad and I was up really late a lot or just not sleeping because of the pain. I more really started just searching online different forums, reading different articles, on Instagram and different social media outlets as well. I think at that point is when I really felt like, “Hey, I can and should talk about this. There are other people going through the same experiences and the same struggles. I don’t need to be doing it alone.”

Research on online communities has primarily focused on a single context, such as a Facebook support group. However, Natalie’s description suggests that her sense of community resulted from an aggregation of experiences across an interlinked network of both social media platforms and more static forms of digital content (such as articles, blog posts). While contributors initially spent time reading articles and blog posts, they often sought out more personal connections with the people who generated content that resonated with them. For example, Natalie explained how “following” specific
individuals via platforms like Twitter and Instagram reinforced identification with the community. As she noted that “social media accounts for most individuals are so personal, [it tends to] be a much stronger connection than something like a forum or an article might because you can have that one-on-one conversation with someone.”

Frequently, contributors utilized this network of connections to provide and solicit social support. For instance, they spoke about being able to reach out to a community of people who would understand, particularly when they were awake late at night due to chronic pain. In addition, contributors spoke about how social media enabled them to learn about the impressive work that other members of their community were engaging in. “It’s very inspiring,” Natalie explained, “There’s all these people doing amazing things, and not just physically. People who are writing books, people who have blogs . . . they’re all over the world.” Meriah Nichols emphasized how connecting with these role models helped to reinforce her identification with the disability community, recalling how she had met “so many REALLY CAPABLE, really professional and PROUD disabled people [emphasis included in typed comments].” As contributors located admirable role models in their community, they began to consider their own capacity to, as Cedar put it, “connect and to be of service.”

**Summary and Discussion**

In the foregoing analysis, I have described how receiving a diagnosis provides a powerful sense-making tool—particularly for individuals who have long remained undiagnosed, self-diagnosed, misdiagnosed, or underdiagnosed. Diagnosis initiates and directs the interlinked sense-making processes of re-narrating the past, constructing a
“new normal,” and re-imagining the future. These sense-making processes were captured in the stories that contributors constructed for publication on The Mighty. Indeed, as Babrow, Kline, and Rawlins (2005) articulated, “narratives comprise the means by which individuals organize a host of random emotional, perceptual, physical, and social experiences into a meaningful account of their situation (p. 34). Further, “narratives simultaneously work as agents of self-discovery and self-creation, a primary communicative practice through which the author’s identity evolves, is enacted, and put to use [emphasis in original]” (Harter et al., 2005, p. 10). In the context of disability and chronic illness, narratives facilitate re-discovery and re-creation as individuals attempt to revise non-disabled selves in light of disability in ways that allow them to envision livable presents and hope-filled futures. Thus, in the process of soliciting and publishing these stories, The Mighty curates a multi-voiced, multi-faceted exhibition of human resilience.

Additionally, engaging in the process of narrative revision sometimes restored individuals’ cognitive authority after the self-sundering trauma of epistemic invalidation. Wendell (1996) described cognitive authority as “the authority to have one’s description of the world taken seriously, believed, or accepted generally as truth” (p. 117). In an increasingly medicalized society, “scientific Western medicine has both the cognitive and the social authority to describe our bodies to ourselves and to others” (Wendell, 1996, p. 117). Individuals experience epistemic invalidation when healthcare professionals discount their claims; they may suggest that “lay” individuals lack the expertise to correctly interpret their symptoms, they may attribute claims of physical pain to
psychological problems, or they may accuse the person of malingering (fabricating symptoms to obtain drugs or to get out of work). As Wendell (1996) notes, the impetus for epistemic invalidation arises from the “myth of control”—the belief that medicine can and should protect the populous from physical and cognitive impairment. Intractable and inexplicable forms of illness and disability challenge this myth of control, eliciting defensive responses from healthcare professionals socialized to project a sense of certainty (Gawande, 2009; Katz, 1984; Montgomery, 2006). As Lupton (2012) writes, these “abject bodies” “disturb order, challenge systems of thinking, disrupt assumptions” (p. 37).

Writing to re-narrate the past allows individuals to reclaim their embodied knowledge, and to reject their “abject” status and reassert their position as legitimate knowers. By cultivating a repository of these types of stories, The Mighty showcases laypersons’ individual and collective agency to resist epistemic invalidation and to articulate the complex, messy, unpredictable experience of embodied difference. At the same time, however, the contributors I interviewed were more likely to re-narrate their past after an official diagnosis vindicated previously discounted intuitions. This recognition highlights the pervasive power of biomedicine to story our physical experiences—even when we acknowledge its imperfections.

My analysis also called attention to several, interwoven sources of flux—including diagnostic, physical, and social flux—which complicate efforts to construct stable identities. Attending to these sources of flux involves recognizing that both selves, and the stories we narrate to understand those selves, are always unfinalizable (Bakhtin,
1981). Johnstone (2004) describes the fluidity of disability identity, noting that “although certain constants are always ingredients to identity (like a particular impairment), identity itself is subject to fluctuations of self and society” (para. 32). My analysis suggests that even the physical experience of impairment may not be constant, particularly in the context of episodic or progressive conditions. For this reason, I have turned to PI theory to explore how these sources of flux interrupt sense-making processes.

PI theory asserts that we make sense of ourselves and our worlds by developing and integrating both probabilistic orientations about what is likely to occur or to be true and evaluative orientations about how (un)desirable some event or circumstance may be. However, as the sources of flux that I have identified suggest, individuals with disabilities and chronic illnesses struggle to form probabilistic orientations with regard to numerous foci. They face considerable uncertainty surrounding incorrect or incomplete diagnoses, erratic physical abilities, changeable responses to medication, (in)accessible physical environments, and the unpredictable experience of social support or scorn in response to self-disclosure. Additionally, they may struggle to formulate evaluative orientations with regard to their disability identity. Ambivalence may be especially salient here; as Johnstone (2004) noted, “disability is at once a source of pride or a source of scorn. It is conjointly a catalyst for empowerment and a source of pain” (para. 29). Similarly, identifying as disabled creates the potential for solidarity among those with embodied differences, but doing so further solidifies an individual’s status as an “Other” (Wendell, 1996). While uncertainty and ambivalence are commons forms of PI experienced by people with disabilities and chronic conditions, they likely experience
additional forms as they encounter overlapping, context-dependent, temporally-situated sources of flux.

Babrow et al. (2005) suggested that the experience of PI provides a primary impetus for storytelling. They describe narratives as coping mechanisms, contending that “we create stories—from ‘myths’ to relatively context-specific narratives—to construct meanings when we face diverging expectation and desire, uncertainty about substantial values or interests, marked ambivalence, or impossible wants and wishes” (Babrow et al., 2005, p. 47). These narratives draw from culturally-accepted formulae to participate in, or push back against, larger discourses about what embodied difference means and how to live as a person with a disability or chronic illness (Harter et al., 2005; White & Epston, 1990).

In the above analysis, I have attended to how the metaphors embedded in the narratives published via *The Mighty* implicate various discourses of difference—discourses that facilitated individuals’ attempts to formulate evaluative orientations toward an evolving disability identity. They employed metaphors of destruction and brokenness to frame difference as devaluation, and constructed metaphors that depicted their condition as a burden and as a hijacker to frame difference as hard reality. These narratives invited writers/readers to personify the character of the warrior or clever gameplayer, situating the self in opposition to the body in order to focus on ways to thrive *despite* living with pain and physical impairment, as well as with social stigma. Alternatively, metaphors of partnership transformed the condition itself into a character, one which might offer useful lessons about the nature of resilience, the joy in small
accomplishments, and the importance of living mindfully in the moment. Similarly, journey metaphors (sometimes) allowed the teller to adopt the character of the hero, moving through the plot of a “quest narrative” (Frank, 2013) in search of lessons learned because of embodied difference. Finally, Mighty contributors leveraged metaphors of otherness to participate in the discourse of difference oppressed, framing disability as a marginalized cultural group that is both worthy of pride and deserving of social justice.

As framed thus far, my analysis appears to suggest that Mighty contributors consistently draw on discourses that support either the master narrative of biomedicine or the counter-narrative represented by the social model of disability. However, this framework is limiting in its apparent tidiness. It does not acknowledge individuals’ ability to both create new narratives and revert to earlier drafts, authoring different versions/visions of self in the process. Indeed, Babrow et al. (2005) suggest that “when PI is particularly pronounced…actors likely struggle often unsuccessfully to maintain any one story. Accordingly, we develop multiple, competing, perhaps conflictual, stories through time” (p. 49). As individuals encounter various sources of flux, they may embrace contradictory metaphors and their accompanying narratives, drawing from and participating in incongruous discourses of difference.

The messy project of self-authorship highlights the inherently partial accounts of difference captured by both the biomedical and social models of disability. Disability scholars have long acknowledged that the biomedical model ignores the ways in which social forces constitute disability—both by creating the resource-scarce, toxic environments that lead to illness and physical impairment (for instance, when improper
disposal of industrial chemicals causes birth defects), and by creating inaccessible spaces and ableist norms that marginalize, stigmatize, and ‘Other’ different bodies (Shakespeare, 2013; Wendell, 1996). However, disability scholars have also begun to acknowledge that the social model of disability downplays or ignores the embodied experience of impairment. Doing so potentially alienates individuals who recognize the disabling impact of systemic oppression, but who also desire freedom from pain and other undesirable physical challenges (Stephens, 2011). This approach reifies the socially-constructed dividing line between chronic illness and disability, while also ignoring significant variations in physical experience (e.g., “visibility, stability, degree of interference with physical, mental or cognitive functioning, degree to which impairments are life-threatening, degree of pain, degree to which impairments pose ongoing medical problems”; Barnartt & Scotch, 2001, xvi) that shape the ways in which individuals make sense of their identity. Both of these factors make it difficult to theorize about a collective disability identity. Indeed, Johnstone (2004) concluded: “Thus, the conception of a unitary identity for people with disabilities is impossible (and perhaps undesirable) to codify. Rather, disability as an identity is often a personal construction, a purposive attempt to make meaning of self in the world” (para. 11).

My analysis suggests that, rather than identifying with a single, unitary disability identity, Mighty contributors shifted between relatively narrow and broad collective identities. Narrow collective identities, such as “crohnie” and “lymie,” formed around shared experiences of condition-specific physical or cognitive impairment, and the social experiences implicated by these corporeal realities. Attending to these specificities
foregrounded the sense that disability and chronic illness are experienced in and through the body, sometimes creating biosocial communities defined by the shared experience of physical suffering. As individuals adopted broader collective identities, however, they increasingly shifted their focus to attend to shared experiences of marginalization, stigmatization, and “Othering.” For example, while the “zebra” label represents the shared physical experience of occupying a relatively unique, often impaired, body, it also captures shared social experiences such as having “to constantly defend [them]selves and [their] diagnoses to new doctors” (Kaye, 2016) and being turned away by doctors who “don’t feel comfortable treating a disease they’ve never heard of” (Bogner, 2016, para. 4). Mighty contributors who identified as disabled especially emphasized social responses to embodied differences, echoing Alice Wong’s description of disability as “not always something that is part of my body,” but instead “a political and cultural identity. . . a protected class with rights and legal protections . . . a larger class marked by difference.”

This description compliments Caldwell’s (2011) finding that leaders of the self-advocacy movement, designed to secure disability rights, constructed a disability identity that “was not confined to separate realms of impairment or disability but, rather, grounded in lived experience and resistance to oppressive forces and structures that devalue that experience” (p. 323).

Both narrow and broad collective identities emerged as individuals wrote and read about experiences of chronic illness and disability shared via digital and social media platforms, including The Mighty. This phenomenon reflects the idea that “when individualized experiences are asserted, communities of common experience grow”
(Johnstone, 2004, para. 4). Johnstone (2004) suggested that collective identities formed from common experience become “institutionalized” as individuals describe them in similar ways across the interconnected digital spaces that constitute the internet, cultivating in-group norms and shared goals. These collective identities become the bases for social movements and for collective/connective action. In the following chapter, I explore how Mighty contributors drew on emergent collective identities to write purposeful stories, pursuing multiple, sometimes contradictory goals.
Chapter 5: Writing Purposeful Stories: Self-Advocacy and Collective/Connective Action on *The Mighty*

In my discussion of Chapter 4, I explored the ways in which narratives foster sense-making in the midst of PI-inducing diagnostic, physical and social flux, allowing contributors to author resilient versions of themselves in the process of writing. Indeed, *Mighty* contributors like Cedar acknowledged the “profound therapy” of writing. My interviewees frequently described how writing allowed them to make sense of confusing, painful, and frustrating experiences. For instance, Jo explained:

> When you’re going through stuff, you’re not always thinking clearly, because you’re in the middle of it. It’s like a giant tornado and you’re stuck right in the middle and you can’t always say or do what is really inside. It doesn’t come out right. . . . When you write for *The Mighty* sometimes it helps you understand what’s going on . . . it lets you put it down, and say it, and then deal with it.

Similarly, Jo viewed writing as a tool with which she could translate the complexities of life with Ehlers-Danlos syndrome, a rare condition, into a coherent narrative that might help others to both understand and empathize. She noted that when you write, “it’s there in front of you. You can read back over it, you can see what you wrote. It’s more physical. . . . You can rewrite it until you feel like you’re giving the right impression.”

For contributors who used writing in these therapeutic ways, getting the story published was more of an afterthought than it was a primary goal. As Renee explained, “sometimes I share them and sometimes I delete them . . . it’s a way of coping.”

However, *Mighty* contributors also recognized the therapeutic value of making their stories public. Publishing their stories allowed them to “break out of their shells,” shattering the constraints of (self-)censorship. For example, Emily talked about how
writing publicly allowed her to reclaim the bolder, more vibrant version of herself, explaining, “when I started getting sick, I found myself shutting up and hating everyone. . . once I’ve started to find my voice again, then it was like, ‘Okay. I can still be me. I just have to do it differently.’” Additionally, sharing their story with an invisible, anonymous, yet supportive audience provided Mighty contributors with an opportunity to experience validation. Maurine wrote for The Mighty in part because she wanted “to put [her]self out there,” claiming her story in front of witnesses. “One of the things that surprised me was the number of positive comments I received,” Maurine recalled. “I didn’t know how much I needed this validation, but it made me feel really good that I not only shared but that someone heard. I felt like my voice mattered.” These comments support Caldwell’s (2011) assertion that, as individuals who have been repeatedly marginalized, stigmatized and “Othered” attempt to develop an empowered self-advocate identity, they first engage in an “elemental form of resistance: claiming personhood and finding a voice” (p. 319).

As Mighty contributors began receiving feedback on their stories, they started to recognize their capacity to impact other people. For example, Danielle described how, in the process of writing a book to grieve her mothers’ passing and explore her experiences as a daughter and sibling to loved ones with a rare, genetic condition, she met others who needed her story. “[The book] was written originally for me, but what I discovered was there was a voice that a specific community needed, and a story of universal human truth that more and more people will face,” she explained, “And it was worth crying through the revisions of the hardest moments of my life in order to try to make those moments a little easier for somebody else down the road.” Similarly, Rose recounted how a response
to one of her articles pushed her to think about writing as a service to others. “There were a lot of people who asked, ‘Can I print this off and take this to my doctor?’” she explained, “And those have really stuck with me because I'm like, ‘That’s my goal, that’s my purpose in writing, is to put words to feelings and try to write out eloquently what you’re trying to convey.’”

As Rose’s comments suggest, *The Mighty* became an important outlet for writers who sought to reclaim a sense of purpose in a life disrupted by both physical impairments and social rejection. In the current chapter, I explore how, in the process of writing “helpful stories,” *Mighty* contributors enacted (a) refracted self-advocacy, (b) collective self-advocacy, (c) allyship, and (d) collective/connective action. I discuss how each of these forms of communicative labor require the writer to position themselves in relation to an imagined audience, communicatively constituting collective identities in the process. Additionally, I consider how *Mighty* contributors’ engagement in collective/connective action draws on varied discourses of difference to co-create and pursue collective goals for advocacy and activism, including (a) fixing “malfunctioning” bodies, (b) validating self-advocate perspectives, and (c) protesting oppression. Finally, I consider how *Mighty* contributors enacted advocacy and activism in digital spaces.

**Writing to Reclaim a Sense of Purpose: Helping through Stories**

Contributors described how their experiences of chronic illness or disability created an identity threat; they felt that they were not “contributing to society” (Emily) and struggled to answer the question, “what do you do?” (Bailey). Alicia noted that *The Mighty* inspires people to write by helping them to “have an end game in mind,”
observing that “some people don’t like to write for themselves. And so [The Mighty] gives people a reason to and that’s important. . . . Everybody wants to feel a sense of purpose.” Jo expanded on this theme, explaining:

I’m telling myself [that] by writing, I’m helping. I am accomplishing something. . . . I always had dreams of getting out of there. I wanted to be a doctor and go to school and help people. I couldn’t do that when I got sick. . . . I had to find something else. Some other way of devoting my time and making myself feel like I was still accomplishing—[that I] still had a reason to be around.

Contributors spoke of feeling that the challenges they faced were somehow worth it, so long as sharing their responses to those challenges might make another person’s life easier. In writing to reclaim their sense of purpose, contributors began to situate their personal experiences as part of a collective experience, developing an advocate/activist identity. Writing purposeful stories involved engaging in (a) refracted self-advocacy, (b) collective self-advocacy, (c) allyship, and (d) collective/connective action.

**Refracted self-advocacy: Private as public, individual as collective.** Mighty contributors often engaged in what I am calling *refracted self-advocacy*. Here, contributors wrote primarily to address interpersonal challenges that they faced in their own lives, engaging in the public performance of self-advocacy. In healthcare contexts, self-advocacy may involve demanding increased participation in medical decision-making, seeking adequate medical treatments, therapies, and other services, and finding and collaborating with compassionate healthcare professionals. Beyond healthcare, self-advocacy may involve requesting various forms of social support (emotional, tangible, appraisal, etc.) from family members, friends, teachers, employers, co-workers, and others. Similarly, self-advocacy might involve identifying and pushing back against both
inappropriate (though well-meaning) support and intentional ableism. *Mighty* editor, Kara, acknowledged the significance of self-advocacy for people with disabilities, explaining:

I think one part is of course there’s advocating for yourself, which as a person with a disability you really have to do if you’re going to get anywhere. Because otherwise, the world is not unfortunately going to be easy for you or kind to you unless you stand up for yourself, metaphorically speaking. And so it’s something that a lot of us learn growing up.

Articles that engaged in *refracted* self-advocacy accomplished the communicative labor of self-advocacy, but did so in an indirect way; contributors hoped that by publishing and sharing their responses to these problematic interactions that they might educate people in their personal lives and secure supportive resources. In the process of engaging in refracted self-advocacy, writers rendered their private, individual interpersonal challenges public. Doing so acknowledges that these personal experiences are also collective experiences, reflecting the typical challenges faced by members of a biosocial community. Thus, refracted self-advocacy represents an initial foray into collective action, while still primarily reflecting the writer’s desire for better emotional, informational, tangible, and appraisal support in their own life.

The concept of refracted self-advocacy is most clearly apparent when considering *Mighty* articles that were written as open letters, where contributors wrote directly to an individual rather than to a broader, anonymous audience. Some open letters focused on family members, such as, “To the Parent of an Undiagnosed Autistic Girl” (Nibbs, 2016) and “To the Frustrated Parent of a Child with Chronic Pain” (Wagner, 2017). Contributors also wrote to real or imagined romantic partners, for example, “To My Future Partner: What You Need to Know About My Life With ME/CFS” (Holli...
Friends were also popular open letter recipients (e.g., “To the Friends I’ve Walked Away From,” Stevens, 2016). Open letters were often addressed to healthcare providers, for example, “To the Emergency Room Doctor Who Dismissed Me as a Drug Seeker” (Blevins, 2016) and “To the Doctor Who Said My Gastroparesis Was ‘All in My Head.’” (Boka, 2016). Finally, contributors wrote to strangers or to unspecified people in their lives, for instance, “To the Person Who Told Me Fibromyalgia Didn’t Exist” (Caicedo, 2017), “To the Stranger on the Train Who Asked If I Had ‘Lost My Smile’” (Kleinmann, 2016), and “To the Man Who Turned Me into a Meme” (Hodges, 2016).

Emily’s description of her motivation to write most clearly illustrates the concept of refracted self-advocacy. “The Mighty was appealing to me because it was a chance for me to just talk about how I feel personally about what’s going on,” she explained:

The title of my piece was, “What I Wish my Family and Friends Knew about My Chronic Pain.” It’s a way for me to say what I want to say to them, but without having to be emotional or having to put them through some deep conversation. . . . I just pour my feelings out and hope that not only would my family and friends read it and understand but that the family and friends of other chronic pain patients would read it and understand.

Contributors like Emily described how engaging in refracted self-advocacy via The Mighty provided them the dual benefit of (a) being able to craft thoughtful responses to interpersonal interactions that they could not properly manage in the face-to-face moment and (b) being able to preserve a physical and emotional distance that might allow the targets of their articles to really listen to their message. As Eleanor noted, “when I try to talk about it I just feel like all they’re hearing is me complaining and that they’re going to get tired of it. And if it’s an article, you know, then it’s less of a personal thing between
us.” These comments resonate with Suler’s (2004) conceptualization of the online disinhibition effect, which posits that individuals are more likely to reveal “secret emotions, wishes, and fears” (p. 321) in online contexts because of factors like increased anonymity, invisibility, asynchronicity, solipsistic introjection (where “the online companion then becomes a character within one’s intrapsychic world” p. 323), and dissociative imagination (or the sense that “one’s online persona along with the online others live in an make-believe dimension, separate and apart from the demands and responsibilities of the real world” p. 323).

Several contributors gave examples of how refracted self-advocacy successfully helped them to improve their interpersonal relationships. For instance, Cindy observed:

Writing and then having it publicly read helped even the people that are closer to me to understand. You might ask me to go somewhere three times, and twice I might cancel at the last minute. And two years ago, you might have been angry at me for that, but now that you’ve read what my life is, you understand it more.

Similarly, Carolina reported that her father-in-law had read a Mighty article that she had posted to her personal Facebook page. He subsequently broached the topic of her chronic illness during a family camping trip, acknowledging some of the challenges that Carolina typically kept hidden. “It made me feel . . . validated,” Carolina said, “[and] that somebody finally understood.”

Similarly, contributors described how their open letter articles were used by readers to “come out” to people in their own lives. For instance, Eleanor described her reaction to learning that a reader had used her blog post to tell his or her family that they were sick: “That’s when I’m like, ‘Yes, [this] definitely makes a difference in somebody’s life. [I’ve] got to keep going. Can’t stop now.’” Eleanor’s comments
highlight the ways in which engaging in refracted self-advocacy could allow contributors to experience the dual-validation of both (a) feeling better understood by others in their personal lives, and (b) feeling like their writing was helpful to others.

Indeed, several of my interviewees described how their initial desire to respond to a frustrating encounter or to answer a common question caused them to become “accidental” advocates. James articulated this idea in his description of how he began writing for *The Mighty*:

I think I just stumbled on it. . . . It actually started with a piece I did. I had just finished my doctorate and there are lots of pictures in my church. . . . a lot of people made comments about why I was not smiling in the pictures. I had actually stumbled across something online where I saw someone who was writing for *The Mighty*. It just popped up on my Facebook, and I went to this site and there was a link to share your story and I thought “I want to answer this question.” Because it wasn’t just people in my church—I got [this question] my whole life. . . . I just thought if [*The Mighty* is] going to provide a platform for people like me to share some very simple things about why you don’t understand why I don’t behave and what could be socially appropriate, I just thought, “Well, maybe I could just share this one.” . . . And then from there, I just continued to share different questions I get a lot from people. It’s kind of an accident.

Over time, as James began to embrace his role as an advocate, he began to become more purposeful and strategic in his advocacy activities. He developed a Facebook group so that he could cultivate an audience and be more responsive to questions. He sought to “find out where is the gap in the knowledge-base and to try to fill that void or answer some of those questions.” Over time, contributors like James moved beyond their private, individual experiences to more explicitly position themselves as members of a biosocial community.

**Collective self-advocacy: Empowering individuals, constituting communities.**

*Mighty* contributors also engaged in what I have termed *collective self-advocacy*. Collective self-advocacy involved writing directly to other people impacted by a similar
condition. Writers who engaged in collective self-advocacy wrote to advise, support, and empower others so that they might be more likely to advocate for themselves in interpersonal encounters (such as with family, friends, healthcare providers, strangers, etc.). Collective self-advocacy is distinct from collective action in that it focuses on encouraging individuals to act on their own behalf in personal matters, rather than on encouraging communities to act collectively to address public, systemic concerns. Alicia clearly embraced the mentorship role implicit in collective self-advocacy, emphasizing that “more important than being an advocate for the community is just being an advocate for yourself. . . . I would rather help somebody else learn how to advocate for themselves than advocate for them.” Contributors who engaged in collective self-advocacy expressed a desire to “pay it forward,” hoping to alleviate others’ challenges by sharing the strategies and insights they had gathered while contending with their own trials. For instance, Jayson described how the experience of mentoring a girl with his rare condition—a girl he found after reading a post about her symptoms that she left in an online message board—inspired him to undertake additional advocacy efforts. “I was able to locate her [online] and she was just pretty much coming into her condition, being very uncertain and very afraid of what the ramifications of it would mean,” he explained. “I’ve been able to mentor her and walk her through some of the stages of it and how to cope in day-to-day life. That’s how I got into advocacy in the rare disease community.”

Collective self-advocacy was most apparent in three popular Mighty story formats. First, contributors wrote open letters to an earlier self, articulating the emotional, informational, and appraisal support that they wished they had been given during a
particularly challenging time, such as “To Myself on the Day of My Cushing’s Disease Diagnosis” (Krejsa, 2016) and “A Letter to Myself at the Beginning of My Journey with Crohn’s” (Parker, 2016). These articles took on some of the indirect character of refracted self-advocacy; writing to a younger self provided a way to heal old wounds while also helping others. Contributors also wrote open letters directly to others, envisioning an audience of people like themselves, for instance, “To the Spoonies who Don’t Think They are Worthy of Love” (Kalustian, 2017) and “To the Only Child in School Who Uses a Wheelchair” (Edwards, 2017). In these articles, authors drew on their personal experiences to empathize with an imagined reader, writing phrases like “My friend… I and many others have been there. We aren’t saying our situation is worse than yours, but we do understand. You are not alone” (Edwards, 2017, para. 3). In the process, these contributors began to explicitly speak as “we,” adopting a collective identity and communicatively constituting a biosocial community. Finally, contributors wrote in list-style formats, outlining advice for others.

Contributors enacted collective self-advocacy to accomplish several purposes. First, they sought to empower others through emotional and appraisal support, helping them to accept their conditions and, in some cases, to be proud of them. For example, Candice Clifford (2016) advised other people with Ehlers-Danlos syndrome to focus on breathing as a means of coping and accepting, writing that “finding your breath” will “help you through the painful moments, the moments when you want to give up and those moments you feel challenged. Your breath will calm you when you feel overwhelmed, and will give you the power and strength to self-advocate” (para. 9).
Jessica Acton (2016) urged others with rare conditions to “never hide who you are. Always embrace and be proud you’re different, because that’s what makes you special” (para. 7).

Second, contributors shared self-advocacy strategies for use in healthcare encounters. For instance, Kit J. (2016) urged readers to “find a provider you trust,” “take care of your mental health,” “keep [medical] records,” and to, ultimately, “be your own advocate.” “Unfortunately, many medical providers are overworked and don’t have adequate time to give to their patients,” she observed:

Your provider may not have the time to explain all the pathophysiology of your disease to you, but should be able to point you in the right direction (not Google) of where to find it. Always ask questions about your care and treatment, and if you aren’t happy with your treatment, make it known to your provider. The more involved you become in managing and understanding your illness, the better outcomes you might have. (para. 6)

Contributors like Kaye (2016) moderated this advice, writing “fight for what you need — just remember that you may not have to fight that fight. Don’t go into every appointment assuming it’s going to go poorly. Start off being open” (para. 12). Other contributors shared similarly pragmatic self-advocacy strategies in contexts that were similarly defined by imbalances of power. For example, Kerry Magro (2016) urged autistic readers to engage in self-advocacy when accepting a new job:

Carefully read the job guidelines and see what accommodations if any you may need to succeed in that position. After that, figure out whether disclosing is the right thing for you. Whether you talk to your employer about receiving accommodations is an individual decision. If you believe you need them though, go in with confidence, because those accommodations will maximize your potential at your workplace. (para. 9)
While these contributors alluded to systemic issues (such as overworked healthcare providers, potentially inaccessible workplaces), they did not advocate for systemic change; rather, they focused on equipping individuals with self-advocacy tools to have “better outcomes” and to “maximize [their] potential” despite systemic challenges.

Finally, *Mighty* contributors enacted collective self-advocacy to equip readers with strategies to secure supportive resources from friends, family members, and strangers. They urged readers to ask for help from others when necessary, emphasizing that “people are more than willing to help, if they know you need help. So speak up, fellow Lymies (and everyone else with an invisible illness)! . . . ‘Say it loud, say it proud’” (Hamoline, 2016, para. 19). They also provided advice about how to “come out” with a disability. For example, Ashley Esper (2016) outlined the steps she takes to disclose her Crohn’s disease diagnosis to others, including heuristics like “only share what I am comfortable sharing,” “explain why I am telling them,” “if necessary, request they keep the information private,” “always share a bright side,” “offer to accept any questions,” and “don’t underestimate people.” Further, contributors prepared their readers to handle the invalidating experience of being rejected by others, writing advice akin to Becki Parker’s (2016):

> You’ll see people you thought were your friends disappear. You’ll try and try to keep those relationships alive, but sometimes you have to learn when you stop CPR and call it. . . . It’s normal to outgrow people. It’s normal for them to not understand or learn with you. Adapt to your situation and respectfully move on. (para. 10)

Ultimately, contributors focused on “telling your story” as an empowering tactic for self-advocacy. For instance, Joe Valente (2016) explained:
Once people know my story, they can relate better and may offer help and support in ways I never thought possible. It is scary and takes courage to share my story, but putting it into the light can be healing and bring new people into my life. There is always the fear that someone may criticize me, and if someone does, that is my opportunity to remove that negativity from my life. Your story can set you free. (para. 4)

While “telling your story” was frequently framed as an individual act in the context of personal self-advocacy efforts, contributors also recognized the collective power of sharing similar personal stories publicly. For example, in her open letter to a healthcare provider who had dismissed her as a drug-seeker, Vanessa Blevins (2016) wrote:

If I share my story, and the next person shares their story, and we all keep sharing our stories, maybe eventually, someday, enough people will get pissed off that things will start to change and doctors who dismiss patients’ pain will be out of a job. Until then, my readers and all their friends are more than welcome to share this. (para. 9)

Blevins’ comments invoke the logic of connective action—uncoordinated, individual actions undertaken by members of an affective public, connected by digital stitching mechanisms (such as sharing, liking, re-tweeting, using hashtags). However, some contributors acknowledged that not all readers may be in a position to advocate for themselves.

Allyship: Advocacy as speaking for, speaking with. When I asked Meriah Nichols to define what it means to be an advocate, she replied, “Advocate—I try and speak out when it’s not necessarily easy or comfortable to do so, for populations that face discrimination.” While Meriah had participated in #crippingthemighty and disliked the site, her definition corresponds to descriptions offered by both Mighty staff members and contributors. For instance, when I asked Mighty editor, Anna, to describe advocacy, she responded:
It’s speaking up for people who need it, and then I think also preferably you’re one of those people. You’re also in the community and for whatever reason you have the platform or you have the voice or you’re just really good at breaking down ideas.

My interviewees often described the significance of speaking up for others, acting as allies for those who could not speak for themselves. They recognized that some members of their community might feel too vulnerable, both physically and emotionally, to voice their own needs. These writers acknowledged that they benefitted from forms of privilege that others did not enjoy. For example, Maurine talked about how she considered herself “very lucky,” elaborating:

I have a great family, a husband who loves and supports me, I am employed with health insurance. . . I know how fortunate I am from talking to the ladies who are lonely, hungry, and poor in addition to getting sicker every day.

Writers who had previously experienced living in an oppressive environment and were now in a “safer space” (Adelle) felt called to write. Jo explained:

When I was growing up, I actually was part of an abusive home. You didn’t talk about it. You couldn’t talk about it. If you did, you paid for it. . . . Being a writer gives me a way to voice [my] emotion and reach people that need [to be] reached, but sometimes they’re afraid to talk. Sometimes they’re in that situation where they’re not able to talk about it or not able to deal with it the same way. I can. I’m in a better state of mind or a better situation. I have a better support system. I can talk about it.

In addition, individuals who identified with multiple marginalized groups acknowledged the heightened importance of making their personal story public on others’ behalf.

Although critical of The Mighty as an outlet, Alice Wong—who identifies as Chinese-American—clearly articulated this point: “My experience is not something you typically see. In mainstream media, you still don’t see that many disabled women of color. In the
mainstream media, or even within the disability community, there is just [a] lack of diversity.”

Contributors also realized that access to platforms like widely-followed personal blogs and social media accounts, as well as to The Mighty, provided them with potentially powerful positions from which to shape perceptions of a condition. Similarly, they recognized that their ability to write skillfully afforded them a type of linguistic privilege, allowing them to “say things that [others] weren’t able to actually articulate in the way that made sense to people who didn’t understand” (James). In some cases, this linguistic privilege was quite literal—contributors acknowledged that others in their community were nonverbal and/or had developmental or cognitive challenges that made it difficult for them to write. For instance, in her poem entitled, “Autismally Beautiful,” Victoria Thunberg (2016) wrote:

I am one in 66.
But I am not someone that needs a cure or a fix.
Or for someone to explain to me that I’m different.
No, I’m saying this to be a reference.
To be a voice for those that cannot speak,
and not because they are in any way incompetent or weak. (lines 7-14)

In the process of acknowledging their own privilege(s), Mighty contributors accepted their heightened responsibility to speak up. They felt that they “owe(d) it to people” (Adelle), and that it was “not fair . . . to have these experiences and not let other people in on them” (Jayson). As James explained, “I had to use my platform . . . there was a responsibility to not just tell them my story, but to help people understand that there are lots of . . . [people] in our community who are also on the [autism] spectrum.” This sense of obligation to advocate on behalf of others simultaneously empowered
contributors to advocate for themselves. For example, Renee observed, “I think of myself as probably an advocate for others, but then doing, I’ve found that I am being an advocate for myself. And continuing it kind of pushes it all the way around.” Similarly, Natalie did not feel like she could advocate for her own needs as a woman with endometriosis until she heard the phrase, “you have to fight like it was someone else’s battle.” “If you saw someone you love sitting there suffering and not getting the treatment they needed or doctors brushing them off, you would never stand for that,” she explained. “I think that [recognizing that] is why I started writing about [endometriosis] more . . . right around the time I started being really my own advocate.” Interestingly, Natalie recognized that finding her voice through speaking for others provided a means to circumvent constraining gender roles. She noted that, “as a woman, you’re like, ‘I don’t want to be a nag. I don’t want to be annoying.’” In contrast, enacting allyship allowed contributors like Natalie and Renee to leverage the gendered expectation that they should nurture others, tapping into a “mama bear” persona.

Adelle articulated an important criticism of allyship as speaking for others, highlighting its potential to further silence marginalized voices. She described her approach to allyship as shifting away from speaking for and towards speaking with. “I view myself, not necessarily as a leader, but I walk hand-in-hand with leaders,” she explained. “I have a voice where a lot of my peers don’t, [but] I want them to be heard as well . . . they are leaders in their own right, so I share the microphone.” This metaphor of allyship as “sharing the microphone” depicts acting in solidarity with others—amplifying
their voices without appropriating them. Ultimately, this sense of solidarity facilitated true collective/connective action.

**Collective action: Advocacy/Activism as public, systemic, political.** Refracted self-advocacy and collective self-advocacy focus on equipping writers/readers with the words, skills, and confidence needed to pursue their private interests (such as disclosing a condition, asking for support, receiving the best medical care). In contrast, contributors who engaged in collective action wrote to transform private interests into public concerns. In doing so, they recognized systemic challenges that disadvantaged their biosocial community as a whole, adopting a politicized collective identity “linked to a broader social critique that views structural inequalities and the uneven distribution of social power as responsible for the causes and/or triggers of” impairment or of disabling aspects of the social and physical environment (Brown et al., 2004, p. 60). Contributors conceived of themselves as a political constituency, acknowledging their status as both a protected class with rights granted by the ADA and their potential collective power to lobby for additional resources and legal protections. In enacting allyship, contributors pursued others’ private interests and others’ collective concerns, moving between individual focus of collective self-advocacy and the systemic focus of collective action.

Politicized collective identities are communicatively constituted, drawing on various discourses of difference to develop an understanding of what it means to be chronically ill or disabled. These discourses also shape how collectives locate the source of their shared struggle (Zoller, 2005)—is it the presence of environmental toxins? A lack of scientific funding to research treatments and cures? Inadequate access to healthcare?
Culturally insensitive practices in doctor-patient encounters? Inaccessible physical environments? Stigma, ableism, and institutionalized prejudice? The answers to these questions shape how members of a biosocial community select and pursue collective goals. In the following sections, I explore several collective goals pursued via *The Mighty*, including (a) fixing malfunctioning bodies, (b) validating self-advocate perspectives, and (c) protesting oppression.

**Advocacy and the biomedical model: Fixing “malfunctioning” bodies.** In cases where *Mighty* contributors viewed their condition through a biomedical lens, collective goals involved securing research funding to better understand and more effectively treat/fix their malfunctioning bodies. These contributors placed their faith in scientific progress; in fact, they often used religious terms when discussing medical research. For example, Cindy reflected, “if I think about treatment 10 years ago to where I am now, there’s huge leaps and bounds, so I am praying for even bigger ones.” Similarly, Jayson described the National Institute of Health (NIH) as “Mecca for rare disease,” explaining, “you pilgrimage there, you go there and they have an entire wing that’s just devoted to research and development.” Essentially, these contributors worship the myth of control. As Wendell (1996) explained, “scientific medicine participates in and fosters the myth of control by focusing overwhelmingly on cures and lifesaving medical interventions” (p. 94).

For these contributors, advocacy meant “raising awareness”—educating both the lay public and medical healthcare professionals about the etiology, symptomatology, and prevalence of their conditions (or about the lack of information regarding each of these
categories). They reasoned that “raising awareness will drive research for treatments and better healthcare systems” (Eleanor) and that “the more loudly we speak, the more likely there will be funding” (Cindy). Through raising awareness, advocates hoped to influence how researchers directed limited resources. For example, Jayson described attending NIH advocacy day during Rare Disease Week, pushing to screen newborns for rare blood disorders and lobbying congress to fund rare disease research.

Additionally, some advocates raised awareness to convince healthcare professionals to recognize the legitimacy of their illness experience. My interviewee, Bailey, explained the frustration of living with a condition that is not officially recognized by medical experts. “The CDC basically has claimed that chronic Lyme doesn’t exist,” she explained. “They have admitted that there is post-treatment Lyme disease, but the problem is that there isn’t a whole lot of research about it.” This approach to advocacy was particularly common among contributors with rare conditions, where both information and funding were scarce. For example, Melissa Bogner (2016) writes to “spread awareness in hope of finding a cure” for erythromelalgia (EM), a condition that impacts one in 100,000 people and causes episodes of severe, burning pain in a person’s feet, hands, face, ears, and limbs. In her article, she outlined the frustration of living with a condition that remains a mystery, even to medical experts:

We’re still somewhat living in the stone ages in understanding EM. The exact underlying cause remains unknown. . . . Several doctors turn patients away because they don’t feel comfortable treating a disease they’ve never heard of. Some physicians aren’t willing to work with patients when it comes to experimenting with various medications until some form of relief is found. Unfortunately, there’s no understanding on which type of doctor a patient should see – neurologist, dermatologist, hematologist, rheumatologist, podiatrist, geneticist, internal medicine, cardiologist, pain management or a primary care
physician. . . . Like lab rats, we’re forced into experimenting with various medications, vitamins and herbal remedies due to our poor quality of life. (para. 4-5)

For patients with rare conditions like Bogner’s, The Mighty provides a valuable opportunity to raise awareness. As Jayson noted, “big diseases” often get “a lot of exposure and they get a lot of funding . . . and the rare disease community is the one that falls by the wayside.” In contrast, he noted The Mighty’s potential to “serve a community that is not highly visible—to create that visibility within itself and within the able-bodied world as well.” As he discovered more about the site’s “multi-platform” nature (its use of articles, newsletters, videos, fund-raising initiatives, and non-profit partnerships), Jayson recognized “an opportunity to contribute in a unique way to help other people get perspective from the patient, as well as to allow other patients . . . to possibly see themselves in the community.” He discovered that many of the people he had met through his rare disease advocacy work had also begun writing for The Mighty, and together they generated several collaborative articles. “I love that we as the contributors are able to lean on one another in that sense,” Jayson emphasized, “We just grow as a community from doing so, using these platforms.” Jayson’s comments illustrate how the impetus to engage in collective/connective advocacy both stems from and reinforces the sense of belonging to a biosocial community. His desire to share the patient perspective suggests that “raising awareness” also involves validating self-advocates experiential knowledge.

*Advocacy from “our side of the fence:” Validating self-advocate perspectives.*

Raising awareness typically involved educating individuals about underrecognized
conditions by spreading technical, medical information about etiology, symptomatology, and treatments. This form of advocacy lionizes medical expertise, reinforcing medicine’s cognitive and social authority to determine what we can “know” about the human body (Wendell, 1996). In contrast, some advocates focused on (re)asserting the value of their self-knowledge, positioning themselves as experts on their own bodies. Validation of self-advocate perspectives functioned to place lay individuals in partnership with scientists and healthcare professionals. Self-advocates urged medical experts to consult with them in the process of selecting research goals and developing treatment recommendations. For example, self-described “patient advocate,” Andy Jablonski, wrote about the need for doctors to listen more to their patients. He explained, “Doctors can learn from the experts who come into their offices and hospitals every day. Then, they would have a better understanding and a more ‘complete picture’ of the patient experience” (para. 11).

Additionally, “raising awareness” often involved framing a condition as sufficiently fear- and pity-inducing that it merits public concern, such as Autism Speak’s framing of autism as “working” “faster than pediatric AIDS, cancer, and diabetes combined” (Mastroianni, 2013, para. 4). These rhetorical approaches to raising awareness frequently perpetuate ableist perceptions of disability. In contrast, some self-advocates shared their perspectives to alter public perceptions of their condition, seeking to create a more supportive social environment. To that end, advocates pursued three interlinked collective goals: (a) educating for understanding, (b) correcting misperceptions, and (c) seeking acceptance.
Educating for understanding involved contextualizing medical descriptions of a condition, providing a clearer sense of what the condition actually means in the context of a person’s day-to-day experience. Some contributors wrote to educate others who had been recently diagnosed. For example, Heather spoke about how, when she was first diagnosed with multiple sclerosis, “the only people that were sharing their stories were the people who had been affected in the most dire ways, and so you were just like, ‘Oh, that’s my future.’” She wrote to provide recently-diagnosed others with an example of how a person with multiple sclerosis might live a successful and fulfilling life. Other contributors wrote to educate would-be support persons. For example, Renee spoke about how limited, medicalized information about ankylosing spondylitis created awkward encounters with semi-informed people who believed they could help her. She elaborated:

> When you Google it . . . it’ll say . . . lower back pain, disease of the spine, exercising helps, treatments available. So, people that really aren’t invested in your journey are going to be like, “Well, I might be able to help . . . I will find this exercise.” And you think . . . “I just woke up with a fever of over a hundred today” . . . So, Googling it, it’s hard because it doesn’t explain . . . the flu-like crap that you have to go through.

Her account illustrates how incomplete, uncontextualized medical descriptions of a condition can impart a false sense of understanding, encouraging people to offer flippant advice that further enhanced the recipient’s sense of marginalization.

Educating for understanding involved sharing personal stories that “paint a more relatable picture for the public” (DG). James provided a particularly clear description of educating for understanding, noting that, while many of his counterparts were advocating for autism acceptance, he found that the general public still had relatively little understanding of what it means to be on the autism spectrum. James explained:
People know the word, but they have limited experience of what it actually means, and you have [a] multitude of professionals, educators and PhDs, and people who have studied it, but you don’t have a lot of people who are able to translate it into everyday life. . . . For me, advocacy means taking the real-life face of autism spectrum disorder and translate it into a way that people can understand, educate them in ways that even help them to kind of decipher some of the things that they have experienced or they have been experiencing with coworkers or family or friends.

Similarly, Justin Herbst (2016) described his approach to dealing “with a ton of ignorance” about cerebral palsy: “I wake up thinking every able-bodied person is ignorant of my disability. . . I think it’s my job to teach every able-bodied person I know of the disability struggle, so it can be understood and viewed as beautiful” (para. 5).

Many Mighty articles reflected this commitment to educating for understanding, focusing on depicting “what it’s like,” as in, what it’s like to have a meltdown, to live with limited “spoons,” to date, travel, or go on a job interview as a person with a disability, etc. For contributors who became chronically ill or disabled later in life, writing for The Mighty provided an opportunity to share new insights they had learned. For example, Eleanor described her inspiration to write as something “[that] triggers the memory and it’s like, ‘Oh, I need to explain this’ because I still have this . . . healthy feeling brain . . . so I still remember what it’s like to be on the other side.” Educating for understanding, then, involved translating the ill or disabled experience for a non-disabled audience or newly-disabled audience.

Correcting misperceptions involved unsettling stereotypes and ableist assumptions that trivialized, distorted, stigmatized or devalued self-advocates’ experiences. For example, several of my interviewees described writing because others doubted that their conditions were legitimate or serious. Natalie recalled the frustrating experience of having
to tell her boss that she needed to miss work because of endometriosis: “He was like, ‘Yes, I live in a house with women, so I get how that stuff goes.’” Similarly, Kaite Rosa wrote about the silencing impact of being “told by both doctors and our loved ones alike that periods are supposed to hurt. That the pain is all in our heads. That we’re just being dramatic” (para. 3). Likewise, Jo told me about how her own doctor believed that her fibromyalgia was in her head, elaborating that “when you have fibro, it’s just something that you deal with. You realize you have to fight to get anything and most people won’t believe you. The people that are supposed to believe you won’t believe you.”

Notably, this kind of trivialization was frequently experienced by people with conditions that had few visible or measurable markers. Indeed, Natalie noted that endometriosis required much more of her advocacy energy than her two other conditions, explaining, “With migraines, people get that a bit. Hyperthyroidism, you see it in your blood work. Whereas endometriosis is very grey.” It is also important to note that the two conditions discussed here primarily impact women; as Emily noted, “people don’t believe you when you say you have pain—especially females and especially minority females.” Indeed, even when women claimed broadly-accepted conditions, like autism, they sometimes struggled to make others believe that they really were autistic—particularly when their autistic characteristics did not conform to classic descriptions of autism largely developed to capture what autism looks like in boys/men.19 In the absence of demonstrable, medical evidence, self-advocates must build a rhetorical case to frame their claims as both...

19 Research increasingly suggests that autism presents differently in women, causing many women to remain undiagnosed. See this article, published in Scientific American: https://www.scientificamerican.com/article/autism-it-s-different-in-girls/
credible and doctorable—a communication challenge made more difficult in the face of prejudice. Advocacy efforts, then, aim to provide additional rhetorical force to otherwise contestable disability/illness claims.

Advocates also corrected misperceptions that distorted expectations about what it means to be “chronically ill” or “disabled.” For example, Natasha Lipman (2016) explained that representations of disability in the media often portray a “traditional” understanding of disability. She emphasized that this “makes it difficult for people with invisible disabilities to be believed and understood because it is still not socially acceptable. How can you be disabled when you look able bodied?” (para. 7). Advocates with invisible conditions frequently wrote about the resulting social sanctions they endured. They were berated for parking in accessible spots, using accessible bathrooms, sitting down in the midst of supermarket aisles, etc. Julie Cerrone (2016) described telling a Transportation Security Administration (TSA) agent that she was disabled: “he looked at me, scoffed, and responded with ‘No, you’re not’” (para. 12), and then “proceeded to say ‘This line is for people in wheelchairs. So, if you’re not in a wheelchair, you have to stand in line’” (para. 16). Cerrone wrote her Mighty article to explain that “disabilities come in all forms and we need to treat each and every one of us – regardless of race, sex, gender, ability, disability, religion, etc. – the same. With respect and dignity” (para. 33). Further, she emphasized the collective nature of her goal, writing, “This is why we need each other. This is why we need to share our stories. This is why sharing the patient voice is so important. This is why I do what I do!” (para. 27).
Similarly, Christina Carrell (2016) wrote about how distorted perceptions of chronic illness as stable, constant impairment can lead to unsupportive interpersonal interactions. She describes a television show in which “Sue” sees who she believes is a person from her dorm floor playing volleyball; she and her other floormates had given this girl a prime dorm room location because she had described how chronic fatigue syndrome (CFS) impairs her daily activities. Sue confronts the girl, saying, “We know you’re faking it. . . . It’s called chronic fatigue syndrome, not intermittent fatigue syndrome” (para. 6-7). While the episode is written around a classic identity mix-up (the girl playing volleyball is the floormate’s twin sister), Carrell uses it to dispel misperceptions about the nature of chronic illness. “Actually, Sue, that’s exactly what [CFS] is: a condition, like many others, that can come and go unexpectedly” (para. 8), Carrell wrote. “So, yes, Sue, chronic illness can be ‘intermittent,’ and we don’t owe you any explanation for our good days” (para. 12).

Similarly, Mighty contributors used their personal stories to contest stigmatizing discourses. Frequently, contributors described the stigma attached to taking medications to manage chronic pain. Friends and family members judged them for relying on pain pills, viewing them as lazy and attention-seeking. Similarly, doctors used the discourses associated with the “opioid epidemic” to reject requests for medications beyond Tylenol and aspirin—medications necessary to cope with persistent, severe pain. When I asked Rose to describe what motivated her to write for The Mighty, she explained that she wanted people to “see the conversation from our side of the fence. . . . We’re not drug addicts, we’re not attention seekers, we have a real legitimate problem, and it might be invisible, but that doesn’t mean it’s not there.” Once again, Emily explained how stigmatizing
depictions of chronic pain patients as drug-seekers interacts with sexism to constrain women’s access to healthcare. She shared her own experience of being denied pain medication:

When [the doctor] came in to see me, he didn’t approach the bed. He stood across the room. I explained to him the intricate health history that I had. . . . Even though I had lab tests that showed what was going on and I had all this, I came prepared with paperwork and information, but he refused to give me a pain medication. Then, I heard him go to the gentlemen next to me who had an upset stomach and he sat down, pulled his chair next to the bed . . . and proceeded to offer him pain medication now, pain medication to take home, and none of the labs showed anything, but “we hope you feel better.”

Finally, correcting misperception involved contesting stereotypes that devalue life with a disability. They pushed back against the idea that they were pitiable victims of their disabilities, writing statements like “my wheelchair is not confining, and I do not suffer from my disability. My mobility device gives me freedom” (Parks-Williams, 2016, para. 5). In addition, they addressed stereotypes that assumed that they were always dependent on others. Tina talked about constantly being asked where her “caregiver” was whenever she was out in public alone, and recounted times when strangers came up to her daughter to say, “Oh, it’s so nice to be taking care of your mom.” Relatedly, contributors reported receiving judgment from people who questioned their ability to be parents as people with disabilities. Walsh-Abbot (2016) wrote:

In my life, I’ve frequently been asked if I’m doing what’s best for my daughter: “Don’t you think it’s unfair to her? You being so sick?” “What about playing? You can’t run in the park with her. You can’t be at every sporting event or school play. Don’t you think she deserves that?” “She shouldn’t be burdened by your disability.” (para. 6)

Contributors rejected stereotypes that suggested that they could not be desirable, sexy romantic partners. As Jessica Grono (2016) emphasized, “I am lucky to have my husband,
but not because he accepts my disability. . . . I’m lucky to have my husband because he’s funny, kind, considerate, handsome, likes to have fun, responsible and a good cook” (para. 8). Finally, autistic contributors debunked dehumanizing stereotypes that positioned them as “Other.” For instance, Spenser Stephen Roberts (2016) provided a powerful account of how his attempts to connect with neurotypical peers remain unacknowledged:

They say I feel nothing. Frequently I feel too much. I love too hard, I take a conversation into fragments, diagramming and re-diagramming and seeking that one tiny flaw and beating myself with it, long and hard, until days, weeks, months, years later I take out the much-battered sentences and show them to the person I spoke the words to and they wonder what I am thinking of. Them. I am thinking of them. And they, well, they think about me, so science says, for about 17 seconds on average. (para. 10)

Ultimately, through educating for understanding and through correcting misperceptions, contributors hoped to advocate for acceptance. In some cases, acceptance referred to self-acceptance—acceptance of living life in a body with capacities that differ from “normal” or “typical.” In other cases, acceptance referred to public acceptance—the idea that we should “accept people, because they’re different. It’s okay to be different” (Jo).

While many Mighty contributors emphasized how sharing personal stories could help to achieve understanding, correct misperceptions, and encourage personal and public acceptance, some also recognized the limitations of understanding. Jo acknowledged that simply writing and sharing one’s personal story did not guarantee that it would make the desired impact. “As a writer that’s something you really have to be aware of;” she explained. “There will be people that aren’t ready for what you write, or won’t be able to
understand it or handle it.” Further, Rose described the emotionally-taxing experience of hoping for understanding while continually confronting ignorance. She observed:

People set themselves up for failure because, as you see when you read these articles, there is a lot of trying to get people to understand. I do think you can convey things . . . you can convey, “Here is what a glimpse of what it looks like.” But I don’t think it’s fair for us to expect people to understand, because you only really understand if you have it.

Rose explained that accepting the limitations of understanding “makes it a hell of a lot easier.” It allows her to recognize that, even when people say and do things that are offensive, they typically do not intend to offend. As individuals moved from engaging in advocacy to enacting activism, they shifted their focus from changing individuals’ perceptions and behaviors to changing the social institutions that shaped these norms in the first place.

Activism and “actionary” anger: Protesting oppression. When I asked Meriah Nichols to define what it means to be an activist, she replied, “Activist—I try and be present to help change political and social realities.” This definition of activism focuses attention on altering or dismantling oppressive social structures. Rather than working within existing systems to enact change, as advocacy-oriented groups do, “activist-oriented groups engage in direct action, challenge current scientific and medical paradigms, and pursue democratic participation in scientific or policy knowledge production by working largely outside the system” (Brown et al., 2004, p. 53). Thus, while Alice Wong perceived of advocacy and activism as relatively similar activities, she identified differently depending on the kind of group she intended to work with. For example, she claimed the term “advocate” when working with mainstream disability
organizations, frequently created by non-disabled allies, acknowledging that “activist”
“sounds too hard edged” in these contexts. However, she identified as an “activist” when
working to develop edgier initiatives, particularly via social media.20

Activism and anger are closely interlinked. For example, Adelle described anger
as a consequence of acknowledging and resisting internalized ableism—it fueled a shift
away from “constantly apologizing” for being a “burden” on her parents toward the
catharsis of saying “I don’t give a fuck.” Similarly, Sakari described anger as response to
the double trauma of being “put through hell” by healthcare professionals and
“abandoned” by trusted friends who would not accept her criticism of the “heroes” of the
“medical establishment.” Ultimately, she framed these traumas a “radical liberation”;
freed from caring about what others thought, Sakari found that she could speak out
against the emotional and physical violence she had endured as a patient.

Activists like Adelle and Sakari acknowledged the potentially transformative,
liberating power of anger; anger served as the catalytic force behind their activism. For
example, Adelle explicated the difference between internalized bitterness and
externalized anger:

I’m not bitter, I’m angry—there’s a difference. . . . Anger is an action word; you
can use that anger in other ways to do things. Bitterness just sits on your chest.
I’ve dealt with a lot of bitter people, who don’t know how to process the fact that
they’re disabled—who are angry at the world, versus angry and actionary.

20 For example, Wong recently organized the hashtag initiative, #criptheyvote, designed to “engage both
voters and politicians in a productive discussion about disability issues in the United States, with the hope
that disability takes on greater prominence within the American political landscape” (Wong, 2016, para. 3).
Similarly, Katarina Showalter (2016) explores the ways in which anger might activate social change. “As long as I learn to direct my anger at problems and inaccessibility and not at people,” she wrote, “I don’t think I mind being an Angry Disabled Girl” (para. 22). Showalter’s comments highlight the importance of channeling anger to tackle systemic problems—problems pervasive enough to generate the kind of collective anger that animates marginalized biosocial communities. *Mighty* contributors transformed collective anger into activism to (a) protest inaccessible healthcare, (b) protest ableist representations, and (c) protest institutionalized ableism.

*Protesting inaccessible healthcare.* In her conceptualization of health activism, Zoller (2005) identifies medical care access and improvement as one focus of activism. This focus involves “efforts to expand access to medical care and health insurance, along with movements to improve the quality of medical care delivery and communication” (p. 348). Several *Mighty* contributors wrote to protest inaccessible systems of healthcare. In some cases, they noted that there simply were not enough specialists to meet would-be patients’ needs. For example, Jill Fuersich’s (2016) article described why simply “raising endometriosis awareness” is not enough. “The director of research and evidence-based medicine at the Vital Health Institute in Los Gatos, CA, has created a map of endometriosis specialists,” Fuersich wrote. “As of today, there are 138 specialists on that map. That’s 138 specialists for the 176 million women with endometriosis worldwide” (para. 4).

Contributors also frequently highlighted how insurance policies limited their ability to afford life-altering surgeries and treatments. For example, Jenneh Bockari
(2016) recounted her experience of being stuck with a $115,000 medical bill after her insurance company decided not to reimburse the cost of her life-changing surgery, writing, “a fire has been ignited in me to seek justice for all of these people, for my fellow people with chronic illness and for myself, in any small way I can” (para. 7). Similarly, Alethea Mshar (2016) described being denied coverage of a medical procedure because her symptoms were not “severe enough” (para. 2), despite experiencing progressive nerve damage that made it difficult for her to stand or walk. *Mighty* editor, Karin Willison, wrote about how many U.S. states do not provide sufficient Medicaid waiver programs for home health services for people with disabilities, concluding that “We need legislation like the Disability Integration Act to ensure home health care access for everyone” (para. 11).

*Mighty* contributors also discussed systemic issues that made important medications inaccessible to patients. For example, Eleanor’s activism was motivated by the desire to ensure that people with rare conditions could afford treatments. She explained, “[There was a] California State bill that I helped pass a couple years ago, and that was about transparency for state health care exchange. About drug costs, drug price for specialty medications.” Emily described how legislation around pain medication had been shaped by the “opioid hysteria,” creating a “civil rights” and “patients’ rights” issue where patients were unable to obtain necessary medication. She recounted her own traumatic experiences in the healthcare system, illustrating how these pushed her to engage in activism:

I unjustly was fired from a clinic and they didn’t refer me to any other doctors. . . . I was on a very high level on opioids as well as using other methods of pain
relief, and I suddenly had nothing and my primary care physician refused to write me anything even to help me until I can find a doctor. ... So I reached out to this woman that runs the Kentucky Pain Care Action Network ... and she told me there’s really nothing you can do but start advocating. Pretty much that day, I just started writing and making phone calls and writing Congressmen. ... I’ve been trying to contact the ACLU and the Human Rights Campaign or Human Rights Watch, trying to get them because mainstream media will not report on anything to do with the patient’s side mostly because they’re funded by the Big Pharma.

In general, contributors used The Mighty to insert their voices directly into healthcare policy debates. At the time that this dissertation project was conducted, Mighty contributors were writing to explain how efforts to repeal and replace the Affordable Care Act might impact access to important resources and accommodations, publishing op-ed articles and open letters addressed to specific politicians. For example, several articles responded to Republican Representative Jason Chaffetz’ advice to those worried about affording healthcare: “rather than getting that new iPhone that they just love and want to go spend hundreds of dollars on that, maybe they should invest in their own healthcare” (Scott, 2017, para. 3). Contributors like Stephanie Tait (2017) pushed back against the stereotype “that people who can’t afford their medical care don’t know how to live within their means” (para. 3), detailed the exorbitant costs of their care, and noted the ridiculousness of expecting chronically ill people to live in a permanent state of austerity: “if we . . . need care for the rest of our lives, does that mean we shouldn’t ever be allowed anything more than a bare minimum? . . . Is our value attached to how much money we have?” (para., 10).

Finally, contributors described how, even when healthcare was affordable and hence “accessible,” it often remained inaccessible to people with physical impairments or alternative communication needs. For instance, Tina described how healthcare providers’
practice of relying on video remote interpreting (VRI), rather than on-site interpreters, to communicate with Deaf/deaf patients is less than ideal. Hospital Wi-fi connections frequently stop working, off-site interpreters and patients frequently have trouble seeing each other when the VRI system is positioned incorrectly, and patients who have low vision or who are deafblind prefer tactile signing. Similarly, Sakari described how medications and other therapies used by mental health professionals resulted in an iatrogenic brain injury, an injury in part caused by incorrect assumptions that her brain was neurotypical. Disability activists like these pushed for healthcare resources that acknowledged and accommodated physical and cognitive differences.

Zoller (2005) described “illness and disability activism” as a second focus of health activism, defining it as “bringing attention to particular diseases, developing research and treatment, and altering public perceptions and norms related to illness and disability” (p. 349). This definition is appropriate for individuals who recognize the ways in which systems of power direct medical resources in ways that perpetuate patterns of privilege and marginalization. Certainly, contributors touched on some of these oppressive forces in the above discussion of healthcare (in)accessibility. Indeed, *Mighty* contributors were particularly vocal about how “women’s issues” received less attention from the medical establishment. For example, Rosa (2016) asserted, “if 176 million men were suffering from a disease that covered their reproductive organs in painful adhesions and cysts while crippling their fertility and sapping their sex lives, the treatment options wouldn’t include cutting body parts off” (para. 10). Her comments highlight how gender
bias in medical institutions shapes research agendas and treatment protocols—a recognition embedded in the activism of women’s health movements (Zoller, 2010).

However, Zoller’s (2005) definition of illness and disability activism places “developing research and treatment” and “changing public perceptions and norms” in the same sentence, suggesting that these are goals are typically interlinked and equally desirable. In doing so, this definition potentially pathologizes difference in ways that would not be accepted by disability activists who embrace an integrative or social model of disability. While such activists may acknowledge the need to address some physical impairments through better, more accessible healthcare, their main goal is to address the disabling impact of ableist norms perpetuated by the media and embedded in other social institutions (including healthcare).

Protesting ableist representations. Contributors made use of The Mighty’s platform to protest the ways in which disability and chronic illness are frequently portrayed in mainstream media. As Wendell (1996) noted, “the lack of realistic cultural representations of experiences of disability not only contribute to the ‘Otherness’ of people with disabilities by encouraging the assumption that their lives are inconceivable to non-disabled people” (p. 43). In attempt to resist “Othering,” Mighty contributors critiqued ubiquitous, problematic disability tropes. They described the objectifying impact of inspiration porn, which transforms people with disabilities into the passive recipients of able-bodied goodwill. In addition, they described carrying the “weight of expectations” (Young, 2016, para. 3) associated with the assertion that all people with disabilities can “overcome” their physical impairments to become the “super crips”
depicted in Paralympics advertisements. “We are told to look at these amazing people and, ‘If we just tried harder’ or ‘worked more’ or ‘believed in ourselves’ we could achieve just as much,” Lipman (2016) explained. “We wouldn’t go up to a perfectly healthy able-bodied acquaintance and tell them if they worked hard enough they could be the next Mo Farrah or Michael Phelps” (para. 8). Alternatively, they described how the media reinforced the notion that people with disabilities should be viewed as objects of pity. “People with disabilities are shown as ‘the other,’” Jacob Lesner-Buxton (2016) explained. “Artists have a tendency to show people with disabilities as being burdened by isolation all the time. . . . [they] are oblivious to the fact that people with disabilities can have friends and large support networks” (para. 9).

Contributors described the very real impact of these (mis)representations of disability. For example, Adelle shared the heartbreaking experience of learning that one of her childhood friends was murdered by his mother. She explained, “a lot of people will take up the murderers as a ‘saint,’ for a lack of a better term here, because caring for a disabled person is ‘burdensome.’ And we are often thought of as ‘well their life was hard anyway so therefore they are expendable.’” Indeed, a white paper published in March of 2017 by the Ruderman Family Foundation analyzed 219 news articles, written between January 2011 and December 2016, that reported on murders of people with disabilities by parents or caregivers. They found that media frequently framed these murders as “mercy killings,” erasing victims’ voices and centering the perpetrator’s perspective.

Of particular interest is how contributors used The Mighty as a platform from/through which they could protest current movies, television shows, advertisements,
song lyrics, and other popular culture artifacts. Publishing on *The Mighty* provided a tool to bolster activist efforts launched simultaneously via their personal blogs, social media platforms like Twitter, and petition circulation websites like Change.org.\(^{21}\) For instance, *The Mighty* published eight articles written in response to the movie, *Me Before You*, in which the lead character (played by an actor without a disability) has quadriplegia as a result of a motorcycle accident. He elects to die by suicide despite finding the love of his life—ostensibly to save her from living “half a life” with him. *The Mighty* provided a platform to express the outrage captured in the resultant Twitter hashtag, #betteroffdeadthandisabled, which highlighted Hollywood’s stigmatizing framing of disability as a fate worse than death. Writers protested the use of non-disabled actors to portray disabled characters, and described the dangers of both devaluing life with a disability and romanticizing suicide. As MaryLynn Johnson (2016) explained:

Disabled or not, everyone has struggled with wondering if their life matters and if anyone will ever love them for who they are. The difference is that when this struggle is put in the context of disability, it’s not as quickly negated. . . . The facts in the world around us yell into our lives that those thoughts of worthlessness and never being loved are justified. . . . Not only does this story contribute to the stigma in our culture today against those with a disability, it may be the very thing to cause someone to consider ending their life. (para. 3-4)

Given that *The Mighty* increasingly participates in constructing mainstream media conversations about disability, contributors clearly acknowledged its potential to resist/change harmful disability discourses embedded in popular culture. However, they also wrote *Mighty* articles to protest other forms of institutionalized ableism.

\(^{21}\) This is an example of what I have termed the “sign-boosting” function of *The Mighty*, discussed in Chapter 6.
Protesting institutionalized ableism. Some Mighty contributors wrote from a social justice perspective, illustrating how institutionalized ableism shapes policies that restrict their rights. As Mandy summarized, “I write a lot about, you know, ‘we have a right to jobs, we have a right to relationships, housing, marriage, we have a right to everything.’” Through their writing, contributors pushed readers to recognize and reject their own (internalized) ableist assumptions. For example, Laura Steenerson (2016) wrote to critique a viral news story about how Canada’s popular Prime Minister, Justin Trudeau, had carried a man in a wheelchair down a flight of metro station steps.

“Although I don’t want to completely plow over the feelings of ‘Yay! We helped,’” she wrote, “I have questions about this situation and why it had to happen at all:”

1. Where is the elevator, and why wasn’t he using it? I’ve since learned that in Montreal there are only four or five elevators in all of the metro stations combined.
2. Was carrying him down the stairs the only option? If so, that is unacceptable. (see #1) (para. 3-5).

Similarly, Mighty editor, Karin Willison (2016), wrote about how such questions can ignite the “actionary” power of collective anger. She asserted, “If we channel our feelings into action, we begin to realize the problem with our favorite store having a step isn’t our inability to climb that step. It’s the fact that nobody bothered to build a ramp” (para. 13).

In her discussion of accessibility challenges in the context of airports (for example, being carried onto an airplane, being fondled by airport employees in the process of transfer, finding that mobility devices were damaged in transit), Athena Stevens (2016) makes an even more direct call to engage in activist activities to secure disability rights, including suing airline companies for mistreatment. She wrote:
From Rosa Parks to Gandhi, many major civil rights battles have involved transportation. I see no reason why disability rights cannot be the same, if we are bold enough to stand up for our rights instead of assuming that equal access is “too difficult” or just a “nice thing to do.” . . . Why is the pressure to “make it work” placed on those of us with disabilities rather than an inflexible system that clearly does not respect the rights of the most vulnerable? When people assume that those of us who make use of the laws and regulations designed to protect us are looking for a quick payout, we are living in a profoundly ableist society. (para. 4-5)

*Mighty* contributors detailed the ways in which institutionalized ableism curtailed their ability to receive an education. For instance, Juana Ortiz (2016) described her childhood experience of being turned away from a Catholic school in the Dominican Republic because the school was structurally inaccessible, and because teachers did not have the knowledge to “deal with” her. Writers used *The Mighty* as a platform to engage in the current debate on school policy. Several wrote articles to respond to then-nominee for Secretary of Education, Betsy DeVos’s, suggestion that federally-funded schools should decide on a state-by-state basis whether or not to abide by the Individuals with Disabilities Education Act (IDEA). They called out the absurdly ableist notion that defending the civil rights of an entire class of people should be optional.

Similarly, contributors spoke about how ableism constrained their ability to get and keep a job, despite laws designed to protect against such discrimination. For example, *The Mighty* partnered with the Muscular Dystrophy Association to create a collaborative, list-style article in which people in the community described their employment experiences. One participant shared,

I have been overqualified for jobs and when I walk in with forearm crutches or roll in with my wheelchair, I never get the job. A year and a foot reconstruction later I walked in and got the job. I didn’t take it because discrimination is real and happens every day. (Musallam, 2016, para.13).
Similarly, Jayson noted that, even when a person can secure a job and reasonable accommodations, they face judgment from non-disabled colleagues: “you can try to have a normal day-to-day job, but people give you a double take because you need to sit while you’re doing your job versus everyone else has to stand.”

Finally, *Mighty* contributors wrote about how various policies even restricted their right to marry. For example, Mandy wrote about assumptions about (in)ability to consent created legal barriers for her and her partner, Bob:

> We want to be together and we can’t because his disabilities are more severe than mine. . . It’s like yes, there are certain situations where if you are dating somebody who has severe disability, you kind of sort of break the law. But the thing is . . . as long as you can make your own decisions and be informed about it . . . you can have legal guardianship of yourself—and that’s what Bob has. So, people who have guardianship of themselves and a couple with disabilities, they have a right to be married.

Similarly, Jennie Lewin (2016) described how laws governing access to financial and medical assistance meant that marriage would mean ineligibility for vital services. “I have no option to marry, nor will I ever if the laws regarding this inequality don’t change,” she explained. “This injustice obviously needs attention and to be rectified, but for today, I must accept it and move forward” (para. 2). Clearly, writing for *The Mighty* provides an opportunity to render these systemic, yet normalized, injustices visible to a broader audience.

Yet, the communicative labor involved in resisting oppression sometimes exacted an emotional toll from self-advocates. Contributors wrote about the exhausting emotion labor or emotional labor (Hochschild, 1979; Tracy, 2000) inherent to continually engaging in self-advocacy. For instance, Kaye (2016) explained:
As a person with chronic, invisible illness, I feel like I have to always be ready for a fight. A fight against a doctor, a pharmacist, a friend, a family member, a stranger, a coworker, a fight to defend myself and not take no for an answer, a fight to get what I need and to make sure people understand that there’s more to me than meets the eye. I have to always be on guard, and it’s exhausting. (para. 1)

Similarly, Adelle described the emotional labor involved in being continually expected to speak on behalf of others—particularly because her visibility marked her as a member of a minority group. “I am voicing and representing a minority group whether or not I want to,” she explained. “I’m always kind of be representing a minority group each time I open my mouth because I am minority.” Managing this emotional labor becomes even more complex as contributors began to publicly perform an advocate/activist identity in digital spaces.

**Enacting connective action: Advocacy and activism in digital spaces.** As Alice Wong observed, social media has leant a renewed sense of agency to communities whose members have long been both physically and socially marginalized. She emphasized: “there’s something very significant about the way people [who] have been traditionally without power . . . have really been able to use social media in ways that I think most people with privilege don’t really think about.” Social media provides accessible digital spaces in which to engage in activism. Adelle recognized this when describing her response to being called a “keyboard warrior.” “I don’t like that term because to be honest if spaces were more accessible, I’d be out in the world and doing these things,” she explained. “However, they’re not . . . so I do consider [blogging and using social media] a form of activism.” In addition to providing an alternative to on-the-ground activism, social media allows activists to voice their concerns without censorship. Alice
noted that social media platforms had given her a means to engage in the “constant work” of “chang[ing] people’s minds, chang[ing] their culture and ethics” in relation to disability: “Twitter has been the way to do that without a filter, without gatekeepers. I don’t have to work at writing an op-ed for the New York Times. It will be rejected. So I just tweet it all.”

Contributors’ digital advocacy and activism efforts involved making strategic use of multiple social media platforms. Several of my interviewees provided example of how they used specific platforms for specific purposes. In general, my interviewees described using Facebook primarily to connect with friends and family and to publicize recent blog posts or Mighty articles. In some cases, they used Facebook as a way to engage in direct and refracted self-advocacy. For example, Eleanor explained:

Sometimes I just put out a call like, “Hey, can somebody bring me dinner?” or “I need a ride to the doctor next week” and it’s a sort of crowd sourcing help for me. . . . Another interesting thing is that it’s also been a way to put out PSAs for example, for people in my church who are scared to hug me because they don’t want to hurt me. I could put a Facebook post out that says, “Hey, hug the hell out of me. The only way you’re going to hurt me is if you turn me upside down and shake me.” Things like that where it’s like, I don’t want to target that one person who is scared of hugging me, but, in general, I can tell people.

In contrast, interviewees identified Instagram as the platform they used to facilitate personal connections with others in their biosocial community. When I asked Heather about why she used Instagram in this way, she replied:

I think because it’s very easy to be like, “Here’s where I am, look what I did,” or “look what I found today.” I think it’s just a more intimate way of sharing your

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22 These observations lend context-specific insight into theories related to media use, such as uses and gratifications theory, supporting attempts to adapt them for use in the social media environment (e.g., Whiting & Williams, 2013).
life with other people, where I feel like Facebook is more of a way of sharing the things you read and use, and articles, and less about pictures.

Certainly, the visual nature of Instagram encouraged a sense of interpersonal immediacy, strengthening users’ perceptions that they participated in each other’s lives and “knew” each other more intimately. More than this, however, Facebook and Instagram attracted different publics, soliciting different responses even to the same shared images. For example, Natalie described the different comments she received in response to a before-and-after surgery picture; she received general well-wishes from friends and family on Facebook, but received tailored supportive responses from a “sister hub” of interlinked Instagram users who had created endometriosis-focused accounts, for example, “We’re in it together” and “Here’s something that works for me. Probably it might work for you too in terms of pain management.”

Finally, contributors like Eleanor identified Twitter as their “political platform.” While Alice Wong noted that Twitter had allowed her to build friendships with other activists, she spoke extensively on Twitter’s ability to “galvanize communities.” She emphasized that joining Twitter had allowed her to cultivate a “totally different editorial persona,” one that allowed her to exercise an “editorial” power through posting links to articles and offering commentary on them. Through hashtag movements like #crippingthemighty, Twitter provided Alice Wong with a tool for “holding folks accountable for us [the disability community] on social media” by calling out misrepresentation and mistreatment. She also described how Twitter had “opened up doors” to reach a wide audience, explaining, “people are following me, inviting me to speak at presentations, I’ve got job offers.” She was even given the opportunity to be the
first person to visit the White House using a telepresence robot, meeting President Obama via a video screen mounted to a wheeled, remote-controlled stand.23

Alice Wong described the “gratification” she experienced from being able to use Twitter to express her personal opinions, allowing her to state, “this is who I am, this is what I care about, these are my opinions.” At the same time, however, she acknowledged that Twitter is “very public.” “I am very careful about how I present myself,” she explained, “I have to be mindful of what I say.” Her comments highlight the performative nature of enacting an advocate/activist identity in online spaces. Several contributors discussed the emotional labor involved in enacting this role. For instance, Eleanor noted that sharing her story via her personal blog had exposed her to the “emotionally exhausting” work of responding to readers who reached out to her through various social media platforms. She elaborated:

I find myself in this situation where I’m having to find these resources or push people away to these resources without—I recognize I’m a public figure, so in order to maintain my “fan base”—which I don’t like calling it that, but it is—I have to be polite and helpful, but to the point where I’m not giving too much of myself.

Worse, contributors noted that publishing their stories opened them up to criticisms and inappropriate “support” from both friends and strangers. James explained how exposure to others’ questions and comments was particularly challenging for him as an autistic person:

As [do] most people on the spectrum, I have a tendency to get intensively focus or something. I can lose myself in that world, if I’m not careful, and it can consume

23 See Alice Wong’s account of her visit in this blog post for the Disability Visibility Project:
https://disabilityvisibilityproject.com/2015/07/21/ada25-at-the-white-house/
me. So, I needed to create a healthy boundary so that I don’t allow myself to be so consumed with what people were saying.

Additionally, contributors like Renee spoke about how constantly writing and reading about their condition might cause them to get “sucked into obsessing” about their own challenges. Rose described the importance of recognizing when initially positive engagement with illness-related online content “starts going downhill” toward negativity, explaining:

I have to climb back out to the world of my actual life where I’m an aunt, and a dog mom, and a cat mom, and I have a family that’s great and wonderful, and remember all the positive things about my life that have absolutely nothing to do with sickness, or doctors, or hospitals, or anything.

My interviewees described several strategies to manage these challenges. These included refusing to respond to certain types of comments, directing readers to interact through more manageable social media platforms, avoiding posting highly personal pieces to platforms frequented by friends and family members, and simply closing the laptop. Most interestingly, however, Eleanor described how *The Mighty* could serve as a kind of buffer, adding a level of distance between her and her readers that did not exist on her personal blog and her social media accounts. “*The Mighty* is this sort of--it’s not a person, it’s not a person’s face,” she observed. “It’s easier to pretend that I don’t see someone’s comment asking me advice.” Just as contributors used social media platforms differently to capitalize on both their actual features and the social norms associated with them, contributors used *The Mighty* in instances where they wished to speak out on behalf of themselves and/or others, but wanted to avoid the emotional labor associated
with a more interactive, less moderated space. In the following discussion section, I explore this and other implications for self-advocacy and collective/connective action.

**Summary and Discussion**

The preceding analysis treats *The Mighty* as a microcosmic context for exploring the genesis of collective/connective action, tracing the ways in which writers activated both individualized self-advocate identities and collective advocate/activist identities in the process of writing publicly about experiences of embodied difference. Indeed, as Zoller (2005) notes in her work on collective health activism, communication scholars are well-positioned to explore the ways in which individuals (re)constitute fluid identities in ways that emphasize and galvanize sources of commonality. In this study, I have described three forms of communicative labor that occur both previously to and alongside collective/connective action: (a) refracted self-advocacy, (b) collective self-advocacy, and (c) allyship.

First, I assert that *refracted self-advocacy* provides an initial means by which individuals begin to envision themselves as part of a collective. Refracted self-advocacy involves using *The Mighty* as a platform from/through which to address specific interpersonal challenges, especially (but not exclusively) via the strategy of writing open letters. In doing so, *Mighty* contributors transform their private experiences into public ones. Wendell (1996) asserts that the “public world” is “the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults” (p. 40), whereas experiences of pain, chronic illness, and physical impairment remain hidden in the private sphere. She argues that “the more society regards disability as a
private matter, and people with disabilities as belonging in the private sphere, the more disability it creates by failing to make the public sphere accessible to a wide range of people” (Wendell, 1996, p. 40). By engaging in refracted self-advocacy, Mighty contributors trouble the line between private and public, indirectly recognizing that their individual experiences might, in fact, be collective ones. Indeed, the work of refractive self-advocacy takes on the character of writing a diary for public consumption, an act that strategically activates an audience’s sense that they are ethically compelled to listen and respond (Parsloe, 2017). Little (2010) echoes Bernstein’s (1997) use of the concept, “identity deployment,” to describe this process of publicly expressing identity in a way that transforms the individual person into a “terrain of conflict” (para. 5). However, Little (2010) notes that identity deployment is “not yet social movement activism because the person takes the action in an individual context” (para. 5). Similarly, while refracted self-advocacy hints at collective identity, it is not yet collective action because it articulates the interpersonal challenge in a highly individualized way, for example “Dear Husband: You Can’t ‘Fix’ My Fibromyalgia” (Matthews, 2017).

Second, I describe the communicative labor of collective self-advocacy. Collective self-advocacy involves sharing advice to encourage others to advocate on their own behalf. Mighty contributors who engaged in collective self-advocacy more directly acknowledged their membership in a biosocial community, writing to an imagined audience of similar others and using words like “we” and terms like “spoonies” and “lymies” to communicate a sense of collectivity. However, collective self-advocacy is distinct from collective action in that it inspires dispersed, individualized activity rather
than organizing concerted efforts for social change. Collective self-advocacy complements theoretical approaches to disability that grapple with the task of envisioning a truly unified, disability identity in light of diverse physical realities and varied, often contradictory, political commitments. In response to such a challenge, scholars like Kelly (2010) instead conceptualize a “collective of individuals”: “a loose grouping of individual subjectivities, who will often disagree” (para. 33). The process of mobilizing a collective of individuals takes on the idiosyncratic, self-motivated, dispersed character of connective action (Bennett & Segerberg, 2013), facilitated by the internet’s ability to support increasingly specialized, niche audiences.

Third, I describe allyship as the process of speaking/with for those who have limited agency to advocate on their own behalf. At its core, allyship is motivated by the broader moral imperative to support others’ rights to dignity, inclusion, and the resources necessary to live a comfortable and fulfilling life. Allies recognize this moral imperative most acutely when their communication with others causes them to realize both their own privilege and others’ marginalization. Positioning oneself as an ally inherently invokes a sense of being connected to others. However, while allies may identify as members of biosocial community, they often speak of themselves as peripheral members. For instance, Adelle responded to a question about whether she viewed herself as an advocate/activist by saying, “I have a voice where a lot of my peers don’t, [but] I want them to be heard as well . . . they are leaders in their own right, so I share the microphone.” Her response illustrates the idea that allyship involves de-centering one’s own perspective in order to center another’s.
In the remainder of this chapter, I have considered the ways in which *Mighty* contributors used the site to facilitate collective action, transforming private interests into public concerns by identifying shared, systemic sources of inequity. Following Zoller’s (2005) lead, I have suggested that the discourses of difference that contributors drew on shaped the ways in which they located the source of their shared struggle. Adopting the biomedical model meant focusing on the challenge of physical impairment; it involved raising awareness and raising funds to pursue scientific fixes for “malfunctioning” bodies. Adopting the social model involved attending to the disabling impact of oppressive social systems; it involved protesting inaccessible healthcare, ableist representations, and institutionalized ableism. These approaches to collective action appear to activate/be activated by contradictory “frames,” defined as “the interpretive packages that activists develop to mobilize potential adherents and constituents” (Poletta & Jasper, 2011, p. 291). In other words, *Mighty* contributor’s narratives are political; they “(de)legitimate certain modes of culture, consciousness, and practice” and they “emerge as contested terrains” (Harter et al., 2005, p. 23). This observation reflects central conundrums articulated by disability studies scholars: how might the disability community organize to alleviate physical suffering without further “Othering” and devaluing different bodies? How might the disability community organize to protest disabling social structures without minimizing or ignoring embodied challenges? Indeed, Kelly (2011) suggests that organizing for collective action in the midst of intractable tensions requires embracing ambivalence and ambiguity. She writes that “ambivalence and ambiguity may be more accurate descriptions of how many people with disabilities
think about various political issues and if and when they choose to identify as ‘disabled activists’” (p. 21).

Indeed, in his attempt to move beyond the limitations of identity politics, Davis (2013) suggested that it is the very instability of disability as an identity category that lends it power to move beyond the fracturing exclusivity of more clearly-defined identity groups (e.g., race, gender, sexuality). He suggests that embracing this instability allows us to take a more “malleable view of the human body” (p. 273), one which recognizes that all bodies are “disabled by injustice and oppression of various kinds” (p. 276). He argues for a dismodernist ethic of the body, one which acknowledges three areas of concern: (1) care of the body, characterized as the consumerist compulsion to purchase and use product and technologies to perfect the body; (2) care for the body, defined as the use of medical services to “fix” bodies; and (3) care about the body, described as a concern for human rights, civil rights, and freedom from oppression. As people seek common connections amidst the myriad differences in their physical experiences, they find that the broadest collectivities adhere around care about the body. As Davis explains, attending to the instability of disability facilitates the realization that “caring about the body subsumes and analyzes care of and for the body. The latter two produce oppressive subjection, while the former gives us an ethic of liberation” (p. 275). In summary, Davis’ dismodernist ethic of the body illustrates how broad collective identities form around interdependent efforts to ensure equity and inclusion.

What remains, then, is the importance of validating self-advocate perspectives as testimony about both challenging physical impairments and disabling forms of
oppression. Indeed, this was the object of a third purpose of collective action apparent on *The Mighty*; contributors wrote to educate for understanding, correct misperceptions, and seek acceptance. In doing so, they worked to expand non-disabled audience members’ capacity for empathy. More than this, they rejected their status as “Other,” even as they emphasized the potential value of embodied difference as an aspect of human variation. In the following chapter, I explore how *The Mighty* itself attempted to create a platform that would validate self-advocate perspectives, even as it contended with the ambiguity and ambivalence inherent to organizing multiple, often contradictory, viewpoints.
Chapter 6: Building A Mighty Platform

Up until this point, I have structured my analysis in ways that center self-advocates’ perspectives. I have considered how the content of their stories reflect sense-making processes tied to identity construction, how the metaphors used in these stories draw from and activate various discourses of difference, and how contributors begin to develop both narrow and broad collective identities through writing/reading about their own/others’ experiences. Additionally, I have explored how contributors use The Mighty as a platform through which they can participate in (refracted) self-advocacy, allyship collective self-advocacy, and collective/connection action reflective of the challenges associated with various models of health and disability (for instance, the biomedical goal of fixing malfunctioning bodies; the social justice goal of eliminating systemic ableism).

In the sections that follow, I turn toward an analysis of The Mighty itself, considering the communicative processes that shape how the organization functions as both a digital platform and a for-profit media company. For this chapter, I am motivated by an interest in structuration theory (Giddens, 1986) and adaptive structuration theory (DeSanctis & Poole, 1994); I seek to understand how organizers’ efforts to build a mighty/Mighty platform both respond to and shape the ways in which contributors interact with the site’s digital infrastructure. I explore how these structurating processes push The Mighty to innovate, producing multiple forms of organizational hybridity (Ashcraft, 2001; 2006). Additionally, I tease out three dialectical tensions (Harter, 2004) implicated by these hybrid forms. I start, however, by considering how the organizational...
narrative (Mumby, 1987) Mike Porath tells about his initial vision for the site in turn shapes how his staff members conceptualize, and carry out, The Mighty’s purpose(s).

Telling an Organizing Narrative: The Mighty’s Purpose

This afternoon, I sat down with a researcher from Ohio University who is visiting us. She reached out earlier this year and asked if she could spend the next 12-18 months doing her doctoral dissertation on The Mighty. She said she was fascinated by our platform and wanted to study how people used it and were affected by it. I said of course. I thought it was cool that someone wanted to spend a whole year studying this thing we had created. And selfishly, I wanted the data to help us make it better.

After interviewing our team members over the last couple days, she walked up to me this afternoon and asked a great question. “Do you have a map that shows how this whole thing works?”

I did not, but I spent the next hour laying out our thesis, the operation, what we have learned and where we want to take The Mighty. I told her I’d write something up for her and then realized I should share it publicly. We’ve got more research projects coming up soon. So here goes…

The idea for The Mighty began with my frustration with health sites. My daughter was diagnosed with a rare chromosome disorder and after many hours over many weeks, I gave up on WebMD and their competitors. They just weren’t helpful. The truth is, they aren’t designed for people. They’re designed for Google’s search engine, which directs you to page on a health site that includes a short medical definition and lots of targeted, high-priced, drug ads.

What actually helped my wife and me was connecting with people who had a child with Dup15q syndrome, our daughter’s condition, or with other special needs. Sharing experiences really helps people who are facing health challenges. Online, those shared experiences often take the form of stories. So to truly help people facing a disability, disease or mental illness, we needed to do three things.
1. Get lots of credible people to share great stories with us.
2. Get those stories in front of people who identify with them.
3. Get as many of those people as we can to join our community. (Porath, 2017, para. 4-9)

Mike Porath emailed the link to this LinkedIn article, entitled “The Place Where Digital Media Becomes Digital Health,” soon after I returned from conducting my fieldwork at the The Mighty’s Burbank office. It was a generous gesture on his part—a gift that helped me in a practical way by providing a clear outline of The Mighty’s current
structure and future aspirations. More than this, reading about the “researcher from Ohio University” provided a unique opportunity to view the research process from the other side of the proverbial table. It illuminated the ways in which the questions I ask as a researcher can reverberate in participants’ minds long after I leave the room, sometimes initiating new actions through their aftershocks.

I have selected the above excerpt to introduce the heart of this chapter because it clearly illustrates the ways in which Mike Porath’s personal narrative as a parent seeking support provides the structural blueprint for The Mighty itself. As Mike Porath transformed his personal narrative into an organizational one, he identified a hole in available resources (as in a lack of story-driven resources for people seeking to understand various condition) and developed a three-step pathway toward filling that hole for both himself and for a broader community. Essentially, the process of telling his personal narrative publicly captures the communicative labor of collective action, transforming his private interests into the kind of shared concern that merits creating a collective action organization (Flanagin et al., 2006). Porath’s account lays out the actionable steps he believes will help him to “to truly help people facing a disability, disease or mental illness.” These steps enable both organizational self-structuring and activity coordination (McPhee & Zaug, 2009), communicatively constituting the organization by providing the conceptual scaffolding necessary to both design the site’s digital infrastructure and guide staff members’ concerted efforts in generating, gathering, and editing stories. At the same time, however, the idea of “helping people” remains
relatively abstract, providing opportunities for staff members to continually re-constitute *The Mighty* as they communicate in different ways about the site’s ultimate purpose(s).

**Mission-driven work: Buying Mike’s vision.** *The Mighty* emerged from one father’s desire to “do something good” in response to learning of his daughter’s rare diagnosis. In the process of creating *The Mighty*, Mike Porath transformed his experiences as a parent into a compelling argument about how a for-profit media company might be capable of “making a difference” in the lives of people impacted by chronic illness, disability, and mental health challenges. Mike Porath’s personal tale became a powerful tool for recruiting others to participate in his vision. As one staff member explained, “hearing his story about why he started *The Mighty* and about his experience with his daughter and his family, I just felt like there was really a mission behind the company that I could get behind.” My interviewees referred to their work at *The Mighty* as “mission-based” and “mission-driven.” They described how this mission-driven approach differentiated *The Mighty* from their previous professional experiences in media, where their work felt “shallow” and “soulless.” Mark, an experienced journalist, noted:

> I think it’s important to have that mission. Mostly I’ve worked at the *New York Times* and there’s the mission: they’ve got the “best accurate stories.” Or work in *Yahoo News*: “getting out breaking news.” . . . [*The Mighty*] is something that actually has a bigger goal in mind.

Staff members described how participating in this “bigger goal” was personally fulfilling for them; Rachel explained that “every single piece of content, every contributor we work with, every new thing I learn about a condition or a perspective is helpful. I find a whole lot of meaning every single day.”
This sense of doing meaningful work was even more apparent when staff members expressed personal connections to health and disability-related issues. Indeed, Mike recognized that The Mighty’s ability to expand so quickly as a company was in part due to the pervasiveness of such connections. Sharing his personal story often elicited similar stories from would-be investors and employees. “In most conversations, people would start talking about their own thing that they were dealing with,” Mike explained, “It could be an uncle, it could be themselves or a brother or whatever, but I think what we were trying to do, people felt good about trying to help build this thing.” Essentially, then, connecting Mike Porath’s narrative to personal experiences related to disability, chronic illness, mental health conditions, or rare disease became a vital aspect of staff member’s membership negotiation (McPhee & Zaug, 2009), influencing the communicative processes tied to both recruitment and socialization.

The Mighty’s pro-social mission, as informed by Mike’s personal story, acted as an organizing narrative for this rapidly-evolving company. While The Mighty has continually changed both in terms of its staff, contributor network, and audience makeup and size, and in terms of the features that characterize its digital platform, the editor-in-chief insisted that “the core of it really hasn’t changed.” “If anything, it’s grown,” she explained:

We want to help people. We’ve gotten more specific in how we want to do that, I guess, but it really hasn’t [changed]. . . The goal, every single day we come in, is like, “How do we help these people who are telling these stories?” To the outsider, that can look as like, “Look. You’re just trying to get clicks and traffic,” but it’s just not true. Everybody here is really invested in it.

As this quote suggests, the goal of “helping people” is a broad and nebulous one. In practice, pursuing this goal requires developing specific answers to the question, “how do we help?” Answers varied across the lifespan of the organization, evolving in response
to the profit-related concerns of the company; the availability of monetary, technological, and other resources; and the changing needs of contributors and readers. However, answers also varied in response to the ways in which staff members conceptualize *The Mighty’s* specific purpose at any point in time. Prioritizing some answers to the question “how do we help?” over others (re)structures both the physical features of the site and the editorial practices responsible for its content.

**Defining *The Mighty’s* purpose(s).** Staff members defined three main purposes for *The Mighty*. These included: (a) crowdsourcing information and co-creating knowledge, (b) creating a community, and (c) providing a platform. These purposes were also taken up by contributors in their response to my questions about what they believed *The Mighty* intended to accomplish.

**Crowdsourcing information, co-creating knowledge.** When I asked the Head of Product about why she wanted to work at *The Mighty*, she explained: “I just got really excited about the potential to change the way people find out about conditions that they care about, or are suffering from, or are interested in, or think they might have.” Her response captures one definition of *The Mighty’s* purpose: to transform how people gather, develop, and share both (a) medical information (diagnoses, symptoms, treatments) and (b) “human” knowledge (“what it’s like”). In defining this purpose of *The Mighty*, staff members both identified the limitations of health professional’s expertise and emphasized the value of “authentic” experience.

* Mighty staff members noted that health professional’s expertise is limited in that individual doctors provide “just a slice of information”—a slice that may be incomplete
or incorrect. The Mighty’s Head of Product asserted that “the future of health and information” involves crowdsourcing the expert advice individuals have received from health professionals throughout the country (and the world). Crowdsourcing medical information can provide patients with a more complete picture of both their condition and potential therapies or treatments—especially in cases where a condition is rare or frequently misunderstood. For example, one editor with cerebral palsy (CP), explained the importance of publishing a story in which a woman with CP described the startle reflex:

Especially as a kid, I had huge issues with things like popping balloons and fire alarms and stuff. Well, this girl wrote in about that same topic and she said that she didn’t know until she was an adult about startle reflexing and I didn’t either. I would just have this happen to me. And I thought, “Is this an anxiety disorder? Am I just a big chicken? What’s wrong with me?” . . . So as soon as I saw this I was like, “We have to publish this because this is going to reach hundreds of people that may not know about this, that really need to.”

This piece of medical information, which may have seemed trivial from a doctor’s perspective, holds transformative sensemaking significance for this editor, the contributor, and others with CP.

In some instances, crowdsourcing might reveal and correct mistakes made by healthcare professionals. For instance, one staff member gave the example of an article written by a woman who, after discovering that she had been misdiagnosed for 20 years, finally found a treatment that quickly resolved her symptoms. The story went viral and was picked up by several prominent news outlets, leading at least 20 additional people to discover that they had been similarly misdiagnosed.
Crowdsourcing medical information may also assist patients in the process of making treatment decisions. Elizabeth described the limitations medical experts face in providing treatment advice:

It’s all about percentages that doctor sees. It’s like, ‘Well, we’ve seen this has a 15% chance of working, this one has a 20% chance of working.’ You get to decide as a patient. Well, guess what? This one, this 15% might work on your body 100% of the time. So, it’s a weird world. It’s a crazily complex world . . . Two people with different cell structures and different genetic makeups, they both respond in medicine completely differently, and so when you start connecting with people and hearing about different treatments and things that didn’t work for them . . . That’s really where you can definitely save lives.

Elizabeth recognizes the ontological uncertainty inherent in the imperfect “art” of medicine. Uncertainty is ontological when it reflects “the character or nature of the world” as opposed to the character of knowing (Babrow, 2001, p. 557), such as the fundamental unpredictability of complex interactions among multiple genetic and environmental factors shaping responses to treatment. Ontological uncertainty may cause us to ask questions like, “How can a doctor know with certainty which treatments will work for any given body?”

Elizabeth proposes crowdsourcing as a strategic response to this ontological uncertainty, describing the process of “people talking to people” as a means by which individuals can “stumble” into discovering the “miraculous thing that worked.” “It’s always just some serendipity of meeting,” Elizabeth explained. “Serendipity is a very, usually a low chance of happening. So, it’s like, if we have a platform that just makes serendipity 50% more likely.” Her statement appears to be an oxymoron; how can we increase the predictability of an event that is, by definition, unpredictable? Her words reflect the data-driven vocabulary of a person whose job involves quantifying “success”
in terms of clicks, likes, and shares in pursuit of traffic and search engine optimization (SEO). Yet, this oxymoronic phrasing highlights the epistemological distinctions between the deductive logic of biomedical research and the generative logic of crowdsourcing. Both logics rely on gathering a large amount of “data.” Yet, while quantitative biomedical research obscures individuality in pursuit of generalizability, crowdsourcing—like inductive, qualitative research—preserves individuality by curating personal accounts. Crowdsourcing stories produces a multiplicity of specificities. It retains the contextual details of lived experience in the hopes that readers might “serendipitously” discover the particulars of their own story in someone else’s narrative. The logic of crowdsourcing validates lay, embodied knowledge in a context where “experts” have enjoyed considerable, often unexamined and uncritiqued, power.

Alongside crowdsourcing medical information, The Mighty supports crowdsourcing advice: “that golden piece of information that you just can’t find by going to 10 doctors.” For instance, Kathleen described how readers might use the site to find answers to obscure or uncomfortable questions, like “What do I do if my kid’s hypermobility is so severe that she can’t sit in a chair?” and “Where do I buy diapers for a kid who’s 12?” Crowdsourcing offers a means by which contributors and readers can respond to emergent, everyday needs of their community—needs that aren’t typically reflected in the research and treatment priorities of medical experts.

Relatedly, Mighty staff members emphasized medical experts’ limited ability to articulate the daily experience of life with a disability or chronic illness. In some cases, staff members focused specifically on the inadequacies of the doctor-patient encounter.
For instance, Kathleen described the experience of diagnosis in this way: “the doctor comes in and gives their spiel and then they leave, because they have ten more people to see.” She envisions the emotional turmoil a person experiences at the moment of diagnosis, narrating their inner dialogue: “What do I do right now? God, I’m sitting here really upset.” For this imagined reader, The Mighty provides a kind of sensemaking intervention; Kathleen describes Mike’s dream of a future in which doctors would literally hand their patients a tablet displaying The Mighty’s website. Mike explained that, instead of “playing out roles in your head about what life is going to be like . . . [where] you imagine this terrible future,” individuals can visit The Mighty to “read about what real people are dealing with.”

Expanding beyond the moment of diagnosis, staff members envisioned The Mighty’s potential to connect with readers at each stage of their “life cycle” (Elizabeth). This concept of “life cycle” captures the medicalized milestones of diagnosis, treatment, coping, and end-of-life, as well as the moments between these milestones, for example, a month after diagnosis. It also refers to the pivotal movements of life in general: “‘The first day of school’, . . . ‘applying for a job’, . . . ‘going to college’” (Kathleen). Framed in the language of PI theory, The Mighty assists individuals in formulating probabilistic and evaluative orientations toward a diagnosis, and toward the medical and life milestones implicated by it. Thus, at the threshold of an unknown future, The Mighty provides visions of concrete potentialities. It assists individuals in the sensemaking processes of (a) re-narrating the past, (b) constructing a new normal, and (c) re-imagining the future.
With this purpose in mind, *Mighty* staff members discussed their site’s ability to tell the “human side” of health and disability, providing readers with a “human resource” offering visions of livable futures. They noted that traditional health sites, like *WebMD*, focus on a clinical description of symptom, treatments, and diagnoses. Elizabeth observed that “the legacy of health and health space in general has not been a consumer-friendly place . . . They don’t have or understand the human touch.” She attributed this to their reliance on “scientific-minded” experts, explaining that “journalists and scientists generally think very differently; there’s more of an artistic side with journalism.” Eva, whose previous job involved writing content for a health column, noted that even journalists tend to mimic “doctor speak” and write in “clinical terms.”

Instead, editors emphasized the importance of telling stories using “authentic” voices—voices which model agency and resilience in ways that empower potential readers. Mark described how, after spending a career in journalism crafting well-constructed, grammatically impeccable stories, he began to recognize the compelling power of publishing pieces that “may not be the most polished,” sometimes accompanied by grainy, amateur photos. “You can probably bring in a freelance writer,” Mark explained:

But will it have the same feel? I think at end of the day when you read the story and it’s the person’s byline, it’s their story. And even though it may not have been written as well as a freelancer [could write it] . . . it has a lot of heart and soul about it. . . . Every aspect of *The Mighty*, from the photos to the writers to the . . . contributors that are on live on the Facebook Live videos, all that has that really authentic feel . . . I want to say society in general is moving more towards “this is authentic, this is grounded.”

This emphasis on authenticity validates lived experience as a form of expertise, and simultaneously frames *The Mighty* as a credible source of this expertise. Rachel
explained what *The Mighty’s* focus on publishing “Real people. Real stories” communicates to readers: “It’s not necessarily, ‘You have to believe us, we’re the experts.’ It’s saying, ‘No, we’re talking to the experts. We’re talking to the actual community . . . we’re getting everything straight from the source.’” Indeed, *Mighty* contributor, Renee, encapsulated *The Mighty’s* capacity to crowdsource both medical information and “human” knowledge by describing the site as “a hospital of words.” “It’s almost like it has different—when you go into a hospital and you have different specialties, like this is rheumatology floor, this is so and so. It’s almost like that.” Renee explained:

> It’s a safe zone where you can just at least get by for the day, like an emergency room until you can see like a bigger doctor or you can be connected to a doctor right then if it’s an emergency. But they’re not really doctors . . . [they are healing] with just words [by letting you] know that you are not alone in all this.

Renee invokes a medical metaphor to equate the physically healing expertise offered by healthcare providers with the emotionally-healing support inherent to sharing “human” knowledge of both “what it’s like” and how to live with it/through it/because of it. Yet, *The Mighty* doesn’t just share “human” knowledge from a community that exists beyond itself; it co-constructs knowledge in the processes of creating its own community.

**Creating a community.** In the same breath that staff members defined *The Mighty* as a repository for medical information and lay knowledge, they often identified a second purpose: to create a community. Staff members described how *The Mighty* facilitates connections between people who “get it,” cultivating an affective public (Papacharissi, 2016) characterized by feelings of “being at home,” being “all in this together,” and being “part of something much bigger.” For instance, Vera described “the strength of the site”
as “the connection that it can create between someone who has felt a certain way for a long time or experienced something, and felt very alone or unheard in that experience.”

Staff members frequently referred to times when readers made comments like “Wow, me too,” “I’ve found my people,” and “I never knew anyone else felt this way. I’ve never been able to explain how I feel.” These sentiments were particularly powerful when expressed by individuals impacted by rare or rarely recognized conditions; by including a rare disease section, The Mighty facilitates their connection to “that one person on the other side of the planet going through exactly what you’re going through.”

Staff members resisted characterizing The Mighty as simply an “online publication,” preferring terms like “story-telling community.” They recognized the significance of their “story-first approach,” acknowledging that stories provide “the building blocks to a community.” Mighty contributor, Cedar, recognized this community-building potential as The Mighty’s greatest strength, explaining that the site encourages people to “really begin to put words along that condition and tell our story about it, and a story that other people can understand and relate to, and that builds community that takes away the loneliness, that takes away the shame.” Indeed, Mighty contributor, Danielle, described stories as a key component of both community-building and advocacy, explaining, “advocacy, for me, is the human connection of one story to another that allows people to not feel alone.” These descriptions highlight how reading and telling stories enabled individuals to situate themselves as members of narrow and broad biosocial communities, enabling them to develop the collective identity necessary for collective/connective action.
Stories have an affective power, one that can “pull people in” to the community and encourage them to become active, engaged participants. Elizabeth clearly articulated this idea, explaining:

You have to get people to a platform through a story that they can connect with emotionally that makes them, inspires them to also contribute or also share the story. . . Nobody’s going to WebMD and finding some write-up on breast cancer and being like, “Oh my God, this is so moving, I have to share it with my Facebook friends.”

Clearly, this explanation highlights the idea that publishing stories that resonate with audience members is good for The Mighty’s bottom line; resonance drives traffic and generates additional content. In addition to this utilitarian function, however, publishing stories that resonate with readers initiates a “cycle” of sharing, where readers who connected to and/or were helped by a story feel empowered to write their own. Building on this idea, Anna discussed the politicizing potential of stories. She talked about pulling people in with “trendier” pieces in the hopes that they might also learn about political and systemic issues. She described “relatable content” as “a first step to hopefully getting people impassioned and involved about the stuff that actually affects their lives.”

Thinking about The Mighty’s capacity to empower contributors and readers recognizes that the site can become more than just a “platform” in the sense articulated by Elizabeth, as in a digital infrastructure. Instead, it imagines The Mighty as a platform in a metaphorical sense, as in a space that elevates contributors above the information-saturated morass of social media to expand the reach of their message, creating opportunities for individuals to articulate stances and initiate action.
Providing a platform. Recognizing The Mighty’s power as an increasingly influential media presence, staff members defined a third purpose of The Mighty: “to have a platform where [staff] can give a voice to people who don’t always have a voice,” providing “a place where they can be heard.” Ironically, these phrases reflect assumptions about ability and forms of self-expression, emphasizing verbal speech and the capacity to hear. However, they express the general idea that the Mighty can insert otherwise marginalized and silenced experiences and perspectives into mainstream conversations.

For example, Vera explained that the purpose of The Mighty is:

. . . not only to give people space to share their own experiences and perspectives, but also teach others who may not be familiar with certain perspectives and experiences. I think the biggest goal is that space of connection and sharing. And through that, the ability to really educate and advocate.

As a platform, The Mighty allows writers to pursue the interlinked, collective goals of educating for understanding, correcting misperceptions, and seeking acceptance. Editors described The Mighty’s capacity to improve interpersonal interactions by encouraging “empathy in a world where someone with a disability would just be brushed off.” Mark explained how reading about autism provided him the vocabulary he needed to talk to his own brother about parenting a child on the autism spectrum. He recounted his brother’s response to their conversation:

[My brother] was like, “I really thank you for just talking to me about that for a little bit.” Because he says he doesn't really get to talk about that too much. . . . The way he explained it to me, is if you're a big baseball fan and you meet someone who doesn't know anything about baseball. He was basically saying for him it's really frustrating because I don't want to have to explain the whole game to this person.
Perusing articles on The Mighty can provide a reader with at least a rudimentary understanding of “the game,” equipping them to respond to others in more empathic and supportive ways.

Relatedly, The Mighty provides a platform for (re)shaping the ways in which disability and chronic illness are represented in mainstream media, supporting the collective goal of protesting ableist representations. The news editor, demonstrated this potential use of The Mighty while describing the site’s approach covering breaking news. Her job involved “repackaging” news stories in a “Mighty way,” either by interviewing members of the site’s contributor network, pitching the story to contributors and soliciting full-length articles, or simply publishing contributors’ unprompted responses to newsworthy current events. For instance, the news editor invited contributors to write responses to a viral story about a football player who sits with a young autistic student at lunch, describing how the story acts as inspiration porn by transforming the autistic student into an object of pity and the recipient of “charity.” Similarly, she interviewed contributors to “repackage” her reporting of a widely-circulated image of two parents who passed out from a heroin overdose while their child was in the backseat. While mainstream media outlets used the image to present evidence of an alarming opioid epidemic, The Mighty covered a Twitter hashtag movement created by chronic pain patients to discuss how opioids facilitate their ability to be a “functioning person in society,” particularly given the inaccessible cost of alternatives like physical therapy. The news editor explained, “No media outlet is covering this and then talking about chronic pain patients. They’re just shaming all these people . . . And here was this large group of
people saying, ‘You don’t listen to our voices.’” Interestingly, while editors initially believed that The Mighty was unique in the attention it gave to self-advocate perspectives, they began observing that other publications were taking a similar approach. “I don’t know if it’s because people [are] picking up The Mighty or just more news outlets are starting to understand maybe we should be telling these stories, too,” Mark told me. “I’ve been watching CNN or reading a story in the New York Times, where like, ‘Wow, this is kind of a Mighty story.’”

While Mighty staff members clearly articulated the site’s purposes to (a) crowdsource information and co-construct knowledge, (b) create communities, and (c) provide a platform, they also recognized their evolving nature. Rachel described how the present purposes emerged over the course of The Mighty’s growth, offering a potential future direction:

Now our purpose is not just to share content that helps people, but we also realize that our contributors are also looking for a community where they can share those stories. Now it’s two-fold because we evolved in the sense where contributors and readers can just follow people and get content that they are looking for. It’s evolving almost into a lifestyle aspect of it, as well as health resources. I think even further down the line we also want to get [to] a point where we can actually have medical experts weighing in on content . . . as we grow, our purpose evolves along with us.

These evolving purposes also reflect how staff members’ “center of judgment” has grown— their ability to learn about what is meaningful for their audience, and to “change tactics” in response to new insights. Kara noted that the evolving nature of The Mighty’s purpose(s) means constantly “trying to find what direction it’s going,” which in turn shapes the structure of the site: “Do we want to publish lots more stories than we do right now, or do we want to focus more on quality? Are we trying to become more of a social
network, or are we more of a magazine?” These questions hint at the reflexive, recursive processes inherent to the communicative constitution of organizations. They implicate a “dynamic theory of [organizational] form,” one which acknowledges that “organizing is an unfolding accomplishment” (Ashcraft, 2006, p. 59). Such a theory of organizing draws attention to the ways in which The Mighty develops hybrid organizational forms in its attempt to satisfying multiple, changing, and potentially conflicting purposes.

**Developing Hybrid Organizational Forms**

In my conversations with Mighty staff members, individuals frequently expressed the idea that they were actively creating something that had never been done before. They emphasized that they were “building something from the ground up,” and that they “don’t have it figured out” yet. Vera described the nascent nature of The Mighty in this way:

> When I talk about us—the space itself and us as a company—growing and evolving and learning as we go, I think that it's a big part of it because I don't know that there’s anyone else doing it exactly like this, on this level. Which is why we really want to do it the best way that we can. And obviously, we’re going to learn a lot as we go and evolve from it, hopefully, in really good ways.

The idea that The Mighty is unique and unprecedented reflects the site’s hybrid nature. Ashcraft (2001) argued that hybrid organizational forms represent “organized dissonance”: “the strategic union of forms presumed hostile” (p. 1304), designed to accomplish conflicted goals” (Ashcraft, 2006, p. 58). Thus, hybrid forms emerge in response to paradoxes and dialectical tensions.

Several forms of hybridity interact to develop The Mighty’s structure. First, The Mighty is a for-profit company operating in a context typically populated by non-profit organizations. Rafael describes this hybrid nature of social entrepreneurship, describing
*The Mighty* as having “two bottom lines”\(^\text{24}\): (1) “maximizing share-holder value” and (2) “making a positive difference in the world.” Second, *The Mighty* is a hybridity of audiences, connecting the broad categories like “disability,” “chronic illness,” and “mental health” to create a cross-condition space. Elizabeth emphasized *The Mighty’s* unique potential to accomplish this, explaining that “while some non-profits have built great micro-communities, they’re never going to be the ones to build a macro-world community.” Third, as Kara’s description of the *The Mighty’s* unclear status as a social network or a magazine illustrates, *The Mighty* represents a hybridity of genres; it is “Quora\(^\text{25}\) meets Facebook meets a publishing company.” Vera clearly articulated the liminal quality of genre hybridity: “we’re not quite a platform because we definitely still approve stories . . . and there is editing involved. But, we want to include as many people as possible . . . We’re somewhere in between”

Each of these forms of hybridity contribute to *The Mighty’s* potential to innovate, both as a company and as a resource for its audience(s). At the same time, however, these hybrid forms produce and reflect dialectical tensions linked to combining alternative logics of structure and function, which in turn shape the way *The Mighty* represents chronic illness and disability on its site. In the process of confronting these tensions,

\(^{24}\) This “double bottom line” structure inherent to the hybrid organizational form that is social entrepreneurship has expanded in some contexts to a “triple bottom line.” For instance, eco-friendly companies organize around seemingly contradictory aims to fulfill social, environmental, and financial goals.

\(^{25}\) Quora’s creators describe it as “a question-and-answer website where questions are created, answered, edited and organized by its community of users” (see [https://www.quora.com/Getting-Started-on-Quora-What-is-Quora](https://www.quora.com/Getting-Started-on-Quora-What-is-Quora))
Mighty staff members attempt to balance (a) doing good and doing well, (b) universality and specificity, (c) inclusivity and selectivity.

**Tensions of doing good (for the community) and doing well (as a company).**

Tensions of doing good and doing well reflect the organized dissonance present in hybrid logic of social entrepreneurship. Ashcraft (2006) identified a similar tension in her work on feminist-bureaucratic control, describing it as the tension between moral and instrumental imperatives. Here, staff members acknowledged how the pragmatic constraints and goals linked to running a business interacted with their desire to help their developing biosocial community.

While The Mighty’s espoused pro-social mission of “helping people” causes readers and others to assume that it is a non-profit organization, Mike created the company with the idea that a for-profit structure would enhance The Mighty’s ability to carry out this mission. During our conversations, he explained how his involvement with the Dup15q Alliance, a non-profit, made him aware of how the constant need to fundraise placed limitations on what such organizations could accomplish. He also recognized that it would be much harder to fundraise for an organization that would not be dedicated to just “one disorder, one disease, one disability,” reasoning that people are much more likely to donate to an organization that focuses specifically on the disability or condition to which they feel most closely attached. Finally, he recognized that, as a for-profit company, The Mighty would be more able to develop the infrastructure necessary to support his vision of becoming an inclusive community and an influential platform. He explained:
When I look at the top websites in the world, I don’t think there’s any in the top 100 or even 500 that are non-profit organizations. They’re for the most part digital publishers. . . . We’re ambitious. We want to build this into something that is far bigger than what a typical non-profit would be.

Yet, Mighty staff members recognized that the profit-driven logic of running a business sometimes undermined or clashed with their pro-social intent, creating a dialectical tension between doing good for their community and doing well as a company. For instance, Rafael and Hoyt outlined two clear tensions tied to monetizing the site via advertising revenue. First, including advertisements might detract from the user experience, undermining the sense of developing an organic community. Second, they described wanting to stay at “arm’s length” from “horrible” pharmaceutical companies while recognizing that these companies represent lucrative advertising opportunities. “Hopefully the good we do in a moral seesaw balances out,” Hoyt explained, “but I think that is an unfortunate component to the business.” Similarly, while Hoyt wished that he could offer formal partnership opportunities to all non-profit organizations, he recognized that, as a business, The Mighty must attach a certain value to its site space; it must focus first on developing partnerships with large non-profits whose significant social media followings might substantially expand The Mighty’s readership. Finally, staff members articulated criticisms levied by #crippinthemighty participants and other detractors, namely that editors are “number-hungry monsters” who profit from unpaid writers’ stories by transforming them into clickbait. Rafael provided a general summary of the tensions inherent to the hybridity of social entrepreneurship:

We would probably be . . . more laser-focused on achieving the most impactful thing for the members of our community if we didn’t have to also make a business out of it. And I think that that is always going to be a challenge for The Mighty. . .
A lot of that feedback when I hear it, I often think if I could just really say what I feel about why we can’t do those sorts of things, it’s because we’re a business. . . . we actually love those ideas of answering every email immediately, and paying everyone for their contributions, and avoiding all controversy and all those things, but we make mistakes, we’re real people, and we’re dealing with a set of constraints that we need to optimize against.

*Mighty* staff members tried to mitigate this criticism by striking a balance of doing good and doing well. In some cases, they prioritized doing good. For instance, Eva explained her reasoning behind publishing stories even though they are unlikely to drive traffic to the site: “We are going to cover that rare disease even though there’s very little audience, and we are going to cover this story that’s really important. Even if fewer people read it, and are helped, it’s still worth it.” Editors expressed a moral imperative to be “a force for good.” “It’s not like any other newspaper who are out trying to sensationalize something to get people who are curious to click in,” Anna explained. “I am literally writing for people who have that condition. If they are not going to be okay with reading it, that’s a failure on me.” Similarly, Eva described her decision not to publish a parent-written article that felt potentially exploitative from the child’s perspective, even though this decision negatively impacted her productivity that day. The staff actively maintained this commitment to prioritizing doing good over doing well, circulating positive emails from contributors alongside daily numerical measures of the site’s performance. Artifacts of *The Mighty’s* capacity to do good permeated the physical space in the organization’s Burbank office, expressed most poignantly by the collage of hand-written letters, printed emails, and pictures of *Mighty* t-shirt-wearing contributors that dominated the main wall in its break room.
In other cases, *Mighty* staff members sought to do good and well in equal measure, balancing these two goals. “I think it’s just trying to find the best of both worlds,” Danielle explained, “Trying to find the story that’s going to do the most for the community and for us and try and balance that.” In this way, staff members hoped to maintain “integrity” while also growing “at a huge pace.”

Finally, some staff members integrated the dual goals of doing good and doing well, explaining how the company’s success was integral to its ability to help members of the community. They adopted the mantra “good stories do well,” while also recognizing the utility of a snappy headline. For instance, Kara, who was hired because of her experiences as a blogger in the disability space, explained:

The reason that I wanted to work [at *The Mighty*] is because I felt like they were doing something that hadn’t really been done before, in terms of telling stories about disability and disease in a way that would really reach people and would have a big community, big traffic, and all that. You know, there’s a lot of disability sites out there, but a lot of them struggle to get the traffic. . . . And then they’ll sort of turn around and knock The Mighty, they’ll be like, “Oh the clickbait headlines” or whatever. But you know what? That’s how you get people to read it.

Mike emphasized the idea that, while the process of monetizing the site might prove contentious, advertising revenue would allow *The Mighty* to make donations to non-profit partners and to develop an increasingly useful resource for the community. Similarly, Hoyt noted that the push to develop and implement more interactive digital features represents an area where “what’s good for *The Mighty* is good for the community”; these features provide new ways for community members to connect while also “building a moat” around consumers who might otherwise be lost to social media sites like Facebook or to competing online publications. However, the evolving format of these features, and
the general layout of the site, implicates a second set of dialectical tensions: tensions of universality and specificity.

**Tensions of universality and specificity.** While Mike initially developed *The Mighty* because of experiences with his daughter’s rare condition, he recognized that he could not “build a site like this that’s for just people with DUP15Q—there’s 1,200 people world-wide.” Instead, he envisioned developing a broader biosocial community. In our interview, he described how Andrew Solomon’s (2012) book, *Far from the Tree*, provided a narrative structure that could connect seemingly heterogenous experiences of disability, chronic illness, a mental health challenges. The book laces together chapters about parenting children with physical or developmental disabilities, children with schizophrenia, children who are prodigies, children who identify as gay or as transgender, and children conceived through rape, and children who commit crimes. Some disability advocates have critiqued the book as ableist; Shannon Des Roches Rosa, editor of the influential book/blog, the *Thinking Person’s Guide to Autism*, explains:

Solomon is eloquently critical of discrimination that affects him personally (he is gay and has depression), yet reinforces chronic biases against autistic people . . . Solomon’s book does feature many autistic voices, but it presents autistic subjects who aren’t able to speak for themselves and who have high support needs as burdens. He even allowed parents and caregivers to publicize their autistic loved ones’ most vulnerable and private moments, a potentially degrading exercise, in the name of ‘honesty.’ (Des Roches Rosa, 2016, para. 5)

However, Mike was inspired by Solomon’s ability to link such seemingly disparate topics using a unifying theme: the experience of parenting someone who is different from yourself. Similarly, Mike created a unifying narrative structure by locating a “common thread,” connecting people who are “facing day-to-day challenges and don’t necessarily
have a place to call home.” The resulting site captures a broad array of topics and experiences, resulting in what Nicole called the “Mighty basket:”

If you have a particular disability, you all pretty much deal with at least an assortment of common things. . . . But everybody is in this big Mighty basket, none of us look the same, none of us all have the same things. It's just every imaginable scenario.

In the process of managing this collectivity of differences, staff members encountered tensions of universality and specificity—tensions tied to the desire to recognize broad, universal commonalities while also attending to specific, fine-grained differences regarding what it means to live as a person with a disability or chronic illness.

In response to this set of tensions, some staff members emphasized the potential unifying power of focusing on broad, universal themes. They talked about how, because people with disabilities and chronic conditions share many general experiences—such as being misunderstood by others, or struggling with inadequate health insurance policies and the complex process of applying for disability—readers were often able to say, “I can relate to certain aspects of this story even though I don’t have this particular condition myself.” Danielle described this phenomenon of universality in the context of chronic illness:

There’s so many times when someone might write an article and they say, ‘I have lupus’ and then someone will comment and will be like, ‘I have Ehlers-Danlos syndrome and I feel the exact same way.’ . . . Someone who has Ehlers-Danlos syndrome wouldn’t necessarily go to a lupus site to find that kind of thing, but on The Mighty they can just be like, “Oh, yeah, I know there’s other people with chronic illness that we’ll talk about the same things I’m experiencing—it doesn’t matter what we have.”

By focusing on intersecting experiences, The Mighty encourages contributors and readers to cultivate increasingly broader collective identities, moving from a narrow collective
identity category like “Lymie” or “Chrohnie” toward more inclusive categories like “disabled,” “spoonie,” or “zebra,” ultimately moving towards recognition of a collective identity rooted in shared experiences like “being different” and “facing oppression.”

Indeed, Mighty contributor, Jane, explained the value of facilitating readers’ exposure to other conditions through publishing a broad range of stories:

> I’ve read lots of things that I might not necessarily have read otherwise . . . I think it maybe exposes people to a larger range of opportunities. Somebody who has a child with autism, they become so hyper-focused on autism that they don’t read anything else. . . . And yet, if they are on The Mighty and they get these links sent to them, and they get an article sent to them about something else, and they read it . . . and they realize, “Oh, my God, I had the same thing happen, but for a different reason.” So, I think that cross exposure is really healthy because again, I think people can start to understand that everybody goes through something.

Editors also realized that stories that focused on broader, universal themes were more likely to generate clicks and shares, satisfying a pragmatic desire to do well as a company. The site’s news editor described being more likely to write a news story about “taking opioids for chronic pain” than about “ankylosing spongilitis,” while contributor editors talked about being more likely to promote stories that focused on more general themes on The Mighty’s main Facebook page. However, Danielle noted that this elevation of the universal might “neutralize” or “hide” the details of a condition, often by encouraging contributors to “back off on the specifics” after observing The Mighty’s tendency to paint in broader strokes. “Which is good if you want everyone to relate,” Danielle explained, “but not so great for the people who actually have lupus, who might actually really want to know about that specific thing.” As Mighty contributor, Alicia, recognized:
Different kinds of disabilities are different. Different kinds of illnesses they have different effects on your life. Even just chronic illnesses versus life-threatening like a cancer versus MS or lupus. That’s a whole different view because with things like MS, you are dealing with what’s going to happen 20 years from now. . . Whereas with cancer, it’s what can I do right now? It’s . . . a different lifestyle. It’s a different mindset. It’s a different . . . kind of planning. I think in some ways that’s really hard, and it’s very easy for people to generalize on a site like [The Mighty].

Indeed, staff members recognized that, while some readers enjoyed learning about other conditions and recognizing shared experiences, others preferred varying levels of specificity, reflecting their identification with narrow vs. broad collective identities. For instance, a person with a chronic illness might be unlikely to read a disability- or mental health-related story, and may even be unlikely to read a chronic illness story that did not address their actual diagnosis. Further, readers might come to The Mighty to seek out stories related to their particular position in the “life cycle of the condition.” In addition, they might seek stories that resonate with their particular understanding of what it means to live with a condition—stories that correspond to the discourses of difference they have embraced to frame their condition as a source of devaluation and hardship, or as a valuable culture and political constituency resisting systemic oppression. For instance, Kara noted that people with disabilities who have embraced their disability identity and have developed disability pride might not want to read articles about “people who are upset,” but rather would like to “read [about] people who are fighting for their rights, and fighting for accessibility.”

Ultimately, staff members framed tensions of universality and specificity as linked to the limitations of the site’s digital infrastructure. Rafael described the problem in this way:
Factually, some people only really care about their condition, and some people care about the whole community. The challenge is that they’re all distinct communities. Even if you take mental health as a big group, we also have disability. We also have chronic illness. We also have cancer. They’re all very different communities with different challenges, and different priorities, and different experiences. And if you try to design one product for all of these different communities, it’s harder to solve the unique challenges that that community faces. You have to make a product that uniformly applies across all of these heterogeneous communities, and make it so that they all want to use it, which is a challenging design and product task.

In response to this task, The Mighty’s team of engineers and designers continually develop new strategies for “getting information to people” at the “right place, right time.”

**Shifting toward customization.** As Mighty staff members recognized the tensions associated with universality and specificity, they envisioned new features that provide readers and contributors with increased agency to navigate between universality and specificity. Essentially, they enhanced the site’s capacity to “organize dissonance” through the process of (adaptive) structuration (DeSanctis, & Poole, 1994), responding to the evolving ways in which Mighty “users” interacted with the existing structure.

Initially, the fledgling company accomplished this by creating topic-specific Facebook groups in addition to a general Mighty Facebook group, allowing readers to like and follow the groups that most interested in. However, staff members sought ways to shift away from Facebook to create this kind of customizability through their own platform. Just before I traveled to the organization’s headquarters to conduct my interviews, the company launched its personalized newsfeed feature. This feature allowed readers to create an account with The Mighty and select specific topics of interest, such as “multiple sclerosis,” “Lyme disease,” and “rheumatoid arthritis,” prompting the site to send personalized newsletters at a pace set by the user (daily, once per week, etc.). Even these
topics emerged through the process of adaptive structuration; *Mighty* staff members monitored data attached to the specific topics that users most frequently read about, developing newsfeed categories based on which topics generated significant interest.

Further, *The Mighty* created a “follow” button feature which allowed registered users to view stories written by their favorite contributors—essentially giving them the ability to read only those stories written from perspectives that resonated with them.

Certainly, developing these features allowed the company to pursue its desire to do well as a company by building and retaining an increasingly large audience. Mike Porath (2017) focused on this aspect of the site’s “follow” feature while describing what occurred after its rollout:

> We gave registered users the ability to “follow” our thousands of writers and hundreds of topics. They get personalized stories delivered to them several times a week. Nearly 70% of our users are opening these email notifications, which is about three times the rate of most publishers.

> . . . In the last month, 5,000 people have joined [the bipolar community] and in that time the average user is reading over 30 stories and spending more than an hour on our site. That’s more than three times as long as what a registered user spends on LinkedIn each month.

> In the first six weeks . . . we’re getting a new registered user every two minutes. . . . As we give users more ways to connect and interact across more topics, we can keep doubling that rate.

However, staff members also recognized that site’s increasingly customizable features created a better experience for users by allowing them to interact with the site at the level of universality or specificity that matched their needs and the ways in which they construct their collective identity. Additionally, Danielle noted that these features might ensure that those stories that could not be promoted because of their limited appeal would still find their way to the people who most needed to read them. She explained, “even the
stories that are little too specific to go on Facebook, like that lupus story . . . someone who’s registered for the site and checked off lupus as a condition . . . they’ll find it now.”

However, while Mighty staff members could adjust the site’s digital features to address aspects of tensions tied to universality and specificity, they also face more complex tensions associated with determining which stories could/should be included on the site in the first place.

**Tensions of inclusivity and selectivity.** Tensions of inclusivity involved the paradox of building a platform that provides a “home” for stories that would otherwise remain marginalized, while also recognizing that not all stories could be included on the site—both because The Mighty needed to protect its brand by publishing stories that adhered to conventional notions of quality storytelling, and because truly including all stories might ignite existing tensions in the community and expose contributors and readers to harmful, ableist narratives. Ultimately, this tension is a consequence of The Mighty’s status as an organizationally-enabled network, a hybrid organizational form constituted when organizations “utilize social media platforms – both commercial and custom – to aid individuals in developing their own sense of community. These same platforms are used to develop ties with supporters and organizations from other communities and social movements” (p. 910). By melding the logics of connective and collective action, The Mighty faces organizational dissonance tied to the clash between self-motivated, idiosyncratic peer-production and more formally controlled, coordinated activities. Below, I explore several, potentially contradictory, organizational aims,
including the desire to create an inclusive, neutral platform and the desire to cultivate both safe spaces and helpful content.

**Accepting all narratives: Cultivating an inclusive multiverse.** The Mighty’s staff members consistently articulated a strong commitment to “including as many people who want to be in the community as possible.” In discussing this commitment, staff members (a) articulated their logic of inclusivity, (b) framed The Mighty as a neutral platform, (c) noted that some voices remained missing or underrepresented on the site, and (d) acknowledged tensions inherent to including all perspectives.

**Articulating the logic of inclusivity.** Initially, the logic of inclusivity adopted by Mighty staff members reflected Mike’s desire to provide a “home” for stories about rare conditions like his daughter’s. For instance, Rachel noted that “by not saying no to any condition,” even if it means having only a single story about a rare chromosomal disorder, The Mighty provides a space for “that one story [that] can help one other person on the planet feel like they’re not alone.” Similarly, Eva described the “amazing” experience of scrolling through the conditions included in The Mighty’s A through Z directory, emphasizing the breadth of the site’s coverage by noting, “you could spend 20 minutes just scrolling through the As.”

However, staff members also recognized that the logic of inclusivity extended beyond simply collecting conditions. Many acknowledged that people with disabilities and chronic conditions have “fought long and hard” to “have a voice,” making it morally imperative that The Mighty avoid inadvertently perpetuating historic censorship. Kara clearly expressed this idea:
A lot of people with disabilities and health conditions have trouble getting their voices heard. They are not heard by society, by their doctors. And so, my feeling when I approach a story is that this person has something important to say, and can I make this work for our website?

Further, staff members recognized the need to avoid endorsing any one way of making meaning from the experience of disability or chronic illness, defending a contributors’ right to claim their unique emotional journey. Kathleen explained *The Mighty’s* inclusive ethos in this way:

If our writer’s really upset with their disability and their goal is to walk again, or they’re going through a lot of depression because of it, my job is not to explain to them that they’re not upset because they have a disability. They’re upset because the world isn’t built for disability. Which, that’s probably true, in one small sense. It sucks if you roll up somewhere and there’s not a ramp. That’s contributing to why you’re upset. But maybe they’re also just upset because they used to walk and now, they can’t, right?

... We don’t feel that's our job, as a company, to tell people how to feel about their disabilities. And we think that all of those perspectives can exist in one place. Some people, when they have a disability, they’re looking for support. Other people are looking for empowerment. And we’re not going to be a site that just hosts one and pretends that the other side of it doesn’t exist.

Relatedly, staff members recognized the complex and contested nature of the term, “disability.” “If you go out on the street and said ‘disability’ to 30 people, you’re going to get a ton of different reactions,” Kathleen explained, describing a person who draws on discourses of difference as devaluation and hard reality and a person conceives of disability as a source of pride. “We’ve sort of settled on the idea that neither of those people are right or wrong.” Rather, editors emphasized the importance of gathering alternative perspectives with the goal of putting them in dialogue with each other. Rachel described the logic of inclusivity in this way: “to really start a conversation you can't silence any part of it... That's the only way that you can really change thinking about an issue or just start more meaningful dialogue.”
*The Mighty’s* editor-in-chief expanded on the notion of fostering dialogue to consider how inclusivity can facilitate readers’ empowerment. She described how, by including stories about the struggles individuals and parents face in navigating disability or a chronic health condition, the site “establishes a level of trust with the reader.” These kinds of articles meet struggling readers where they are, validating their difficulties in such a way that they continue returning to the site. In doing so, they encounter the perspectives of other writers who express pride about, or acceptance of, their condition. Kathleen emphasized that, “By giving people support, they can reach a level where they begin to look for empowerment.” Continuing in this vein, she focused particularly on the logic of including parent voices on *The Mighty*—a source of contention for self-advocates worried about the potential for parents to appropriate their child’s experience or to frame disability as a burden. She explained that, by only including stories that suggest that a parent should accept their child’s diagnosis from “day one,” *The Mighty* might cause parents to think “I’m a complete monster because this person just accepted it, and they loved their kid no matter what. And I love my kid, but I am having trouble with this. What’s wrong with me?” She explained that this kind of sentiment could “build up in a very real way that affects the kid. . . . Letting them actually voice what’s going on, helps them get to that acceptance level much faster, and in turn, helps the child faster.” Kathleen also acknowledged the empowering potential of publishing parent-written stories alongside stories written by self-advocates:

I think that it actually is stronger if those [parent and self-advocate stories] exist in the same place . . . Some of the adults [with disabilities] write about, “My parent never did accept me,” and I think that it helps the parents, then, realize, “I need to
get to this space where I’m advocating and not just wallowing in what’s going on with me.”

Given staff members’ commitment to the logic of inclusivity, they emphasized the idea of The Mighty as a neutral platform on and through which all comers could express themselves.

**Framing The Mighty as a neutral platform.** Staff members focused on framing The Mighty as purely a “space for people to share”—one that doesn’t “take sides” or “take positions on a lot of controversy.” This commitment to preserving neutrality extended to the company’s for-profit partnership program. Specifically referencing Autism Speaks, an organization that has generated protests from autistic activists and other members of the autism community (Parsloe & Holton, 2017), Rafael said:

> The end goal would be, all non-profits are signed up; the controversial and the non-controversial ones . . . we need to make it clear that we’re not endorsing everything that Autism Speaks has ever said. But do they have a role in this community that we’re building? Absolutely.

However, this goal of providing a neutral platform was not always recognized or appreciated by The Mighty’s readers and contributors, who sometimes mistook a contributors’ opinion for The Mighty’s official position, or demanded that the site take a stronger stance on a particularly contentious issue.

> Additionally, staff members described their own personal biases as threats to The Mighty’s neutral stance—particularly when they had personal connections to disability or chronic illness. In cases where their own “philosophy” or “baggage” threatened to cloud...

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26 This organization’s logo has since appeared on the site, indicating its status as an official non-profit partner.
their judgment, they consulted with other members of the staff to answer the question, “Is my wishing to not publish this my personal issue, or is it really that this isn’t something that we want on the site?” In cases where they felt overwhelmingly biased, they delegated the work to other editors who could make editorial calls more objectively. Ultimately, they reminded themselves that “this isn’t about me.” Nicole even refrained from publishing frequently about her own disability experience on The Mighty, citing her desire to avoid “blurring the line.” Interestingly, while Nicole’s experiences as a person with a disability might seem to qualify her to speak with authority on issues in the community, she expressed being even more conscious of the fact that her personal perspective is limited: “I grew up the only disabled person around able bodied people, I think the first group of people I was around that [included people with disabilities was when] I was 27. I don’t really know the rules and I don’t want to hurt anybody’s feelings.” Over time, as staff members became increasingly committed to creating an inclusive, neutral platform, they also became increasingly conscious of the fact that some perspectives remained unrepresented or underrepresented on the site.

*Seeking missing narratives.* Staff members expressed awareness that, while they fully embraced the logic of inclusivity, some narratives remained missing from The Mighty’s site. Both Mighty staff members and Mighty contributors recognized the preponderance of mostly white, mostly middle-class, women contributors. Indeed, as a Latinx Mighty contributor, Bailey recognized a lack of cultural diversity on site. She explained that “there are different cultural views [of chronic illness and disability], but it’s never talked about on The Mighty.” Similarly, Mighty contributor, Sakari, noted that
discussions of race and ethnicity remained absent from the site. “As a mixed disabled person, my ethnicity I think has played a big role in some of my really toxic interactions with the health care system,” Sakari explained. “And I’m not going to erase that from the conversation because that’s just ludicrous. The Mighty is truly white.” Similarly, both staff members and contributors acknowledged a lack of gender diversity on the site. They talked about the challenge of recruiting men who, stereotypically, are less “open about their feelings” and “want to seem strong.” Staff members also noted that some individuals might be excluded from the site because they are unable to write, either because they don’t have the energy or ability to write a full-length article in English, or as Anna noted, because they are “in jail or homeless . . . [or] are more severely ill.” Additionally, differences in the prevalence and level of impairment associated with specific conditions might influence the likelihood that The Mighty would receive articles written by affected individuals.

Alternatively, The Mighty might simply gain traction in some communities more quickly than others, creating an influx of articles about one condition or about a certain category of conditions such “mental health.” The uneven expansion of each of The Mighty’s main sections (news, parenting, autism, disability, mental illness, chronic illness, and rare disease) translated into unequal representation on the site. Readers sometimes interpreted this as intentional, saying “your site is just for this, your site is just for that, what about us?” Those who perceive that the site is not really “about” them may elect not to contribute to it, perpetuating unequal coverage. However, when members of a specific community embraced The Mighty’s potential as a platform, they could boost the
amount of coverage their condition received. For instance, Kara noted that, even though Ehlers-Danlos syndrome is a relatively rare condition, it is well-represented on the site due to the concerted efforts of several prolific contributors.

Finally, the site’s initial publication of relatively uncritical articles—typically written by parents—may have discouraged self-advocates from contributing pieces that address topics like disability rights and systemic ableism in relation to subjects like education, employment, and housing. Vera envisioned The Mighty as a resource for people who “want to learn how to advocate for more inclusive accommodations. If they want to learn how to advocate for themselves in the workplace [or] with their professors. If they want to understand the process of applying for disability.” However, getting “more of that” proved difficult initially. For example, Anna reported reaching out to a prominent mental health advocate known for his criticisms of anti-stigma campaigns. He “politely declined” Anna’s invitation to write, saying “I’m not sure you guys would respect my work.” This interaction illustrates the challenge editors faced in framing The Mighty as a credible authority and a progressive publication, rather than a repository of “fluffy stories.”

The Mighty’s editor-in-chief acknowledged that, in some cases, the patterned paucity of certain narratives might be an artifact of the way in which The Mighty launched—by reaching out to prominent “mommy bloggers” who frequently focused on personal challenges and triumphs from a parent perspective. She acknowledged that she had let the parenting section “blow up,” instead of making “a bigger effort to grab more perspectives from the get-go.” “I still want to get a more diverse blogosphere of sexes,
and sexual orientations, and race,” she emphasized. “We’re making leeway in that, but not in the way that I want it to be. If we’re going to represent the population, we should actually represent the population.”

With this goal in mind, staff members sought answers to the questions, “Who are we not reaching? Who can’t write for our site? And how do we still include them?” They recognized the need to “go on the offensive,” enacting several strategies to expand the variety of perspectives on the site. First, staff members wrote targeted articles to acknowledge missing segments of the population. For instance, the mental health editor wrote a story entitled, “To the People We’re Not Writing Mental Health Content For.” In it, she acknowledged that individuals who are especially disenfranchised and unable to access resources like The Mighty (for instance, people who live on the street, in prisons, in group homes, etc.), and/or people who might be further stigmatized by rhetoric that aims to normalize mental health challenges while “excluding” and “othering” people with particularly severe forms of illness. Second, staff members actively recruited writers who filled an underrepresented demographic category or expressed a new perspective—they directly contacted bloggers found via Twitter, Facebook, and other social media platforms, and collaborated with non-profits whose constituents might be willing to write. Third, staff members developed writing prompts tailored for missing populations. For instance, the editors created a prompt asking for people in the LGBT community to write about their experiences with disability. “We got a ton of amazing writers out of that,” Kathleen told me, “People who had never written for us, but they saw that prompt and they’re like, ‘Well, that’s me, and no one else is asking me to write. So, I’m going to put
my story out there.” Finally, when they received a story from a contributor who offered an alternative perspective, they included a story prompt at the bottom of the article to encourage readers to generate similar submissions. By proactively collecting missing narratives, staff members hoped to show potential contributors that their story would be valued on the site. As Vera noted, “the more stories we receive and are able to feature, the more people see, ‘Oh, this is a space for me too.’” For instance, the mental health advocate who initially declined Anna’s invitation to contribute submitted a piece unsolicited several months later—an event that Anna cited as a sign that The Mighty was both successfully diversifying its content and gaining credibility.

**Selective inclusivity: Filtering stories.** As The Mighty gathered a more heterogenous mixture of contributors, tensions between their perspectives became more apparent. Editors discussed their attempts not to “veer too far one way or the other” in depicting controversial topics, or even in framing the experience of disability or chronic illness in ways that emphasized positivity or struggle. They also talked about the challenge of allowing contributors to “feel the way they feel,” but not allowing them to “express it in a way that makes other people feel put down.” These and other concerns highlighted a need for selectivity—a need that exists in tension with the logic of inclusivity. Editors defended the necessity of selectivity by emphasizing the importance of protecting a “safe space.” Creating and preserving this safe space involved applying an evolving set of editorial guidelines to filter out stories that violated the “Mighty tone.”

**Inaccuracy, incivility and the “wild wild west”: Protecting digital “safe spaces.”** Staff members expressed profound respect for contributors’ willingness to make
themselves vulnerable in their writing, explaining, “that’s a lot of people trusting you with . . . stories of their children or their own lives, and it means a lot to have that trust” (Mark). In addition, they acknowledged that the stories they choose to publish can have a profound impact on readers’ sensemaking and medical decision-making processes, catching them at their “worst moments.” For these reasons, they recognized that, ethically, the The Mighty’s site could not “just be completely Wild Wild West.” Instead, they focused on developing and protecting a “supportive place” and “a safe, secure environment.”

Staff members conceptualized “safe space” in two different ways. First, they conceived of it as avoiding “false information” and ensuring the “accuracy and integrity” of contributors’ words. In some cases, this meant consulting with experts to confirm the veracity of medical claims—or at least including a statement at the end of an article emphasizing contributors lack of medical expertise and encouraging readers to consult a doctor. Often, however, ensuring accuracy meant editing submissions to differentiate opinions from facts and to clarify generalizations. Mark gave several examples of editing for accuracy, explaining that a contributor might say “‘ Everybody has these bad experiences,’ but you can say something like, ‘I had a bad experience and this is what happened to me’ [instead].”

Second, staff members conceptualized “safe space” as a place “where you feel like you are welcome and you feel like you can come and tell your story or state your opinion without the fear of being attacked for it.” The “duty” of maintaining this form of “safe space” fell largely to the community manager, whose job was to delete offensive
Facebook comments, to ban commenters who resort to ad hominem attacks, and to filter out advertisers who might otherwise “prey” on community members by leaving comments about their products. To accomplish this, she used a filtering tool designed to flag problematic words and phrases; she could catch and review potentially hurtful comments before they could be published on the site. As she encountered additional patterns in the words and phrases that “trolls” and other abusive commenters used, the community manager added these to her filter to create a dynamic repository of vitriol.

The community manager expressed considerable satisfaction in banning people who purposefully use “horribly outdated words like ‘mongoloid,’” taking pride in her role as protector. However, she also discussed the heartbreaking experience of having to delete comments that simply reflect a person’s lack of knowledge about correct terminology. She described a case where an older man wrote a comment about his brother, a “cripple”: “he clearly loved his brother with everything he’s got, [but] he used the wrong word. To him, it’s not the wrong.” Despite this recognition of positive intent, the community manager was required to delete the post without explanation; an explanation of banned terms would allow “trolls” to circumvent her filtration system by purposefully misspelling these words. The community manager also discussed the emotional burden associated with the fear of failing to protect. She explained, “I feel I live with responsibility to protect these people’s feelings. I did not realize how much that was going to impact me, how I feel personally responsible if somebody gets their feelings hurt. I feel like I let them down if a comment came in overnight while I was asleep.”
Despite devoting considerable effort to protecting a safe space, staff members noted that *The Mighty’s* community rarely produced as many vitriolic “trolls” as they had witnessed in other online communities. They attributed this to the idea that it is difficult to respond in venomous ways to an individual’s personal narrative. For instance, Vera noted that *The Mighty’s* generally supportive climate might be a “natural byproduct of the stories,” explaining that, “When you read them, for that one minute or two minutes that you’re reading it, you’re getting to know this person.” The vulnerable, authentic nature of *The Mighty’s* content encouraged readers’ dialogic engagement with writers, making it more likely that they would productively reflect on criticism and respond with statements like, “You know what, I used to be that person, but I’ve just read this and I don’t want to be that person anymore. Thank you for telling me what was going on.” Similarly, contributors recognized that the relative safety of *The Mighty* was linked the site’s tendency to attract readers who were likely to understand and empathize. For instance, Renee compared both the *Mighty’s* editors and supportive commenters to a “neighborhood watch group,” elaborating:

> So many of us have been [judged] . . . You learn to be treated coldly. It’s a very refreshing thing to be treated warmly when you have a weird disease that everybody asks you to repeat it all the time. . . . You are vulnerable and then bam, somebody’s kind to you. It really makes an impact. It’s a place where you can go and be treated exactly like you are.

While the community manager worked to protect contributors from offensive and hurtful attacks, editors worked to protect readers by being “extra sensitive” to the terminology used in published stories. Editors described working as “translators,” using their knowledge of the nuanced norms within particular communities to help contributors “communicate [their story] in a way that makes it effective” and appropriate. For
example, they reported changing the phrase “suffering from” to “living with,” and using the term “meltdown” instead of “tantrum”—edits that reflect the desire to avoid potentially stigmatizing and trivializing language. However, this editing process was not always clear-cut. Staff members acknowledged the fact that certain terms and phrases are contested within communities, particularly in instances where portions of the community are working to reclaim previously offensive wording. For example, staff members learned that some members of the autism community prefer to be referred to as a “person with autism,” differentiating themselves from their condition, while others claim autism as an empowering identity/cultural category and prefer to be called “autistic.” Likewise, they learned to differentiate empowering and derogatory uses of the same term. For example, Kara described allowing a contributor to use the term “crip” to refer to themselves, but changing their use of the word “crippling” to describe the nature of their condition. The role of translator is a particularly complex one in the cross-condition context of The Mighty, where the terminology norms associated with one sub-community might ignore or conflict with the norms of others. The reality that “nothing exists in a vacuum” required that editors from each section of the site collaborate to ensure that terminology remained “very sensitive all across” The Mighty. Anna provided a helpful illustration of this:

What may be okay to say in the mental health world isn’t okay [elsewhere]. For example, a lot of people say “crippling anxiety.” It’s very common. Our disability editor one day was just like, “Hey, how about we not say ‘crippling anxiety’?” And I was like, “I never thought of that.”
While this process of translating applied to stories that had been accepted for publication, editors also used their desire to create a safe space as an initial criterion for deciding which stories should be published or rejected.

Red flags, gut responses and the Mighty tone: Rejecting stories. In discussing the process of accepting and rejecting stories, Mighty staff members described identifying “red flags” by paying attention to “little instincts,” “gut reactions,” and the feeling that something is “a little bit off.” The editor-in-chief trained her team to attend to these emotional responses to stories, encouraging them to ask questions like “Why don’t I feel good reading this piece? . . . Is it their overall message? Do I not trust what they’re saying? . . . What is going on here?” Such questions emphasize the validity of intuition as a form of knowledge, attending to the ways in which “knowing” can be an embodied, sensory experience—much in the same way that scholars like Ellingson (2006) have conceptualized the knowledge-generating process of conducting ethnography.

Additionally, editors often used Slack, an app designed to facilitate team communication, to ask each other for second opinions. This allowed team members to validate their initial gut responses by “pinging” each other with questions like, “Is there anything about this that you feel a little iffy about or weird about?” Essentially, their communication (re)constituted a sense of collective intuition. This collective intuition facilitated activity coordination, helping editors learn how to assess whether a piece struck the right “Mighty tone.” While editors struggled to pinpoint exactly what the

27 See https://slack.com/is
Mighty tone looked and sounded like, they could easily describe stories that would violate it. These included “stories that are very pitying . . . stories that are extremely angry without any type of constructive purpose” and stories written by parents that focus solely on “fixing” their child, rather than learning how to support them.

In addition to assessing an article’s tone, editors asked several key questions to filter out unpublishable stories. They critiqued submissions using two primary queries: “Does this have a purpose?” and “Is this constructive?” Acceptable purposes included helping others feel not alone, educating or revealing something that others might be unaware of, covering a topic not yet included on the site, and venting in a way that offered something useful to others. Questions about purpose were particularly useful in helping staff members to decide if a feel-good article was really an instance of inspiration porn. Editors told me that they were unlikely to report on the forms of inspiration porn that typically receive viral attention on other media sites, such as the “promposal,” the homecoming king/queen, and instances of when non-disabled people sat with or sent birthday cards to “lonely” people with disabilities. “We’re trying to promote inclusion,” the news editor explained, “but at the end of the day you have to ask yourself, ‘How inclusive is it, if we always single out people? . . . What’s the value added? What does it really do for the community?’” When she did report on stories that might fit the inspiration porn genre, the news editor attempted to add a more critical, Mighty angle. For instance, she described an “inspirational-y” story of a shoe store salesperson who recognized that a young child with autism was becoming overstimulated by the back-to-school crowds. The salesperson took the boy and his family to a staff lounge where he
could try on shoes in a sensory-friendly environment. Rather than reporting on how nice this one manager was, the news editor instead wrote an article that emphasized that “these are the accommodations we should be thinking about for shoppers.”

In addition to asking if a story had a constructive purpose, staff members asked, “Does this need to be public?” They considered whether articles formatted as open letters had a purpose for the larger community, or whether they really should be sent privately to individuals. They evaluated whether contributors had processed their personal experiences and were ready to publish them, or if perhaps the story reflected something that was too raw and undigested—something better left on the pages of private diary.

They also considered whether stories written by parents, caregivers, and others preserved the “dignity and the privacy” of the people being written about. In these cases, editors grappled with answering the question, “How much of their story is yours to tell?” This question rose to prominence in response to criticism levied by supporters of #crippingthemighty; the editor-in-chief noted that “people wanted to read more voices of someone with the condition, so we very acutely responded to that.” Indeed, several employees noted a deliberate shift from The Mighty’s initial focus on publishing parents’ stories about their children toward showcasing people writing about themselves. “I know that people who do have disabilities and illnesses appreciate it,” Erin told me, “because they know that parents aren’t always the best authorities. I think they really appreciate seeing their own voices on the site.” This shift in what kinds of stories get published, as

28 Note that this kind of judgement call affords Mighty editors significant power, and might be perceived as a kind of paternalistic act where editors assume to know what is best for any individual writer.
well as changes in how editors enact their translator role, reflect staff members’ reliance on an evolving set of editorial guidelines.

**Co-constructing evolving guidelines.** The editing procedures described in the previous sections reflect the current, potentially revisable, outcomes of a “trial and error” process of asking “is this right?” Rachel described the considerable uncertainty that staff members faced when *The Mighty* initially launched, where editors continually asked, “Is this the right way to approach it?” The editor-in-chief attributed this uncertainty to the idea that mainstream media outlets had yet to cover disability and chronic illness in this in-depth, non-medical, extremely personal way. She explained:

People haven’t set rules around this stuff yet, or guidelines, and we’ll probably be the space that does that. You can find very general guidelines around reporting on suicide, or reporting on disability. And they’re great, and we use them. But they’re still kind of limited for how in-depth we’ve been getting. So . . . we’ve started to develop a *Mighty* guideline, essentially, about how we think you should report or write about conditions across the board. We call them “guidelines” because I don’t want to say that they’re like strict “yes” and “no.” Because it changes all the time. . . . It becomes this kind of fluid conversation that we have.

Given the unsettled nature of “the rules,” *Mighty* editors co-constructed their guidelines in collaboration with each other, with readers, with contributors, and with healthcare and other professionals. At times, this “fluid conversation” was driven by readers’ responses to published stories. For instance, Kathleen described an incident where *The Mighty* published a story in which a mother referred to her preemie child as a “miracle.” Readers explained that this phrasing can be understood by some in the community to mean “If I didn’t pray hard enough, that’s why my kid died.” In response to this incident, editors became much more aware of, and careful about, publishing stories that contain this kind of wording. In some cases, editors proactively initiated a conversation with contributors.
They consulted with members of the community about whether and how to cover certain topics, using their contributor portal system to solicit answers to the question, “How do you guys feel about this type of story?”

Editors also leveraged personal connections with their contributors to solicit advice on sensitive topics, tapping into others’ intuitive, embodied knowledge. For instance, Anna asked contributors for feedback about whether an article might be triggering or exploitive. She recounted the process of evaluating an article in which a woman wrote about her mother’s schizophrenia: “I sent it to one of our writers who has schizophrenia. I said ‘Hey, Elizabeth, do you mind reading this over? How does it make you feel?’ Because I always have to imagine someone with schizophrenia reading the piece.”

Finally, editors consulted with experts to ensure that graphic or otherwise questionable pieces would not be harmful to readers. For instance, Kathleen enlisted an expert’s opinion to determine if she should publish a piece about using violent video games as a coping mechanism. “If they say, ‘Yeah. It’s fine, if it’s written in this way,’ then we know, moving forward, that we’ll allow this if X, Y, Z is presented in a piece,” Kathleen explained. “It might become an internal guideline of, ‘anything that mentions violent video gaming needs to go through two editors and see if it still meets our guidelines.’ So, we’re still developing all the rules as we go.”

These various forms of feedback, as well as insights gathered by individual editors from both personal experiences and extensive reading, allowed editors to co-construct a set of nuanced, flexible guidelines based on a growing repository of
knowledge. Rachel summarized in this way: “As we’ve built up our team, and as we’ve added contributors . . . constantly polishing a certain area, you start to build up this expertise.” Learning from “people within the community” helps editors internalize a sense of their audience’s preferences. In attempting to remain an all-inclusive, neutral platform, editors navigated conflicting opinions about how particular topics should be represented—respecting critiques of ableist terminology without alienating people who identify with mainstream, yet contested, terms like “special needs.” Ultimately, editors focused on the mantra: “it depends on who’s telling the story.” This individualized approach respected the perspectives of particular contributors, but also muffled the Mighty tone, curbing its ability to take on the edgy, progressive notes of disability activism. However, the site’s shift from purely storytelling toward community building might make room for more strident voices.

**Shifting from storytelling to community-building.** Just as Mighty staff members responded to tensions of universality and specificity by shifting toward customization via changes in their digital infrastructure, they envisioned ways in which they could address tensions of inclusivity and specificity by creating new features. These features would create new opportunities for readers to interact with the site as participants, rather than simply as passive story consumers. Thus, the site’s organizers envisioned shifting the ethos of the site beyond the traditional storytelling focus embraced by traditional digital publishers and toward the community-building capacities inherent to social media platforms. Mighty staff recognized that, in doing so, they could eliminate some of the pragmatic reasons for selectivity (such as including only edited, high-quality content that
reflected well on *The Mighty*’s brand) by creating alternative avenues for participating—avenues that would enhance *The Mighty*’s ability to be inclusive.

The crux of shifting from storytelling to community-building involved creating “community hubs”—sub-communities within *The Mighty* defined by a particular topic (e.g., autism). The site’s head of product and the editor-in-chief each described how each hub page would include a description of the condition written in a *Mighty* tone, developed in consultation with contributors. The hub would also include stories written in article form about that topic, organized into sections like “latest stories” and “top read stories,” as well as into categories of interest to the community, such as “relationships on the autism spectrum.” Additionally, the hub page would feature prominent contributors, non-profit partners, and, eventually, medical experts. Indeed, at the time that this manuscript was written, *The Mighty* had already begun to launch preliminary versions of hub pages with most of these features. However, staff members also envisioned creating archivable discussion forums to accompanying the “premium” article content on its hub pages—forums that would both facilitate crowd-sourced answers to community-generated questions and allow readers to engage in conversations about the articles themselves. Kathleen described how this last feature of hubs would create a more inclusive, participatory structure, explaining:

You could be a part of the community, but you wouldn’t have to submit a blog post, necessarily, to do it. And then the blog [article] writers would sort of elevate then to this kind of celebrity level, like you’re a *Mighty* writer and these commenters could follow you specifically, communicate with you, and ask you questions.
Additionally, Kathleen described how moderation of these hub page discussion forums would be driven by community members themselves, ceding some of the decision-making power with regard to what counts as (in)accurate and (in)appropriate content.

Kathleen explained:

When we come up with the commenting system, we want to make sure that there’s some way to navigate it well. Reddit does it really well, or Quora.com does it really well. The community drives [the conversation] by upvoting, or having a moderator that can push great comments or conversations up. . . . We [will] have a community leader—in the beginning, it’ll probably just be the editor. But when we expand, we can hire someone to specifically do that, to facilitate how that works.

Kathleen’s comments—which cite two social media platforms—underscore the company’s desire to emulate the participatory nature of social media, more fully realizing its ability to construct an organizationally-enabled network (Caraway, 2016). In part, these aspirations were driven by the company’s for-profit motive; staff members sought strategies to encourage users’ sustained engagement with their platform, making the site more appealing to potential advertisers. Simultaneously, however, The Mighty’s staff members sought additional ways to act as second-tier advocates.

**Defining Advocacy from Mighty Organizers’ Perspectives**

Across interviews with Mighty staff members, in general, participants defined advocacy as both speaking up for oneself and speaking out for others. Their descriptions correspond to the ways in which contributors themselves conceptualized and enacted an advocate/activist identity. However, editors acknowledged that The Mighty was best-suited to facilitate refracted self-advocacy and collective self-advocacy. For example, Anna framed The Mighty as a “first step” for contributors who are in the process of
developing an empowered self-advocate identity. She reported receiving emails from contributors who disclosed things like, “this is the first time I’ve ever written about this” or “I’m going to show this to my family, it’ll be like how I tell them that this is something that I go through.” *The Mighty*, then, becomes a platform for people to “come out” with a condition, a “place where are people are reclaiming or they’re identifying with.” As Danielle explained, this coming out process is particularly important for people with invisible conditions who often write stories to the effect of “I just want people to understand what it is that I’m going through behind this facade that looks completely ‘normal.’” “So, I think that’s what a lot of them are trying to do,” Danielle conjectured, suggesting that contributors were “just trying to expose themselves and their voices that they don’t really think anybody ever listens.

Essentially, “coming out” on *The Mighty* entails the public performance of self-advocacy. Such a performance inherently requires the contributor to imagine themselves in conversation with an audience, positioning themselves in relation to both similar others as well as readers who are unfamiliar with “what it’s like.” The process of writing requires that the contributor (re)consider their relationship to a biosocial community, encouraging their development of a collective identity.

In this way, the public performance of self-advocacy takes on the qualities of collective action—particularly with the interlinked goals of educating for understanding, correcting misperceptions, and seeking acceptance. For instance, Charlie defined advocacy as an exchange of empathy, where contributors write to say, “Hey, take a minute and see this slightly different person/story/perspective that is different from yours.
And don’t do that thing where it’s like, ‘It’s different, I don’t like it.’” Similarly, Danielle described advocacy as “teaching other people,” by “using yourself and your perspective to teach others something that they might not have known, so that they can then go out and be a better person.”

Defining advocacy in this way, Mighty staff members focused on the interconnections of storytelling and advocacy. For example, Vera recognized that individuals become advocates because they have a story to tell. She explained:

Expressing what they’ve been through, what they want other people to know, what they wish people would talk about more—that’s their way of saying, “Yeah. My voice matters and I want you to listen to it.” So, I think that for a lot of people can even be a step toward even bigger advocacy.

In addition, they recognized storytelling as a strategic tool for advocacy, noting as Charlie did that storytelling is “the most primal way to get to one’s empathy, and tug at heartstrings, but in a non-inspirational way. Because it’s more of like, instead of looking down and going, ‘Ah.’ It’s like, ‘I’m going to walk with you instead.’” Through storytelling, advocates assert, “I’m human.” Finally, they recognized that receiving a story can generate the impetus for allyship, causing readers to respond with sentiments like, “Oh, wow, I had no idea that this is what it’s like for you. I should change the way I think about this or I’m inspired to spread awareness about this.” Equating storytelling with advocacy emphasized the potential power in The Mighty’s “story-first” approach. Yet, while staff members recognized that contributors used The Mighty to advocate on behalf of their community, they often expressed discomfort in claiming an advocate identity themselves.
Am I an advocate? Community positioning and advocate identity. As part of my interview process, I asked *Mighty* staff members to describe how they positioned themselves in relation to the community the *Mighty* serves. Staff members like Rachel felt like they are part of the community, explaining that “it’s really impossible not to feel a part of *The Mighty* community. A lot of people on the staff will have their own story to write—we all have them.” Vera teared up when describing how her work at *The Mighty* personally affected her, recalling the initial feeling of “reading a couple of stories . . . and them really resonating with me in a way that I hadn’t really experienced before.” This sense of being emotionally invested in the community was closely bound up in editors’ perceptions that they knew contributors on a personal level. The editor-in-chief explained:

I don’t view myself as a corporate business editor that’s very removed from it. . . . It’s unlike any editing job I’ve had. I feel very connected to the writers. They email me often . . . It doesn’t feel like a writer-editor conversation all the time, that’s why we hand out the [*Mighty*] t-shirts and they send us these selfies. It’s hard not to feel connected to it on a much deeper level than just like, “This is my job.”

Yet, while all editors expressed feeling “part” of the community in some sense, they did not necessarily think of themselves as fully “in” the community. Clearly, staff members who identified as non-disabled recognized their outsider status. However, even staff members who had personal experiences with disability and chronic illness sometimes reported being a peripheral member of the community. For instance, Eva described how, after spending years creating and participating in a support group, she felt that she had “graduated” in that she no longer felt the need to turn to others for support. Instead, she
positioned herself as a kind of community facilitator, explaining, “I’m a part of the people who built the community, I’m not part of the community.”

The ways in which staff members positioned themselves in relation to the community shaped how they responded to the question, “Do you consider yourself an advocate?” Staff members who conceived themselves as fully embedded in the community were more likely to claim an advocate identity. For instance, Kara responded, “Oh, definitely. Absolutely,” when asked if she was an advocate, citing her lifelong commitment to advocacy as a person with a disability:

I was involved with the organization that my mom used to run and I am involved with them again. ... In college, I was a member of a disability group ... [after a recent home invasion] I had to apply for help with services to pay for my in-home care and things like that. And I just started dealing with how awful the system is. And it made me get involved with activism again.

However, others’ responses were much more tentative. Staff members who did not claim a condition, but did feel emotionally invested in the community, defined their work as advocacy, but downplayed their status as an advocate. For example, Kathleen explained, “I’m in no way, shape, or form, as powerful of an advocate as some of these people who live and breathe it every day, but sort of by nature, what I do, it becomes advocacy.” Staff members who positioned themselves as being at the periphery of the community—either because they had “graduated” or because they had only recently been initiated—expressed discomfort with claiming an advocate identity. For instance, Eva described herself as an advocate, but clarified that she preferred to advocate via the objective stance of journalism. “I don’t really want to talk about myself,” she emphasized. In contrast, Anna described herself as a “baby advocate.” “I’m still in the learning phase,” she explained. “I do think that eventually I would love to break out and have more influence.”
. . [but] until I have enough time to really, really delve into it, I’m not really confident in expressing my opinions.” While several contributors similarly hesitated in claiming an advocate identity, all focused on the ways that their efforts could support self-proclaimed advocates.

**A Mighty ally: Enacting second-tier advocacy.** Rather than claiming an advocate identity, staff members frequently defined themselves as “second-tier” advocates. They referred to themselves as “middlemen,” “translators,” “vessels,” and the “people who give advocates their space.” The editor-in-chief described the concept of second-tier advocacy in this way: “I’ve found myself in this place of ‘power;’ I have this platform at my disposal. So, it becomes my and the team’s responsibility, like, ‘Okay, let’s get these people out and talking about what’s affecting them.’” She compared *The Mighty’s* role to that of allies working to support marginalized groups in their activism, explaining:

> It’s very similar to how I don’t want to read a Black Lives Matter piece from a white writer who’s not affected by it as much. You saw that conversation on Twitter, of people being like, “If you’re asking what you can do in this situation, and as a white person, it’s to help black people get their voices out.” And so that’s how I try to view what we’re doing here.

For *Mighty* staff members, acting as a second-tier advocate meant leveraging expertise in journalism and website design to enhance advocates’ capacity to reach and influence audiences. They enacted second-tier advocacy in two primary ways: (a) signal-boosting and (b) editing.
**Signal-boosting as second-tier advocacy.** When I asked The Mighty’s Head of Growth for his opinion about why contributors elect to write for The Mighty, he highlighted the site’s growing capacity to expand writers’ reach. He elaborated:

Doing this on a grand scale and publishing tons of stories across tons of conditions, and using all the social media channels to get them out there, and doing this over a course of several years with a big group of people has allowed us to build our reach to a level that a blog just can't even come close to matching. And so that is another benefit that we provide writers.

This description highlights one way in which The Mighty’s staff members act as second-tier advocates: by facilitating signal-boosting. UrbanDictionary.com defines a “signal boost” as:

Posting to a community forum (mailing list, social networking site, discussion board) in hopes of getting more attention for an event or cause. This is not the primary or first announcement, but rather one of many auxiliary posts or cross-posts to communities with individuals who are likely to take interest.  

Signal-boosting bolsters contributors’ capacity to place their stories in front of ever-expanding audiences by ensuring that it gets picked up and spread across the internet, preferably in viral fashion. Indeed, contributors often spoke about turning to The Mighty as a PR strategy—a tool to promote their existing work, to get “more exposure” (Adelle), and to “drive traffic…[to get] more search engine optimization” (Sakari). As Mighty contributor, Heather, explained:

I use The Mighty as a way to just grow that platform, to say, “Look, here’s what I’m doing. Oh, yes, I may have only written a few articles on The Mighty, but I have a book, and I have 10 other articles across the Internet from Psychology Today to xoJane, to every other different thing.” So, it’s just getting your voice out there in a bigger way, than if I just sat at home and played on Instagram.

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The Mighty participates in signal-boosting by sharing articles via its Twitter, Instagram, and Pinterest accounts, its main Facebook page, and several tailored Facebook communities. The staff continually searched for ways to satisfy the stipulations of Facebook’s ever-changing algorithm, attempting to formulate their social media posts in ways that increased their likelihood of being featured on users’ newsfeeds. For example, they recognized that Facebook’s newest feature, Facebook live, is currently the “epitome of the algorithm.” They capitalized on the signal-boosting potential of this tool, turning the controls of their Facebook page over to contributors who fielded live questions from The Mighty’s followers. However, while The Mighty’s use of multiple, interlinked social media accounts enhanced its ability to signal boost, staff members described the frustrating challenge of being unable to reliably predict if a story would achieve widespread reach.

The Mighty’s non-profit partnership program emerged in part as a strategy to stabilize unpredictable social media traffic, and as a tool for engaging in an additional form of signal-boosting. This program acts as an important stitching mechanism for The Mighty, providing the site with a source of “constant exposure to new audiences.” Rafael explained the signal-boosting potential of the partnership program in this way:

We’ll post something on our main page . . . Sometimes it’s like, “Oh this is doing really well, let’s get 10 more partners to share it [on Facebook].” And so they get their audience engaged, and they’re all sending traffic to our site. So literally Facebook is used as just a way to find people that care about the stories and get them to the site to read it.

While this program clearly enhanced The Mighty’s reach, it also benefitted its non-profit partners. Indeed, The Mighty’s Director of Community Partnerships envisioned the partnership program as a stitching mechanism that linked the two components of “the
world of health”: (1) the “on-the-ground” world of non-profits designed “to fund research, to create meetup groups, to disseminate resources” and (2) the “human health resource world” of The Mighty, designed to offer “resources for sharing, resources for expression, resources for a feeling of connection.” Through this stitching mechanism, The Mighty could leverage its growing influence to support the more focused, tangible outcomes pursued by non-profit organizations. Engaging in second-tier advocacy, then, meant providing signal-boosting tools to non-profit partners. Hoyt described using his expertise to consult with non-profits about how they might maximize their own use of social media. He also outlined his vision for improving The Mighty’s digital infrastructure in ways that would help non-profits to “get their resources out there”:

I want to move the resource box up into the middle of the story so that more people can see it. I want to build out the ability for partners to publish directly to The Mighty so that they can harness followers that they now have or they can have on The Mighty to communicate directly. I want to give them a calendar. I want to make it very easy to fundraise for partners through individual month campaigns.

Digital support for non-profits complemented staff members’ desire for The Mighty to increases its presence offline, participating in events like conferences and 5k fundraisers. These activities provide a means to avoid enacting a second, tongue-in-cheek definition of “signal boost” offered by Urbandictionary.com: “Spreading the word, or ‘raising awareness’ of an issue without actually doing anything useful (like, say, donating money).” One editor directly expressed their concern about becoming/remaining a “slackivist” signal- booster, saying:

I do think that it’s important that we acknowledge the limitations of storytelling. . . . I think that we can take advantage of our platform to hopefully actually help people in a meaningful way. . . . Every community has their specific troubles and
issues that a story won’t fix. So I think it’s really cool, I’m really glad we have a non-profit program.

However, while stories do have limitations in that they cannot directly provide resources or change policies, editors did talk about how publishing an article can act as a signal boost in the sense of the third definition offered by Urbandictionary.com: “A communique intended to spread awareness of an issue, typically through mass media such as amateur radio or the Internet.” In this case, good storytelling is signal-boosting. For example, editors wrote breaking news stories about hashtags trending in their various sub-communities, boosting the impact of these hashtags by bringing them to their readership’s attention. For example, Kathleen described an incident that occurred when the representatives from the American Foundation for Suicide Prevention attempted to raise awareness of their cause by standing in the crowd outside of Good Morning America’s studio, sporting t-shirts that read “Be the Voice #StopSuicide.” “The cameraman, or somebody there, told them that they had to move to be off-camera, because ‘they didn't want suicide on the brain at the top of a morning show,’” Kathleen told me. “That was the phrasing. It was really callous. And the president or vice president of the association wrote a response to it and gave it to us. And so, we blasted it . . . No one would have known about it, otherwise.” The resultant story received 34,000 shares via The Mighty’s social media channels. A follow-up article, written by the non-profit’s Communications Coordinator, described how the organization was using #SuicideOnTheBrain to generate conversations around this taboo topic.

Similarly, Anna recounted her work with researchers who were trying to get people to donate their social media data, or social media data from a deceased loved one,
to support suicide prevention research. The researchers had struggled to promote their initiative. As Anna explained, “their brains are very technical and they would have maybe a harder time parsing out what information’s important for the public to know.” Using her journalistic training, Anna wrote an article that captured the essence of the scientists’ initiative, boosting the number of donations they received. In this case, Anna enacted second-tier advocacy by writing a story on others’ behalf. However, editors also enacted second-tier advocacy by mentoring their contributors to tell shareable stories.

**Editing as second-tier advocacy.** “This is my strength. I know how to get people to read your story. You write the piece and I will help you get this out in a big way.” This assertion from *The Mighty*’s editor-in-chief highlights the way in which editing itself can act as a form of second-tier advocacy. Rafael elaborated on this idea, describing the “service” that *The Mighty* provides its contributors:

> There are great writers out there, but there are also people that aren’t fantastic writers who have a story to tell, and our editors can help you tell that story. I think that service that we provide people is unique, and you don’t get that . . . posting something on . . . your own Wordpress blog.

*The Mighty* staff members used their editorial expertise to support contributors in two ways: (a) packaging shareable stories and (b) mentoring aspiring storytellers.

**Packaging shareable stories.** Packaging shareable stories involved working with writers to provide them with “a good headline and a good photo, to make sure that it’s as successful as it can be in drawing people into it.” While contributors could suggest a headline for their story, editors noted that they often had little sense of how to maximize search engine optimization (SEO) or pique reader interest. Kathleen recounted the conversation she has with writers, “I need to get people to click into your story and read
Editors enacted second-tier advocacy by (re)packaging stories with click-generating headlines, replacing generic titles like “Before You Lose Hope, Read This,” with tailored versions such as “When a Therapist Threw out Her Lunch to Help Me in My Lowest Moment.”

While the above example captures the retrospective process of repacking stories to make them more shareable, editors also used prompts to encourage contributors to write in a shareable structure to begin with. Editors created prompts based on imagined headlines that they believed would be particularly interesting to their audience. As *The Mighty’s* editor-in-chief explained, prompts accomplished two things: “[They] answer questions we see pop up, but they also phrase them in ways that I know I could get people into. It’s a combination of a need and also this editorial insight.” Staff members developed prompts based on popular topics they observed in sub-community conversations, newsworthy or seasonal events (such as the launch of the disability-related television show, *Speechless*, and subjects or demographic categories that remained underrepresented on the site. They disseminated these prompts in several ways: (a) by posting monthly writing prompts on the site’s submissions page, (b) by including prompts at the bottom of related articles, and (c) by sending daily writing challenges to those registered in the Mighty Voices contributor portal.

Mark emphasized that, while these prompts encourage writers to develop shareable stories with a *Mighty* tone, they don’t necessarily impose a “cookie-cutter system.” He asserted that while several contributors might respond to the prompt,
“Here’s a letter to my younger self,” each of those letters are going to be different in their own way, too. So there’s this construction they can work in, but they can tell their story.” His comment invokes the Bakhtinian (1981) interplay of structure and creativity—the productive dialectal tension between the centripetal force of genre, a “horizon of expectations brought to bear on a certain class of texts” (Bakhtin, 1981, p. 428) and the centrifugal force of heteroglossia, or the quality of being multi-voiced and multi-languaged. Contributors are expected to write within the journalist genre of a “shareable” story, conforming to a unitary system of language—an ideological sense of how stories of embodied difference should be told—implied in the Mighty tone. Yet, while editors conceived of prompts as a disciplining tool, reflected in the editorial board’s recognition that “we need to steer them in a direction,” they also recognized their potential as a generative force—a way to communicate, “If you’ve never done this before, start here.” In some cases, editors broke the “rules” of the story genre to acknowledge the especially compelling nature of a writer’s words. Anna explained:

The idea really trumps the writing. I think there are a few times when the piece was so beautiful, that even though I could see that it would be maybe hard for me to frame, I would just take it, because I would be like, “This piece is so beautiful, I want it to be on The Mighty.”

This tension between constructing shareable, Mighty stories and validating writers’ unique styles and perspectives was particularly apparent in staff members’ discussions of their editing process.

Mentoring aspiring storytellers. The Mighty’s editorial staff emphasized that editing contributors’ stories was necessarily a much different process than editing a story written by a professional freelance writer. They acknowledge that many of their
contributors were not professional writers, and that submitting a story was an inherently personal and vulnerable process. For this reason, they rejected the image of being the “evil editor who just wants to take all the spirit out of your story.” Instead, they framed themselves as “a mentor and a coach” responsible for “polishing” stories and providing “gentle nudges” and encouragement. They expressed a sense of obligation to contributors. “Contributors are never just contributors,” Rachel emphasized. “We want to make sure that they feel they’re getting something back, they’re really benefiting from contributing these stories.” Anna explained that “ultimately, at the end of the day, it’s important for them to know how valued they are. And so, it’s my goal and I think, the company’s goal, just to make sure that they know that.”

Mentoring aspiring storytellers often involved identifying the “heart of the story,” the interesting “kernel,” or the “one thing that really sticks out” and trying to “edit around it.” In some instances, editors were moved to provide additional guidance to a writer who had “a really strong voice,” but was “right in between a ‘no’ and immediate ‘yes.’” They mentored these writers by pitching headlines for an altered version of their story, or by asking follow-up questions like “Do you have advice for anyone else with a similar experience?” and “What’s something you wish other people understood?” Mark told me several stories of times when he reached out to contributors by phone to offer encouragement and guidance. For example, he recalled mentoring a young woman who had been diagnosed with thyroid cancer and who submitted a very technical description of various treatment options. He called her and gave her this advice:

I think you’re a really strong writer, I can really tell this, but your particular story works really well for an audience that just understands thyroid cancer. . . . But
since *The Mighty* has a very large audience, you have a chance to be talking this to an even larger audience. . . . Just pretend you’re doing a TED talk and you’re talking in front of a bunch of people.

This kind of feedback validates the writer’s efforts, while also challenging them to write with *The Mighty’s* audience in mind. Through mentorship, contributors began to internalize the qualities of a shareable story and the *Mighty* tone. For example, Mark observed that, after successfully publishing several articles with *The Mighty*, the contributor he had mentored “circled back to the original story . . . [and] understood, ‘Okay, I’m going to sort of take that first idea I had and make it more of a Mighty story.’”

However, this process of mentoring aspiring storytellers did not always go smoothly, particularly when contributors felt that the editorial process had stripped their story of its authentic soul. Rachel narrated an editorial experience that highlighted the necessarily collaborative nature of mentorship:

> I pretty much butchered [the story] on the first try . . . And working with [the contributor] we were able to get it to a point where it’s like, “This is actually my point, this is actually my story.” And that’s one example that I’ll never forget because I realized first and foremost I never want a contributor to feel that way again—that their message, their actual voice is not coming across. . . . Also, just realizing the positives of having a very open and honest dialogue. . . . That was really huge to me because it helped me understand so much about what our role is and how we can work.

Collaborating in the dialogic way that Rachel described requires that editors understand each writers’ place along the “spectrum of contributors,” differentiating between “serious” contributors who prefer to be consulted throughout the editing process, and “people who will write a blob of a paragraph and be like ‘I don’t care what you do to this, just make it good.’” It also required that editors ultimately concede to contributors’
preferences—even when these concessions made the story less technically polished or less likely to generate traffic.

Relatedly, mentoring aspiring storytellers also involved cultivating and retaining contributors’ trust, allaying concerns that their story would be mangled. To that end, *Mighty* staff members described developing very personal connections with their writers. This sense of being personally connected to contributors often arose naturally from the fact that editors’ work required learning about contributors’ personal details and following them on various social media platforms. Some editors described engaging in reciprocal self-disclosure, revealing aspects of their personal experiences with disability and chronic illness. “I want them to know that I get it,” Anna explained, “I’m not judging you, I really understand what’s going on in your head. I also think that I get a little benefit from it too because then I can . . . give a little bit of myself.” Staff members frequently described this opportunity to create relationships with contributors as one of the most meaningful aspects of their jobs. For instance, Charlie described his experiences with preparing contributors to host a Facebook live session:

It’s like dating, but I’m starting my first date on the 25th date, where you tell me your deep dark secrets. . . And I just get to listen to their stories. . . . I’m not a therapist. But I feel like I’m just being their friend. . . . I’ll have to add them on Facebook and then I’ll see them post a status like, “I just had the best call with this guy named Charlie from *The Mighty* and he wants me to go live, can you guys believe it? This is the best thing that’s ever happened to me.” And I get to see that, and I feel like I just gave out Disneyland tickets.

As this quote from Charlie implies, *Mighty* staff members viewed mentorship as a mutually-validating experience. For instance, Mark described the “extremely gratifying moment” of reading a contributor’s elated response to being published, articulating the
“kick” he got out emailing: “I just want to be the first person to tell you—you’re a writer.” Indeed, several of the contributors I interviewed described the editors as “warm,” “nurturing,” and “reinforcing,” and reported receiving personalized feedback like, “your writing is really brave, we love your story, [and] we’re really happy that you’re sharing your story” (Marielle). Amy noted that one editor even attended a performance of her one-woman, autobiographical play.

While cultivating this sense of personal connection was a key aspect of doing good for the community, it was also an important aspect of doing well for the company. These connections enhanced The Mighty’s ability to develop and maintain an active contributor network, distinguishing its brand from potential competitors. The editor-in-chief emphasized the strategic value of encouraging contributors’ identification with The Mighty, explaining:

That’s going to be our next big challenge, is how do we make sure people are enjoying their experience and coming back, and they want to write more. Because it’s true—they have a million places they could publish. So it becomes, “Why are they publishing here?” We think we offer them the community, but on our own end, we want to make sure that they enjoy working with us, and that they don’t feel like a statistic . . . We just want to maintain that human-to-human connection here.

Her comments highlight the sense of organizing as a continuous process of evolution, while also emphasizing contributors’ collective agency in re-structuring The Mighty. I draw on concepts from structuration theory and theorizing about hybrid organizational forms to explore both of these ideas in the following discussion.
Summary and Discussion

In summary, the foregoing chapter explored the communicative practices that (re)constitute *The Mighty* as an organization, highlighting organizing as the communicative process through which organizational members produce, identify, and respond to contradictions, paradoxes, and dialectical tensions. I have described how Mike Porath transformed his personal narrative as a parent seeking sensemaking resources in the wake of his daughter’s rare diagnosis into an organizational narrative (Mumby, 1987). In doing so, he engaged in the communicative practice of collective action, defined by Flanagin et al. (2006) as “efforts by people to cross boundaries by expressing or acting on an individual (i.e., private) interest in a way that is observable to others (i.e., public)” (p. 32). The resulting collective action organization arose as new staff members were recruited and socialized via their identification with *The Mighty’s* “mission-driven work,” aligning their personal desires to “help” people with disabilities and chronic conditions in ways that coordinate their activities (McPhee & Zaug, 2009). In the process of talking with each other about what it means to “help,” and what *The Mighty’s* capacity to “help,” might be, staff members (re)conceptualized the purpose(s) of the site. They envisioned it alternatively as a tool for crowdsourcing both medical information and “human” knowledge, as a community built from stories’ affective capacity to foster collective identification, and/or as a platform meant to center marginalized stories and support social change.

As staff members prioritized and pursued each of these purposes differently over time, they engaged in the process of structuration. As Giddens (1979) explained, “to
study the structuration of a social system is to study the ways in which that system, via
the application of generative rules and resources, and in the context of unintended
outcomes, is produced and reproduced in interaction” (p. 66). Rules (shared knowledge
that produces and reproduces practices) and resources (vehicles of power, enabling actors
to achieve their will) constitute structures that constrain and enable action (Giddens,
1979). For example, *The Mighty’s* staff members abided by editorial guidelines that
shaped both their use of different condition-related terms and phrases, their sense of what
constitutes a *Mighty* tone, and their decisions to accept or reject a particular story.
Similarly, *Mighty Staff* members developed writing prompts designed to elicit stories that
addressed desirable topics and took sharable forms. Essentially, they asked writers to
conform to a *Mighty* genre—formulae that bind creativity to structure (Bakhtin, 1981).
*Mighty* guidelines and *Mighty* prompts represent “structures of signification,” defined as
“organizational rules that inform and define interaction” (Orlikowski, 1992, p. 404). In
addition, these examples illustrate the duality of structure and agency inherent to
structuration (Giddens, 1979). As contributors and readers comment on articles and
 correspond with editors to assert their preferences for various terms and phrases, or to
push back against edits made in the interest of creating “shareable stories,” *Mighty*
community members exercised their individual and collective agency to alter the site’s
editorial guidelines. Hence, as the editor-in-chief explained, the site’s guidelines evolved
in response to a “fluid conversation” with each other, with readers, with contributors, and
with healthcare and other professionals. Similarly, in the process of interacting with *The*
Mighty’s story prompts, contributors either reproduced or altered topical and formal rules regarding what “fits” the Mighty story genre.

However, each of the social actors who participate in structurating The Mighty (readers, contributors, staff members, non-profit partners, advertising partners, etc.) has asymmetrical access to power, defined as the capacity for human action to “transform the social and material world” (Orlikowski, 1992, p. 405). For example, as the site’s ultimate architects, The Mighty staff members communicatively constitute organizational structures of domination, defined as the tools used to exercise power (Giddens, 1979). They serve as the gatekeepers who determine who can access the discursive resources afforded by the site. Staff members’ abilities to edit or reject stories serve as normative sanctions that penalize social actors for non-compliance with established rules (as in editorial guidelines) (Giddens, 1979). Alternatively, their abilities to publish and signal-boost stories, and to provide additional visibility to non-profit partners, represent staff members’ ability to constitute structures of legitimation, i.e. their capacity to validate particularly narratives of disability and chronic illness and the discourses of difference they invoke. In doing so, The Mighty generates the transformative power to shape the publishing industry as a whole—an institution constituted by “practices which are deeply sedimented in time-space: that is, which are enduring and inclusive ‘laterally’ in the sense that they are widespread among the members of a community or society” (Giddens, 1979, p. 80). Thus, acting as a second-tier advocate, The Mighty can reproduce or challenge sedimented norms of disability (mis)representation.
Similarly, structuration occurred as *Mighty* staff members and “users” interacted with, and altered, the site’s digital features. Indeed, Orlikowski’s (1992) structurational model of technology and DeSanctis and Poole’s (1994) adaptive structuration theory consider how Giddens’ ideas about the duality of structure and agency apply to organizations’ use of technology. Orlikowski (1992) proposed that technology is physically designed and socially constructed by users, at the same time the human actors reify and institutionalize technology via their habitual use of its features. In describing this “duality of technology,” she described the interplay of two iterative modes: design mode, where designers create new technological features; and use mode, where human agents (re)produce or alter a technology’s intended function through the ways in which they “interpret, appropriate, and manipulate it” (p. 408). In the case of *The Mighty*, staff members designed new features such as the personalized newsfeed, follow button, and hub pages. They changed the site’s digital infrastructure in an attempt to customize users’ experiences, cultivate a more participatory community, track registered users’ data, and encourage the kind prolonged site visit attractive to advertisers. These technology changes became objectified when they were consistently, habitually used by *Mighty* contributors. However, these features also evolved as *Mighty* staff members collected and acted on data regarding the ways in which users interacted with the site. For example, new followable topic and hub pages emerged and disappeared according to whether or not the content associated with them generated a significant uptick in page views.

Gidden’s (1979) suggests that the impetus for the kind of incremental, evolutionary change produced via structuration is the presence of contradiction(s). He
defines a social contradiction as “an opposition or disjunction of structural principles of social systems, where those principles operate in terms of each other but at the same time contravene one another” [emphasis in the original]” (Giddens, 1979, p. 141). This definition suggests that paradoxes and dialectical tensions are inherent to Ashcraft’s (2006) definition of hybrid forms. The Mighty provides a useful case study for exploring the phenomena of hybrid forms, created by and in response to the contradictory structural principles that exist on the site. Most clearly, The Mighty exemplifies the hybrid nature of social entrepreneurship; a contradictory union of the structural principles inherent to capitalism and philanthropy. Consequently, Mighty staff members respond to dialectical tensions linked to the need to do well as a company while doing good as a second-tier advocate. Their most effective response involves communicating to reframe this contradiction, emphasizing the ways in which doing well as a company enhances The Mighty’s ability to do good for/with the community.

In addition, The Mighty represents a hybrid form in that it is a cross-condition platform. As such, its staff members contend with the contradictory nature of being a collectivity of specificities, organizing around the need to highlight broad shared experiences while also showcasing the particularities of individual conditions. They responded by engaging in the organizational equivalent of what Baxter and Montgomery (1996) termed “spiraling inversion,” shifting back-and-forth between universality and specificity in their editorial practices. They also developed digital features that would allow users to navigate between these dialectical poles as desired. However, The Mighty’s hybrid status as a cross-condition platform also implicated two additional social systems:
the biomedical and social models of disability. As the previous analysis chapters have illustrated, Mighty contributors’ stories reflected discourses drawn from each of these models, abiding by alternative sets of narrative rules to (re)produce contradictory accounts of embodied difference. Similarly, parent and self-advocate contributors crafted stories using different criteria regarding what representations of disability are (in)appropriate and (dis)empowering. I will explore the resulting tensions of allyship and appropriation in the following chapter.

Finally, The Mighty represents a hybrid form in that it is an organizationally-enabled network. The Mighty is both a typical media publishing company and an aspiring social media platform. As such, it melds the contradictory structural principles of collective action (Flanagin et al., 2006), where members have relatively specific roles and activities are purposefully coordinated, and connective action (Bennett & Segerberg, 2013), where individuals engage in the idiosyncratic activities of peer production and self-motivated sharing. Mighty staff members grappled with the resulting tensions of inclusivity and selectivity. In communicating about this tension, staff members emphasized the dialogic potentials of inclusivity and a journalistic preference for neutrality, but also emphasized the moral imperative to construct and protect “safe spaces.” Ultimately, they adopted a policy of inclusive selectivity—seeking to gather multiple perspectives and secure missing narrative, while also filtering these stories to adjust potentially problematic language or unconstructive narratives. At the same time, editors recognized the site’s self-structuring nature—The Mighty tended to elicit stories from contributors who identified with the kinds of topics already present on the site, and
who emulated the *Mighty* tone apparent in existing stories and in story prompts. Thus, the site’s commitment to inclusivity was partially limited by the tendency for writers with very different, or more radical, perspectives to avoid submitting to *The Mighty*.

Clearly, *The Mighty* captures the confluence of multiple contradictory structural principles. Its staff members contended with contradiction via the process of structuration, organizing dissonance by (re)creating hybrid organizational forms and by (re)framing dialectical tensions through their communication. However, as Giddens (1979) contended, “the more there is a fusion, or ‘overlap’ of contradictions, the greater the likelihood of conflict, and the greater the likelihood that such conflict will be intense” (p. 145). In the following chapter, I explore how the various tensions present on the site intersected to produce one explosive instance of conflict: #crippingthemighty.
Chapter 7: #CripplingtheMighty: Resisting Exploitation, Appropriation, and Censorship

The previous chapters highlighted the potentially positive impact that *The Mighty* might have; the site facilitates contributors’ engagement with the therapeutic practice of writing their story, encourages identification with narrow and broad biosocial communities, enables contributors to engage in forms of advocacy and activism, connects readers to crowd-sourced information and “human knowledge,” and signal-boosts self-advocates’ voices in ways that may alter simplistic or ableist cultural narratives about what it means to be disabled or to experience chronic illness. However, *The Mighty’s* ability to act as an empowering second-tier advocate is constrained both by its for-profit structure and its aspiration to connect with such a wide array of sub-communities—including parents. The hashtag, #crippingthemighty, emerged as means by which disability activists could critique *The Mighty’s* status as a helpful resource for the disability community. In the following chapter, I explore the criticisms levied by both ambivalent contributors and fully-fledged opponents who participated in #crippingthemighty. Additionally, I consider how #crippingthemighty has functioned as an exemplar of cyberactivism, and how this incident shifted the company’s organizational and editorial practices.

From Ambivalence to Repulsion: Disidentifying with *The Mighty*

While *The Mighty* has certainly cultivated a large following of enthusiastic contributors and readers, it has also inspired considerable ambivalence in some of its more critically-minded, politicized community members. Ambivalence is defined as a
form of problematic integration that individuals experience when they are confronted with similarly-valued, yet mutually exclusive, alternatives (Babrow, 1992). In the case of *The Mighty*, contributors and readers reported the confusing experience of finding articles that resonated with their viewpoints mixed in among articles that Meriah Nichols (2016) described as “disability on click-bait” (para. 17) and sentimental “sop” (para. 20). These individuals experienced ambivalence in that they wanted to remain engaged with *The Mighty* because of its potential to circulate empowering stories, but also wanted to denounce *The Mighty* as the “viral-nova BuzzFeed of someone’s idea of disability” (Nichols, 2016, para. 17).

Contributors described how their initial excitement about *The Mighty*’s potential as a positive platform for people with disabilities turned toward ambivalence over time as they continued to encounter “icky” stories. Some decided to partner with *The Mighty* despite their ambivalence. “Why would I write for a site that I don’t fully agree with in parts?” Carly Findlay (2015) wrote, “Because I wanted to help change the narrative. I wanted to add to disabled voice, which I believe *The Mighty* has but lacks” (para. 8). Essentially, contributors like Findlay were motivated by the belief that they might shift the site in the direction they hoped for, ultimately resolving their experience of ambivalence. Additionally, such contributors were motivated by the pragmatic realization that they had few similar alternatives; as a commenter on Findlay’s blog post observed, “*The Mighty* is servicing the community when no one else is even trying. While they publish a LOT of clickbait they are also raising awareness.” Finally, contributors like Mandy and Adelle continued to partner with *The Mighty* because they felt a sense of
“loyalty” to and “gratitude” for *The Mighty* because writing for the site had connected them with additional advocacy and writing opportunities.

In contrast, ambivalent contributors (and readers) sometimes experienced “last straw,” critical incidents that strengthened their negative evaluation of the site, causing them to shift from feeling ambivalent to experiencing clear-cut repulsion. Essentially, the site’s detractors resolved problematic integration by disidentifying with *The Mighty*. Elsbach and Bhattacharya (2001) define organizational disidentification as “a self-perception based on (1) a cognitive separation between one’s identity and one’s perception of the identity of an organization, and (2) a negative relational categorization of oneself and the organization” (p. 397). The *Mighty’s* detractors associated the organization with values and practices they rejected—namely, the devaluation and marginalization of people with disabilities—and in turn rejected the organization itself. Kathleen Downes’ (2016) experience exemplifies this process of disidentification. She wrote about her response to reading a *Mighty* post entitled, “The Moment You Think Your Child’s a Burden”: “It was that article that cemented my decision to remove my writing from *The Mighty*, as it no longer represents a community I can be part of as an activist or a human being” (para. 4).

For many contributors and readers, the article, “Introducing: Meltdown Bingo,” was the critical incident that cemented their decision to disidentify with, and withdraw from, *The Mighty*. To recap, this article was written by a mother (also on the autism spectrum) who transformed aspects of her son’s meltdown experience into categories on a Bingo-style card. Multiple bloggers wrote to protest the article, outraged by its very
public, seemingly flippant treatment of a private, vulnerable, and terrifying autistic experience. As they broadcast their assessments via their own blogs and via Alice Wong’s hashtag, #crippingthemighty, disability activists elevated this article so that it became a collective critical incident. Essentially, they generated a ripple of repulsion. People who responded to activists’ Facebook posts and blog posts wrote responses such as, “I’ve had a bitter taste about The Mighty for a while now and unfollowed them a couple of months ago. Couldn’t quite figure out why at the time, but you’ve put into words what I had trouble processing” (comment on Findlay, 2016). As contributors and readers engaged in organizational disidentification, they communicated in ways that emphasized what they perceived as The Mighty’s inappropriate handling of tensions tied to (a) doing good and doing well, (a) inclusivity and selectivity, and (c) universality and specificity.

**Tensions of Doing Good and Doing Well**

In the previous chapter, I described the ways in which Mighty staff members attempted to manage tensions linked to the desire to do good for the community while doing well as a company. Staff members sometimes prioritized doing good over doing well, and sometimes spoke about how doing well would allow them to do good on a broader scale. However, #crippingthemighty participants argued that the company’s organizers cared more about generating profits than about being a positive force for social change. “Their nature is to make money,” Meriah Nichols emphasized in our interview. “I mean, they talk about community and so forth, but it is a business. They exist to make money.” The site’s detractors supported this view of The Mighty’s purpose.
by raising (a) issues of signal-boosting and exposure dollars, (b) issues of power and platforms, and (c) issues of Big Data and Big Pharma.

Issues of signal-boosting and “exposure dollars”: (De)valuing disabled labor.

As I have noted in previous descriptions of The Mighty, the organization’s Terms and Conditions page frames the site as a “photo and video hosting/blogging service” (The Mighty, 2016, para. 3). This language suggests that The Mighty functions in much the same way as blog-hosting platforms like WordPress, Blogger, and Medium; it provides a digital infrastructure through which users can connect with both members of their own biosocial community and with a broader, non-disabled audience. Framing the site in this way ostensibly justifies The Mighty’s decision to pay contributors, as one Facebook commenter quipped, “only in exposure dollars.” The Mighty uses its signal-boosting power to connect contributors’ stories to ever larger audiences, enhancing the reach of their messages. Indeed, as described in the previous chapter, Mighty contributors frequently used the site as a tool for publicizing their own work (e.g., books, speaking tours, non-profit initiatives, disability-related products and businesses, budding hashtag movements, etc.) and to drive traffic to their personal blogs. Thus, The Mighty’s staff members continually implemented new strategies (such as developing non-profit partnerships) that maximized their signal-boosting capabilities to better serve their contributors/readers—and to boost the organization’s profit-making potential.

However, #crippingthemighty protestors (and some Mighty contributors), criticized The Mighty’s policy of not paying writers while profiting from their labor. Milder criticisms focused on questioning both the value of “exposure dollars” and The
Mighty’s ability to provide exposure. For instance, DG explained that she only published one article on The Mighty because “as an aspiring professional writer, I really can’t afford to publish a lot of things for free. I don’t need to set myself up to ‘die of exposure.’” Her comments highlight the idea that “exposure dollars” provide diminishing returns to contributors; too much exposure poisons a contributor’s ability to profit from their own labor potentially reducing readers’ need to pay for access to similar content elsewhere. Thus, the decision not to pay contributors makes it more difficult for Mighty editors to recruit and retain “aspiring professional writer[s].” While amateur writers certainly have important insights and experiences to share, relying on their contributions may (a) create additional editorial work for The Mighty staff and (b) mean that the site’s content may not reflect the well-informed, critical voices characteristic of professional writers/advocates/activists who are immersed in disability culture—the kinds of voices capable of identifying and critiquing deep-rooted ableist assumptions.

Additionally, contributors spoke about having limited ability to “tally” their exposure dollars—the ability to determine who viewed their story. The Mighty’s site tracks “likes” and “shares” via social media platforms like Facebook, Twitter, and Pinterest. However, James recommended that organizers develop additional methods to help contributors track their articles’ spread. “Oftentimes as a writer, you don’t know where [your articles] are ending up,” he explained. “I actually had my wife say that a friend of hers told her that they read one of my articles on Yahoo parenting, and I didn’t even know it was on Yahoo.”
Finally, contributors questioned the extent to which *The Mighty* fulfilled its promise of boosted exposure. They noted that certain aspects of the site’s structure rendered their articles less visible. For example, Adelle criticized *The Mighty*’s tendency to churn out massive amounts of content, explaining, “writers get lost in the shuffle, too, because the article doesn’t even have time to really be passed through. . . . [articles are published one] right after another, and there’s no time to survey and digest.” Essentially, by adhering to a fast-paced publishing schedule, *The Mighty* creates exposure for itself as the go-to source for chronic illness, disability, and mental health-related stories. However, it simultaneously undercuts an individual story’s potential to gain traction in an information-saturated digital environment.

This issue was compounded by what contributors and #crippingthemighty critics perceived to be uneven coverage of various conditions. #crippingthemighty activist, Carly Findlay, reported that she and other (former) contributors recognized this issue, sharing, “one writer has told me . . . she thinks autism and Down syndrome gets too much coverage and rare conditions should get more. There is a definite sense of hierarchy in the writers [sic] community” (para. 40). Mandy, a prolific contributor who still writes periodically for the site, felt disappointed that her stories about disability self-advocacy received little publicity. “Some of my pieces haven’t got any views at all,” she explained. “They don’t post them on Facebook usually. But they are really selective of what they post. Their focus is mostly when autistic meltdowns happen or autism and parent blogging.”
Certainly, these priorities are reflected in the way The Mighty’s home page is structured. “Autism” has its own tab at the top of the site’s homepage, while all other conditions can be found under three broad labels: “Mental Illness,” “Chronic Illness,” and “Rare Disease.” Similarly, the “Latest Stories by Topic” feature at the bottom of The Mighty’s homepage only aggregates recent stories in the “News,” “Parenting,” “Anxiety,” and “Depression” categories. While The Mighty has created Facebook groups for several of its sub-communities, only a handful are advertised under the “Join Our Facebook Communities” section of the site’s home page. The Disability on The Mighty Facebook page was notably absent at the time that this project was completed, although this page is followed by nearly 23,000 people. Indeed, the Disability on The Mighty Facebook page is one of the most recent ones created by The Mighty’s staff members; it was first launched in May of 2016—approximately two years after the company was founded. Certainly, these site features appear to communicate the kind of “hierarchy” that Carly Findlay and others described. It also suggests that The Mighty’s organizers have only recently begun to recognize and treat disability as a distinct sub-community, underscoring #crippingthemighty protestors’ arguments that the site cannot claim to be authentically centered around disabled perspectives and disability culture.

Several of the contributors I interviewed spoke about how uneven coverage not only detracted from their ability to gain exposure, but also communicated a “disability

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30 It is important to note that the site’s structure is constantly changing. For instance, previous versions of the site featured “Down Syndrome” and “Epilepsy” main categories, and did not include “Disability” as a category at all. Some of the observations described above may be artifacts from earlier versions of The Mighty, communicating a set of priorities that may not be in keeping with the staff members’ current vision.
hierarchy” in the sense that some kinds of stories appeared to be less valuable than others. As Rose explained, “people with the lesser-known conditions almost feel like, ‘Well, they have no interest. It’s on here, but there’s no interest in it at all.’ Why do you even want to be any part of it?” Such observations reflect tensions of doing good versus doing well that staff members were quite aware of; they struggled to balance a desire to properly showcase stories about all conditions with the pragmatic realization that stories about more common conditions appeal to larger audiences and are more likely to generate site traffic.

These milder critiques of The Mighty focus on whether or not the site really delivers on its promise to expose contributors’ work to a broader audience via its signal-boosting capabilities. However, more jaded contributors and #crippingthemighty protestors characterized the promise of “exposure” as a thinly-veiled excuse to exploit writers. For instance, when I asked Annette about what she thought the purpose of The Mighty was, she replied, “Initially, I thought it was to share information. However, [I] am rather more cynical now, it feels a little like someone is feeding off other people’s difficulties to produce a popular website. It feels slightly predatory.” Detractors acknowledged that issues of fair compensation are rampant in the digital publishing industry in general, where outlets frequently publish content written by unpaid or underpaid bloggers and freelance writers. However, issues of compensation and exploitation become even more complex in the context of disability, where “unemployment is high, and opportunities can be low due to low expectations of people with disabilities. [And] parents who care for their disabled or chronically ill children may
not be able to work” (Findlay, 2015, para. 30). Further, as Dani Alexis Ryskamp noted, disabled writers confront “the additional hurdle of accepting payments in the face of draconian benefits rules” (quoted in Wong, 2016, para. 19)—a hurdle that complicates a publishing company’s ability to offer even part-time compensation. Thus, the decision not to pay Mighty contributors participates in larger economic disparities impacting the disability community. Further, this decision appears to legitimize ableist perceptions that disabled labor is less worthy of monetary compensation. As Ryskamp wrote, disabled writers “are routinely told that their writing on disability is less valuable *because* it is from a disabled person on a topic ‘no one cares about’” (quoted in Wong, 2016, para. 19). Acknowledging these structural and discursive inequities, Ryskamp’s advice to other disabled writers re-conceptualized “exposure” to undercut its seductive power:

If an outlet is offering you “exposure,” walk away. Any outlet that can give you enough exposure to boost your career is well-known enough to pay you. Any outlet that cannot afford to pay you is not well-known enough to give you meaningful exposure. “Exposure” is not what *they* give *you.* It’s what *you* give *them* by consenting to have your work appear in their publication. (quoted in Wong, 2016, para. 28)

Her comments restore power to individual writers, suggesting that “exposure” is a consequence of good content. However, individuals’ power to generate and share quality content competes with the power that platforms, like *The Mighty*, have to structure and colonize digital spaces.

**Issues of power and platforms: (Infra)structuring and colonizing digital spaces.** Mike Porath and his staff envisioned their organization’s potential to become the biggest platform in “digital health,” asking questions like, “how do we scale this thing into a platform that helps far more people?” (Porath, 2016, para. 25). This question
frames “scale” in a way that equates doing well as a company with doing good for the community. As Porath explained, scale is not about “attracting the most number of eyeballs. Viral stories are a bonus, not a business model. For us, scale is about making The Mighty more valuable to more people by helping patients, doctors, caretakers and more share their experiences” (para. 26). Additionally, Porath linked achieving scale with the process of building an increasingly interactive, networkable digital infrastructure. He wrote:

The foundation for scaling The Mighty is the technology we’re developing. We’re making it easier to submit and publish stories, easier to discover and promote them, easier to share experiences in different formats (especially video), easier to connect with others, and we’re analyzing the data behind all of this to drive performance. (para. 27)

While The Mighty’s supporters similarly viewed scaling as providing increased power to build communities and to re-shape discourses of difference, detractors framed scaling as a threat to grassroots organizing and authentic disabled voices. They recognized that existing disabled bloggers had limited ability to scale, creating what Alice Wong referred to as “inequity in terms of access and representation.” Indeed, Andrew Pulrang (2016) wrote about how the explosive uptake of #crippingthemighty was in part fueled by a kind of “jealousy,” explaining,

The Mighty has millions of dollars and apparently high-profile supporters to catapult it to prominence and social media saturation. Meanwhile, we disability bloggers grind away at our blogs and hope for a few modest paying gigs, while writing about disability in ways we honestly think are better for the disability community. Jealousy isn’t an admirable emotion, but sometimes it’s understandable. Someone had exactly the kind of opportunity all of us dream of . . . to establish a widely-read disability-based website that’s a force not just for good, but for progress . . . and instead they gave us slicked-up versions of the same old stories we’ve seen for decades. (para. 13)
Relatedly, Meriah Nichols spoke about various challenges that had derailed her efforts to create her own digital publication. “I started up Two Thirds of the Planet with the idea that we could fill a void that we need for stories,” she explained. I would really love to develop something that goes across the disability spectrum but, practically speaking . . . it’s a tremendous amount of work. No money. A lot of people doing their own thing—like I noticed that instead of writing for Two Thirds, some people started their own thing. Which is cool, but then how is anything ever going to gain enough traction?

These comments highlight the fact that disabled bloggers are limited by both lack of resources and by the community’s tendency toward fragmentation. These factors encouraged individuals like Meriah Nichols to focus on building up their own pages to participate in “cross-disability alliance-building” via strategies like guest blogging, sharing others’ articles, cross-posting to multiple sites, and coordinating conversations and actions via Twitter hashtags (e.g., #crippingthemighty, #cripthevote, #disabledandcute, #boycottautismspeaks, #autisticwhileblack). Essentially, disability activists engage in connective action, using digital stitching mechanisms to facilitate self-motivated sharing and to connect the dispersed, idiosyncratic products of peer production (Bennett & Segerberg, 2013).

In contrast, The Mighty enjoys infrastructural advantages that allow it to engage in the more purposeful, highly coordinated communication labor of collective action, while also fostering connective action. The company’s increasingly successful scaling efforts have allowed The Mighty to structure and colonize digital spaces linked to health and disability, expanding its power to both direct attention to specific topics and frame the ways in which these topics are discussed. Alice Wong acknowledged that those who
structure organizations like *The Mighty* make “invisible decisions . . . that completely shape the way disability is perceived.” However, she noted that *The Mighty* implements a “structure that’s created by predominantly not disabled people—people with access, people with money, capital.” Indeed, David Perry (2016) cited *The Mighty*’s own description of its founding to emphasize this point:

> If you read the “why we created The Mighty” page, the editors discuss their process: Over the last several months, I’ve bought a lot of drinks and dinners for friends and colleagues. . . . These are talented people I respect and trust who do amazing work for the likes of ABC News, NBC News, The New York Times, The Huffington Post, Yahoo, Forbes, Esquire, MTV, Disney, Google and more. . . . Those are an impressive list of media companies, but notice how none of those include anyone with disabilities, any disability rights organizations, or anyone from the community they are allegedly serving. (para. 15)

Thus, in detractors’ eyes, *The Mighty* reflects an able-bodied notion of disability; “it’s built on the pain of [disabled] experiences, but seen through the eyes of others and explained through their own personal lenses” (Nichols, 2016, para. 20). Alice Wong emphasized the idea that *The Mighty*’s non-disabled leadership likely selects stories in ways that miss “the breadth and nuance of lived experience.” “For me, it’s about the whole spectrum in terms of the beautiful, the ugly, the uncomfortable stuff,” she elaborated. “I feel there’s a lot that could be lost when [the structure is] not situated or centered on actual disabled people’s lives.” Alice Wong drew on the metaphor of disability as culture to frame *The Mighty* as an example of cultural appropriation. “Think about non-Black people creating a site about the Black community,” she advised me. “How weird is that? And yet we don’t see there’s any problem about non-disabled people telling people what disability is about.” Thus, while *The Mighty*’s staff members viewed their work as second-tier advocacy through giving space, Alice Wong and other
detractors instead described the site as *taking up* space. “Most non-disabled people, when they think about disability, go visit *The Mighty,*” Alice Wong explained. “They won’t think about other online publications or other groups that are run by disabled people . . . I feel a sense of real sadness that a lot of people are going to miss out on these voices.”

Alice Wong noted that centering disabled voices by publishing pieces written by (unpaid) disabled contributors is not enough—true change involves ceding power by hiring people with disabilities to fill positions “at the very top” of the organization’s hierarchy. Such moves would place individuals in positions where they might re-shape *The Mighty’s* organizational and editorial practices to center self-advocate perspectives.

Relatedly, Perry (2016) recommended that *The Mighty* relinquish both power and profit potential by using its infrastructure to “signal boost in both directions”—promoting articles written by non-mainstream disabled writers via their personal blogs and websites, rather than exclusively promoting its own content and content published through similarly massive media companies (e.g, *Upworthy* and *Love What Matters*). Signal-boosting in both directions acknowledges the importance of *giving* space not just to those who contribute to the site, but also to those who do important advocacy/activist work in the larger disability community. These suggestions become more challenging to implement as *The Mighty* makes potentially controversial advertising-related decisions in the name of profit.

**Issues of Big Data and Big Pharma: Doing well over doing good.** As I have described in the previous chapter, *Mighty* staff members expressed ambivalence about what they perceived as the unfortunate necessity of monetizing the site via
advertisements—particularly by appealing to pharmaceutical companies and others in health- and disability-related industries. Again, they equated doing well as a company with doing good for the community, explaining that in order “to grow [The Mighty] into a global brand that empowers tens of millions of people, and to give back to our community in meaningful ways, we have to make a lot of money” (Porath, 2016, para. 29). Mike Porath also focused on the potential for advertisements to connect readers with desired resources. “Beyond advertising, brands are asking us to connect them to people who are interested in clinical trials,” he wrote. “They want to sponsor our events and invite our contributors to speak at theirs” (Porath, 2016, para. 30). These interconnections between The Mighty and pharmaceutical companies may seem attractive to individuals who embrace biomedicine and who seek treatments and cures for their physical impairments. For those who operate from a social model of disability, however, such partnerships appear to support the medicalization of different bodies, reinforcing discourses that undercut disability pride by framing disabled bodies as deviant and broken.

Partnerships with pharmaceutical companies were particularly distasteful to individuals, like Twilah Hiari, who recognized the physical dangers of relying on medication to “fix” people. Hiari had experienced physical and emotional trauma from years of being given inappropriate psychiatric drugs. She briefly joined The Mighty’s staff in hopes of transforming its chronic illness content to empower readers. However, as Hiari wrote in a blog post, she decided to resign from her job after discovering The Mighty’s advertising goals. Hiari (2017) described feeling “horrified” after learning about
this aspect of the organization’s revenue stream, relaying what she learned from *The Mighty*’s Chief Revenue Officer:

“\[If the CEO for Abilify was in the front row right now, he’d be salivating,\]” she declared. She had just explained her strategic plan for monetizing the site with pharmaceutical advertising. But the plan didn’t end there. *The Mighty* planned to give drug companies user data that would help focus the pharmaceutical manufacturer’s marketing efforts. (para. 8)

Hiari, and those who supported #crippingthemighty, interpreted this revenue-generating strategy as evidence that *The Mighty* prioritizes doing well over doing good—exploiting both unpaid contributors and uncritical readers for profit. At the same time, however, Hiari’s (2017) account reflects the sense of ambivalence generated by her recognition that *The Mighty*’s staff members are genuine people doing their best within resource-linked constraints, and that the company had significant potential to enact positive change. “\[The staff at *The Mighty* are not greedy ogres at the exclusive beck and call of big pharma,\]” Hiari wrote:

They are real human beings who care deeply about changing perceptions about disability via the sharing of stories written primarily by disabled people and their families. They seek to promote ideas of inclusion and acceptance in the face of pervasive ‘othering’ and discrimination. . . . They want to monetize the operation in large part so that they can be in a position to pay contributors, who they readily acknowledge are the site’s raison d’être. (para. 13-14)

However, this experience of ambivalence shifted toward repulsion when claims of exploitation were combined with accusations of appropriation, especially when #crippingthemighty detractors took umbrage at the site’s editorial practices.

**Tensions of Inclusivity and Selectivity**

While #crippingthemighty emerged in part from a need to address some of the structural issues linked to exploitation of disabled labor and inequitable access to
powerful platforms, it was also fueled by emotionally-charged disputes about who can speak about disability and how. Disabled activists pushed back against “mommy bloggers” and others who wrote about disability in ways that de-centered disabled voices and violated a disabled individual’s right to privacy. Using #InspoPornResolution, they circulated guidelines meant to generate more appropriate depictions of the disability experience both on social media and in mass media publications. The Inspiration Porn Resolution included the following statements:

1. I will not co-opt the disability experience for the consumption of others.
2. I will not assume understanding of disabled experience. I will check my privilege and ask questions.
3. When in doubt about language, I will ask and respect the way disabled people self-identify and use resources such as the style guide from the National Center on Disability and Journalism for general guidelines.
4. I will ask my publication to hire and pay disabled writers, editors, collaborators, consultants. (Wong, Jackson, & Taylor, 2016, para. 1)

Consequently, #crippingthemighty and #InspoPornResolution initiated both dialogue and discord between parents and people with disabilities, both of which were strikingly apparent in The Mighty’s private Facebook group for writers, Mighty Voices. These discussions implicate tensions of inclusivity versus selectivity; parents and self-advocates questioned the extent to which The Mighty should adhere to and enforce editorial guidelines that prioritize self-advocate narratives over parent-centric ones. As a result, #crippingthemighty highlights the unintended negative consequences of “neutrality.”

“Walking a delicate path:” Appropriation versus allyship. To understand how tensions of inclusivity and selectivity impact The Mighty’s organizational practices, one must first explore how these same tensions influence the ways in which parents, self-advocates, and others define what it means to write “appropriately” about disability for
any public (digital) platform. In the following sections, I explore how parent writers engage in what Meriah Nichols described as “walking the delicate path” between appropriation and allyship. Additionally, I discuss how disagreements about what counts as “appropriate” can either foster meaningful dialogue or foment conflict via platforms like The Mighty.

**Defining Appropriation.** Riffing off more widely-recognized terms like “man-splaining” and “white-splaining,” disability activists used the term “able-splaining” to describe the appropriation of disabled experience(s). Meriah (2016) defined able-splaining as “when an able-bodied person is attempting to explain our experience; often to us [emphasis included]” (para. 15). She elaborated:

> I think you can imagine how it must feel to me and to others in the disability community, to reach this point of acceptance and pride in who we are and what we bring to the table, and have some able-bodied parent (or similar disability-ally) try and explain components of our experience! (Nichols, 2016, para. 16)

Worse, self-advocates recognized that able-splaining is often treated as more legitimate than accounts developed by disabled people. As Sakari explained, “even in these digital spaces, we get lost in the shuffle because your voice as somebody that is able-bodied [and] that quote-unquote ‘cares for us’ still outweighs ours.” Melissa Stolz, a non-disabled parent, described this phenomena in an article exploring whether or not parents are speaking for or with the disabled community. She observed that it is a “rare day that we invite people with Down syndrome to the table to talk. Even a recent television show that purports to be “about” people with Down syndrome heavily features their parents, and certainly holds the parents as authority” (para. 11).
Indeed, this problem of speaking for was particularly apparent when parents wrote about children who had developmental or communicative impairments. For instance, in her article entitled, “I Won’t Apologize for Writing About my Daughter,” Phoebe Holmes wrote, “I am [my daughter’s] voice. She can’t advocate for herself, so I shall do it for her. She can’t share her experiences with other parents of kids like her, so I shall” (para. 22). Commenters pushed back against these assertions, writing, “You are not your daughter’s voice. Every human being has their own voice.” Another commenter clarified that, “It isn’t that you shouldn’t ever write about your child’s disability, but it is that you cannot write about it from her perspective.” Meriah Nichols (2016) elaborated on this point, explaining, “Your interpretation of an event, an expression, an utterance, is all based on your own experience, history, personality, perceptions. You simply cannot tell someone else’s story for them” (para. 13). Instead, self-advocates urged parents to speak/write as parents rather than as/for their children. They acknowledged that parent perspectives provide valuable, yet distinct, accounts of what it means to raise and support an individual with a disability.

However, speaking/writing from a parent perspective remained problematic when doing so involved threatening the “rights of disabled kids to the same expectations of privacy, dignity, and respect that non-disabled people take for granted.” Parents sometimes engaged in “oversharing”; they wrote in graphic detail about their children’s personal hygiene issues and shared images of their children in vulnerable states (i.e.,

31 This comment was generated in response to Griffio’s (2015) editor’s note about why The Mighty removed Bingo Meltdown
physically exposed, in pain, having a meltdown). Yet, as blogger Sophie’s Trains (2016) noted, what would be abhorred as a privacy violation when written about a non-disabled child is frequently praised as “‘honesty’ and telling it ‘like it is’” when written about a child with a disability (para. 8).

Self-advocates protested these privacy violations by centering their perspectives as disabled adults. For example, Kathleen Downes (2016) explained:

The lives of disabled people and their loved ones or caregivers overlap. But that does not mean they can share the most intimate details of our lives unchecked. . . . My disability causes me to need help with virtually everything from bathing to putting on socks. . . . I wouldn’t want the details of these private moments to be available for public consumption. My story, my body, and my life belong to me. The thought of them becoming public property is terrifying. (para. 3)

Additionally, self-advocates pushed back against parents who wrote in the hopes of securing “toxic ‘parent support’” (PACLA, 2016, para. 2). Indeed, self-advocates sometimes referred to these individuals as “paaaarents,” mocking “mommy bloggers” who write primarily to describe the “tragic” and “burdensome” nature of raising a child with a disability. Indeed, self-advocates recognized that these kinds of posts draw from and perpetuate discourses that frame both parents and their disabled children as “victims,” eliciting widespread support from non-disabled readers. As Elsa Henry (2016) noted, “People all across the internet pity those parents. They feel badly that they have a disabled child.” Indeed, one such parent commented in response to coverage of #crippingthemighty in the Washington Post (Gibson, 2016), writing, “Why isn’t it fair to talk about the huge burden we live with? Or are we expected to be the silent martyrs? . . . What about my experience with meltdowns?”
In response, self-advocate commenters refocused attention on how articles such as “Meltdown Bingo” have harmful consequences for people with disabilities—especially in cases where the subjects of such articles are nonverbal and/or are assumed to be incompetent. As one commenter wrote, “many of these children and adults deemed incapable of understanding, are in fact fully cognizant, and are fully aware of the harmful ways people speak about them, most especially their family.” While disabled adults acknowledged that parents needed spaces to vent about the challenges associated with parenting a child with a disability (or any child, for that matter), they asserted that these “thoughts and feelings should be addressed offline” and “have no place on a forum designed to advocate with and uplift others” (Downes, 2016, para. 4). Kathleen Downes (2016) implored parents to envision the “harmful” and “dangerous” impact that their publicized pity parties might have on potential readers, writing:

One of them may be a fragile seventh grade girl in a wheelchair who reads those words and worries that her parents wish she were “normal.” One of them may be a newly disabled man asking if his life still has value, who needs more than anything for someone to tell him “yes.” One may be the sibling of a disabled child who wonders if you really meant it when you said that people like her brother were a burden. Think about those readers. What would you tell them? . . . You tell the world if society should value disabled lives or not. You help that fragile seventh grader grow to be proud or you fuel her feelings of shame and doubt. (para. 9-13)

**Defining Allyship.** In contrast, self-advocates and parent advocates explored what it means for parents to act as allies for people with disabilities. They described allyship as speaking *with*, rather than *for* people with disabilities. For instance, Melissa Stoltz (2016) urged fellow parents to reconsider the nature of their role as allies, writing:

We can be in this together, but parents need to scoot over a bit, even when our children are non-verbal. Part of advocating for our nonverbal children is making
sure the voice of their community is amplified and heard; it doesn’t stop at merely being the voice for our own children. (para. 24)

Her description invokes what Adelle stated in our interview: “your job [as an ally] is to pass the microphone, not to use it.”

These comments capture three key aspects of allyship, expanding upon the conceptualization of allyship offered in Chapter 5. First, allyship involves “scooting over” and “passing the microphone” in deference to self-advocates, ceding access to public platforms so that the disability community might express “its own lived experiences, it[s] own desires, and its own hopes for the future” (Stolz, 2016, para. 17). Disability advocate and #InspoPornResolution co-creator, Liz Jackson (2016), blogged about an experience that exemplifies this concept of allyship as “passing the microphone.” Jackson was permitted to “borrow” Medium’s32 Twitter handle for 24 hours, allowing her to “[go] berzerk. Cripply-style”33 (para. 3). She tweeted directly to the blog-hosting site’s horde of Twitter followers (over two million as of April 2017), showcasing #DisabilityStories on Medium. “When my final Tweet had posted, I logged off and teared up,” Jackson wrote. “To have so much trust instilled in you and to be given so much access is quite terrifying. To feel heard, to know people were reading #DisabilityStories when they would have normally been reading about Donald Trump is thrilling” (para. 5).

Second, when allies do make use of their own access to powerful platforms, they do so to amplify—or signal-boost—disabled voices in ways that remain “accountable” to

32 See https://medium.com/
33 “Picture a penguin doing the robot” (Jackson, 2016, para. 3).
self-advocates. For example, Perry (2016), described the importance of connecting with disabled mentors as a “relatively neurotypical and able-bodied journalist,” explaining, “I reach out to them, I talk to them. I elevate their voices in my pieces for mainstream media. I mess up. They call me on it. I try to do better. I hold myself accountable to the community” (para. 19). Indeed, #crippingthemighty participants suggested that The Mighty should implement a peer-review program to foster similar accountability among contributors by pairing non-disabled writers with disabled mentors.

Third, allies acknowledge that disability is not just the individual experience of impairment, but the communal and cultural experience of both pride and systemic oppression. As allies, parents can work to connect their children to disabled adults and to accounts of disability history, facilitating their ability to develop a collective identity linked to their membership in a biosocial community. In the process of doing so, parent allies learn about disability from the community’s perspective and incorporate these lessons into their parenting practices. For example, one commenter on Holmes’ (2016) blog post wrote:

My parents did a lot of things right, but also made mistakes. They were very focused on “fixing” me physically, when all I wanted was to be accepted as I am. But as I got older, my mother became involved with the disability rights community, met successful adults with disabilities, and realized that her daughter was going to be OK. . . . If she had been online, writing and reading what others have to say, would she have come to this realization sooner?

Similarly, people with disabilities act as allies in helping others to recognize the power of adopting a collective disabled identity. For instance, Meriah Nichols explained that she sought to help others with disabilities recognize that:
It’s not about overcoming stuff. It’s about figuring out what’s most important to our life, which is a much deeper question than simply disability. It’s about CREATING our world. Accepting power. Accepting responsibility for our lives, actions. . . . So I do want to help empower others with disability to understand that, and share resources and tools to make those unfolding[s] happen.

By initiating conversations about the nature of appropriation versus allyship, #crippingthemighty participants like Meriah Nichols hoped to foster dialogue between parents and self-advocates.

Fostering dialogue, leaning into discomfort. For some #crippingthemighty participants, the hashtag movement represented an exciting opportunity to engage in a vital dialogue about disability and representation. As Meriah (2016) explained in her blog post, “we are all having discussions RIGHT NOW that are the type of discussions that help us shape culture. We are re-thinking and examining our values, prejudices, assumptions” (para. 14). She acknowledged that “this is a first-time adventure for all of us” (para. 15), recognizing that parents are trying their best to learn how to advocate for their child just as self-advocates are “trying to find [their] voices and frame [their] beliefs” (para. 15). Dialogue, then, requires viewing parents and advocates as co-learners and responding in supportive and productive ways to their mistakes. Indeed, Shannon Des Roches Rosa, Carol Greenburg, Patricia George, and Christine Langarer (2015) collaborated on a blog post that addressed how the especially vitriolic and accusatory backlash to incidents like #crippingthemighty might further alienate well-intentioned individuals who are simply unfamiliar with concepts like ableism and inspiration porn. “When people—disabled or not—make mistakes that hurt people with disabilities – do
we actually want those people to learn from their mistakes so they don’t make them
again?” they asked fellow self-advocates and allies.

[We need] to pause before going on virtual decapitation sprees with regards to
those who err. . . . we need to remember that autism and disability advocacy is
really damn hard, and kind of a minefield. We need to do better when detonations
occur, we need to be able to talk to each other afterward even if it’s difficult, even
if it means making ourselves uncomfortable. (para 14; 19)

Concurrently, Meriah Nichols (2016) advised parents to ask “Why, as a parent, do
[I] feel silenced (and defensive) by the voices of the disabled community?” (para. 23).

She recognized that honestly answering this question involves “leaning into discomfort”:

Asking yourself about your own ableism and about ways in which you are ableist
isn’t comfortable. And once you’ve seen it, it’s not easy to un-see. Once you’ve
seen it, most of you know that you need to do something about it, and that’s also
not much fun. The real fun comes when you’ve done some of the work and can
feel the shift in yourself. (para. 27-28)

Indeed, several parent bloggers responded to #crippingthemighty by leaning into
discomfort, and described how they had shifted their approach to writing. For example,
one parent wrote this comment in response to Stoltz’ (2016) blog post about writing with,
versus for, the disability community:

Even though I bristled in response to the *way* some of their points were
expressed to me, I did listen, I did lie awake thinking about it, and I did take it to
heart. I understand where the anger comes from, even though it makes it hard to
listen. I have incorporated a number of blogs by disabled adults (including Carly
[Findlay’s]) into my regular reading. My attitude is evolving and I am growing, as
a parent and a person, from this discussion.

Indeed, Carly Findlay (2016) herself noted that one of the “best things to come out of this
whole sorry mess is the friendships formed – between parents and adults with disabilities.
We’ve got each other’s backs. We’ve got to know each other’s stories and really learn
and connect” (para. 20). However, in some cases, #crippingthemighty, and the individual
and organizational reactions to it, fomented toxic, defensive responses to conflicting perspectives

_Fomenting conflict._ While some parents actively leaned into their discomfort to consider self-advocates’ perspectives, others responded with defensiveness; they framed #crippingthemighty as an attack on the legitimacy of their experiences as parents. These defensive responses were particularly prevalent in *The Mighty’s* closed Facebook community, The Mighty Voices, designed to allow contributors to connect and share ideas for future stories. In her article, published in *The Washington Post*, Lauren Swick Jordan provided an account of #crippingthemighty that captures some parents’ perceptions of being attacked by the disability community. She wrote:

Suddenly, on the Mighty Contributors Facebook page, I was seeing all these terms I had never heard of before: “inspiration porn,” “mommy martyrs,” “pity party writing,” and “#crippingthemighty” – a name given to the movement of protest. . . All of us “mommy bloggers” were collectively scolded by this disabled community. Suddenly, there was a published list of rules we were to told we must follow by the protestors, otherwise, they said, we are disgracing our children (if we should write at all, that is). That we cannot be our children’s voice, and we can never know what our children are living through. That we need to listen to them – they are trying to teach us all something – and it’s time to shut up and learn. . . . Parents are now apprehensive to write anything, for fear of being misunderstood and being ripped to shreds by this group. The good that has been done by *The Mighty* and by parent writers is grossly overshadowed by this one movement of protest. (para 9-15)

Parents like Jordan painted #crippingthemighty as a form of censorship, where well-meaning parents were being bullied into silence by self-advocates who demanded “nothing about us without us.” These parents particularly objected to accusations that they were creating “inspiration porn”; they both rejected the salacious nature of this phrase and asserted that the term “minimizes the importance of basic accomplishments.
for disabled people” (Gibson, 2016, para. 19). Further, as Jordan’s emphasis on “this one movement of protest” suggests, defensive parents (and people with disabilities) labeled #crippingthemighty participants as a particularly militant minority group within the larger disability community. “How is it, then, that the entire disabled community can be represented by this one group, #crippingthemighty?” Jordan asked (para. 16). With this question, Jordan minimizes the validity of #crippingthemighty participants’ concerns. Finally, Jordan and other parents created their own blogging community, called “Special Needs Advocates and Parents” (SNAP). In doing so, they legitimized arguments that parents and self-advocates should simply write in parallel, segregated spaces (for instance, by creating separate sections for parents and self-advocates on The Mighty), without engaging in any dialogue about what representations of disability might harm/benefit disabled people. This logic is clearly displayed in one commenter’s response to The Washington Post’s (Gibson, 2016) initial coverage of the controversy:

If [The Mighty] is for BOTH disabled people AND their caregivers, then some articles will target one perspective or the other. Which means that if you’re a disabled person who doesn’t want to read about the trials that a person caring for her disabled child experiences, then DON’T READ THEM. . . . In short: grow up. Just because the perspective is one you don’t understand doesn’t mean it was an attack on you.

In response, self-advocates reasserted the idea that their perspectives should be prioritized over parents’ given the fact that stigmatizing depictions of disability fuel widespread ableism. “I am really tired of people with disabilities being labelled as victims, bullies and rude when we speak up about our rights,” Carly Findlay (2016) wrote. “We speak up because we are discriminated against” (para. 17). Again, self-advocates invoked the metaphor of disability as culture to respond to parents’
defensiveness. For instance, in response to Jordan’s (2016) Washington Post article, one individual commented:

Some of the most respected disability rights activists in the world objected to the treatment of disabled people on The Mighty and you are complaining that you are scared to write articles now? This is exactly like saying, “I am a white person, I want to write about the Black experience and Black people complained about it. Now I am afraid to write anything because they may not like it. This is so unfair.”

Additionally, parent allies came to self-advocates’ defense, contradicting Jordan’s characterization of her interactions with members of the disability community. “Your description of what is happening in Mighty Voices is disingenuous and completely inaccurate,” one self-identified “mommy blogger” commented, “Never was I attacked, never was I ripped to shreds. Never did anyone tell me to stop writing or that my perspective as a parent was inaccurate.” In fact, self-advocates described how they were the ones who frequently torn to shreds. “The Facebook group was probably one of the worst experiences I’ve ever had on social media,” Michele Guba emphasized. “Many of the parents were bullying and attacking disabled writers who pointed out lack of privacy and ableist views being shared by the parents. Ableist slurs [for instance, “crazy”] were used to attack anyone who stood up to them” (Wong, 2016, para. 6).

These instances of bullying were certainly not perpetrated by The Mighty’s staff members themselves; they reflect a history of tensions tied to disability (mis)representation that is much older and bigger than the site itself. However, #crippingthemighty detractors held the company responsible for allowing such a volatile “detonation” of simmering disagreements to occur. Indeed, as Des Roches Rosa et al. (2016) contended, while it
might be unfair to expect that the author of “Meltdown Bingo” would be well-versed in concepts like ableism, “*The Mighty* should have known”:

They have professional editorial staff, who are sitting on many months of direct feedback from disability, autistic, and neurodiversity advocates, who constantly ask them to center rather than exploit the perspectives of people with disabilities. The editors should have been aware enough to warn the author that Meltdown Bingo could be problematic in a large, autism-oriented arena. (para. 5)

Similarly, detractors noted that *The Mighty* provides few resources to equip contributors to respond when their articles receive public criticism. “While the editors have tried to foster a community, I am not sure of the level of guidance (if any) they provide their writers,” Findlay (2016) wrote:

I don’t mean editorial guidance, but the emotional support that is so important in handling the feedback that comes with writing online. . . . Vulnerable people (perhaps inexperienced, unprepared writers who have a lot going on with their/their child’s illness or disability) who want their stories to be read submit to *The Mighty*, unaware of the reach and reactions to their articles. . . . The editors might well be throwing inexperienced writers under a bus—intentionally or not. (para. 45-47)

Indeed, by engaging in what detractors dubbed “clickbaiting,” *The Mighty’s* staff may inadvertently exacerbate the backlash that individual contributors face. For instance, Mandy described how one of her stories was re-titled in a way that appeared critical of parents. “I got the biggest freaking backlash from people,” Mandy emphasized. “People reamed me . . . I got one death threat out of it.”

Finally, #crippingthemighty detractors panned the lack of effective moderation in the Mighty Voices Facebook group. Indeed, this event prompted the company to hire a

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34 Note that these incidents occurred before the company hired its community manager, who acts as an important, yet invisible, mechanism for protecting contributors from bullying in *The Mighty* voices and in article comments.
community moderator\textsuperscript{35} and to institute clearer moderation rules. However, staff members also used this incident as a reason to remove 70 Mighty Voices participants who had not contributed a new story in the last four months—ostensibly to make the group more manageable and to prepare for the newly-hired moderator’s arrival (Gibson, 2016).

However, several of #crippingthemighty’s more vocal participants were removed as part of this cull, causing contributors to conclude that The Mighty was unwilling to listen and respond to their concerns. “Many people who have been removed from the group are upset,” Carly Findlay wrote in an open letter to The Mighty:

> You met with Cara on Thursday, and removed her on the same day. She offered some great editorial advice to you and then shared it with the writers group. Before she could blink, her post was removed, and then she was removed. (para. 19)

The move effectively stymied both conflict and dialogue, yet left self-advocates feeling “Mighty burnt” (Findlay, 2016, para. 22). As a result, Findlay expressed fears that “disabled advocates (and moderate parents) will be silenced. The parents who decry ‘I will write what I want, you can’t stop me’ will overrule. And so, oversharing, ableism and heightened stigma around disability will continue” (para. 22). Essentially, they framed The Mighty’s logic of “neutrality” as a form of complicity.

**Neutrality as complicity: Perpetuating ableist narratives.** In the previous chapter, I described the ways in which Mighty staff members articulated the logic of inclusivity and framed the site as a neutral platform—one that doesn’t “take sides” or

\textsuperscript{35} This is the community moderator I interviewed; her comments are included in Chapter 6

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“take positions on a lot of controversy.” However, #crippingthemighty detractors contended that the site’s neutrality was compromised by organizers’ desire to make money from stories “designed to tug your heart and jerk your tears” (Nichols, 2016, para. 23) by relying on popular disability tropes. Perry (2016) asserted that this profit motive undercut The Mighty’s ability to remain accountable to self-advocates, explaining that “such accountability would get in the way of publishing inspirational/tragic pieces that drive traffic. The Mighty is happy to publish good pieces about identity and lived experience, but those aren’t the money makers” (para. 20). This aspect of tensions linked to inclusivity versus selectivity fueled a brief resurgence of #crippingthemighty at the tail-end of March 2017. Autistic self-advocates, preparing for the Light it Up Blue-onslaught associated with April (autism awareness/acceptance month), discovered that The Mighty had formed a non-profit partnership with Autism Speaks. Consequently, Kirsten Lutz (2017a), an autistic Mighty contributor, wrote two blog posts expressing her concern that The Mighty would partner with an organization focused on “‘fixing’ the child and relieving the burden of being a parent with a disabled child instead of on helping the child grow” (para. 4). Lutz (2017b) published the response she received from The Mighty’s editor-in-chief:

We do understand the concerns about Autism Speaks. We added them to our partnership program only after they announced the change to their mission in the fall of last year [to remove references to “curing” autism]. As a company, we

36 Light it Up Blue is Autism Speak’s annual initiative to raise awareness (more recently reframed as “acceptance”) of/for autism. Autistic activists who wished to #boycottautismspeaks created their own counter-initiatives, including #RedInstead for acceptance. They also created parody campaigns such as Tone it Down Taupe, which circulated images of a taupe ribbon with googly eyes alongside messages like “We need AWARENESS of those who tragically lack autism. The ribbon is taupe to symbolize the toned-down sensory and emotional experiences of those lacking autism. The eyes represent the incessant demands for eye contact from people lacking autism” (see https://www.facebook.com/Toneitdowntaupe/).
believe autistic people and their families need acceptance and understanding, and we do not support curing or eradicating autism.

We do believe a crucial element of our partnership program is that our site and community helps the partners’ audiences. By us sharing more content by autistic writers and autism community advocates, it can help educate and change perspectives for the better both within and beyond our Mighty community. We are now one of the largest platforms for autistic writers, and sharing our writers’ stories with Autism Speaks can help their readers who may still be struggling to understand and accept autism.

. . . We actively work to fight ableism and content that disparages the disability community. We are committed to sharing the voices of autistic writers and the diverse voices of the larger disability and health community. (para. 4-5; 7)

This response illustrates the logics of inclusiveness and neutrality, evoking the idea that including all voices might foster productive dialogues. In contrast, Lutz (2017) viewed this partnership as complicity in the name of neutrality, writing:

You say sharing these stories with AS [Autism Speaks] may help them understand. Unfortunately, autistic people and organizations have been doing this since AS started. AS does not care and does not understand. They are using The Mighty to legitimize their place as a ‘charity’ and to try to change how people see them. Until they have actually made changes, this is hurting you and your readers more than it’s helping them. . . . You’re associating yourselves—and, by association, your writers—with an ableist hate group created for parents (not autistics) that has the support of eugenicists and white supremacists. (para. 12; 18)

She underscored her argument by sharing a list of “Actually Autistic” organizations that The Mighty had not yet partnered with. In sharing this list, Lutz highlights one of the ways in which a commitment to neutrality might censor the voices of more radical self-advocates.

Neutrality as censorship: Muffling disabled voices. As I have explained in the previous chapter, The Mighty’s staff members viewed the process of filtering story submissions by assessing their match with the Mighty tone as an important part of creating and preserving a “safe space” for contributors and readers. Additionally, they
spoke about editing to package shareable stories and mentor aspiring writers—both aspects of enacting second-tier advocacy. However, #crippingthemighty detractors, as well as ambivalent contributors, framed these activities as forms of censorship.

“Sometimes they like to censor things,” Mandy explained. She and other contributors described how aspects of their pieces that were deemed too angry, too negative, too sarcastic, or too controversial were frequently removed or softened to fit the Mighty tone.

“I cursed in my article and they deleted it,” Adelle recalled. “Like as opposed to using the curse words, or even finding [an] alternative, they instead put asterisks.”

Some contributors expressed ambivalence about this editorial process, recognizing that it cultivated a site that was both “safe” and “incredibly vanilla” (Adelle).

“I get that when you’re trying to play it safe, you do become very limited, and so I respect that,” Alicia explained. “I wish sometimes you could be more frank on that site than you can, but I get why they don’t [allow it].” Emily articulated a similar sense of ambivalence, explaining:

I think that [Mighty editors] try to stay neutral on anything that could possibly be perceived as political. . . . I have this theory that everything and everyone that we love, sometimes the thing that we love about them most is also the thing that . . . bothers us. [The site] is really inclusive and positive which is great, but then that’s what also keeps them from publishing stuff that could be a little bit more edgy or provocative. . . . but it’s a safe space. It’s very innocent in a way and I wouldn’t want them to change that.

Even when contributors understood and accepted the logic behind The Mighty’s editorial policies, they felt slighted when they perceived that editorial decisions were made unilaterally and without explanation. “There is no dialogue about it,” Sakari stated:

They just make edits, and then you get an email like, “your story’s up now.” And I look at them like, “Wow, you edited this and that and this, and you didn’t
consult me before hand.” And they say, “We edit in similar editorial guidelines.” Well, that’s fine, let me know what those are and I will write by them from the beginning. . . . I’m open to an editorial process, but I want there to be communication.

Contributors sometimes felt that these edits substantially changed the tone of their story, rendering it a less authentic depiction of their experiences.

Additionally, contributors spoke about how story prompts participated in creating and preserving this safe, yet vanilla, space in ways that muffled writers’ individual voices. “When each writer gets the same prompt, their voices eventually can mold together and sound the same,” Adelle noted. “The good message is getting lost [in] the shuffle.” Similarly, Bailey pushed back against the feeling of being put “in a box,” especially when prompts encouraged contributors to write in list form. “I [don’t] necessarily always want that for my writing,” she explained. “I only get in my paragraph form because I can add more humor to it. Sometimes, I feel they’re taking a little bit away from the writers’ own personal voice.”

Cedar and I explored how The Mighty’s prompts create and participate in an overarching narrative about what disability is—a narrative that might limit writers’ ability to envision and participate in more empowering narrative structures. “I feel what I really want to say goes beyond their narrative,” Cedar told me. When I asked him to describe what The Mighty’s disability narrative was, he replied:

I think that this is not just true of The Mighty, but of society in general—there seems to be a glass ceiling on, not what people with disabilities can accomplish, . . . but on how they can define their story. Like having a disability in society [is] like “poor you.” And so the goal within that “poor you” mindset is to get respect, get what’s legally owed, to function at the highest capacity within the “poor you” level. But the truth that I’ve found in my own life . . . [is] that there is a life way beyond the purview of your glass ceiling. . . . To me The Mighty, I mean they’re
helping. They’re huge force within that room with the glass ceiling, helping people expand in all directions within that room, but to me they don’t yet . . .
guide people beyond that room.

Instead, Cedar envisioned how writers might flip the “poor me” narrative to both identify their own “gifts” and to focus on inviting dialogue with non-disabled readers (rather than “pointing fingers” at ignorant others). He suggested that The Mighty’s prompts might become a kind of narrative intervention by asking questions like, “In what ways, if any, has your condition been a gift to you?” and “What have you learned from your condition?” “[Those prompts] require different stories,” Cedar explained. “People will write a different story, and then they’ll be thinking about a different story, and then they would make their own discoveries, and that would be out there in the world for other people to begin interacting with.” Cedar’s proposed prompts encourage potential contributors to invoke discourses of difference empowered, rather than discourses of difference devalued or difference as hard reality.

Contributors like Cedar found ways to work within The Mighty’s existing narrative, structuring the site in the processes of both commenting on existing articles and interacting with prompts. For instance, Cedar described employing a “Trojan Horse” strategy to “infiltrate” problematic prompts and offer his own productive twists, hoping to gradually shift both readers’ and editors’ perceptions of what a disability narrative could be. Over time, new Mighty prompts might begin to ask the kinds of questions that contributors like Cedar truly wanted to respond to—generating stories that, in turn, might cause readers to question entrenched assumptions about what being disabled means.
In contrast, #crippingthemighty detractors and other ex-contributors withdrew from the site completely, arguing that its goal of maintaining “neutrality” involved muffling disabled voices to facilitate mass consumption. They acknowledged that The Mighty represents a microcosm for systemic issues in the publishing industry. For example, Dani Alexis Ryskamp observed that:

The demand for “writing about disability” in the mainstream media is still a demand for narrowly-told stories that have an inspirational bent, invoke pity, and/or are told “about us without us.” The audience is everywhere presumed to be nondisabled, and the preference remains for the author to be nondisabled as well. When the author is disabled, they are expected to perform a particular type of inspiration or desire to be nondisabled. (quoted in Wong, 2016, para. 18)

Thus, detractors understood The Mighty’s editorial practices as censorship designed to cater to this “demand.” For example, in their Change.org petition targeting The Mighty, PACLA (2016) accused the editors of “tokenizing the disabled and neurodivergent adults and the parents who actually get it right,” explaining that Mighty staff members do this by, “editing their voices to suit [The Mighty’s] agenda by making our concerns more palatable to parents . . . and by insisting on language that [the editors] prefer over what we tell [them] is offensive and ableist” (para. 4). This sense that The Mighty truly caters to a non-disabled audience also infused tensions tied to universality versus selectivity.

Tensions of Universality and Specificity

In the previous chapter, I described tensions of universality versus specificity as tied to decisions about whether to publish stories about specific conditions or to publish stories that capture the broader experience of having a disability, chronic illness, and/or rare condition. However, my interview with Alice Wong shifted the way I thought about this tension. She described the problematic nature of categorizing stories by either a
specific diagnosis (e.g., autism) or a broad category linked to diagnosis (e.g., rare disease). “That really is an able-bodied idea, that ‘Oh people want to see stories specific by disability,’” Alice Wong explained. “That absolutely may be true, but by separating us out, it’s saying something. . . . They are thinking about it as these separate and different diagnoses. And it’s really [that] disability is much [more] than just a diagnosis.” These comments highlight how, even by making the seemingly logical decision to organize stories according to the contributor’s condition, *The Mighty* draws on and legitimates the “[bio]medical model” as a system for sorting and categorizing bodies. This approach to categorizing stories jives with Mike Porath’s original vision of the site as a story version of WebMD—*The Mighty* preserves the legacy of “expert” medical sites in its DNA (to use a medicalized metaphor). In contrast, Alice Wong described an alternative organizational structure:

> I would do it as themes such as by “education,” “discrimination.” I think that’s much more holistic, [it’s] about disabled people versus autism stories or mental illness stories. There’s so much that we have in common that I feel that by doing that it just really loses the richness.

Indeed, her suggestion resonates in some ways with contributors’ repeated calls for more depictions of the “day-to-day.” Some contributors focused on capturing how individuals navigate mundane challenges like “dropping things 30 time a day.” “What are you going to do when you drop a stack of paper?” Renee asked. “Do you grab one of the little grabby arm things? The trash grabbers? I don’t know.” Such stories might highlight how individuals respond with resilience and ingenuity to both physical impairments and ostensibly inaccessible built environments. They might also illuminate microaggressions and unrecognized accessibility challenges. Additionally, “day-to-day” depictions focus
on illuminating what it means to be a person—not just a patient, not only a person with a disability, not an “Other.” For instance, Jayson recommended that The Mighty create mini, day-in-the-life documentaries featuring contributors so that the site’s readership “will get to see these people, the contributors, in their day-to-day and get to know them interpersonally.” Re-thinking The Mighty’s approach to categorizing stories and, in turn, the kinds of stories that might populate these categories, provides opportunities for what Cedar described as “bridging from the island of disability through the commonality that all humans have . . . not to minimize the condition, but to connect.” Disability activists like Alice Wong hoped to foster such connections through cyberactivism.

**Crippling as a Verb: Transforming Digital Spaces via Cyberactivism**

In sections above, I have focused on describing what #crippingthemighty can tell us about the nature of exposure and exploitation, allyship and appropriation, dialogue and defensiveness, and the problematic practice of pursuing “neutrality” in ways that preserve an ableist status quo. However, #crippingthemighty also tells us about the disability community’s capacity to organize for resistance, generating what Findlay (2015) described as a “movement to take back our voice” (para. 5). Further, it highlights how social media platforms like Twitter have enabled cyberactivism (Parsloe & Holton, 2017).

Attending to the “cripping” part of #crippingthemighty situates this hashtag as simply one rallying point in a larger social movement. As Alice Wong explained, “In a way, I’m using [The Mighty] to talk about this larger, endemic issue in publishing.” Thus, her choice of the word “cripping” infuses the hashtag with the activist character of the
disability rights movement. “It was really interesting, because through this hashtag, people knew what that was about,” Alice Wong explained:

To crip something up, it means . . . to infuse it with disabled people’s experiences. So, ‘how do we transform organizations like The Mighty?’ There is this whole idea of crip culture. . . . It’s really politicized. It’s a lot of reclaiming that word that was really hurtful for a lot of people, but that term is really about deliberate pride and ownership of our culture. To me, I thought that was really a wonderful way of activating, using a verb, to really change The Mighty.

Using the term, “criping,” as part of this hashtag served to strengthen a sense of disability pride and showcase crip culture in the process of educating Mighty staff members. As Alice Wong explained, the hashtag provided a tool through which participants could “give visibility to a lot of great disabled writers” while “also just giving this very free advice to The Mighty in terms [of], ‘These are all the people you’re missing out on.’” She described one “gratifying,” unintentional side-effect of the hashtag’s “ripple effect”: it spurred participants to publicly “give a shout-out” to individual self-advocates across the world, “letting all these communities . . . see their camaraderie.” Essentially, using the term “criping” called forth self-identified “crips,” reinforcing this in-group’s collective, politicized identity. Additionally, Alice Wong noted that using the term “criping” provided an opportunity to “reach people who are uncomfortable with that word,” introducing other disabled people and would-be allies to the idea that crip culture is a “part of the disability community that’s very strong and very real.” Indeed, supporters used former contributors’ and readers’ ambivalence toward, and disenchantment with, The Mighty as an opportunity to encourage others to participate in the vibrant crip community present on social media. For instance, in response to Carly Findlay’s (2016) blog post, one commenter wrote:
Come join us on Twitter. The disability community on there has the same divisions and falling outs but it’s led by and for the community, not for abled people, parents or people who prefer to debate our humanity than actually talk to us.

While the hashtag clearly functioned to both build crip community and provide advice to The Mighty’s staff members, Alice Wong recognized that it also served as a type of public shaming. “I wanted to stir up a little bit of trouble, I guess,” she explained, “Be a pain in the ass.” She acknowledged that she was initially motivated by her anger at what she perceived to be disrespectful treatment of her friends. She was also frustrated by the idea that The Mighty had not proactively reached out to prominent disability activists before this point. In response to the “Bingo Meltdown” fiasco, The Mighty’s staff members posted an apology inviting feedback from the disability community. “That’s what really drove me up the wall,” Alice explained, “[They] asked questions like, ‘Who are the disabled writers we should be learning from?’ All you have to do is look. That was really the impetus for us. Several hundred of us on Twitter. You asked for disabled writers? Here is a tsunami of writers that you should know about.”

Importantly, rather than respond via emails and phone calls, Wong and her colleagues orchestrated this “tsunami” via Twitter. In doing so, they leveraged the public nature of this social media platform to gather witnesses—witnesses with collective power to shame The Mighty into changing its practices and policies. Further, Twitter amplified individual self-advocates’ ability circulate and signal-boost open letters to The Mighty, revealing “insider” knowledge about the conflict within the Mighty Voice Facebook group (Findlay, 2016), the company’s plan to partner with pharmaceutical companies (Hiari, 2017), and The Mighty’s non-profit partnership with Autism Speaks (Lutz, 2017).
Thus, while *The Mighty*’s staff members espoused their internal commitment to “doing good” for the community by listening to and addressing its concerns, #crippingthemighty participants leveraged the threat of public shaming to ensure that company truly remained accountable to #actuallydisabled people. Lutz (2017) exemplified this strategy of public shaming in her open letter to the company, writing:

I urge you to check your social media mentions because, as this gets out more and more, people are extremely upset and swearing y’all off as a resource. This is going to lead to a lack of writers because of people like myself leaving, too. (para. 20)

Indeed, Alice Wong asserted that cyberactivism, as exemplified by #crippingthemighty, represents “the future of activism.” “I don’t know if *The Mighty* really were impacted in any way,” she told me, “but even if they weren’t, I’m very proud of what happened. Because I think we made a statement. I think sometimes that’s just a start.” Indeed, this “start” put some significant changes in motion as *The Mighty*’s staff members grappled with the concerns raised by #crippingthemighty.

**Responding to #crippingthemighty: (Re)structuring *The Mighty***

While *The Mighty*’s initial responses to #crippingthemighty—such as removing vocal self-advocates from the Mighty Voices Facebook group—suggested to self-advocates that the company was not willing to listen to their concerns, my interviews with staff members indicated that they perceived this incident as an important turning point in *The Mighty*’s development. For example, Danielle described how #crippingthemighty shaped her understanding of the company as a recently-hired editor. “I was so new,” she explained, “I didn’t really know, if there was a negative response, would that matter to us? And it really does. . . . We don’t want people to be upset or feel
marginalized by our content.” Anna, an editor who had been at the company for a longer period of time, described #crippingthemighty as a “good thing,” elaborating, “I thought it made us better. I thought it was a nice wake up call. . . . I think that we’ve grown a lot.”

However, Mighty staff members also acknowledged that this growth entailed leaning into their own discomfort and resisting the urge to feel defensive. For instance, Eva talked about how “knowing how much care goes into every single story from every single editor” made it challenging not to “take [criticisms] personally” or be “protective” of the site and its staff. Indeed, several staff members shared stories about the pressure they felt to avoid causing contributors to “feel like we’ve done wrong by them in some way.” “I think every editor will say there are some situations where contributors come back upset, it affects you,” Rachel explained, “Trying not to let it really set you back I think is one of the biggest challenges. . . . There’s so much guilt—you feel a lot of responsibility.” Kathleen described how she managed to reframe these painful and disheartening criticisms in a way that allowed her to grow from them. “You can be really nervous and walking on eggshells and get mad,” she explained:

But I try to view it as like, “It’s so important to them that it matters, and they’re willing to speak up about it.” And so, to me, even if someone comes at me with a really big criticism of the site, I’m like, “They care about what’s happening and they realize that we’re making a dent, so they want to help us make that dent in the right way.”

Similarly, Anna acknowledged that “Just because we all have good intentions, [it] isn’t enough.” “[Contributors and readers are] not here with us when we’re talking about stories, they’re not hanging with us,” she explained. “All they see is the final result.” Thus, she and her colleagues sought to respond to #crippingthemighty in ways that might
help the company to (re)gain “respectability” and potentially, “get some badass advocates” onto the site. These changes are evident in The Mighty’s (a) evolving guidelines, (b) increasing specialization, and (c) changing hiring practices.

**Evolving guidelines, part deux.** In the previous chapter, I described how The Mighty’s staff members developed evolving editorial guidelines in response to conversations with both contributors and readers. Indeed, Mighty staff members articulated this learning process as part of their apology for publishing “Bingo Meltdown.” The editor-in-chief wrote:

> I’m able-bodied. I’ve grown up in a world designed for able-bodied and “typical” people. In my journalism training, I was taught not to write words like “disabled” or “autistic.” It wasn’t until I edited a post from a potential contributor named Tonia that I realized how truly ableist my thinking was. Tonia respectfully called me out for changing “disabled” to “person with disabilities” in her submission, therefore telling her how to identify herself. That’s not our job as editors; our job is to help you tell your stories. Because Tonia spoke out, The Mighty made a positive shift. . . . When a small team of people are editing submissions from thousands of writers, all with different perspectives and opinions, we rely on you to tell us when we’ve done wrong. (Griffo, 2015, para. 5)

However, this process of developing evolving guidelines through interactions with contributors remains imperfect—most notably because the way in which disability and chronic illness should be represented is still a subject of debate “within the community” itself. Members of “the community” may be more or less familiar with the history of the disability rights movement and its use of particular terms, and may be more or less critical of the ways in which language use can undermine or perpetuate ableism. Indeed, as Chapters 4 and 5 of this dissertation project have illustrated, people with disabilities and chronic illnesses (as well as parents and other would-be allies) draw on varying
discourses of difference to construct sometimes contradictory narratives, and to pursue
sometimes clashing collective goals. Thus, it is important to note that The Mighty’s
guidelines reflect the knowledge, habits, preferences, and goals of those who decide to
contribute to, or comment on, the site. For instance, The Mighty’s initial reliance on
mommy bloggers may have left editors unaware of, and unprepared for, simmering
tensions of representation that later exploded via #crippingthemighty. One editor
explicitly recognized this idea, stating, “I think that some of the challenges we face
could’ve been avoided if from the beginning we were listening more to the whole
community, not just the community that was maybe resonating with us from the
beginning.”

Indeed, this is the point that Alice Wong made when she expressed her frustration
with The Mighty staff’s failure to proactively seek advice from disability activists who
identify with crip culture. However, #crippingthemighty helped to fill this hole in staff
members’ developing knowledgebase. Indeed, as I have described in the previous
chapter, staff members began to incorporate their new awareness of inspiration porn,
privacy concerns, and the importance of centering self-advocate voices into their both
articulated guidelines and gut instincts associated with red flag-worthy stories. Long-
time contributors like Mandy observed the resulting changes in the site’s content,
commenting “after the autistic Bingo fiasco, it seems The Mighty’s kind of cleaned up
their act . . . I think they have taken the time to kind of be more mindful of the things that
people post.” The staff’s capacity for “mindfulness” increased as they sought to develop
more specialized knowledge about each of the site’s sub-communities.
**Increasing specialization.** *The Mighty’s* staff members described their shared vision of a much larger future staff with hundreds of specialized “beat editors.” Rafael explained that, in his view:

> The way to organize [the company] would be to have someone at *The Mighty* that manages each community who is [also] in the community, hopefully. Who can be almost our ambassador for that community, and help with making the stories and building the relationships, and serving [sic] as *The Mighty’s* voice in that community.

The editor-in-chief’s vision for *The Mighty’s* future built on this concept of increasing specialization to consider how the site might manage conflicting perspectives within the same sub-community. “We [would] have an editor who’s maybe dedicated to one perspective, and an editor who’s dedicated to different perspectives,” she explained.

“Like, maybe we would have an autism team, and one person would be an autistic writer, who kind of fields those writers, too. And then, yeah, there would be someone who’s handling parenting blogs.” While staff members emphasized that this degree of specificity was not currently logistically possible for the fledgling start-up company, they acknowledged that they were already making strides in this direction. “We have people who are focusing and have a lot of expertise around mental health. We have someone within the rare disease community—she was a contributor and now she is the rare disease editor,” Rachel noted. “I think continuing along that way, having members of the community . . . with a lot of knowledge around paying attention to very specific areas, is how we are going to continue to grow.” Growing in this direction required that *The Mighty* begin to change its hiring practices.
Changing hiring practices. Alice Wong was emphatic about the idea that true change for *The Mighty* could only occur if the organization began hiring disabled individuals for positions “at the very top.” Indeed, *The Mighty’s* changing hiring practices appear to reflect a similar recognition that hiring self-advocates would go a long way toward building a credible site structured around the perspectives of people with disabilities and chronic illnesses. For instance, when I asked the site’s editor-in-chief to share something she would have told herself at *The Mighty’s* inception, she replied “I would have told myself, ‘Make sure you have your eyes open for these people who would be valuable as employees.’” “That’s something that we’re thinking about very consciously now, as we go about to hire the next round of people,” she emphasized. “I think what I try to do is admit that I just don’t know a lot of the stuff going on, and my solution to that is to just find people who do.” In fact, Eva shared the fact that her application to become the site’s rare disease editor was rejected because Porath and his team went with “someone who has a rare disease because they really know the community.”

Even in the seven months between my field work for this project and this current writing, the company hired three self-advocates, and former contributors, as full-time members of its staff. Indeed, changing hiring practices to focus on incorporating self-advocate expertise helped the site to showcase stories that reflect more facets of disability culture. For instance, since hiring a woman with a disability to edit its disability section, *The Mighty* has featured stories with titles like “My Blindness Doesn’t Make Me Inspirational” (Naert, 2017) and “When Disability Gets Left Out of Conversations About Privilege” (Burns, 2017).
However, while shifts in (a) editorial guidelines, (b) editors’ degree of specialization, and (c) hiring practices appear mighty hopeful, some prominent disability activists continue to feel “Mighty Burnt.” Eva shared the frustration of realizing that some of the site’s critics might never re-engage. Speaking as though she could directly address these detractors, she explained:

It’s changed a lot in the year. You don’t see it, or you just haven’t been visiting the site enough to know that it happened. You just decided like, ‘I hate this and I’m never going to support them or read anything on there again.’

Her comments suggest the idea that while “cripping” as a verb may initiate dialogue in some very important ways, it may also short-circuit dialogue by black-listing a potentially valuable second-tier advocate.

**Summary and Discussion**

Persons on the margins of two societies, members of an oppressed or minority group, and all those who suffer stigmatic or traumatic life transition are particularly enabled to see the processes of social structuration that may forever remain transparent to deeply enmeshed members of the majority whose lives are never disrupted by the rude shocks of history (Pearce, 1989, p. 19)

As this quote by Pearce (1989) emphasizes, those on the margins of society are often more capable of discerning the multicolored threads with which it is woven. More than this, they are more aware of the fact that those with access to power design the structure of the loom, shaping the nature of the social fabric. The foregoing analysis underscores the idea that “politicized” disability activists leverage their marginalized standpoint to critique and resist the stigmatic, oppressive processes of social structuration. #Crippingthemighty serves as case study for examining “cripping” as a form of collective/connective action, particularly as facilitated by social media. It also
provides an opportunity to adopt a critical approach to health communication.

“Conceptualizing power as structurally situated in relationships, institutions, and networks, critical health communication examines meanings of health that are circulated globally, and the communicative processes that carry over these meanings in policies, programs, and reports” (Dutta, 2015, p. 16). Taking this critical stance requires identifying “the discourses that shape ways of thinking about and acting upon the human body” (Lupton, 2012, p. 14), considering how “emergent narratives [of embodied difference] enable and constrain the human spirit” (Harter et al., p. 21).

My analysis of tensions related to doing good and doing well suggests that The Mighty detractors perceived the site as a form of neoliberal organizing. Dutta (2015) defined neoliberalism as a “complex web of political and economic thought that considers at its heart the principle of free market as driving mechanism for political, economic, and social organizing” (p. 11). Framing The Mighty in this way draws attention to the way in which the organization might function to perpetuate ableist hegemony by mobilizing “communicative inversions,” defined as “interpretations that are reversals of the material manifestations” (p. 12). For instance, while The Mighty’s organizers speak about how their work provides exposure to individual writers, in actual practice the site might really create exposure for itself while burying individual stories in an avalanche of content. Additionally, while The Mighty’s organizers speak about providing space for marginalized voices through scaling its platform, it may in practice take space away from grassroots, #actuallydisabled activists with limited ability to create an equivalently scalable infrastructure. Through #crippingthemighty, disability activists enact their
collective, connective agency by revealing these otherwise invisible communicative inversions to witnesses present in the Twittersphere.37

Second, my analysis of tensions related to inclusivity and selectivity excavates the power dynamics associated with allyship, appropriation, and a commitment to “neutrality.” I have argued that seeking “neutrality” in ways that preserve existing imbalances of power can inadvertently censor radical voices, communicating complicity in the social processes of stigmatization, marginalization, and “Othering.” More than this, however, my analysis reveals two intertwined, yet contradictory, conceptualizations of dialogue. I argue that The Mighty’s organizers defend the logics of neutrality and inclusivity because they conceive of dialogue in the Bakhtinian (1981) sense. This sense of dialogue involves cultivating heteroglossia—the symphony and cacophony produced by the intersection and collision of multiple voices, and by the layering and interweaving of multiple languages, or ideological systems. By publishing all perspectives (or as many as fit the site’s evolving editorial guidelines), The Mighty’s staff orchestrate heteroglossia by positioning individual voices in relation to the unitary system of language constituted by The Mighty tone. Contributors like Cedar participated in the playful agency inherent to this form of dialogue, subverting The Mighty’s unitary Mighty tone by “Trojan Horsing” story prompts and infusing these generic forms with new perspectives.

37 Please note that I am not suggesting that The Mighty’s staff members leverage these forms of communicative inversion in any overtly malicious way. Indeed, as Twilah Hiari’s ambivalent assessment of The Mighty expressed, the company’s organizers genuinely hope to achieve positive social change for the community they serve. Rather, these dynamics reflect a general move toward neoliberal ways of organizing that pervades the current moment in Western society. Additionally, as my analysis of the ways in which the company has shifted suggest, The Mighty’s staff members have begun to envision ways to ameliorate some of the unintentional problems inherent to their initial organizational structure.
In contrast, disability activists sought dialogue in the way Buber (2010) articulates, as the interplay of I and Thou. Dialogue in this sense captures the ethical imperative to lean into discomfort—to consider another’s perspective without consuming the Other by appropriating their story in the process. As Gurevitch (1990) asserts, “the dialogic imperative is two edged: to invite the Other into the world of the self and yet to distance so as to endow the Other the right of otherness” (p. 185). These sentiments capture the dialogic nature of allyship—a communicative activity that requires speaking with, validating and creating space for the perspectives of people with disabilities while resisting the temptation to speak for them.

Third, my analysis of #crippingthemighty as an exemplar of cyberactivism suggests the ways in which disability activists mobilize a collective “crip” identity via social media, leveraging the flexible, dispersed, creatively generative logic of connective action to resist exploitation, appropriation, and censorship. My own previous research has explored how hashtag movements like this one strengthen in-group identities at the same time that they foster disidentification with organizations perceived to be ableist (Parsloe & Holton, 2017). In the case of The Mighty, the use of a hashtag created a ripple effect of repulsion, transforming “Meltdown Bingo” into a shared critical incident that galvanized otherwise ambivalent Mighty contributors/readers/observers. It also allowed activists to introduce The Mighty’s editors to key opinion leaders for, and characteristics of, crip culture while also engaging in a form of public shaming. Their efforts subsequently initiated changes in both The Mighty’s editorial and organizational practices. This case study emphasizes the ways in which social media and cyberactivism lend agency to
members of the disability community. Indeed, an edited volume published by Ellis and Kent (2017), entitled *Disability and Social Media: Global Perspectives*, devotes 21 chapters to exploring this topic. In the following conclusion chapter, I review this and other theoretical musings from this chapter to offer potential practical implications and directions for future research.

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38 Note that the way in which the features of social media are designed still make it inaccessible for some members of the disability community (see Hollier, 2017).
Chapter 8: Conclusion

What would it mean, then, in practice, to value disabilities as differences? It would certainly mean not assuming that every disability is a tragic loss or that everyone with a disability wants to be ‘cured.’ It would mean seeking out and respecting the knowledge and perspectives of people with disabilities. It would mean being willing to learn about and respect ways of being and forms of consciousness that are unfamiliar. And it would mean giving up the myths of control and the quest for perfection of the human being (Wendell, 1996, p. 84).

This dissertation project was motivated by my desire to seek out and respect the knowledge and perspectives of people with disabilities. I have approached *The Mighty*, and the attendant Twitter hashtag, #crippingthemighty, as a case study for understanding how individuals with disabilities and chronic illnesses (re)construct individual and collective identities through writing and publishing personal narratives. I have also used this site to theorize about the interlinked communicative phenomena of (refracted) self-advocacy, allyship, and collective/connective action. Finally, this site provided an important opportunity to consider various tensions of representation emerging from both pervasive ableism and from the heterogeneity of disability experiences. These tensions created organizational challenges for *The Mighty* and catalyzed resistance from disability activists.

I have elected to construct “summary and discussions” sections at the end of each of my four analysis chapters. This choice allowed me to structure a layered manuscript that better reflects the abductive process of grounded theory, and created space to engage in sustained theorizing about each facet of the project. Consequently, the first section of this dissertation chapter will simply provide a summary of the theoretical claims I have already made. The remainder of the chapter will propose practical implications for this
research, identify some limitations of this research, suggest directions for future research, and offer some personal reflections on the process of completing this dissertation project.

**Theoretical Implications: A Review**

Each of the four analysis chapters that comprise this dissertation respond to multiple, interrelated research questions. Chapter 4: Chronic Illness, Disability, and Identity (Re)construction on *The Mighty*, attempts to answer questions about how people with disabilities and chronic illnesses (re)construct their identities through the process of writing and publishing their story. I was especially interested in exploring how these stories dissolve or solidify the blurry line between disability and chronic illness. I have contended that, for those individuals who are not born with a disability, receiving a diagnosis provides both a tool and impetus for three sense-making practices tied to revising a non-disabled self. First, contributors’ stories and interview responses reflected the sense-making process of *re-narrating the past*. They began to attribute past challenges to an unacknowledged diagnosis, alleviating guilt and frustration associated with appearing inexplicably less capable than neurotypical, non-disabled peers. They also experienced vindication in the face of “epistemic invalidation” (Wendell, 1996) perpetrated by healthcare professionals who doubted or discounted their knowledge of their own embodied realities. Second, contributors engaged in constructing what Harter (2013) described as “new normals,” crafting narratives that reinforced the dual refrain of “it’s OK” and “I’m OK.” Third, contributors *re-imagined the future*. Most interestingly, they re-examined the meaning of terms like “hope” and “success,” envisioning ways in which they could cultivate contentment by pursuing achievable goals and by being more
mindful of the pleasant minutiae of daily life. However, while this discussion stems from the premise that diagnosis is a vital sense-making tool—and also a key prerequisite for treatments, therapies, and other support services—it is also important to recognize that emphasizing the value of diagnosis reinforces biomedicine’s social and cognitive authority to describe and classify bodies (Lupton, 2012; Wendell, 1996). Indeed, disability studies scholars like Charlton (1998) reject labels as sources of limitation and fragmentation; diagnoses “allow the dominant culture to institutionalize those of us they consider outcasts and misfits” (p. 163).

Chapter 4 also applies PI theory to examine how various, overlapping sources of flux disrupt these sense-making processes. Changes in individuals’ corporeal characteristics, their (in)access to and (non)use of assistive technologies, their interactions with (un)supportive interlocutors in various social settings, and their encounters with (in)accessible physical and political structures shaped by shifting macro-discourses rendered various foci and forms of PI more or less salient across time. These sources of diagnostic, physical, and social flux compelled contributors to construct multiple, sometimes contradictory narratives in an effort to align their probabilistic and evaluative orientations toward simultaneously embodied and social experiences of self. In doing so, these contributors constructed metaphors that pulled from discourses of difference devalued, difference as hard reality, difference integrated/empowered, and difference oppressed.

Finally, Chapter 4 offers implications for theorizing about how individuals develop narrow and broad collective identities, situating themselves as members of
particular biosocial communities. My research suggests that narrow collective identities (e.g., Lymies) formed primarily around shared experiences of the specific physical realities associated with a condition. These collective identities satisfy a need to seek and provide highly-tailored forms of social support. However, as individuals adopted ever broader collective identities (e.g., zebras, spoonies), they became increasingly cognizant of how their physical differences elicited similar interpersonal challenges, such as being doubted by healthcare professionals and others, or receiving inadequate or inappropriate social support. Ultimately, contributors who identified as disabled shifted toward a social model of disability, creating a collective identity grounded in the shared experience of oppression, but also the shared recognition of disabled peoples’ individual and collective agency to resist stigmatization and marginalization. This collective identity minimizes attention to distinctions made on the basis of physical characteristics. As Charlton (1998) explained, “the differences are real; the categories and preconceptions are false” (p. 167).

Developing this kind of collective disability identity requires acknowledging that:

Although there are numerous natural differences among those with disabilities, it is on the basis of these false categories and preconceptions that the common experience of disability oppression is experienced. This paradox or contradiction—out of difference comes unity—is the basis of the disability rights movement. (Charlton, 1998, p. 167)

Davis (2013) moved beyond the disability rights movement to situate disability rights as simply human rights. He predicted that “the fracturing of identities based on somatic markers will eventually be seen as a device to distract us from the unity of new ways of regarding humans and their bodies to further social justice and freedom” (p. 275).
In Chapter 5: Writing Purposeful Stories: Self-Advocacy and Collective/Connective Action on The Mighty, I acknowledge the political nature of stories (Harter et al., 2005). Stories represent contested terrains in which contradictory discourses duke it out. Ultimately, they direct individual and collective action by locating the source of challenges associated with disability and chronic illness (for example, the failure of science, the uneven distribution of medical resources, systemic ableism, etc.) in ways that shape collective goals (Zoller, 2005). In this chapter, I focused on answering two research questions: (a) How do contributors understand the relationship between their individual self-advocacy activities and their participation in a larger collectivity? and (b) What tensions emerge in contributors’ construction of difference and their pursuit of advocacy goals? I have introduced the concepts refracted self-advocacy and collective self-advocacy to theorize about the ways in which writing publicly about private experiences mobilizes a “collective of individuals” (Kelly, 2010), encouraging social change via individualized, daily acts of self-advocacy in interpersonal contexts. Additionally, I offer a conceptualization of allyship, suggesting that acting as an ally involves claiming peripheral membership in a biosocial community. Allyship captures a moral commitment to interdependence, and to foregrounding marginalized perspectives. Finally, I have explored the nature of collective action as expressed through advocacy and activism. I have adopted Flanagin et al.’s (2006) definition of collective action, and have attended to the ways in which Mighty contributors communicate to link individual experiences of disability and chronic illness to systemic issues in ways that transform private interests into public concerns (Flanagin et al., 2006). In doing so, contributors
develop a "consciousness of active opposition" or an "empowered consciousness," informed by the desire to act collectively to empower others (Charlton, 1998, p. 119).

The remainder of Chapter 5 explores the ways in which collective action, as expressed via *Mighty* articles, reflects three potential contradictory goals informed by various discourses of embodied difference. These goals included (a) fixing "malfunctioning" bodies, (b) validating self-advocate perspectives, and (c) protesting oppression. As a site that publishes stories in support of each of these goals, *The Mighty* pits aspirations for normalcy against critiques of "normal," and places calls for awareness to find treatments and cures alongside calls for acceptance and expressions of disability pride. As a result, *The Mighty’s* site takes on the dialogic character of heteroglossia (Bakhtin, 1981)—it is multi-voiced and double-languaged, placing both individual authors and the ideological systems they embrace in conversation with each other. I have suggested that organizing across tensions linked to varied physical experiences of, and evaluative orientations toward, disability involves embracing ambivalence and ambiguity (Kelly, 2011).

In Chapter 6: Building a Mighty Platform, I sought to answer the question: How does *The Mighty* provide opportunities for both self-advocacy and collective/connective action, even as it amplifies tensions tied to these communicative activities? Essentially, I responded to Ashcraft’s (2006) call for researchers to engaged in the grounded study how organizations and their members “navigate entrenched, habitual contradiction and to what effects” (p. 80). I have applied Gidden’s (1979) structuration theory, as well as variations of structuration theory applied to technology design (DeSanctis & Poole, 1994;
Orlikowski, 1992) to explore how intractable tensions provided the impetus for structuration. Structuration occurred as key stakeholders interacted with and shifted the site’s rules (like its evolving editorial guidelines) and as they used/avoided/redesigned its resources (such as digital features like the personalized newsfeed). Additionally, I have extended Ashcraft’s research on paradoxical hybrid forms, attending to forms of hybridity that shape the Mighty’s organizational structure. These included its status as a social entrepreneurial enterprise, its design as an organizationally-enabled network (Caraway, 2016), and its cross-condition format. I have explored how The Mighty’s staff members attempted to organize contradictions inherent to these hybrid forms, responding to tensions linked to (a) doing good and doing well, (b) inclusivity and selectivity, and (c) universality and specificity. My analysis suggests that, by designing an increasingly customizable, participatory digital experience, Mighty staff members ameliorated some of these tensions by lending users additional agency to interact with the site in ways that reflected their needs and preferences.

Chapter 6 also conceptualizes what I have termed second-tier advocacy. Essentially, second-tier advocacy is a form of allyship which positions the organization itself as an ally. As Charlie explained:

The Mighty is a celebrity, it’s like an influence . . . And when you have a brand that’s well-respected . . . People are malleable, people go with what. And I think that The Mighty is using that for good. It’s a powerful tool that is being used for good in the world.

The Mighty engaged in second-tier advocacy through leveraging editorial expertise to craft and package shareable stories. Additionally, it acted as a second-tier advocate through the process of signal-boosting, rendering contributors’ stories increasingly
visible by using stitching mechanisms (Bennett, Segerberg, & Walker, 2014), such as the non-profit partnership program, to connect otherwise siloed audiences. In doing so, staff members constructed an increasingly massive affective public (Papacharissi, 2016).

Finally, Chapter 7: #CrippintheMighty: Resisting Exploitation, Appropriation, and Censorship, examined why and how disability activists disidentified with The Mighty and organized in protest of the site. By publishing articles that endorsed contradictory discourses of difference and periodically reinforced harmful disability tropes, The Mighty produced a sense of ambivalence in more critical contributors and readers. Through #crippingthemighty, disability activist Alice Wong transformed a single terrible publication choice into a collective critical incident, one which instigated a ripple of repulsion amongst previously ambivalent contributors/readers/observers. This hashtag captured an instance of cyberactivism, one which leveraged the dispersed, idiosyncratic, networked logic of connective action (Bennett & Segerberg, 2013) to “crip” The Mighty’s editorial and organizational practices. Crippling involved publicly exposing the “communicative inversions” inherent to The Mighty’s neoliberal, non-disabled logic. These included reframing “exposure” as exploitation, contending that the site takes digital spaces away from disabled activists rather than providing a new platform, and identifying the ways in which striving for “neutrality” in an ableist world acts as censorship and complicity. Thus, disability activists pushed for dialogue in the Buberian sense between self-advocates and non-disabled individuals who wished to be allies. Finally, I explored ways in which “cripping” inspired Mighty editors to alter their editorial practices and to change hiring practices to center disabled voices. While this
progress was instigated by #crippingthemighty, this hashtag ironically limited future transformation by discouraging Mighty staff members from further consulting its participants.

Theoretical Implications: Social Media

Throughout this dissertation project, I have offered analyses of the ways in which Mighty contributors, organizers, and detractors make use of various social media platforms to engage in refracted and collective self-advocacy, collective action, and connective action in digital spaces. I have referenced Suler’s (2004) conceptualization of the online disinhibition effect to consider how the relatively invisible, somewhat anonymous, typically asynchronous nature of online communication encouraged Mighty contributors to make otherwise secret, private experiences public, rendering their hopes, fears, and frustrations known via published articles. Several contributors described how the act of writing about an encounter allowed them to better articulate complex, confusing, and emotionally fraught experiences for an imagined audience. The online disinhibition effect lent contributors the ability to indirectly confront those who are un- or misinformed, who provide inadequate social support, and/or who engage in ableist behaviors. Indeed, refracted self-advocacy expressed via open letters sometimes constituted a contributor’s initial foray into more direct forms of collective action. James’ experience illustrated how writing one article on The Mighty as a response to the repeated questions he received in his own life lead him to become an “accidental advocate;” he began to envision himself as an advocate in the process of responding to commenters, and expanded his online presence across various social media platforms as he attempted
to reach a wider audience. Further, contributors described how the asynchronous nature of online communication allowed them to engage in advocacy work when that they had both the physical and emotional energy to do so.

Emboldened by the online disinhibition effect, contributors divulged personal details that communicate a sense of authenticity and vulnerability, generating the kind of heightened sense of intimacy that Walther (2007) describes in his hyperpersonal model of computer-mediated communication. *Mighty* editors recognized this as part of the affective pull of contributors’ stories; readers saw the details of their own lives in these articles and began to feel parasocially connected with particular authors, perhaps as they imagined these authors as likeable characters through the process of solipsistic introjection. As readers and contributors formed a network of such affiliative ties, they begin to envision *The Mighty* as a community or “neighborhood” whose members might have shared experiences and interests and, thus, collective goals.

Additionally, I have explored how contributors often thought of *The Mighty* as one outlet in a network of interconnected, digital advocacy/activism efforts. They spoke about how they used various social media platforms to achieve slightly different goals. For instance, some participants described how they used more visual platforms like Instagram to find and build relationships with others who were impacted by similar conditions. In contrast, they used platforms like Facebook to update and educate family

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39 Of course, one might question the extent to which *Mighty* articles are authentic, given that they are filtered through staff members’ editing processes. Do *Mighty* articles represent authenticity, or the illusion of authenticity? Better questions might be: “where do these articles fall along a spectrum of ‘authenticity,’ and who has the power to make that determination?”
members. Twitter was frequently used to engage in advocacy and activism, particularly via hashtag movements such as #betteroffdeadthandisabled (the disability community’s response to the film, *Me Before You*).

For #crippingthemighty participants, *The Mighty* represented a potential threat to the disability culture—especially the politicized, activist nature of crip culture—that had emerged online as self-advocates sought power to shape the discourses surrounding their community. From their perspective, *The Mighty* undercut activists’ ability to make their own work visible in an increasingly crowded digital environment. For contributors, however, publishing on *The Mighty* provided a way to produce narrative digital content that might be shared across interlinked social media platforms. In addition, publishing on *The Mighty* allowed contributors to tap make use of the company’s signal-boosting capacity, offering the possibility that their story would reach beyond their personal social media network to impact broader discussions of disability and chronic illness.

Additionally, some contributors noted that publishing through *The Mighty* meant speaking through a kind of intermediary—a second-tier advocate—rather than speaking directly through their personal blog or through their own social media account. In this way, publishing on *The Mighty* might enhance the online disinhibition effect by adding an additional sense of anonymity and invisibility, while also relieving the contributor of some of the emotional labor of responding the commenters.

Finally, I have explored how the structural affordances embedded in the site itself shape both the way users interact with *The Mighty*, and what *The Mighty* communicates about the nature of disability and chronic illness. For instance, as Alice Wong noted,
organizers’ choice to organize the site’s according to diagnostic categories, rather than around broader themes, reinforces the biomedical model and encourages contributors/readers to position themselves with relation to a narrow, condition-specific collective identity. At the same time, the choice to differentiate “disability,” “chronic illness,” and “rare disease” on the site offers slightly broader collective identity categories while also preserving the blurry, contested lines between these designations. Indeed, *The Mighty’s* organizers must decide which stories fit where, arranging their position on the site and in its search engine archives by tagging them with hyperlinked designations. Further, the decision to prominently feature certain conditions, such as autism, Down syndrome, anxiety, and depression, communicates the idea that these conditions are priorities for *The Mighty*, even as staff members emphasize the company’s intent to be inclusive. However, as *The Mighty’s* staff members develop features like the ability to follow particular contributors, to build a personalized newsfeed, and to contribute to themed discussions on hub pages, the site offers new opportunities to navigate between narrow and broad collective identities, and to consider how topics might transcend condition-specific categorizations. I have referenced DeSanctis and Poole’s (1994) adaptive structuration theory to consider how, in the process of interacting with *The Mighty*, users can reshape the site’s structure by interacting with or avoiding certain types of stories and particular features. These and other findings might be applied to various practical ends, and offer potential avenues for future research.
Practical Implications

This research offers a series of practical implications. First, this project illustrates how storytelling communities, like *The Mighty*, can serve as sense-making interventions for people who have been newly-diagnosed with a condition, or for people who are facing new forms of PI in responses to experiences of diagnostic, physical, and social flux. Indeed, Mike Porath envisions equipping healthcare facilities with tablets that would allow individuals to access the site soon after receiving a diagnosis. By crowdsourcing knowledge via storytelling, communities like *The Mighty* offer rich accounts of life with various conditions to fill gaps left by medicalized, jargon-filled descriptions of diagnoses present on sites like *WebMD*. Further, by crowdsourcing informational advice and expressions of emotional and appraisal support, sites like *The Mighty* can foster a sense of individual and collective self-efficacy in would-be self-advocates. Readers of such sites might be better equipped to respond with resiliency to physical impairments, inaccessible environments, and invalidating interpersonal encounters. Additionally, crowdsourcing medical information provides self-advocates with an alternative resource to counter healthcare professionals’ inherently uncertain, partial knowledge—particularly in cases where individuals have rare, difficult-to-detect, or overlapping conditions that may remain undiagnosed, misdiagnosed, or underdiagnosed.

Relatedly, these research findings have implications for healthcare professionals. For instance, my participants described numerous traumatizing instances of epistemic invalidation, most clearly illustrated in my discussion of re-narrating the past, where their
concerns were doubted or discounted by doctors and others. They shared the confidence-eroding impact of being constantly questioned by others. For instance, Cindy described being “crushed” and driven “underground” by a doctor who told her that she was “fat and lazy,” constraining her ability to engage in self-advocacy. Sakari described the victim-blaming she experienced in the course receiving treatments for mental health challenges, recounting: “When I said, ‘this isn’t working,’ they said I wasn’t trying hard enough.” Sites like The Mighty can expose healthcare professionals to patients’ perspectives, helping them to empathize with patients and value their status as knowers. For instance, Mike Porath emailed a link to a video and article created by speech-language pathologist, Dr. Raj (2016), which described how reading articles written by self-advocates and parents helped him to understand what his clients craved as part of their interactions with him. Further, open letters to healthcare professionals that have been published via The Mighty provide patients with the language they may need to counter the threat of epistemic invalidation.

This project also adds to research by media scholars, like Beth Haller, to outline the ways in which the mainstream publishing industry might perpetuate, or resist, ableist disability tropes. The Mighty’s use of evolving, co-created editorial guidelines provides a useful blueprint for thinking about how media companies might remain responsive to shifting tensions of representation tied to both disability generally and to specific conditions. However, this case study also offers a cautionary tale. It illustrates how jumpstarting a disability-related site by relying on parent voices and journalistic expertise may de-center self-advocate perspectives and communicate complicity in a history of
misrepresentation. Those looking to organize and to develop digital content in this context should focus first on gathering perspectives from well-regarded advocates and activists in the community—especially by hiring disabled writers and editors.

Contributors and detractors also offered practical advice for *The Mighty* itself. This included developing digital tools to allow contributors to track their articles’ spread, offering clearer explanations of editorial changes, hosting interactive editing workshops, providing resources to emotionally prepare contributors for potential criticisms of their articles, and pairing parent writers with self-advocate mentors to prevent unintentional appropriation and oversharing. Contributors also recommended that *The Mighty* strategically rotate the attention and space it devotes to individual conditions, perhaps using a “condition spotlight” section on the site to draw attention to articles that otherwise might get “lost in the shuffle” of more popular articles. Building on this idea, I would advise the *The Mighty* to take a critical look at how layout choices, like the choice to highlight only certain *Mighty* Facebook communities on the site’s main page, communicate the site’s priorities in ways that may discourage potential readers/contributors. *The Mighty*’s staff members might also attend to Alice Wong’s observation about how organizing the site around diagnoses medicalizes differences and fragments the community. As *The Mighty* moves forward in creating its community hub pages, its staff could focus on organizing content around day-to-day experiences and holistic themes like “education” and “discrimination.” Creating these categories will require close consultation with self-advocates. Lastly, *The Mighty* might consider the ways in which its current digital features remain inaccessible. How might more visual
forms of storytelling be used to empower those who are nonverbal or who may be unable to write articles that meet *The Mighty’s* standards for publication? How might *The Mighty* incorporate additional elements of accessible web design, such as the use of image descriptions and enlargeable text, to ensure that those with a variety of impairments can interact with the site?

This research also has practical implications for those who wish to generate social movements in the context of disability and chronic illness. It suggests that providing individuals with opportunities to engage in refracted and collective self-advocacy might initiate the processes by which individuals begin to imagine themselves as members of a biosocial community. These communicative activities take small steps toward moving disability out of the private sphere and into the public world—a pre-requisite for collective action. Further, as Alice Wong explained, making disability history increasingly accessible and prominent online and elsewhere might enable individuals to situate themselves as “part of something bigger,” offering a scaffolding for sense-making that depicts disability as a shared, rather than a (purely) individual, experience. Further, this research hints at the ways in which movement organizers might strategically activate narrow or broader collectives by shifting between a focus on condition-specific physical experiences and the recognition of systemic sources of social injustice. Creating and invoking specific terms, such as “Crohnie,” “zebra,” and “crip,” provide shorthand ways to accomplish this. As illustrated here, Alice Wong’s decision to use the term “cripping” called forth a collectivity united in their identification with crip culture and their politicized commitment to identifying and countering ableism.
Finally, this research provides practical application for organizations contending with the contradictory interests inherent to paradoxical hybrid forms. Much can be learned from observing the ways in which The Mighty’s organizers (re)designed the digital features of their site to satisfy users’ different, sometimes divergent, needs. Other organizations might similarly develop technological resources that allow key stakeholders greater agency to navigate toward their preferred pole of an intractable dialectic.

**Limitations**

Any research project is inherently partial and shaped by the researcher’s standpoint. As such, it is important to acknowledge the limitations of this work. First, this project is limited by my personal standpoint as a neurotypical, non-disabled, white, linguistically and educationally privileged woman whose training is grounded primarily in communication studies. My non-disabled status makes it difficult for me to recognize ableist assumptions that may be embedded in the language and structure of this project. Further, like The Mighty’s editors, I have struggled to decide between using various terms and phrases that have political significance for different members of the disability community. For instance, I have made the decision to use person first language throughout most of the dissertation, given that some contributors—particularly those with a chronic illness—wish to be seen as people, independent of biomedical categories. At the same time, I recognize that those who have cultivated a sense of disability pride often prefer identity first language, claiming disability as a culture and political constituency.
Additionally, as primarily a communication studies scholar, I have only begun to learn about the ways in which disability studies scholars theorize about disability identity and representation. While I have cited disability studies scholars such as Charlton, Davis, Shakespeare, Linton, and Wendell in this project, I acknowledge that I have only a cursory grasp of this field. A grounded approach to research has helped me to stay accountable to the disability community; I have foregrounded my participants’ voices, especially those of activists like Alice Wong, to focus on the discourses they embrace and the work that their communication accomplishes in the context of *The Mighty*.

Second, this research is limited in that the articles that comprised the main corpus of my dataset capture just a two-month span of *The Mighty’s* publication activity. This approach to data collection provides a limited sense of the ways in which *The Mighty’s* publishing practices changed over the course of the company’s short lifespan. However, as described in the methodology chapter, I did follow several *Mighty* Facebook pages during the year I spent conducting this research. This gave me some ability to track the ways in which publishing trends evolved in the time that I was working on this project.

Third, while I was able to directly email *Mighty* contributors to invite their participation in this study, I received the initial list of contact information from the editors themselves. As such, I had to rely on them to curate this list—a list that I had hoped would capture people who were both prolific and one-time contributors, and people who endorsed and were critical of the site. The editors used the sorting tools available in Excel to construct a list that would reflect these criteria, but it is possible that their knowledge of the contributors shaped which names made it onto the final list.
However, judging from the variety of perspectives captured in my dataset, I do believe that I have compiled a decent cross-section of *Mighty* contributor types. Of course, my corpus of interviews does not capture the broad range of conditions included on *The Mighty*’s site.

Fourth, for this study I have purposefully avoided interviewing or reading articles written by parents or other non-disabled allies. Instead, I focused primarily on self-advocate perspectives. However, parent perspectives play an important role on the site, particularly in the ways that these stories either speak *with* or *for* people with disabilities and reinforce or resist ableist narratives. I have also not included interviews with or articles by contributors with mental health conditions. In part, this decision stemmed from a pragmatic recognition of my own time and energy limits. However, it also reflects the sense that mental health conditions mobilize their own distinct set of discourses, further complicating an analysis focused on the communicative constitution of disability. In recent months, however, stories about mental health conditions have comprised a large percentage of the articles published on *The Mighty*. Exploring both mental health’s fraught relationship to both disability and chronic illness, as well as its growing presence on *The Mighty*, is one of many directions for future research.

**Directions for Future Research**

This project suggests myriad avenues for further study. I have already suggested that attending to mental health content on *The Mighty* will be an important next step in this project. Relatedly, I am fascinated by two addition sub-communities present on the site: rare disease and “undiagnosed.” I imagine that both of these circumstances offer
fruitful contexts in which to study phenomena such as the experience of PI, epistemic (in)validation, and self- and collective advocacy. Individuals who are persistently undiagnosed or who have a rare disease continually encounter the limitations of biomedicine, unsettling the myth of control. Wendell (1996) describes this as particularly vulnerable position: “No matter how trustworthy you are now, you need only contract a rare or previously unknown illness to become a suspect witness and to have your sanity questioned” (p. 126). Future research might consider how people who are undiagnosed or who have a rare condition communicate to counter others’ doubts about their illness claims—or, alternatively, communicate in ways that undercut their bids for social support. Further, this research might explore how these contexts unsettle the traditional power dynamics in doctor-patient relationships, requiring more egalitarian partnerships.

Second, I am interested in exploring other case studies which capture approaches to cross-condition organizing. What are some of the collective action frames (Poletta & Jasper, 2011) that creators and members of such organizations draw on to justify broader organizing? How do organizers contend with tensions tied to building a more inclusive organizational framework? How do these organizations position themselves in relation to other social movements?

Third, I intend to study additional examples of disability cyberactivism, and the potential for connective action to “crip” non-disabled digital spaces. For example, while I have explored the impact of #crippinthemeighty here, and have published research on #boycottautismspeaks, these case studies have primarily focused on Twitter as a tool for resistance. In the future, I would like to consider how disability activists make use of
multiple, interlinked social media platforms to constitute collectivities and to coordinate efforts to achieve a shared goal. This research necessarily requires focusing on the ways in which digital media remains inaccessible to some people with disabilities (see Elcessor, 2016).

Finally, I would like to pursue the recurrent theme of emotional labor as tied to self-advocacy, allyship, and collective action. What causes advocates, activists, and allies to experience burnout? What strategies do they use to prevent burnout? How do they respond to criticisms of their publicized personal narratives? How might second-tier advocates like The Mighty equip individuals with the tools they will need to engage in vulnerable work in digital spaces that can never fully be “safer spaces?” I touch on some of these themes while offering some final, personal reflections on the nature of academic allyship.

Some Personal Reflections on Academic Allyship

I wake with a jolt in the cobalt dawn. My heart is beating bloodied fists against the bars of its bone cage, trying in vain to escape the insidious, grasping fingers of Self-Doubt. Those fingers have already woven themselves into the folds and fissures of my brain, sundering synaptic connections. Neurons flicker and flare like downed powerlines, casting a lurid glow that renders once-familiar thoughts alien, strange. I cannot move. I cannot stop moving. I feel like I weigh a thousand pounds, even though my body shrinks as I pace, pace, pace around my tiny, lonely apartment. I reach compulsively toward my phone, but I’m not sure who to call. Mom and Dad? Kevin? Austin? JW? Patricia? But I
have called each of them too many times. I dread hearing the echo of my own despair in their words: “I don’t know what to say.”

***

Throughout this dissertation project, I have referenced participants’ admissions that advocacy, activism, and allyship require significant emotional labor (Hochschild, 1979; Tracy, 2000). As a researcher, I also aspire to act as an ally. I recognize that my privileged position as an academic—as a person afforded a legitimized platform from which to spout knowledge claims—comes with an ethical obligation to center marginalized voices and to avoid complicity in ableism and other forms of oppression. However, as Des Roches Rosa et al. (2015) put it, “disability advocacy is really damn hard, and kind of a minefield” (para. 19). During my visit to The Mighty’s Burbank offices, I empathized with editors, like Anna and Rachel, who described the overwhelming sense of responsibility attached to “getting it right,” and the immobilizing fear of “getting it wrong.” I felt these acutely as I began this dissertation project, heightened by the “imposter syndrome” common among fledgling (and experienced) academics. I also grappled with my own ambivalence toward The Mighty. I recognized it as a potentially valuable resource for the disability community and a rich site for study, while also absorbing #crippingthemighty criticisms and reading the “icky” articles mixed in with empowering content. This experience of PI trapped me in a downward-spiraling thought loop, making any forward movement seem impossible. In this, the conclusion of my dissertation, I claim these challenges to consider the sometimes emotionally fraught nature of academic allyship. I illustrate the danger of centering others’ perspectives in
ways that obliterate the individual and consume the self, especially when engaging with complex, politicized, and contentious contexts.

***

The musical tones of a Facebook messenger notification pull my attention away from the blinking cursor on my computer screen. “How are you, Sweetie?” It’s another message from Aunt Karen. I talk with her almost daily now. Periodically, I have long phone conversations with Aunt Jane. I have never spoken with my aunts in this way before—talking directly about things that make us feel vulnerable and inadequate. We share stories of our respective mental health challenges. We know that sometimes it’s ok for sentences to have raw, unfinished edges. We find that we now have access to a shared vocabulary where, before, we struggled wordless and alone. These renewed and deepened connections with my aunts are unexpected gifts. They are windfalls knocked loose by the tempestuous gales of anxiety and depression.

***

I have long been interested in how individuals communicate to construct collective identities, and to regain a sense of agency and resilience in the face of identity threats. As this narrative illustrates, learning how to situate myself as part of a collective became vitally important to overcoming a pervasive sense of isolation and alienation. My aunts helped me to recognize that I was not truly alone in my experiences. The new sense of connection I developed through my conversations with them mirrors connections contributors and readers experience when they read resonant stories on The Mighty.
Additionally, telling this narrative illustrates a shift in the kinds of metaphors I used to make sense of my experiences with anxiety and depression. I moved my focus away from metaphors of destruction, brokenness, burden, and hijacking to make use of terms like “gift” and “windfall.” This narrative move reflects new discursive resources that became available to me over time, as both my cognitive state and the social responses to my distress shifted across time.

***

“I’m writing again . . . roughly speaking. Really, I am curled up on Stephanie’s couch eating homemade Easter candy gifted by her neighbors. She’s sitting in the chair across from me, working on revising a manuscript. Stephanie’s presence lends me energy to undertake the meticulous work of smoothing out crumpled thoughts. I retrieve them from where they have been heaped, haphazardly, in the bin of my mind—a bin some mean-spirited prankster has mislabeled “garbage.” There are thoughts worthy of being recycled in here. There are thoughts that are nearly brand-new, still wrapped in their awkward, lumpy packaging. Through this process of un-crumpling old thoughts, I find the courage to create new ones.

***

“When you’re going through stuff, you’re not always thinking clearly, because you’re in the middle of it,” Jo told me. “[Writing] lets you put it down, and say it, and then deal with it.” As an academic, writing’s status as a therapeutic sense-making tool is not so clear-cut. Writing was both the source of my anxiety and a means of liberation from it. I have been trained to write as I have done here—to transform my personal
experiences into fodder for theorizing and for statements of positionality. Consequently, the process of writing feels like standing in high heels, waiting for the curtain to go up, rather than standing in slippers, waiting for the tea to boil. To write this dissertation, I needed to be ok with going barefoot—with being vulnerable.

***

“Who here has a dream?” bravery coach, Jason Freeman, asks his audience. I raise my hand while thinking about the confluence of events that has brought me here to this dorm meeting room at San Diego State University. I met Jason by chance at Triple Crown, the local watering hole our mutual friend had selected as the site for her birthday celebration. Shouting over bar noises and beer glasses, we chatted about our shared interest in teaching public speaking. After learning about the general trajectory of my research, Jason asked, “Have you heard about The Mighty? It’s a site I’ve written several articles for.” Jason could not have known that I was, at that moment, struggling to settle on this site as the context for my dissertation research. Yet, several months later we met at a local Starbucks to talk about disability narratives and the power of self-authorship. I connected Jason to a colleague at SDSU, setting in motion the logistics behind the current speaking engagement.

I smile ruefully as Jason describes a giant Rubbermaid bin half-buried in his closet—the one containing all the unpublished manuscripts he has hidden away from potentially critical eyes. It seems we both have literal and metaphorical bins filled with crumpled thoughts. Jason describes how we short-change ourselves by not taking that first, most vulnerable step toward a dream. “Embrace your imperfect best,” he advises
us. I try to internalize Jason’s advice as I write job application after job application, flinging the seeds for my future into the unpredictably fertile universe.

***

Meeting with Jason and watching him speak, I began to think more about the ways in which embracing vulnerability allows others to be vulnerable and, in the process, experience validation. I learned this lesson repeatedly in talking to participants in this research. Mighty staff members talked about how publishing “real people. real stories” initiated a cycle of sharing, prompting readers to become contributors. They also described how, after reading the very personal reflections captured in contributors’ submissions, they felt compelled to respond with small details about their own experiences. “It might be a little bit selfish but I think I get something out of it,” Anna said. “I want them to know that I get it. . . . I also think that I get a little benefit from it too because then I can just give a little bit of myself in that as well.” Similarly, contributors spoke about publishing their story in the hopes that it would allow others to tell their own. As communication scholars, we might refer to this as a form of reciprocal self-disclosure. Yet, this framing seems to understate the healing properties of being reciprocally vulnerable.

Facebook messenger pings again; it’s a message from Jason. I wonder if he is following up on last week’s Skype meeting, where we had brainstormed strategies to publicize his brand-new book, Awkwardly Awesome.40 We had also talked about my

progress on the dissertation project. I’d sent him a draft of my first analysis chapter, which spoke to our common fascination with self-authorship and identity construction.

“Hi! I’ve started reading the chapter and your writing is simply lovely,” Jason wrote, “I feel more that I’m reading an expertly put together collage of rich and important stories than a dissertation. That’s really, really hard to do.” His message reaches me as I sit on a couch on the seventh floor of Ohio University’s Alden Library, walled in by both the building’s ugly cinderblocks and by the final barriers to dissertation defense. Jason’s words buoy my floundering spirit as I write to unravel interconnections of allyship, appropriation, and dialogue.

***

In the process of conceptualizing allyship, I have written my way to a clearer understanding of what it might mean to act as an academic ally. It involves leaning into discomfort by reaching for more participants and unfamiliar literature; it requires centering participants’ perspectives by creating, in Jason’s words, a “collage of rich and important stories”; it means using my access to various platforms—the classroom, conferences, academic publications, the popular press—to sign-boost marginalized narratives. However, this description of allyship preserves a sense of paternalism, reifying a dichotomy between “people who are privileged” and “people who are ‘Other.’” This kind of framework can cause us to overlook the importance of interdependence. Interdependence is reflected in Sakari’s vision of “pan disability” advocacy, driven by the recognition that “while [others’] experiences and limitations are very different than mine, I’m really moved by the challenges they face.” She illustrated this approach by describing
what it would mean to go shopping with a friend who uses a wheelchair. She can drive them to the store, and he can assist her in making sense of speech and other sounds that her brain has trouble processing. Similarly, interdependence involves recognizing each individual’s unique sources of power and privilege, and also their sources of physical impairment and social marginalization. Equity hinges on interdependency; we flip between acting as a self-advocate and as an ally, between being an individual and participating in a collective. Vulnerable and strong, we stand in solidarity to structurate a more inclusive world.
References


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Boka, K. (May, 29, 2016). To the doctor who said my gastroparesis was “all in my head.” Retrieved from http://themighty.com/2016/05/to-the-doctor-who-didnt-believe-i-had-gastroparesis/


Cerrone, J. (July 12, 2016). When I told a TSA agent that I was disabled and he said “No you’re not.” Retrieved from http://themighty.com/2016/07/when-a-tsa-agent-wouldnt-let-me-through-disabled-security-line/


Dix, R. (June 1, 2016). 7 things that blindsided me when I became ill. Retrieved http://themighty.com/2016/06/unexpected-side-effects-of-chronic-illness/


Giddings, R. (June 3, 2016). I can walk, but that doesn’t mean I don’t need a wheelchair. Retrieved from https://themighty.com/2016/06/learning-to-accept-wheelchair-use-with-a-chronic-illness/


Hamoline, M. (May 31, 2016). We shouldn’t have to tell strangers we’re sick while traveling—but we need to. Retrieved from http://themighty.com/2016/05/advice-for-traveling-with-lyme-disease/


doi:10.1188/12.cjon.408-412


Jablonski, A. (June 13, 2016). When a doctor told me “helping others with my condition should be left to trained professionals.” Retrieved from https://themighty.com/2016/06/patient-advocacy-for-short-bowel-syndrome/


Jordan, L. S. (January 6, 2016). Writing for The Mighty, for my son and with my son. Retrieved from


McKnight, J. (June 1, 2016). When my doctor gave me a lifetime diagnosis at 17. Retrieved from https://themighty.com/2016/06/accepting-an-addisons-disease-diagnosis-in-your-teens/


Meadowlark, C. (June 7, 2016). When I realized I don’t have to “get better” to be ok. Retrieved from http://themighty.com/2016/06/learning-to-appreciate-life-while-facing-chronic-pain/


Olson, K. (2011). Essentials of Qualitative Interviewing. Walnut Creek, CA: Left Coast
Press.


Schultz, K. (March 29, 2017). An open letter to The Mighty on their continued support of the hate group Autism Speaks. Retrieved from

https://medium.com/@KirstenSchultz/the-mighty-autism-speaks-part-deux-d125f0f1041


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https://storify.com/SFdirewolf/crippingthemighty


https://disabilityvisibilityproject.com/2016/01/27/cripthevote-our-voices-our-vote/

Wong, A. (January 31, 2016). Dear Julianna: Interview with Emily Wolinsky and Laura Halvorson, part one. Retrieved from


Wong, A. (December 20, 2016). #CripplingTheMighty 1 year later: Disabled writers on publishing. Retrieved from

https://disabilityvisibilityproject.com/2016/12/20/crippingthemighty-1-year-later-disabled-writers-on-publishing/


Young, S. (2014). I’m not your inspiration, thank you very much. Retrieved from

https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript?language=en

Young, T. (July 12, 2017). Why it’s not my job to be your “inspiration.” Retrieved from


Appendix A: Founder Interview Guide

Hello __________. Thanks again for agreeing to participate in this interview. As you know, I am interested in understanding how your communication with others both inspired and allowed you to organize your advocacy efforts surrounding HEALTH CONDITION. You’ve read through the consent form I emailed to you and you know that you can decline to answer any question or end the interview at any time. You will be assigned a pseudonym so that your identity will remain confidential. Do you have any questions before we begin? Is it alright if I recording the audio of this interview?

Ok, we’ll start with a few basic questions before moving on to more open-ended ones.

Organization Background Questions:
1.) Please describe the health condition your organization works to advocate for.
2.) What relationship, if any, do you have to this health condition?
3.) What would you say are the main goals or objectives of the organization?
4.) Can you tell me the origin story for your organization? How did the organization come to be?
   a. When was this organization founded/about how long has this organization existed?
   b. How old were you when you founded the organization?
5.) How does your organization work on a day-to-day basis? How does stuff get done?

Questions about the Organization of Advocacy: Now that I have a general understanding of what your organization is like, I’d like to get a deeper understanding of how your interactions with others lead you to organize your advocacy efforts.

1.) Why did you decide to develop an advocacy organization?
   a. Was there a moment when you knew you needed to form this organization? If so, what flipped the switch?
2.) Why didn’t you just join an existing organization (if one was available)?
3.) Think back to the very beginning days of developing this organization. What were the first steps you took to make this organization a reality?
4.) Tell me about some memorable conversations that inspired you to develop this organization.
   a. Who did you talk with and what did they tell you?
5.) If applicable, tell me about an interaction (or several interactions) that frustrated or angered you and strengthened your resolve to develop this organization?
   a. Who did you interact with and what happened?
6.) No everyone starts up an advocacy organization. What do you think made it a possibility for you?
7.) What aspects of your identity (values, past experiences, personality) made you think that creating this organization was a possibility?
8.) What were some turning point moments where you began to see yourself as a
member of an organization, rather than as an individual advocate?
9.) Do you feel like the organization has become bigger than you? How do you know?
10.) What has been your most memorable experience in starting this organization?
11.) What surprised you most about starting this organization?
12.) If you could go back to the beginning, what advice would you give yourself?
13.) Is there anything else you think I should know about how you moved from an individual advocate to advocating collectively as part of this organization?

Those are all of the questions I have for you. Thank you for agreeing to speak with me! Your answers were quite helpful. If you think of anything else, please feel free to email or call me. Would it be alright if I followed up with you to clarify what you told me at a later date? If you have any contacts at other organizations who might be interested in speaking with me, could you send them the study information and my contact information?
Appendix B: Letter of Approval from The Mighty

Dr. Chris Hayhow  
Director of Research Compliance  
Ohio University RTEC 117  
Athens, OH 45701  
(740) 593-0664  
hayhow@ohio.edu

Dear Dr. Hayhow:

The purpose of this letter is to grant Sarah Parsloe, a doctoral student at Ohio University, permission to conduct research with The Mighty in Los Angeles, California. The research project, “Real People. Real Stories: Self-Advocacy and Collective/Connective Action on the Digital Platform, The Mighty” entails Ms. Parsloe visiting our offices, interviewing consenting staff members about their experiences of working with the company, and interviewing consenting contributors who write articles for the site.

I acknowledge that participants will be assured of their rights to privacy and confidentiality, and I understand that these rights will be secured, in part, by obtaining the written or oral consent of each participant. I also understand that staff members and contributors will not be financially compensated for their participation and may withdraw from the study at any time. Ms. Parsloe and I will negotiate how we will recruit participants for the study. I understand that once the members have agreed to participate that she will be responsible for arranging the interviews with participants.

I, Mike Porath, do hereby grant permission for Sarah Parsloe to conduct her study with The Mighty.

Sincerely,

[Signature]

Mike Porath  
Founder, CEO  
The Mighty  
213-379-2407  
mike@themighty.com
Appendix C: Mighty Staff Member Interview Guide

Hello __________. Thanks again for agreeing to participate in this interview. As you know, I am interested in your experiences as a staff member for The Mighty. You’ve read through the consent form I emailed to you and you know that you can decline to answer any question or end the interview at any time. You will be assigned a pseudonym so that your identity will remain confidential. Do you have any questions before we begin? Is it alright if I record the audio of this interview?

Great! Let’s get started. First, let’s talk about a bit about your own relationship to the topics The Mighty covers.

1.) Would you tell me about your personal connection to disability, chronic illness, mental health conditions, or rare diseases? What inspires your work with The Mighty?
   a. Potential follow-ups for staff members with a disability or chronic illness:
      i. When did you learn that you were impacted by [condition]?
      ii. What is [condition]?

2.) In your own words, how would you describe what it means to have a [term used above]?

3.) Would you describe yourself as an advocate for [condition]?
   a. In your own words, define what it means to be an advocate.
   b. How did you come to think of yourself as an advocate OR why don’t you view yourself as an advocate?

4.) Do you see yourself as a member of a community of people with [condition]?
   a. Could you share an experience or set of experiences that made you feel this way? OR Why not?
   b. What about as a member of a larger disability community OR chronic illness community?

Now, we’ll move on to some questions that more specifically address your work with The Mighty.

5.) Tell me the story of how you came to work at The Mighty.

6.) How would you describe the nature of what The Mighty does?

7.) Given what you know of your contributors, what do you think are some of the reasons that they write for The Mighty?
   a. Can you outline the strategies you use to encourage writers to contribute to The Mighty?

8.) Could you walk me through the process of selecting stories for publication?
a. What do you look for?

b. What doesn’t make the cut?

9.) What would you say are some of the most meaningful aspects of your job?
   a. Perhaps you could share a memorable story about an experience that you have had as a result of working with *The Mighty*.

10.) Could you describe some of the stories that you’ve read while working for *The Mighty* that impacted you the most?

11.) What would you say is the most challenging aspect of your job?

12.) What would you say are some of the challenges you face in making editorial decisions for *The Mighty*?
   a. Can you share the story of a difficult experience you had a result of publishing a story?

13.) Since you’ve come to work for *The Mighty*, how has the organization evolved?
   a. Where do you envision it going next?

14.) Think back to when you first started at *The Mighty*. What do you wish you had known?

15.) What do you think are some of the challenges *The Mighty* faces as an organization?

16.) If you could make any improvements to *The Mighty*, what would they be?

17.) I’m sure there’s something I haven’t thought to ask, so I’ll ask you: is there anything else you think I should know about your experiences as a *Mighty* staff member?

Those are all of the open-ended questions I have for you. I’d just like to wrap up with a few demographic questions. Your answers to these questions will help me to report a general description of who I’ve included in this study. Again, let me know if you’d like to skip any of these.

18.) What is your age?

19.) What ethnicity do you identify with?

20.) What gender pronouns do you prefer?

21.) I’ll be using a fake name to refer to you in this study. What would you like to name yourself?

Thank you again for agreeing to speak with me! Your answers were quite helpful. If you think of anything else, please feel free to email or call me. Would it be alright if I followed up with you to clarify what you told me at a later date?
## Appendix D: Mighty Staff Member Participant Job Titles

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<tr>
<th>Mighty Staff Member Participant Job Titles</th>
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<tbody>
<tr>
<td>Community Manager</td>
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<tr>
<td>Director of Community Partnerships</td>
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<tr>
<td>Editorial-Chronic Illness</td>
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<tr>
<td>Editorial-Contributors</td>
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<tr>
<td>Editorial-Contributors</td>
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<td>Head of Product</td>
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<tr>
<td>Senior Editor</td>
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<tr>
<td>Video Producer</td>
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Appendix E: *Mighty* Contributor Recruitment Email

Hello,

My name is Sarah Parsloe, and I am a doctoral student at Ohio University. My work focuses on communication surrounding disability and chronic illness. I’m conducting my dissertation research on the ways in which people make use of digital spaces to share their experiences and/or advocate for themselves and others.

As you know, *The Mighty* provides people impacted by a disability, chronic illness, mental health condition, or rare disease with a digital platform to share their story. I’m interested in learning about your experience as a contributor. What did you hope to accomplish by writing? Why did you decide to partner with The Mighty?

I hope that you might be willing to participate in my dissertation project by completing an interview with me. I’d like to include a variety of perspectives, and to speak to people who are highly active contributors, those who write only periodically, and those who have chosen not to continue writing, for whatever reason.

Interviews will be conducted via phone (xxx-xxx-xxx), Skype (sarah.parsloe), or Google Hangout (sarah.parsloe@gmail.com), using whatever features are most accessible for you. They typically last one hour.

You should know that *The Mighty* is aware of my research and is enthusiastic about receiving feedback. You should also know that your participation will be confidential—none of *The Mighty’s* staff members will be able to link you to the research results. Your comments will be published under a pseudonym.

If you are interested in participating, please email me at sp190313@ohio.edu and let me know when you are available (including time zone) and how you would like to conduct the interview. I’m on Pacific Standard Time, and my schedule is pretty open! I have also attached the consent form, which provides additional information about the project. Please feel free to reach out with any questions!

I hope to chat with you soon,

*Sarah Parsloe*
*Doctoral Candidate, Graduate Teaching Assistant*
*Scripps College of Communication, School of Communication Studies*
*Health Communication*
*Ohio University*
Appendix F: *Mighty* Contributor Interview Guide

Hello __________. Thanks again for agreeing to participate in this interview. As you know, I am interested in your experiences as a contributor to *The Mighty*. You’ve read through the consent form I emailed to you and you know that you can decline to answer any question or end the interview at any time. You will be assigned a pseudonym so that your identity will remain confidential. Do you have any questions before we begin?

Is it alright if I record the audio of this interview?

Great! Before we begin, is there a name that you’d prefer to use as your pseudonym?

Ok, let’s get started:

1.) What condition or conditions do you write about for *The Mighty*?
   a. Potential follow-ups: When did you learn that you were impacted by [condition]?

2.) What is [condition]?
   a. What terms do you prefer to use to describe it, i.e. is it a “condition,” a “syndrome,” a “disability,” a “chronic illness”
   b. How did you to decide to identify yourself with this term instead of with another?

3.) In your own words, how would you describe what it means to have a [term used above]?

4.) How would you say that having [condition] impacts your life?

5.) I know that not everyone chooses to speak so openly about [condition]. How did you decide to write publicly about your experiences?

6.) What do you see as the purpose of your writing?

7.) Would you describe yourself as an advocate for [condition]?
   a. In your own words, define what it means to be an advocate.
   b. How did you come to think of yourself as an advocate OR why don’t you view yourself as an advocate?

8.) Do you see yourself as a member of a community of people with [condition]?
   a. Could you share an experience or set of experiences that made you feel this way? OR Why not?
   b. What about as a member of a larger disability community OR chronic illness community? Now, we’ll move on to some questions that more
specifically address your role as a *Mighty* contributor?

9.) How would you describe the nature of what *The Mighty* does?

10.) How did you decide to publish your stories on *The Mighty*? Tell me the story behind this decision.

11.) Could you describe what you experience as a *Mighty* contributor has been like?
   a. Perhaps you could share a memorable story about an experience that you have had as a result of working with *The Mighty*.

12.) Have you encountered any challenges in deciding to make your story public? What were they?

13.) Imagine that *The Mighty*’s staff members were to ask you to give feedback on what the organization could do better. What might you tell them?

14.) Have you written about [condition] in other venues? If so, where?

15.) Do you participate in any other activities related to [condition]? What are they?

16.) How would you describe the role that social media has played in your life as a person with [condition]?

17.) Is there anything else you think I should know, either about your identity as a person with [condition], the motivations behind your writing, or your experiences as a *Mighty* contributor?

Those are all of the open-ended questions I have for you. I’d just like to wrap up with a few demographic questions. Your answers to these questions will help me to report a general description of who I’ve included in this study. Again, let me know if you’d like to skip any of these.

1.) What is your age?
2.) What ethnicity do you identify with?
3.) What gender pronouns do you prefer?
4.) How would you describe your socioeconomic status? i.e. lower income, middle class, upper class
5.) Are you employed?

Thank you again for agreeing to speak with me! Your answers were quite helpful. If you think of anything else, please feel free to email or call me.

Would it be alright if I followed up with you to clarify what you told me at a later date?

Do you know of any fellow contributors who might be interested in speaking with me? (provide contact information)
## Appendix G: *Mighty* Contributor Interviewee Conditions

<table>
<thead>
<tr>
<th>Condition <em>Mighty</em> Contributor Had/Identified With</th>
<th>Number of Interviewees with Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced stage lipedema/stage 4 lipodermphedema</td>
<td>1</td>
</tr>
<tr>
<td>Ankylosing Spondylitis</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2</td>
</tr>
<tr>
<td>Attention Deficit Disorder</td>
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**NOTE:** Several participants reported multiple conditions
Appendix H: Detractor Interview Guide

Hello __________. Thanks again for agreeing to participate in this interview. As you know, I am interested in your participation in #crippingthemighty. You’ve read through the consent form I emailed to you and you know that you can decline to answer any question or end the interview at any time. You will be assigned a pseudonym so that your identity will remain confidential. Do you have any questions before we begin?

Is it alright if I record the audio of this interview? First, I’d like to get a sense of your personal connection to disability.

1.) What condition or conditions do you have?
   a. Potential follow-ups: When did you learn that you were impacted by [condition]?

2.) What is [condition]?
   a. What terms do you prefer to use to describe it, i.e. is it a “condition,” a “syndrome,” a “disability,” a “chronic illness”
   b. How did you to decide to identify yourself with this term instead of with another?

3.) In your own words, how would you describe what it means to have a [term used above]?

4.) Would you describe yourself as an advocate/activist for [condition]?
   a. In your own words, define what it means to be an advocate/activist.
   b. How did you come to think of yourself as an advocate/activist OR why don’t you view yourself as an advocate/activist?

5.) Do you see yourself as a member of a community of people with [condition]?
   a. Could you share an experience or set of experiences that made you feel this way? OR Why not?
   b. What about as a member of a larger disability community?

6.) How would you describe the role that social media has played in your life as a person with [condition]?

7.) I know that not everyone chooses to speak so openly about [condition]. How did you decide to write publicly about your experiences?

8.) What do you see as the purpose of your writing?

Let’s talk a bit about The Mighty itself:

1.) How would you describe the nature of what The Mighty does?

2.) Did you ever write for The Mighty in the past?
   a. Yes:
      i. Could you describe what you experience as a Mighty contributor was been like?
      ii. Perhaps you could share a memorable story about an experience that you had as a result of working with The Mighty.

3.) Take me back to when you first learned about The Mighty.
a. From then until now, how have your perceptions of the organization changed?
b. What caused them to shift?

Now, we’ll move on to some questions that more specifically about your participation in #crippingthemighty

4.) For founder: what inspired you to create #crippingthemighty OR Not founder: How did you come to be involved in this movement?
5.) How would you describe the goals of this movement?
6.) Can you describe what you see as the factors that helped this movement to gain steam?
7.) Not everyone who has a disability/chronic condition actively participates in movements like this. What made participating important to you?
8.) We are now nearly a year since the #crippingthemighty movement. What impact, if any, do you think that this initiative made?
9.) If you were to stand back and critique this movement, what might be some of its challenges?
10.) Are there any other activities related to disability advocacy or activism that you actively participate in? Please describe them.

11.) Is there anything else you think I should know, either about your identity as a person with [condition], the motivations behind participating in #crippingthemighty, or your perceptions of The Mighty?

Those are all of the open-ended questions I have for you. I’d just like to wrap up with a few demographic questions. Your answers to these questions will help me to report a general description of who I’ve included in this study. Again, let me know if you’d like to skip any of these.

1.) What is your age?
2.) What ethnicity do you identify with?
3.) What gender pronouns do you prefer?
4.) How would you describe your socioeconomic status? i.e. lower income, middle class, upper class
5.) Are you employed?

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Appendix I: Conditions Included in *Mighty* Articles

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