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CHAPTER 5

Managing Stigma

Visual Acts of Resistance

IN 2015 TLC, the widely popular television channel known for its lifestyle reality-television shows including *My 600-lb Life*, *Say Yes to the Dress*, and *19 Kids and Counting*, announced its latest reality show for UK broadcast: *Too Ugly for Love?* This “observational documentary” followed ten adults with “extraordinary medical conditions . . . on their quest to find love” (TLC, 2017b). Each episode tracked the “ups and downs” of dating as an adult with “secret physical afflictions” such as alopecia, missing limbs, vitiligo, skin ulcers, hyperhidrosis, and ostomies. The show was premised on the belief that these conditions make finding love “almost impossible” and therefore lured viewers with the drama of these “too ugly” people navigating the dating world. However, the supposed impossibility of finding love with an “extraordinary affliction” wasn’t the only reason viewers were encouraged to watch. The show promised a look into “a whole world of dilemmas” surrounding the singletons’ and their decisions to conceal or reveal their conditions. The show’s promotional materials asked: “How can you find love when you are hiding your true self? . . . The longer you leave the truth, the harder it can be to come clean and the more dramatic the revelation” (TLC, 2017b). These tensions surrounding

1. Formerly known as The Learning Channel, in recent years TLC has become home to a range of reality shows (“a global leader in real life entertainment”) aimed to “inspire, inform, and entertain” (TLC, 2020).

2. Hyperhidrosis is a condition characterized by uncontrollable, profuse sweating.
the ugly truth of finding love while living with embodied difference enticed viewers for three seasons, totaling twenty-two 45-minute episodes, several of which featured Antony, Marcia, Kieran, and Matt—four ostomates.

*Too Ugly for Love?* illustrates that illnesses and disabilities, including ostomies and chronic gastrointestinal (GI) conditions, are accompanied by specific visual expectations regarding attractiveness and disclosure. The show’s very title implies that having a chronic condition or disability disqualifies people from being attractive and finding love. Further, the show emphasizes the relationship between visuality and stigmatizing practices. Specifically, it equates living with embodied difference with being ugly and romantically out of the question. By centering people living with “extraordinary physical affictions,” *Too Ugly for Love?* serves as a contemporary example of what Garland-Thomson (1997) might call “a spectacle of the extraordinary body.” Indeed, “TLC’s framing of the extraordinary body as a public spectacle,” disability studies scholar Krystal Cleary (2016) has argued, “is both in keeping with the representational history of disability and the channel’s investment in the shocking and unusual.” The show explicitly positions each adult, including those with ostomies, as undesirably different and invites viewers to engage in evaluative visual work by watching the show and the extraordinary bodies it puts on display. Disabled bodies, particularly those visually on display, operate as the “vividly embodied stigmatized other” through “cultural dichotomies that do evaluative work: this body is inferior that one is superior; this one is beautiful or perfect and that one is grotesque and ugly” (Garland-Thomson, 1997, pp. 7–8). Participating in this evaluative economy, *Too Ugly for Love?* conflated ugliness and physical conditions and highlighted the precarity of visual practices for people living with disabilities and chronic conditions. In short, how you look and how you are looked at affect your worthiness and desirability.

Disability studies scholars and rhetoricians of health and medicine alike have shown that visuality is central to the lived experiences of people with a host of conditions and disabilities (see, e.g., Cleary, 2016; Garland-Thomson, 1997, 2009; Johnson & Kennedy, 2020; Moe, 2012; Quackenbush, 2011). Ostomies and chronic GI conditions are no exception. For the most part, these conditions can be hidden from others, kept invisible under clothes, and concealed in private spaces. Although concealing these conditions often allows those living with them to “pass” as normal and avoid being stigmatized, the invisible nature of ostomies and chronic GI conditions also comes at a cost. As much research has demonstrated, the invisibility of chronic conditions

generally, and chronic GI conditions more specifically, often leads to doubt about the reality and severity of these conditions, which in and of itself serves to stigmatize these conditions in many contexts (Defenbaugh, 2013; Moore, 2013; Valeras, 2010; Vickers, 2000). At the same time, revealing an ostomy or chronic GI condition also opens up the possibility for stigmatization and judgment by making others aware of these conditions and thus creating opportunity for others to devaluate ostomy / chronic GI conditions and the people who have them.⁴ For example, when Seven Charles’s ostomy was made visible to his classmates, he was repeatedly harassed (see preface).

Although some visual practices can stigmatize and others run the risk of inviting stigmatization, visual practices are also used within the ostomy and chronic GI community to advocate, empower, and make public these conditions. Specifically, many people living with ostomies and/or chronic GI conditions currently work to resist ostomy stigma by posting pictures online (Frohlich, 2016; Frohlich & Zmyslinski-Seelig, 2016; Rademacher, 2018). Such visual practices (taking and posting photos publicly) not only help bring awareness to ostomies but also further work to destigmatize ostomies through public exposure. For instance, in response to Seven’s death and in honor of his memory, thousands of people posted pictures of themselves revealing their ostomies using the hashtag #BagsOutForSeven.⁵ These images at once eulogized Seven and countered stigma by making ostomies deliberately visible. Similarly, social media campaigns like #GetY ourBellyOut have resulted in thousands of ostomy- and belly-revealing pictures posted to Twitter, Facebook, and Instagram in order to destigmatize and raise awareness of chronic GI conditions.

Overall, visual practices—revealing and displaying—as well as the visual practices they encourage—looking and staring—demonstrate how central visibility is to many of the stigma stories being told and heard about ostomies. This aligns with what scholars have noted about other disabilities and the visual entanglements of disabilities and stigmatized identities more broadly. Visual expectations regarding illness and disability are indeed complex and political. Johnson and Kennedy (2020) have pointed out:

Visibility is strategic. Visibility is insistent. Visibility is an argument—for disabled people, an argument for recognition and rights, a demand to be part of the public and participants in public discourse, a call to be addressed in education and employment policies, seen in accessible spaces, and equi-

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⁴ See, e.g., Rademacher (2018) and Leadley (2016).
⁵ Capitalization of each word added for accessibility.
ably represented in cultures that have discriminated against disabled people for millennia. Visibility is imperative. So imperative, in fact, that it is easy to overlook the risks of visibility for minoritized populations. Visibility is fraught. Visibility is not always voluntary. Visibility brings with it risks, always demanding a calculation of the potential value of revealing oneself. (p. 61)

Johnson and Kennedy make clear the conundrum facing people with disabilities including those living with ostomies and chronic GI conditions: visibility is central to both empowerment and stigmatization.

As many scholars have shown, visual practices are deeply ensnared in stigmatization vis-à-vis ableism. This is especially the case for ostomies and chronic GI conditions. In her recent analysis of Tee Corrine’s (2019) “Scars, Stoma, Ostomy Bag, Portocath: Picturing Cancer in our Lives,” art historian Stefanie Snider (2019) summarized: “Western culture tends to rely on the visual as a way of knowing, especially in terms of marking disability and illness” (p. 133). For this reason, people with disabilities and illnesses are often charged with proving the existence of their conditions and the “truth” of their bodies through visual practices, particularly when a marker of the illness or disability (e.g., a wheelchair or white cane) might not be readily apparent to outsiders. A range of visual practices or ways of looking have been identified as participating in this visual economy: the clinical or diagnostic gaze (Calder-Dawe et al., 2020; Foucault, 1973; Johnson, 2010), the nondisabled gaze (Hughes, 1999), the male gaze (Doane, 1982; Haraway, 1997; Mulvey, 1975), and staring (Garland-Thomson, 2009). Collectively, these ways of looking at disabled or ill bodies work to in/validate particular bodies (Hughes, 1999) and thereby perpetuate ideas of normalcy by “deciphering difference” (Calder-Dawe et al., 2020, p. 141).

Each of these ways of looking participates in systems of power that not only decipher differences but also police, objectify, and dehumanize people with disabilities, including those with ostomies and chronic GI conditions, by categorizing bodies according to “cultural dichotomies” like normal/abnormal, attractive/repulsive, superior/inferior, sexual/asexual, able/disabled (Garland-Thomson, 1997). For example, the clinical, diagnostic, and nondisabled gazes, which participate in a medical model of disability, demand visual proof of an illness or disability. This, in turn, pushes people to engage in what Calder-Dawe et al. (2020) called “proofing practices” or “the range of strategies for evidencing impairments” (p. 148). Importantly, too, proofing practices are strongly influenced by stigmatization. Johnson (2010) asserts, “Stigma is . . . active rhetorical propagation of community norms and values coupled with
the demand for visibility” (p. 475). Although stigmatization frequently leads people to conceal markers of disability or illness, it also often necessitates that people prove their disability or illness through visual displays. For instance, recall the story of Sam Cleasby from chapter 2. Cleasby was publicly criticized for using a disabled bathroom precisely because she failed to display a visual marker of disability with her ostomy hidden beneath her clothes.

Clearly, stigma’s entanglement with the visual is complex, in some instances demanding that particular bodies make visible their difference and in others demanding that bodily difference be concealed to avoid stigmatization and discrimination. Therefore, people with illnesses and disabilities are required to visually manage their conditions, navigating the demands to reveal and conceal in different contexts, toward different goals, and with different repercussions (see Garland-Thomson, 2011, 2017; Rademacher, 2018). As Goffman (1963) described, individuals who “possess” a stigmatizing trait or identity must engage in “information control” practices as part of “stigma management”; they must decide “to display or not to display, to tell or not to tell; to let on or not let on; to lie or not to lie, and in each case, to whom, how, when, and where” (p. 57). These visual tensions and pressures are acutely active in the case of ostomies. Rademacher (2018) has argued:

Anxiety among ostomates, therefore, is closely linked to fears that one’s concealed ostomy may be discovered unintentionally due to a leak of one’s ostomy appliance, frequent flatulence, or while one is emptying their pouch in the restroom, and as a result, face experiences of stigmatization. (p. 3861)

Indeed, people with ostomies and chronic GI conditions are paradoxically trapped, simultaneously required to visually prove their conditions and to conceal these same conditions to avoid being stigmatized. Ultimately, decisions to reveal or conceal are highly rhetorical.

Accordingly, this chapter examines the role of visual practices in stories that stigmatize ostomies as well as those that counter that stigma by querying how people with ostomies and chronic GI conditions navigate visual practices like revealing and concealing, as well as being looked at and stared at. In turn, the chapter argues that people with ostomies and chronic GI conditions rhetorically use visual practices to influence the meaning of ostomies and, in doing so, to actively resist stigmatization. Thus, this chapter reviews a range of stories that demonstrate the central and complex role of visual practices in the de/stigmatization of ostomies including Too Ugly for Love?, social media campaigns like #GetYourBellyOut and #AerieREAL, and stories of individual ostomates including Bethany Townsend, Jessica Grossman, and Sam Cleasby,
whose ostomy-revealing photos have been circulated widely online. Through a discussion of these diverse cases, this chapter shows how stigmatization disciplines bodies across intersectional lines and, more specifically, how visibility-related ostomy stigmatization is deeply entangled with normalcy and normalization, particularly along axes of sexuality, beauty ideals, and gender norms. Moreover, the chapter shows how normalization, while pitched as a means to destigmatize ostomies, inadvertently reinscribes the enactment of stigma itself, particularly when studied intersectionally.

The chapter proceeds in the following way. First, I contextualize the analytic work of this chapter within conversations that have articulated the connections between stigma, normalization, embodiment, sexuality, and visuality. Then, I analyze how people with ostomies and chronic GI conditions capitalize on visual practices, especially on social media, as an act of resisting stigma. I detail how visual practices and textual practices come together to tell particular stories about living with ostomies and chronic GI conditions, specifically stories that work to normalize ostomies and chronic GI conditions through repeat, public displays that invite others to look, even stare, at ostomies. In doing so, I consider the rhetorical risks involved in participating in visual practices. I next trace how expectations regarding sexuality and gender work to control how, when, and why people living with ostomies and chronic GI conditions reveal and conceal their conditions. I end the chapter by contemplating what’s at stake in the goal and practices involved in the normalization of ostomies and chronic GI conditions.

**Normalcy, Norms, and the Impossibility of Normalization**

To understand the rhetorical work and implications of visual practices for people with ostomies and chronic GI conditions, it’s important to first discuss the role of normalcy and normalization in visuality, disability, and stigma. As I’ve mentioned, the idea of the “normal” is the conceptual opposite of the “stigmatized” (see Goffman, 1963). Scholars across fields invested in identity and embodied politics (e.g., disability studies, women's studies, queer studies, critical race studies) have compellingly and repeatedly shown how “normal” isn’t so much a clear-cut identity or embodiment as it is a conceptual opposite, or an unmarked category rendered present only through the identification of what *isn’t* normal. For instance, disabled bodies help define normalcy because disabled bodies (supposedly) aren’t it. As Titchkosky and Michalko (2012) put it, “normal bodies need no explanation” (p. 127). Disabled bodies, on the other hand, are always “requiring explanation”—what went wrong,
how can it be fixed and brought back to normalcy?” (p. 127). As Goggin et al. (2017) have summarized, “Normality is a privileged, yet strikingly vacant and difficult to define category which gains its existence and status from its relationship to the constitutive disavows of abnormality” (p. 337).

Importantly, the stigmatization of disability through rhetorics of “normal is natural” (Cherney, 2019) is intersectional, making multiple normalizing demands at once. As Garland-Thomson (2017) explained, “gender, race, ethnicity, sexuality, class, and ability . . . exert tremendous social pressures to shape, regulate, and normalize subjugated bodies” (pp. 366–367). Recall that Goffman (1963) speculated that the “normal” body is actually White, male, cisgender, heterosexual, athletic, wealthy, and attractive. Thus, any bodies that deviate (read: basically, all bodies) are subject to stigmatization in one context or another, and often multiple contexts simultaneously. This, of course, is foundational to the idea of intersectionality (see Cho et al., 2013; Crenshaw, 1993). Each stigmatized and marginalized identity/embodiment multiplies, resulting in exponential oppression, harm, and subjugation of people who occupy several marginalized identities at once. Ultimately, these (multiply) marginalized identities and embodiments are subject to the pressures and policing of normalcy, and these pressures are acutely active in contexts of ostomies and chronic GI conditions (Hood-Patterson, 2020; Leadley, 2016; Manderson, 2005; Vidali, 2013).

Normalcy, as part of its rhetorical work to characterize disability as abnormal and thus stigma-worthy, manifests through cultural norms (which are then perceived to be violated by abnormal bodies). Norms operate in conjunction with normalization—the social, material, and rhetorical process of becoming normal—that every body is expected to desire and adapt to. These norms range from obvious to insidious. And, importantly, they are “less a condition of human nature than a feature of a certain kind of society” (Davis, 1997, p. 3). In other words, norms, like their counterpart stigmas, are expansive arguments that cultural majorities (implicitly and sometimes explicitly) agree on and enforce. Take, for example, norms regarding the evacuation of waste; people generally agree that there are places where you pee and shit (bathrooms) and places where you don’t (literally anywhere else). Ostomies and ostomates violate this norm in that they don’t require (and in most cases can’t abide by) specific physical places where waste evacuation happens. Ostomies excrete waste whenever there is waste to be excreted. Of course, it is into an ostomy bag, so it’s not really the same as shitting in the street, but it’s often

6. For more on normalization, see Coleman-Brown (1986), Gibbons (1986), and Wolfensberger (1972).
stigmatized as such. Ultimately, ostomies’ proximity to and relationship with feces is frequently cited as a justification for stigmatization. As Yergeau (2018) has argued, shit is a “precondition for rhetoricity” (p. 20). In other words, shit influences meaning-making and, in the case of ostomies, shit’s rhetoricity is preconditioned toward stigmatization.

In addition to cultural norms regarding shit, and more directly relevant to the stories in this chapter, are cultural norms regarding sexuality and gender. “Normal” sexuality is heterosexual and able-bodied (McRuer, 2003, 2011). Therefore, disabled people are required to address and explain their sexuality to others because it challenges the norm. As McRuer (2011) has explained, “‘What exactly do you do?’ in relation to sex is about as frequent a question for disabled people as it historically has been for many queer people (p. 107). Curiosities and assumptions that disabled people inherently have abnormal sexuality and sexual practices is demonstrative of deeply entrenched ideas about disabled bodies, the practices they can and should participate in, and the way those embodiments and practices are presumed to be inherently outside the norm. Even when disabilities have little or nothing to do with sexual function, disabled people are subjected to what Harlan Hahn (1988) has called “asexual objectification,” or the systemic assumption that people with disabilities are “inherently asexual, undesirable, or impotent” (Leadley, 2016, p. 26). The widely held stereotype that ill or disabled people always are (or should be) asexual7 is tied up in a range of other stigmatizing stereotypes and assumptions about disability (see Cleary, 2016; Kafer, 2003; Kim, 2011; Leadley 2016; McRuer & Mollow, 2012; Sandahl, 2003; Santos & Santos, 2018; Shakespeare, 1996). As Cleary (2016) explains, “Because people with disabilities are assumed to be eternally dependent, they are frequently presumed to be infantile and asexual.” In response, disability scholars and activists have countered the convergence of asexuality and disability, advocating that many disabled have fulfilling sexualities and sexual lives.

Importantly, I do not mean to say that asexuality8 is inherently problematic or abnormal, as a sexual identity with related practices that defines heteronormativity, asexuality is itself stigmatized and often discussed as a form of sexual deviance. Outright rejection of the possibility of asexuality for disabled people or the positioning of asexuality as inherently abnormal can inadver-

7. When I use the term asexual, I follow Eunjung Kim (2011), who defines asexuality “broadly to a relative absence or insufficiency of sexual interest, biologically and socially described function, and interpersonal sexual engagement” (p. 481).
8. The Resources section at the Trevor Project (2020) is one helpful starting place to learn more about asexuality.
tently reinscribe problematic assumptions and erase disabled people who are proudly asexual. As Eunjung Kim (2011) has asserted,

the universalizing claim that all disabled people are sexual denies that asexuality can be positively experienced by any subjects with a disability, thus displaying the tendency to negatively generalize about asexuality as unnatural and indeed impossible. (p. 482)

This complex entanglement of a/sexuality, disability, norms, and stigma reminds us that universalizing assumptions are nearly always problematic. Space for all lived experiences and identities is key, and I don’t intend to recapture those frequently stigmatizing perspectives of asexuality here. Instead, I recite this scholarship regarding the asexualization of disabled people to highlight the highly problematic ways in which asexuality is often forced onto disabled bodies. Some disabled people no doubt are asexual, which is, of course, queerfully normal⁹ and none of my or anybody’s business. In fact, Eunjung Kim (2011) has compellingly shown how, for some, disabilities uniquely afford nonsexual sensualities and pleasures. However, the problem arises when that asexuality is demanded of disabled people. The a/sexualization¹⁰ of disabled bodies is especially harmful given its histories in eugenics (see Davis, 1997; see also Kim, 2011). Disabled people have historically been rendered asexual as a means to advance “the notion of progress, human perfectibility, and the elimination of deviance, to create a dominating hegemonic vision of what the human body should be” (Davis, 1997, p. 8).

Further, the a/sexualization of disability intersects with gendered expectations, particularly related to beauty and desire (Calder-Dawe et al., 2020; Cleary, 2016; Loja et al., 2013; Mohamed & Shefer, 2015; Sandahl, 2003). That is, a/sexuality stereotypes and related stigmatization are imbricated in related norms regarding beauty, desire, and sexual attractiveness. Asexual bodies are incongruent with attractiveness and beauty, at least when it comes to sexualization. Garland-Thomson’s (2017) feminist disability theory is instructive for further understanding appearance-related norms that regulate and evaluate disabled bodies. Specifically, Garland-Thomson asserted that normalcy and beauty are “twin ideologies” that “posit female and disabled bodies, particu-

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⁹. I’m playing discursively on the concept of “perfectly normal” here in two ways: first by subbing in the term queerfully to signal resistance to heteronormativity; second, by using the word normal to queer the concept altogether.

¹⁰. Desexualization, the process that divides disability from sexuality and renders sexuality an irrelevant identity, discourse, and practice for disability people, is also tied up in eugenics, stigmatization, and disability. See Kim (2011) for a richer discussion.
larly, as not only spectacles to be looked at, but as pliable bodies to be shaped indefinitely, so as to conform to a set of standards called the ‘normal’ and the ‘beautiful’” (p. 367). Normalcy and beauty norms, in tandem with sexuality expectations, police disabled bodies, especially disabled women, demanding that those bodies conform to the ever-shifting beauty norms of any given cultural moment.11

Of course, many disabled women can never fully conform to Western society’s (impossible) beauty norms, leaving those bodies perpetually abnormal and stigmatized through the mere practices of existing. Ostomates find themselves in this impossible position, though they can mitigate the stigmatization by engaging in concealing practices (e.g., wearing clothes that mask the presence of the ostomy, using belts or other holsters to obscure the full visibility of an ostomy, or, in extreme cases, hiding in private spaces). This is the power of normalcy and normalization. Disabled people, including ostomates, are expected to indefinitely normalize—that is, work to be normal—despite never being allowed to reach normalcy. It is an impossible achievement that disabled people are demanded to work toward but forbidden from achieving.12 As Jean Bessette (2016) has argued in the context of queer rhetorics, “normalization produces bodies, polices desire, privileges the powerful, classifies and punishes the perverse, and remains resistant to intervention” (p. 150).

With the social, personal, and physical pressures that accompany normalcy and thus disability, many ostomates and people living with chronic GI conditions have turned to visual practices to impede stigmatization. Importantly, many of these individuals leverage the visual, especially in online pub-

11. Western beauty ideals have, unsurprisingly, shifted over time. Leaving women in particular with an ever-moving and almost universally unachievable target.

12. An important semi-exception to this are supercrips, who are publicly perceived to “overcome” their disability through superhuman accomplishments like becoming Olympians or celebrities (see Booher, 2011, 2010), in which case the disability is a source of extraordinary strength and ability. The idea that a disability elevates a disabled person to superhuman status has been theorized extensively in disability studies under the “supercrip” trope. See, for example, Hardin and Hardin (2004), Booher (2010), and Gutsell and Hulgin (2013). Many disability studies scholars have shown the negative and damaging effects of the supercrip trope. Specifically, this work has shown how supercrip stories tend to be the only if not the most visible disability stories circulated in the public sphere. Too, supercrip stories tend to valorize disability as something that extraordinary individuals can overcome, thus setting an unreasonable and harmful expectation for other disabled people who cannot or do not live up that expectation. While some recent work has attempted to recuperate the supercrip as a helpful analytical and critical device, its role within disability discourse is complex and fraught (see Schaulk, 2017). Both Vicky Mulholland and Gut Girl animate the supercrip narrative in their own stories (in the next section). Supercrip stories, while positive on the surface, are problematic in that they set an impossible standard for disabled people and further entrench the idea that disabilities are something that can and should be defeated in service of becoming normal.
lic spaces, to “normalize” ostomies, which often seems to be in an effort to shake stigma. As Kristina Gupta (2019) has argued, “in a white supremacist capitalist patriarchy, normalization can be a survival strategy, it can alleviate suffering (including the suffering causes by the system in the first), and it can make bodies, minds, and lives more livable” (p. 3). However, the distinction between destigmatization and normalization is significant, and as my analysis will show, the nuances between the terms are not often clear in the lived experiences and stories of ostomates. Normalization might initially appear to be a reasonable goal; deviance from normalcy is, after all, a primary source of stigmatization for disabled people. However, as the visual stories in the next sections show, normalization as a potential or already achieved goal for (people living with) ostomies and chronic GI conditions not only relies on privilege (racial, gendered, heteronormative, economic) but also recapitulates the normal/stigmatized system that ostomates and other disabled people are working to dismantle.

**Displaying Ostomies and Soliciting Stares**

One primary way that visual practices participate in the de/stigmatization of ostomies is through the posting of photographs and selfies\(^{13}\) online. Previous research on the relationship between online photos and the ostomy community has illustrated that “many members of the ostomy community are using . . . blogs and social media accounts (e.g., YouTube and Facebook) to challenge ostomy stigma” (Rademacher, 2018, p. 3859; see also Frohlich, 2016). My own investigation into lived experiences, ostomies and chronic GI conditions, and stigma confirm Rademacher’s findings. During interviews, when I asked participants whether and how they are individually working to resist stigma, many reported participating in social media efforts to educate others about ostomies through posting and sharing pictures online. For example, one interview participant, Stacy, explained that the space in which she has felt “most stigmatized” is the beach or pool, where her ostomy is made visible. In response to this, Stacy said she shares photos of herself online in her swimsuit to help mitigate this stigmatization and actively promote products designed to support ostomates with fashionable garments like StealthBelt—a “stylish” belt/wrap designed to support and conceal the ostomy—during activities like.

\(^{13}\) To be clear, *selfies* are defined by the *Oxford English Dictionary* (2013) as “a photograph that one has taken of oneself, typically with a smartphone or webcam and uploaded to a social media website.” I distinguish between photos and selfies here because both play an important role in the visual practices of the ostomy community. However, they tend to operate in similar ways.
“sleeping, intimacy, swimming, and intense physical exercise” (StealthBelt, 2020).

Stacy is among thousands of people who have taken and shared photos and selfies online as acts of resistance against stigma. For example, in a tweet (2017) featuring a picture of herself lifting her shirt to reveal her ostomy, a woman named Vicky who frequently posts about life with her ostomy tweeted: “#myillnessisnotyourinsult my stoma makes me superwoman, has given me my life back and makes me awesome. think before you make a joke.” Vicky’s tweet, as part of the #myillnessisnotyourinsult social media initiative, resisted stigmatization specifically through what Sandahl (2003) called “cripping,” or practices that “spin mainstream representations or practices to reveal able-bodied assumptions of exclusionary effects . . . expose the arbitrary delineation between normal and defective . . . and disarm what is painful with wicked humor” (p. 37). Vicky’s image revealed her ostomy, and she used the caption to explain that her life is possible because of her ostomy, and, even more, that her ostomy makes her self “awesome.” Vicky cripped the practices that use her ostomy as insult by using visual and discursive practices to argue that her ostomy “makes her superwoman.” That is, she used the practice of displaying her ostomy to embody the positive, celebratory relationship she has with her ostomy.

Vicky is not the only ostomate who has used visual practices to prove superhuman status and fight stigma. For instance, consider Gut Girl, a self-proclaimed inflammatory bowel disease (IBD) superhero, who, while wearing an ostomy pouch, “fights IBD” and gives others the “tools” to do so, too (Ringer, 2012). To establish this superhero identity, Gut Girl shares photos of herself dressed in typical superhero attire, including a spandex leotard and shiny blue cape, as well as some supercrip special features, including underwear briefs on the outside of the spandex and, most important, a glitter-filled ostomy bag (Ringer, 2012). Like Vicky, Gut Girl wears and displays her ostomy specifically as part of her superhero armor and, in doing so, celebrates her ostomy. By integrating her ostomy as part of her tools to fight IBD, Gut Girl showcases it as part of her superhero self, making the ostomy meaningfully positive. Both Vicky and Gut Girl use visual practices—posting pictures online, revealing their ostomies, and visually highlighting their ostomies by focusing on them in the photos—to evince not only their ostomate identities but also their (super)human or supercrip statuses. The ostomy, according to Vicky and Gut Girl, is both empowering and elevating; it empowers them as women with ostomies and chronic GI conditions to be “awesome” and support others and it elevates them from abnormal to extraordinary.
While individuals like Vicky and Gut Girl work visually to dismantle ostomy stigma, there are also massive online campaigns working toward the same goal. Among the most popular is the #GetYourBellyOut (or #gybo) campaign, which has garnered thousands of Facebook posts, tweets, and Instagram posts. At the time of this writing, a search for #GetYourBellyOut on Instagram returned over 20,000 posts and thousands more on Twitter and Facebook. #GetYourBellyOut (n.d.) “encourages people to take a photograph of their belly and post it to social media.” Shortly after the #gybo campaign began in 2014, one of its founders explained that “what started out as a campaign to raise awareness of an invisible illness that so many people suffer with in silence has turned in to a campaign of INSPIRATION and UNITY!” (Fleetwood-Beresford, 2014). Further, a promotional video on the GetYourBellyOut website explains that the purpose of the campaign is “to raise awareness of inflammatory bowel disease . . . as well as trying to remove the stigma around these conditions” (“GetYourBellyOut,” n.d.). #GetYourBellyOut ultimately asks people with ostomies and chronic GI conditions to deliberately reveal their bellies in order to challenge stigma and draw attention to these conditions.

True to these descriptions of the campaign, the photographs and selfies posted as part of #GetYourBellyOut include photos of ostomies, photos of abdomen scars presumably from surgeries and other procedures, as well as photos that show “no visible signs” of illness or disability (GetYourBellyOut, n.d.). As the campaign explains, “[#GetYourBellyOut] has helped put a visual aid on what is an invisible illness and has helped start the conversation to educate the public” (GetYourBellyOut, n.d.). With this explicit purpose, the #GetYourBellyOut Campaign actively calls on those in the ostomy and chronic GI community to engage in “proofing practices” to help make otherwise invisible illnesses visible (Calder-Dawe et al., 2020). The thousands of photos and selfies shared as part of this campaign suggest that visibly displaying these conditions is an activist effort to collectively respond to stigma through awareness and education.

For the campaign to succeed at these efforts, however, the visual practices at work in a campaign like #GetYourBellyOut require interaction. #GetYourBellyOut directly prompts participants to engage in visual practices, which, in turn, invite outsiders to participate in visual practices as they view the photos. In other words, the #GetYourBellyOut campaign both encourages displays and invites stares by circulating images of bellies and ostomies in the public sphere. As Garland-Thomson (2009) has argued, staring is “a communicative gesture,” led by curiosity and discomfort that can readily transform into
oppression (p. 185). However, Garland-Thomson clarified that this discomfort “can be positive . . . a stare is a response to someone's distinctiveness, and a staring exchange can thus beget mutual recognition, however fleeting” (p. 185). #GetYourBellyOut works to solicit this very kind of positive stare—stares that create an “empathetic exchange” in which “starers imagine what it is like to be” the starees (p. 92). Of course, starees cannot completely control starers or their stares. Staring and being stared at involves a relationship that neither side can fully control. That is, by displaying their ostomies online, ostomates can work to encourage empathetic exchanges, but they cannot guarantee them.

Garland-Thomson (2009) does suggest, though, that there are ways starees can work to exert influence during a staring exchange. She suggests that starees can “coach the public eye” (p. 188) to empathetically stare by including stories that help starers situate what they see within particular stories rather than within public stories that might be implicated in ableism, stigma, and other stereotypes and forms of oppression. We can see this work of sharing stories alongside ostomy images in various posts within the #GetYourBellyOut campaign. Given the volume of posts with #gybo, a complete analysis of the campaign's posts is beyond the scope of my project. However, I have been following the campaign since it started in 2014 and have analyzed approximately 1,500 of the posts. Here, I focus on just two representative examples.

In an Instagram post, a woman I’ll refer to as Petra shared three different images. The first photo shows Petra standing outside what looks like a public place in jeans and a sweater; she smiles for the camera and does not appear to display any obvious sign of illness or disability. The second photo shows Petra again smiling for the camera, only this time her shirt is pulled up slightly to reveal a black ostomy bag affixed to her abdomen. Finally, the third photo shows Petra yet another time, fully covered by jeans and a blouse, still smiling, and taking a selfie in what looks like a bathroom. Included beneath these three photos is the following caption:

I am still the same person despite my IBD. First picture was taken 7 years ago. I had no signs of illness that I knew of, no stoma and had very little knowledge of IBD. The next two pictures are my most recent. I live with a stoma, no colon, no rectum and an illness that I will have for the rest of my life . . . But I’m still the same person as I was in that first picture. I still have the same qualities I had before I got poorly and if anything, being poorly has made me more strong and more confident than I was then.

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14. I chose to anonymize this post in an effort to protect the woman's identity. This post was shared publicly; however, since it is on her personal account, I mask her identity here.

15. Here, I read poorly to mean sick.
This text provides a broader story in which public viewers can situate the images and the display of Petra’s ostomy. As Garland-Thomson (2009) might put it, the text caption helps “coach the public eye” as it views and evaluates Petra’s photos. By explicitly telling viewers that she is “the same person” across these images, Petra works to persuade viewers that her ostomy did not change who she is, even though it did change her body. In other words, Petra insists that she is the same person, identity unchanged, despite the addition of her ostomy and chronic GI condition. In this way, Petra’s post works to normalize ostomies by situating the ostomy within an otherwise normalized story and on an otherwise normal-looking body. This post also actively disrupts the process of her identity becoming totalized by her ostomy through the collective work of the caption and series of images. Petra’s choice to include pictures before her ostomy, with her ostomy revealed, and with her ostomy concealed, emphasizes to viewers that she has maintained the same qualities and sense of self throughout time and over the course of receiving her ostomy. Taken together, the multiple images and caption work to control the story that viewers create from these visual and discursive practices. Rather than allow viewers to rely only on assumptions, stereotypes, or previously heard stories about ostomies, Petra provides viewers her story and experiences to shape how viewers make meaning of her photos.

Another post in the #GetY ourBellyOutCampaign points to the campaign’s empowering and destigmatizing effect. Many posts in the campaign have been shared through participants’ personal accounts; however, many organizations, including GetYourBellyOut as well as Crohn’s and Colitis UK and Ostomy Goffman (1963) might actually call this process “normification,” which he distinguishes from normalization. Normification, according to Goffman, is “the effort on the part of a stigmatized person to present himself as an ordinary person, although not necessarily making a secret of his failing” (p. 30). Despite Goffman’s effort to distinguish between these two processes, the vast majority of disability studies and rhetorical scholarship in which I situate my work does not separate these two terms or processes as distinct. Therefore, following this work, I use the term normalization.

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17. Crohn’s and Colitis UK is “the leading charity for Crohn’s and Colitis” in the UK (Crohn’s & Colitis UK, n.d.).
Awareness, have encouraged people to submit photos and captions to be shared on these highly public accounts. For example, a post shared on both Twitter and Instagram by Ostomy Awareness features a man with his shirt off, revealing his ostomy as he looks away from the camera. The caption reads:

Meet Ste! He says, “Many people still are disgusted by the fact that I wear my stoma with pride, I get it out without thinking about it, it’s posted all over the internet, I wear no shirt when it’s warm out, etc. Why should I not do these things, why should I hide away? Because I poop in a bag? Well I’m still breathing; that bag saved my life.” Thanks for helping to spread ostomy awareness! #ostomyawareness #ostomy #ostomy bag #getyourbel-lyout #nocolonstillrollin

Much like Petra’s post, this photo and caption collaboratively work to shape how viewers stare at and read ostomies and the people who have them. The caption directly calls out the stigmatization of ostomies by revealing the ostomy and explaining that people find it “disgusting” when they see ostomies, and by supplanting that reaction with an alternative way of seeing ostomies: as lifesaving. Together, these two #GetYourBellyOut posts exemplify how people with ostomies use visual practices to destigmatize ostomies, particularly when those visual practices are paired with stories that help contextualize and situate the images within lived experiences with ostomies.

Each individual post in #GetYourBellyOut collaboratively resists stigmatization through visual displays and coaching public onlookers to see the ostomy in specific ways and thus figure ostomies within positive, rather than stigmatizing, stories. In this way, #GetYourBellyOut, in combination with individual posts like Vicky Mulholland’s and the work of Gut Girl, enact the ostomy not as negative, disfiguring entities, but as empowering embodiments that can and should be publicly visible. Central to this work is another layer of visibility—publicity. For individuals like Mulholland, the scope of impact can be limited to personal social media networks even when the posts are made openly public. To overcome this limitation, organizations leverage the affordances of social media, specifically hashtags, to consolidate images and posts and consequently increase their public visibility. However, there are also instances in which individual ostomy photos have gone viral. The next stories I share are three such examples. The first features Bethany Townsend, a UK woman and ostomate whose ostomy-revealing photos went viral (Birch, 2014; Ostomy Awareness is an Instagram account with the explicit goal to “normalize colostomies, ileostomies, and urostomies.” Ostomy Awareness accomplishes this goal by featuring ostomates who share photos and captions.

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Morgan, 2014). In contrast, the second story, from Sam Cleasby, whom I first introduced in chapter 2, demonstrates how norms related to women’s bodies are enforced problematically at the intersection of sexuality, beauty, and disability. Finally, I explore Kieran’s story within the Too Ugly for Love? series, in which Kieran shows viewers the intricacies of dating with an ostomy through highly visual TV episodes. Kieran’s story further complicates and nuances the visual complexities layered onto norms of dating, sexuality, and disabilities.

Visual Rewards and Risks: Sexualizing Disability

In 2014 Bethany Townsend, a UK model and ostomate, used social media to share an image of herself sunbathing in a bikini with her two ostomy bags revealed.19 Within a matter of days, Townsend’s images went viral, receiving over 12.4 million views (Rademacher, 2018; Walker, 2014). When asked about the image, Townsend reported, “It was just a picture that I got my husband to take on holiday and it was just for me and him really” (ITV, 2014). After receiving positive feedback from her husband and others, Townsend shared the image with Crohn’s and Colitis UK, transforming it far beyond a personal picture for her husband. Not long after, Townsend was featured on a variety of news and pop culture broadcasts in the UK, explaining her picture and her ostomies and advocating for ostomy positivity.

Since then, Townsend’s posting of the image has been championed as a heroic act that inspires confidence in herself and others with ostomies and chronic GI conditions, specifically IBD. In fact, Cosmopolitan (2014) called Townsend “the ultimate body confidence queen.” Townsend’s rationale for taking, posting, and sharing this image aligns with her reputation. In the time since her photo went viral, Townsend has explained that she was working to resist stigma both by wearing her bikini in public and by sharing online a photo from that day. Townsend also acknowledged that, in the three years leading up to this photo, she did not wear a bikini or reveal her ostomies in public, because she lacked confidence (Blumm, 2014). However, with the encouragement of her husband, Townsend decided that her ostomies are “nothing to be ashamed of” (Blumm, 2014), which led her to take and post the

19. Though I don’t know with certainty the specifics of Townsend’s ostomies, it is not uncommon for people to have two abdominal ostomies for a variety of reasons. For example, people may have a colostomy or ileostomy to reroute their digestive tracts and a urostomy to reroute their urinary tract. In other cases, they might have an ostomy in their lower abdomen (digestive or urinary) as well as a gastrostomy, which is an opening in the stomach used for feeding.
picture publicly. In response to her photo and story, thousands of other people with ostomies and IBD tweeted to support her and call her an inspiration for the IBD and ostomy communities. One Twitter responder, for instance, wrote that Townsend is “such an inspiration, especially in a world that’s so judgmental about how a woman should look in a bikini” (Walker, 2014).

Although many of the responses to Townsend were positive, some were “less supportive, and sometimes outright negative” (Rademacher, 2018, p. 3873). In his analysis of Townsend’s case and the public comments left in response to Townsend’s image, Rademacher (2018) indicates that despite their destigmatizing efforts, images like Townsend’s are still criticized by some. For example, his analysis compellingly shows how sometimes displays of ostomies can’t fully be controlled and can elicit stares and responses that are oppressive and stigmatizing. Specifically, Rademacher analyzed several comments posted in response to various articles that covered Townsend’s story, including this one:

> Seriously, is there no end to the stuff that people want to shove in other people’s faces for the sake of a few minutes of infamy? For God’s sake, keep it to yourself. I got a toe that looks really nasty—want to see it? My hemorrhoids have also really been acting up. For the love of God people. (p. 3872)

Despite Townsend’s display being largely viewed as an empowering act, it still existed within a public, ableist rhetorical ecology in which ostomies are predominantly stereotyped and stigmatized. In other words, Townsend’s intention to normalize her ostomy through a visual display could not completely ensure how others would see and stare at her. What was perceived as empowering and destigmatizing by some was considered “nasty” by others.

Collectively, Townsend, #GetYOurBellyOut, Gut Girl, and Vicky Mulholand illustrate how people living with ostomies and chronic GI conditions both individually and collaboratively work to destigmatize these conditions by participating in visual practices like displays, especially in digital, social spaces. These visual stories and their visible ostomies also suggest that displaying, posting, and sharing photos also (attempt to) call public viewers to engage in visual work by looking and staring at images of ostomies, chronic GI conditions, and bodies that are often considered abnormal. Unfortunately, however, these cases also stress that despite their intent, visual practices do not always or directly lead to destigmatization. Publicly inviting others to stare at ostomies, even while coaching those stares toward empathy, doesn’t guarantee destigmatization. It may help normalize ostomies, but more normal isn’t the same as fully normalized (and, as I discuss later, normaliza-
tion is a complicated end goal). In other words, making disability—in this case, ostomies and chronic GI conditions—visible is a risky endeavor (Johnson & Kennedy, 2020). Sam Cleasby’s visual stories with her ostomies, as I explore next, showcase these risks, especially when contrasted with Bethany Townsend’s story. While visual practices can productively “resymbolize” (Eiesland, 1994; Garland-Thomson, 2017) life with an ostomy or chronic GI condition, and in doing so, work to normalize these conditions, visual practices are not without risk (Johnson & Kennedy, 2020). When ostomies are revealed with bodies that do not meet other embodied norms related to beauty, sexuality, or gender, those ostomies and bodies become especially vulnerable to stigmatizing stares.

To illustrate this, I turn to Sam Cleasby. Cleasby has become a well-known figure in the ostomy and chronic illness communities as she catalogs her experiences with a range of chronic GI conditions and an ostomy on her website SoBadAss. In 2014 several photos of Cleasby went viral in the UK (Cleasby, 2014, 2015b) but became visible and well known within US ostomy and IBD communities as well. These photos capture Cleasby revealing her ostomy and stoma in a series of color and black-and-white images. Some of the images are close-up shots focused on Cleasby’s abdomen, featuring her ostomy or stoma, and a scar that runs from her rib cage to below the waistband of her black skirt. Other photos show Cleasby boudoir-style, in lingerie, lying on a couch, red high heels and legs propped up in the air. Together, the images display a confident-looking Cleasby, smiling and posing for the camera.

Describing the reason she decided to have her husband take these images and her own motivation for posting them, Cleasby (2015b) wrote in a blog post that accompanied the photos that she “wanted to show that [her] stoma didn’t remove [her] from [her] femininity, sexuality, or who [she] was before.” In an interview about the images, Cleasby elaborated:

My husband is a photographer and we were talking about the lack of great images [of ostomies] out here. They were usually very medical and there wasn’t really that many snapshots that people had taken of themselves at that time . . . I thought it was an old person’s disease and I was just 32; I couldn’t find any images that I could relate to . . . I wanted to do something completely different and show that this surgery hasn’t removed my femininity or my sexuality—it was just a very small part of me and it didn’t define me. (Saul, 2015)

In some of the images, Cleasby has removed her ostomy bag in order to reveal the stoma itself. Recall that stomas are the opening on the abdomen, which in the case of GI ostomies expose an end of the intestine on the abdomen.
Similarly, in the original blog post sharing these images, Cleasby (2014) clearly articulated that she wants to “show that people living with an ostomy can be sexy, fun, and cheeky . . . that this little bag doesn’t define who I am.” The images were originally shared on her personal blog and website but were eventually circulated and viewed across a variety of social media and news outlets (Cleasby, 2014; Saul, 2015). Cleasby’s explanation countered the idea that the person and disability “are synonymous” (Fine & Asch, 1988, p. 8). Cleasby explicitly asserted that her ostomy does not “define” her and offered these photos showing herself being “sexy, fun, and cheeky” to visually demonstrate that her ostomy is just a “small part” of who she is. These reasons for taking and sharing the photos align directly with reasons people have offered for participating in the #GetYourBellyOut campaign, like Petra’s Instagram post analyzed earlier in this chapter.

However, when these images were circulated online, they were not received positively by all audiences. In fact, Cleasby (2015b) wrote a separate blog post specifically to address the criticism she received for sharing them. Cleasby explained that she was critiqued for sexualizing disability in her photos. She opened her blog post by tracing the core of the critiques against her photos: “I have been subject to a few comments about sexualizing disability (and some just telling me that ostomies are gross and I should put it away, but that is a WHOLE other story!!!).” She then considered whether she is “guilty” of sexualizing disability and concluded: “The short answer is fuck yeah! And you know why? Because my sexuality, my femininity, and the person I am didn’t get removed along with my colon.” By fully embracing the idea of “sexualizing disability,” Cleasby cried” (Sandahl, 2003) her criticisms and purposefully agreed that she is sexualizing her disabled self through her revealing photos. It’s clear in reading Cleasby’s blogs and viewing her images together that her decision to display her disabled, female, sexualized self is an act of resistance against how ostomies had been visually represented in other spaces. She insisted that “looking at images [of ostomies online]” left her feeling “terrified” because she repeatedly found images of “stomas that were infected or

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21. Sandahl (2003) describes cripping as practices that “spin mainstream representations or practices to reveal able-bodied assumptions of exclusionary effects . . . expose the arbitrary delineation between normal and defective . . . and disarm what is painful with wicked humor” (p. 37).

22. Cleasby’s rhetorical reversal of the criticisms she received about sexualizing disability remind me of Shiri Eisner’s discussions of “so what” versus “not true” rhetorics. While Eisner’s work is not specifically related to disabilities or ostomies, there are interesting parallels here that are important to acknowledge and amplify. See Eisner’s Bi: Notes for a Bisexual Revolution (2013).
prolapsed or photographs of smiling old ladies” (Cleasby, 2015b). In response, she took photos of herself displaying her ostomy so that others who “are feeling lost in their illness” can find her photos and feel empowered by them.

Cleasby (2015b) went on to stress that the full answer requires an examination of “how disability is seen in our society and also how women are viewed in society” (emphasis added). Here, Cleasby explicitly called readers’ attention to the way disability, sexuality, and gender intersect, particularly in visual ways. What Cleasby seemed to be getting at is the intersection of the male gaze (which visually polices women’s bodies through patriarchal norms) and the ableist gaze (which visually polices disabled bodies through ableist norms). Caught at the intersection of these gazes, Cleasby argued that she was unfairly critiqued because disabled women are not expected or allowed to be sexualized. Specifically, Cleasby questioned why women are viewed and judged differently from men.

It’s so easy to use a woman’s body against them, to suggest that showing flesh is in some way a dart in the heart of feminists everywhere . . . It is odd isn’t it that when we see semi-naked photographs of men that there is no backlash, no one suggesting they are belittling the campaign by showing their bodies.

In this response, Cleasby called out the role and implications of the male gaze directed at her body. Cleasby went on to consider how sexuality, gender, and ostomy are compounded in the backlash her photos received. She directly rejected being “slut shamed” for choosing “to show [her] sexuality alongside her disability,” and she recommended that anyone who finds her sexuality “uncomfortable” “step away.”

Over the course of this blog, Cleasby (2015b) reflected on the oppressive practices and systems that contributed to the backlash her photos received. And, by the end of the blog, she revisited her initial answer to the question: did her photos sexualize disability? Her revised answer clarified:

I wouldn’t say I sexualize my disability, I would say I normalize it. I show photographs from every part of my life, there are photos of me playing with the chickens, hanging out with my kinds, with my husband, my mum, in my gym gear, at the beach . . . I show all parts of my life because my illness and my disability do not change all those parts of me.

23. Cleasby’s comments about “old ladies” hark back to Clara’s comments from the Grey’s Anatomy episode discussed in chapter 3, in which Clara claims ostomies are only for older people. The resonance here demonstrates the pervasiveness of the ostomy/elderly/disability trope.
Cleasby’s corrective move from sexualizing disability to normalizing disability is an important one. Much like Townsend’s photos or the photos participating in the #GetYourBellyOut campaign, Cleasby’s photos rhetorically display the ostomy in particular ways to encourage the normalization of ostomies. That is, according to Cleasby, she deliberately displayed her ostomy in nonmedical-ized, sexualized ways so that viewers see her ostomy as normal. Too, Cleasby resisted her ostomy becoming her defining identity.\(^\text{24}\) Instead, her disability is minimized as one “small” dimension of her identity and she took, posted, and shared photos of herself revealing her ostomy because, as she put it,

> The facts are that I am a woman. I have a stoma. And I live in a country where I have free speech and the freedom to show images of myself. The facts are that I make a difference. I help many people and I do it in my own way. The facts are that I am so badd ass, and I will carry on raising awareness, supporting people and kicking ass!

As these passages indicate, expectations and norms regarding female bodies and disabled bodies intersectionally impacted the response to Cleasby’s photos. Cleasby confronted assumptions that people with disabilities are asexual and relatedly unattractive and undesirable, as well as demands that female bodies are expected to meet specific westernized beauty ideals. Therefore, Cleasby’s sexualized images disrupt both sets of norms—she is at once disabled, female, and sexual. Put another way, Cleasby’s body actively resists the scrutiny of male and ableist gazes, especially as these multiple systems of oppression lead to the condemnation of her photos.

Importantly, however, Cleasby fuses normalization with destigmatization, a common but precarious move, through her images and blog posts, particularly the above two passages. By buttressing normalization and destigmatization, Cleasby’s images have to first accept and then espouse norms related to sexiness, femininity, and ability. That is, Cleasby first moves to equate being sexy with revealing her female body; she then minimizes her ostomy and situates it within a series of presumably normal activities that demonstrate how normal her disability really is. By positing normalization as the goal of her self-described “sexualized” images, Cleasby inadvertently fortifies the very system of normalcy she is trying to dismantle by suggesting that ostomies and ostomates can be made normal so long as they conform to other gendered and beauty norms.

\(^{24}\) See Shakespeare (1996) for more on disability as a definitive or all-encompassing identity.
At the same time, despite the clear intention of sexualization in Cleasby’s photos, her story and the visual practices involved within it illustrate how people with disabilities and illnesses are often presumptively positioned as asexual. It seems that part of the vitriol in response to Cleasby’s pictures stems from the perspective that Cleasby couldn’t and shouldn’t be sexual because she has an ostomy. Such thinking pushes questions about Cleasby’s sexuality and disability into criticisms and policing of her body and her (in)ability to conform to norms. In this way, the critiques she experienced could be traced to stigmatizing assumptions about disability, gender, and sexuality. However, the show *Too Ugly for Love?* opens a different set of questions. Cleasby’s photos and responses both align with disability studies scholarship that has repeatedly demonstrated the asexualization of people with disabilities; however, other examples from within the ostomy community complicate this understanding. To explore the complex sexualization of people with ostomies, I turn now to the case that opened this chapter: *Too Ugly for Love?*

The very premise of a show like *Too Ugly for Love?* is that people with disabilities and illnesses are sexual, or desire to be sexual, but that their sexuality is potentially stunted by the ugliness that disabilities and illnesses cast on particular bodies. In addition, *Too Ugly for Love?* not only perpetuates stigmatizing stereotypes regarding sexuality and ostomies but also potentially destigmatizes ostomies through what Cleary (2016) has called a “discourse of extraordinary normalcy” or the way people with disabilities are figured as extraordinary because they are “profoundly ordinary,” especially through reality television.25 Examples of this discourse might look like congratulating an ostomate for how normal they look or praising them because their ostomy isn’t even noticeable, the message being: passing as normal is a feat worthy of celebration. As mentioned in the introduction of this chapter, *Too Ugly for Love?* included four26 different people living with ostomies, Marcia, Antony, Kieran, and Matt, over the course of its three seasons. In the show’s promotional materials, these ostomates are depicted as “nervous” and “anxious” about dating with an ostomy and filled with concern about how others will react when they find out about their “condition” (TLC, 2017b). For instance, Antony’s biography on the show’s website admitted that he is

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26. At the time of writing, I am aware of four people who were featured on the show. Because this show is on TLC’s UK broadcast, the show is neither available in the US nor fully available online. The analysis presented here is based on what is available online via YouTube, Vimeo, TLC’s website, and the WayBack Machine internet archive.
“afraid [his ostomy] may scare women off,” and Marcia’s described that she finds dating “nerve-racking,” especially as she has to navigate decisions about disclosing her ostomy (TLC, 2017b). These biographies provide some initial context that frames these ostomates and their ostomy experiences in particular for the show’s viewers. Specifically, ostomies are staged, from the outset, through these descriptions and throughout the show’s narration, imagery, and storylines, as embodied entities that invoke nerves, fear, and anxiety, particularly related to appearance and attractiveness. Extending the initial biographies and ostomates’ descriptions, the show episodes pick up these stories as viewers watch Antony, Marcia, Matt, and Kieran date and navigate whether, when, and how to reveal their ostomies to their potential partners. A discussion of all four ostomates’ depictions on the show is beyond the scope of this chapter; therefore, I focus on episodes that feature Kieran in the show’s final season.

Viewers are first introduced to Kieran a few episodes into the series’ third season. The show’s narrator begins Kieran’s story by explaining that after nearly a year of being single, Kieran wants to return to the dating scene. He is briefly shown eating dinner with friends as they discuss the idea of Kieran dating again, but it’s not immediately clear why Kieran is “too ugly for love,” as he appears to have no immediately visible condition. I suspect this is an attempt to build tension; it’s a strategy commonly used in the show to reiterate the stressful decision-making process that orbits dating while “afflicted” with a disability and accompanying ugliness. We next see Kieran in his apartment bathroom as the narrator explains, “dating isn’t easy for Kieran” (Nicholson, 2016a). Kieran then narrates, as he unbuttons his shirt and reveals his ostomy to the camera, “I suffer from Crohn’s disease and as a result, I’ve had to have surgery which has left me with having to wear an ileostomy bag” (Nicholson, 2016a). He then briefly defines ostomy for viewers while removing his ostomy bag to reveal his stoma. With his bag removed, viewers have the chance to see Kieran’s stoma and ostomy site. Unfortunately, Kieran has developed a skin condition where his ostomy bag adheres to his skin, so his stoma appears red, inflamed, and painful. The narrator clarifies that while Kieran’s stoma itself is not painful, the skin condition is severe and challenging for Kieran. Throughout this scene, the camera remains focused on Kieran’s abdomen, giving viewers nearly a minute to stare at Kieran’s stoma and ostomy. On one hand, the introduction to ostomies and stoma provided by and through Kieran successfully depicts the complex realities of living.

27. For context, the show toggles between two storytellers: the show’s omniscient narrator and each “too ugly” person. As I recount Kieran’s story, I work to make clear who the storyteller is within each event and unfolding.
with an ostomy that include changing and cleaning the bag and managing skin conditions surrounding the ostomy site. In this sense, the show provides somewhat of an educational experience for the many people who may have never seen an ostomy or understood their function. On the other hand, it is important to remember the context in which viewers are gaining this exposure to ostomies: on a show that fundamentally judges Kieran (and people like him) as “too ugly for love” explicitly because of his ostomy.

With this introduction to ostomies and Kieran’s experiences, Kieran’s story next picks up as he prepares for his first date on the show and the narrator builds tension: “Today, Kieran has his first proper date in twelve years, and it requires some careful planning.” Standing in his bedroom with clothes on his bed, Kieran anxiously jokes, “I’m going to put my battle armor on, which is my waistcoat and pocket watch. It keeps everything in check and it’s a little, just a little bit of comfort thing to keep everything in check.” Here viewers observe a common practice for people with ostomies: choosing clothes that deliberately conceal the ostomy and help keep it in place. Then, after we watch Kieran nervously get dressed for his date, the narrator declares, “but, before heading out, Kieran has one final thing on his to-do list.” Kieran is shown packing ostomy bags, gauze, a tube of ointment, and other supplies into a paper bag that he carefully places inside a leather satchel. Kieran clarifies: “This is backup, just in case, you know, the worst-case scenario happens, and my bag leaks or tears and you have that dreaded feeling, which has happened on several occasions so from experience just, yeah, pack a spare” (Nicholson, 2016a). Again, Kieran’s practice of packing extra ostomy supplies in case he needs to perform a bag change while on a date is a practice that many ostomates I’ve spoken to have described. Although Kieran does seem concerned about “the worst-case scenario” of a leak, he looks calm as he packs the supplies and self-assured as he places the supplies in his bag and heads off on his date. This is, of course, an extra step that people without ostomies do not need to consider, and it does seem that the show includes Kieran’s packing of supplies to build drama. However, seeing Kieran as he describes this practice could visually communicate to the audience that there are ways to manage these “worst-case scenarios” and leaks and, consequently, shows viewers that ostomies can be manageable, not life-ending. To this point, I can’t help but

28. During my initial ethnographic observations of a weekend-long event for women living with ostomies and chronic GI conditions, attendees spent an entire afternoon sharing a variety of tips for dating, having sex, and managing close, sexual, and romantic encounters while having an ostomy. This day came to be known as “Sexy Sunday,” and much of the discussions focused on lingerie, belts, and other products that could help conceal and/or secure the ostomy.
wonder how seeing Kieran in this way may have potentially helped someone like Julia not feel so “stuck at home” (see chapter 3; CDC, 2015a).

In contrast, viewers operating within ableist ideologies are primed to see Kieran’s get-ready routine as a series of undesirable, extra experiences dictated by an ostomy—packing supplies, worrying about leaks, dressing to conceal, and even changing ostomy bags while experiencing painful-looking skin conditions. All these lived experiences displayed don’t necessarily encourage an empathetic stare from viewers so much as a sympathetic or even abjectifying stare. Together, these experiences could easily be viewed as evidence that life with an ostomy is abnormal and stigmatizing. Kieran’s discursive practices, along with the narrator’s, do provide some guidance for viewers regarding how to make meaning of the ostomy practices made visible through the show. For example, the narrator clarifies that Kieran’s stoma itself isn’t painful, which helps viewers differentiate Kieran’s painful skin condition from assumptions that ostomies and stomas themselves are inherently painful. Additionally, Kieran’s comments about how and why he selects his particular date outfit coach viewers to understand those practices in particular ways. Kieran’s tone in those moments is upbeat and nervous, but those nerves are presented more as typical predate jitters than distress over the difficulty of concealing his ostomy. In these ways, the show simultaneously confronts and complicates stigmatizing stereotypes, and while it doesn’t paint life with an ostomy as universally positive and easy, it doesn’t suggest that it is unequivocally terrible, either.

After an unsuccessful first date, Kieran is shown later in the series meeting up with a friend to discuss his dating strategy. During this conversation, viewers witness Kieran contemplating an online dating profile. With the encouragement of his friend, Kieran decides to go for it, and he quickly begins to scroll through the photos on his phone to consider various images for his profile picture. Kieran swipes to a photo of himself on the beach, arms and legs outstretched in what looks like joy as his ostomy bag is revealed. In reaction to the photo, Kieran exclaims, “Ah! This is the one, with the bag out. Do I? Do I? Do I?” His friend replies, laughing, “So, do you bag or not bag?” The two continue to laugh as Kieran smirks but then turns serious: “To bag or not to bag? . . . You know if someone doesn’t want to date someone with this sort of condition, then they’re not the right person so do me a favor. They’ll know what to expect physically” (Nicholson, 2016a). Ultimately, he decides to

29. To be clear, when I say unsuccessful here, I mean to say that the first date Kieran is shown going on in the show ends with Kieran ultimately deciding he is not romantically interested. The date is depicted as going well in terms of Kieran’s ostomy, which remains hidden and undisclosed to his date.
use the ostomy-revealing picture for his profile, which the show and Kieran insinuate is a high-stakes decision.

Toward the end of the episode, Kieran pursues another date, this time with a man named Matt, whom Kieran met through his online profile that featured his ostomy-revealing photo. The two decide to go rock climbing, and Kieran is shown again packing his “emergency kit” of extra ostomy supplies in preparation. After successfully rock climbing, Kieran privately debriefs to the camera and joyfully reports: “The date went really well, no issues with the bag whatsoever rock climbing. It just went really smoothly.” Kieran and Matt are next shown grabbing a drink, where they get into a conversation about what each other is looking for in a romantic partner. Matt offers that he “really wanted to meet [Kieran] because of how much [he] opened up really, you know . . . that takes quite a lot of strength . . . that’s a really admirable character in a person.” Kieran appears both flattered and relieved and replies, “Well thank you. But, physically, did my bag freak you out, or? Be honest.” Matt pauses momentarily before responding, “Well, it is a bit like [sigh] you know, because it is a bit different. I couldn’t really just be like ‘ew!’ you know, all of a sudden. All the things I think about you, I couldn’t just dismiss it. It kind of made me a bit more intrigued actually because you were so open about it and that just made me respect you quite a lot.” After the date, Kieran is clearly excited. Smiling profusely, he energetically tells the camera that the date went “just brilliantly.”

Though the show never acknowledges this complexity, Kieran’s dating life, sexuality, and disability present an often overlooked and underdiscussed intersection of ostomy experience. As a queer man with an ostomy, Kieran faces many similar but also many different circumstances and potential challenges compared with ostomates like Sam Cleasby or Bethany Townsend. The similar first. Although Kieran, as a man, doesn’t face the same gendered norms that women with ostomies do, there are several similarities between beauty norms for queer men and for heteronormative ciswomen. As Nathan Wheeler, a gay man with an ostomy wrote in a 2020 blog post:

Stigma in the gay community is very high because many people (not everyone, but a lot of people) think that gay men have to be body beautiful. They should have clear skin, abs, hairless bodies, and be over six feet tall. If this is what you base a person on, chances are—you are probably going to be single for a long time!

The specific physical characteristics Wheeler described as norms for queer men mostly parallel those for women: be thin, athletic (but not too muscular); have clear, blemish-free, and hairless skin. This is not to say that gay men and
women are socially expected to look the same way but that there are some similarities in the normative expectations for attractiveness and that these similarities evaluate and policy ostomy bodies across differences in sexuality and gender. Wheeler went on to note that these norms related to appearance are “very apparent online and on social media,” much the same for women ostomates as evidenced by stories earlier in this chapter.

At the same time, there are important differences between the norms Kieran faces and those discussed so far in this chapter. Namely, when it comes to sexuality and the ways in which ostomates can and do meet those expectations, queer men face an entirely unique set of challenges. As Wheeler (2020) explained:

Gay stigma with an ileostomy is even harder because there are certain things a gay man can no longer do if they have an ileostomy and a barbie butt (total removal of the rectum), like myself. Instead the gay community in terms of sex, there are a few options that a man can take. A top, is usually the guy doing the penetrating. A bottom is a male that receives the penetration and a versatile is something who doesn't mind which role they take; they can be either. Obviously, with an ileostomy and having the rectum removed, this is one of the things that can open you up to stigma. People that have had their rectum removed cannot be a bottom or a versatile anymore because there is nowhere to be penetrated. That function is removed from sex. You can, however, be a top. This is just something you have to work around with an ileostomy. (emphasis original)

The considerations and challenges that Wheeler described are made invisible in Kieran’s storyline on Too Ugly for Love? However, that doesn’t mean that they were not factors in his dating experiences depicted on the show, particularly in his anxiety about finding a partner or in the ways his two different dates responded to his ostomy. To be clear, Kieran does not disclose whether he underwent barbie butt surgery. Nevertheless, there are additional norms at work and potentially being defied by Kieran at the intersection of queerness, masculinity, sex, attractiveness, and ostomies. This particular intersection is underdiscussed in general within the ostomy and IBD communities and underrepresented in my research. However, I discuss it now because it further complicates the connections between asexuality and disability. As Kim

30. The language of barbie butt is extremely common throughout the ostomy community. For those unfamiliar with Barbies, Barbie dolls are manufactured with no genitalia or anus. Thus, when the rectum and anus are removed, ostomates often call it barbie butt surgery because their anus is removed, and that opening is surgically closed.
(2011) noted, disability can present opportunities to explore new, alternative, or different ways to experience pleasure, sexual or otherwise, and perhaps these are an affordance to ostomies and surgeries to remove the rectum and anus for some individuals. My point here is that asexuality is not the only way that sexuality-related norms and assumptions are forced onto ostomates’ identities and experiences. Kieran’s story, and the specific nuances it manifests, helps showcase how an intersectional approach focused on the practices and lived experiences with ostomies is both important and necessary for a deep understanding of ostomies as well as stigmatization.

Despite the show’s title and the intersectional experiences that go unexplored in Kieran’s time on the show, the ways in which Kieran is depicted on the show ultimately communicate that dating with an ostomy is not only possible but can be successful. Kieran is never shown navigating a negative response to his ostomy, though the show’s title and premise suggest that negative experiences are the rule, not the exception, for people like Kieran. It’s unclear how the show would have rhetorically managed a negative reaction to Kieran’s ostomy during a date, but the lack of negative experiences has a potentially empowering effect for people living with ostomies. It is possible, given how Kieran and his experiences are displayed on the show, that viewers might conclude that people with ostomies are not indeed “too ugly for love” but are instead fully capable of being loved, going on dates, and managing their ostomies at the same time. In Kieran’s final appearance in the show, several episodes later, the status of Kieran and Matt’s relationship is unclear, but Kieran ends by saying, “It’s been the best experience actually, to go on a date and meet someone. Before I had all this self-doubt but the thing I’ve realized actually is that I have the right to find love” (Nicholson, 2016b).

Kieran’s overall portrayal on Too Ugly for Love? focuses on the potential risks of revealing an ostomy. Viewers watched Kieran navigate whether, when, and how to tell and/or show dates his ostomy—that this decision was contemplated at all suggests that revealing and displaying are risky endeavors for people with ostomies. Further, as Kieran weighs whether to reveal his ostomy on his online dating profile or not, the risks of revealing become clearer and the stakes potentially higher. Revealing his ostomy could scare off potential dates before they even get to know Kieran, or it could make Kieran ugly or less attractive. Additionally, Kieran’s decision to front his ostomy on his online dating profile further risks soliciting dehumanizing stares that could enable viewers of his profile to see Kieran as his ostomy instead of as a person with an ostomy. For Kieran, the decision to visually reveal his ostomy pays off because it allows him to find Matt, who then praises him for his courage in revealing it.
At the same time, Kieran is included under the guise of being too ugly for love and therefore is made a spectacle (Garland-Thomson, 1997, 2009). Audiences are encouraged to stare at and consequently objectify and judge the people featured on the show, including Kieran and the other ostomates. The show’s title and framing place Kieran and the other adults on the show under rhetorical and visual scrutiny in which bodies are valued along binaries including inferior/superior, beautiful/grotesque, attractive/ugly (see Garland-Thomson, 1997, pp. 7–8). Consequently, the inclusion of Kieran and other ostomates on Too Ugly for Love? invites us to question the sexualization of ostomies. The show raises a variety of questions: Do ostomies disqualify people from being seen as sexy? Attractive? Loveable? Can disabled people make themselves attractive enough to find love? What happens when a person with a disability or other physical condition reveals their “true” self (TLC, 2017a)? If Kieran serves as the only evidence, then the answer appears to be no, ostomies do not render people too ugly for love. However, including ostomates on the show positions ostomies and the people who have them in a state of sexual contingency in which their sexuality and attractiveness are bound up directly in their ability to find partners who are willing to love them despite the ostomies. Too, the show encourages viewers to grapple with the risks of living with an ostomy, including those that accompany decisions to conceal and reveal as well as risks like skin breakdown (as when Kieran shows his ostomy to the camera during his introduction on the show) and the potential of ostomy leaks while on a date. These risks are no doubt real, and, in my estimation, the show does a fair job displaying both the existence of these risks and how people living with ostomies can successfully manage them in a way that could potentially destigmatize ostomies, despite the show’s problematic positioning. Nevertheless, although Kieran ultimately does find someone who is “willing to accept his ostomy,” the show simultaneously implores viewers to see living with an ostomy as a risk that could negate any chance at finding love and acceptance.

**Showing Off Ostomies and Arriving at the Destination of Normal**

The stories in this chapter have so far stressed two things: (1) displaying ostomies and being seen as a person with an ostomy can be a risky practice, and (2) a common goal of and/or justification for revealing ostomies, especially online, is normalization. To further interrogate the relationship between visual practices, stigmatization, and normalization, I end this chapter by examin-
ing two final examples that demonstrate the complexity of displays: Gaylyn Henderson’s participation in the #AerieREAL campaign, and Jessica Grossman and her online advocacy organization/campaign, Uncover Ostomy.” My analysis of Henderson’s and Grossman’s highly public visual displays extends the discussions I have explored thus far in this chapter, specifically by considering a different set of rhetorical risks and rewards that emerge at the nexus of disability, visuality, sexuality, and gender, particularly when “normalizing” ostomies is the goal.

People with ostomies and chronic GI conditions around the world have been celebrating Aerie, an apparel company that mostly sells lingerie and athletic wear for young women. In 2014 Aerie launched its “Aerie Bras Make You Feel Real Good” campaign, coinciding with a variety of bra collections designed and advertised for “real women,” which includes women of “all shapes, sizes and colors” (Callahan, 2018). Now called #AerieREAL Life, this campaign works to “spread the brand’s mission to love your real self—inside and out” and to “empower and inspire the Aerie community to be the change they want to see in the world through leadership, advocacy, workshops and philanthropic partnerships” (Owens, 2020) by featuring #AerieREAL Role Models. These role models have included a breadth of women, such as Aly Raisman, a former Olympic gymnast and advocate against sexual abuse,32 and the Tony Award–winning actor Ali Stroker, who was the “first person using a wheelchair to appear on Broadway” (Aerie, 2020a). Alongside these famous women are several noncelebrities chosen to participate in the campaign for their “passion and positive influence” and to “represent and embody” real, relatable women (Aerie, 2020c). Notably, several of these women “proudly display” disabilities, conditions, and illnesses, ranging from Down syndrome and insulin pumps to feeding tubes to, you guessed it, ostomies (Callahan, 2018).

Specifically, #AerieREAL featured Gaylyn Henderson, founder of the online advocacy organization and social media campaign Gutless and Glamorous (Gutless and Glamorous, n.d.). Like the other role models in Aerie’s campaign, Henderson submitted a short video application in hopes of being selected for inclusion as one of the campaign’s models. Once selected, Henderson participated in a photoshoot, where she sported various Aerie bras and underwear and, in most images, clearly displayed her ostomy. These photos not only serve as display photos for a variety of products on Aerie’s website;

31. Readers might recall Grossman from chapter 4, where I discussed her response to Julia’s Tips from Former Smokers video.

32. Raisman famously led the charge against former USA Gymnastics doctor Larry Nassar, who was accused and convicted of raping and sexual assaulting over 200 young women and girls during his tenure as the team’s doctor.
they have also been featured in larger poster displays in Aerie stores across the US. When asked about her participation in the campaign, Henderson said:

I think it is absolutely a step in the right direction. In mainstream media, it’s often referenced as having an ostomy in a negative way. It may seem trivial to some, but popular cultural beliefs can be very impressionable to others. Society can make a drastic impact on a person’s decision to receive an ostomy and can have a drastic impact on a person living with an ostomy. Even though ostomy is a lifesaving surgery many are reluctant to receive them because of the negative stigma. All of these factors combined makes it that much more significant that Aerie recognized how having a model with an ostomy has the ability to change and save lives! (IBD Editorial Team, 2018)

Henderson’s participation in this campaign exemplified the role of visual practices in thwarting stigma. Importantly, too, Henderson is a Black woman with an ostomy and therefore resists not only ostomy stigma but also racialized notions and norms of beauty through her participation in #AerieREAL. Her participation celebrates the beauty of being an ostomate, of being a woman, and of being Black, all of which are entangled in opposition to whitestream beauty norms. Unlike Too Ugly for Love? the Aerie campaign celebrates embodied differences (in fact, many of the same conditions featured on the TLC show have been featured in the Aerie initiative). The #AerieREAL campaign and Henderson’s participation in it benchmark an important public moment because women with disabilities are not just included for token representation; they are celebrated as representations of beauty, leadership, and what “real” women look like.

Of course, this campaign and the company endorsing it are ultimately geared toward selling clothes and making a profit through displays of wom-

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33. I deliberately use whitestream instead of mainstream here, following Cedillo (2018) and Grande (2003). In doing so, I’m signaling the racialized dimensions of mainstream. Inherent in the idea of “mainstream” is the majority and thus systems of power and oppression that subjugate minoritized people. Cedillo (2018), citing Grande (2003), explained, “Whitestream . . . [is] the version of reality ‘principally structured on the basis of white, middle-class experience.’”

34. This discussion of “real” women is not without problems. In implying that Aerie women are real women, they suggest that, somewhere, not-real women exist. Such opposition is nearly always problematic. That said, it seems that the goal of this language for Aerie and its campaign is to challenge westernized beauty norms, which are often manufactured through unrealistic or extreme practices (e.g., extreme dieting, cosmetic surgery, waist-training) or through digital alteration like photoshopping images and falsifying women’s bodies to further instantiate problematic and unattainable beauty norms.
en’s bodies, and I do not mean to suggest that this kind of marketing campaign is without flaw. However, not only has Aerie included disabled women as models, it has also begun to sell products that are specifically designed for disabilities. For example, Aerie now sells products from Abilitee Adaptive Wear, a company focused on “creating adaptive apparel for people with disabilities and medical needs that’s both fashionable and empowering” (Aerie, 2020b). Among Abilitee’s products are undergarments designed specifically for ostomies. The company has claimed that they created ostomy covers after hearing about experiences with leaks from ostomates. For instance, the brand makes water-resistant ostomy covers with phrases like “OH SHIT” and “HOT SHIT” that “are designed to retain leaks, should they occur, so the wearer doesn’t have to worry about staining their clothing” (Aerie, 2020b). This language, paired with products responsive to ostomates’ lived experiences and concerns, is another example of practices that crip and resist stigmatization. In this case, shit puns visibly and boldly displayed on ostomy covers crip the negative affiliation between ostomies and feces. As Yergeau (2018) has argued, similar to visceral emotions described by Johnson (2016), shit talk is often characterized by the need to do something, to fix, cure, or distance ourselves from feces and whatever problem has put feces in proximity. Putting language like “hot shit” on ostomy covers is a comical act of resistance that crip by combining sexiness with shit itself through a play on the common phrase hot shit, in which shit is not really shitty at all.

Ultimately, #AerieREAL raises important questions at the nexus of normalization, visual practices, and stigma. Garland-Thomson (2017) has argued that “disabled fashion modeling,” such as Henderson’s modeling for Aerie, is “at once liberatory and oppressive” (p. 376). On one hand, images that might be categorized as disabled fashion modeling participate in “capitalism’s appropriate of women as sexual objects”; on the other hand, they “produce politically progressive counter images” that integrate “a previously excluded group into the dominant order” (p. 377). Embracing this complexity, Garland-Thomson proposed that disabled fashion modeling can serve as an activist response in which disabled women persist as “embodied paradoxes,” at once beautiful and disabled. I’d like to end by forwarding Garland-Thomson’s insights here to suggest that visual displays, including Henderson but also the many visual practices discussed in this chapter, can do the complex work of “bringing disability as a human experience out of the closet and into the normative public sphere” (p. 376) through repeatedly “refusing to normalize” (p. 377). #AerieREAL, thus, seems to offer one example of how visual practices can crip (Sandahl, 2003) the very practices and systems that subjugate people with ostomies, particularly women with ostomies. Although the cam-
paign could be read as objectifying the bodies of disabled women, there has been extensive public support for the campaign, particularly from within the ostomy community. For instance, one ostomate tweeted, “This is just another reason I LOVE @Aerie. Like I am crying y’all don’t understand. As an ostomate who has been self-conscious about my colostomy, this is just so amazing to see. I’ll never be over how much this means to me.” Another tweeted, “This new campaign by American Eagle [Aerie’s parent company] is incredible. Representation is important. Models of all colors, sizes, and models using mobility assistance devices, all looking amazing! Shout out to Gaylyn (and her ostomy!).” And, even those outside the ostomy community have praised Gaylyn’s inclusion and display of her ostomy: “I can’t express how happy it made me feel the first time I was online shopping & saw an Aerie model with a colostomy bag. As a person with a feeding tube, to see a beautiful woman wearing her disability like a fashion statement is so empowering” (Aerie, 2020c). In reflecting on the response overall, the advocacy organization Ostomy Connection (2019) said, “people” “went totally off-the-wall ecstatic” when Henderson’s pictures began circulating as part of the campaign.

While displaying ostomies comes with many risks, the #AerieREAL campaign, and the many visual displays and stories presented in this chapter, illustrate that along with these risks can come important rewards. In fact, #AerieREAL testifies to the possibilities that can be generated when visual practices are deployed in the public sphere. Visual practices like those of Gaylyn Henderson refuse to normalize (and perhaps are prohibited from doing so), and they embrace dissent through visual displays. In other words, these visual practices undermine negative ostomy stories and resist stigma. Rather than conceal their ostomies and conform to the pressures of normalcy, ostomates like Henderson, and also Townsend and Cleasby, crip selfies by revealing their ostomies and stake claim to their right to not only exist but also celebrate their full embodiments and identities. They take normalized social media practices and spin them into something new and political, a platform for displaying ostomies, increasing ostomy awareness, and destigmatizing life with and bodies with ostomies.

However, public visual practices, as this chapter has repeatedly emphasized, participate in a rhetorical ecology where ostomy stigma, gender norms, sexuality, and normalcy intersect. As disability theorist Lennard Davis (2013) has contended, “The mythos of the normal body has created conditions for the emergence and subjection of the disabled body, the raced body, the gen-

35. Research has further confirmed the positive response to and implications of the Aerie campaign. See Rodgers et al. (2019) and Convertino et al. (2019).
dered body, the classed body, the geriatric body—and so on” (p. 2). Kieran's inclusion in Too Ugly for Love?, accusations against Cleasby for sexualizing disability, and the celebration of Henderson's inclusion as an underwear model all point to the rhetorical complexities that people with embodied differences must navigate when it comes to revealing or concealing their difference. Too, these diverse cases raise important questions about how normalcy and normalization rhetorically impact visual practices themselves. Therefore, I turn now to one final case, with Jessica Grossman, that illuminates the rhetorical impact of normalcy and normalization for disabled, gendered, raced, and sexualized bodies.

Grossman is the founder of Uncover Ostomy, a website designed to educate about ostomies and fight ostomy stigma. On the site's landing page, the first thing viewers see is a collage of six photos of Grossman. In all six photos Grossman looks directly into the camera, which has the effect of engaging viewers through what feels like direct eye contact. Two of the photos show Grossman naked, which displays her ostomy, as her hair and hands cover her breasts. In another photo, Grossman lies on a bed with a sheet that covers her breasts and the area from her hips to her knees, while strategically revealing her ostomy. In the other three photos, Grossman is partially or fully clothed, and in only one of the photos is the ostomy partially visible. The other pages on Uncover Ostomy, including a blog, calendar of events, and contact information, also feature images of Grossman displaying her ostomy. Grossman has become a well-known advocate and ostomate, in part, through revealing images like these. When Uncover Ostomy first began, an initial series of images showing Grossman displaying her ostomy by lifting her white tank top and lowering her unbuttoned jeans helped garner the attention that put Uncover Ostomy on the map.

In a blog post from 2018, Grossman reflects on her decision to start Uncover Ostomy and specifically, to share photos of herself and her ostomy:

9 years ago, when you Googled “ostomy,” you would have wished you didn’t. It was full of very graphic pictures of stomas—not even healthy stomas—clear ostomy bags, bleeding scars, and just a whole whack of photos you

36. Not all responses to Grossman's images have been positive in the eleven years since she started Uncover Ostomy (Frohlich & Zmyslinski-Seelig, 2016; Leadley, 2016). Responses to Grossman's photos have sparked an important debate regarding how and when ostomies should be displayed publicly. On one hand, many have celebrated Grossman's choice to publicly share such images. Onlooking ostomates, people living within chronic GI conditions, and others have praised Grossman for her bravery and willingness to make her ostomy visible. Other researchers have studied Grossman and Uncover Ostomy, specifically to ask questions about visuality, ostomies, and sexuality.
would have wanted to see if you were trying to convince yourself not to have surgery. Not ideal for those who had no choice but to get an ostomy bag.

Grossman’s rationale for posting her photos that reveal her ostomy matches Cleasby’s. Both women were unsatisfied with the images online of ostomies, specifically because many of these images were graphic and unhelpful. Therefore, Grossman spent nearly a decade displaying her ostomies in photos shared online and encouraging others to do the same. Uncover Ostomy is defined by these photos.

However, nearly ten years after starting Uncover Ostomy, Grossman began to publicly reflect on the work she was doing and what she had planned for Uncover Ostomy moving forward. In reflecting on how Grossman wants Uncover Ostomy to evolve and grow in the coming years, Grossman (2018) stressed:

I’m posting more about my life with an ostomy on Instagram, instead of writing entire blog posts. I will continue to write blogs (even though my life is pretty boring these days), but I am going to shift more of my awareness efforts to platforms where society is used to absorbing a lot of information quickly and in visual form. After all, the ostomy is very visual, so might as well capitalize on that, right?

In making this move to share more images, particularly on Instagram because it is visual-focused, Grossman recognizes the important role that visual practices can play in normalizing ostomies and resisting ostomy stigma. Additionally, she seems committed to using visual practices to promote ostomy awareness and “chang[e] the way the world views the ostomy” (Uncover Ostomy, n.d.).

In 2019 Grossman announced big changes for the tenth anniversary of Uncover Ostomy. In a three-minute video posted to the Uncover Ostomy Instagram profile, she announces that she has “an important message” for the ostomy community. That important message? “It’s time to stop showing off your ostomy.” She then unpacks why she is advocating this message and further why it is important for the entire ostomy community to hear:

These past ten years, I’ve worked hard building Uncover Ostomy to break the negative stigma surrounding ostomy surgery. And so have you. Together we’ve come to accept ourselves and we’ve made the ostomy known through social media posts to news articles to companies showcasing people with stomas. The word ostomy has become better understood and incorporated
into everyday terminology. That said, we've done a great job highlighting what makes us different. But I don't want to be different. I'm not different. And neither are you. We're normal, everyday people who just happen to have to use the bathroom in a unique way. Other than that, we're just like everyone else.

Grossman's message argues that displaying ostomies is no longer necessary or helpful in the effort to raise ostomy awareness, empower ostomates, or fight stigma. Specifically, she insists, people with ostomies are “normal, everyday people”; thus, showing off ostomies in photos online serves to differentiate ostomies rather than normalize them. She adds, “We’ve done such a great job at setting ourselves apart from the crowd, but we put ourselves in a category of people with different needs and it’s time to stop that.” One interpretation of Grossman’s argument here is that she is suggesting that people with ostomies need to stop identifying as different and, more specifically, as disabled. As Garland-Thomson (2017) might explain, Grossman was advocating for the ostomy body to become the “unobtrusive body” that “may pass unnoticed” (p. 367) in society and thus go unmarked as abnormal and stigmatized. While she does not use that language directly, her contention that people with ostomies have “put [themselves] in a category of people with different needs” does raise the question of who exactly she means by “people with different needs” and why exactly it is problematic to have different needs. To justify her call for people with ostomies to stop showing them off, Grossman focuses on ostomies’ practical function—to excrete waste. She asks viewers, “I mean, how many other times have you seen someone else flash their butt? Hopefully not a lot.”

Despite her charge to the ostomy community, Grossman (2019) explains that she will continue to release photos “unlike” ones she has previously shared. These new photos, Grossman says, are different in that they do not draw attention to her ostomy bag but instead focus on her because the Uncover Ostomy movement is “about living normally with an ostomy, as if it wasn’t such a big deal because it’s not.” Grossman ends the video with the following directive for viewers:

Don’t stop talking about your ostomy. Don’t stop telling people how it saved your life. But maybe stop voluntarily showing people where you shit from. Instead, show them how awesome you are as a whole. That’s what these photos are meant to represent, and this is the message that I want to take forward. I hope you’ll join me because it’s time to stop showing off your ostomy and it’s time to start showing off you.
Much like Cleasby and the #GetYourBellyOut campaign examples, Grossman rejects her ostomy becoming her sole or total identity. She further argues that people with ostomies should engage in particular discursive and visual practices (those that de-emphasize or conceal ostomies) to normalize ostomies. Notably, Grossman’s comments here enact what Linton (1998) has called the “rhetoric of overcoming” in which disability itself isn’t overcome (for most, this isn’t possible) but instead social stigma is overcome, thus eliminating the problem with disability. Such rhetoric is often extremely problematic, especially when leveraged by individuals who otherwise benefit from privilege. In the case of Grossman, her announcement that ostomies no longer need to be amplified because they put ostomates in “a category of people with different needs” is not only ableist in that it suggests that being a person with different needs is abnormal; it also relies on racial, sexuality, and gendered privilege that many ostomates are not advantaged by. That is, as a White-presenting, cisgender, heterosexual woman with access to healthcare, resources, and support (as evidenced by other posts on her blog), Grossman has little authority to speak on behalf of all ostomates. Many ostomates are Black, Indigenous and people of color (BIPOC); many cannot so readily conceal their ostomies (because of placement of the ostomy itself on the abdomen, access to clothes that conceal, or access to resources that help them manage the ostomy itself); and many across genders do not conform to beauty and appearance norms in the ways that Grossman does.

My analysis here is not intended to belittle Grossman’s ostomy positivity, nor to suggest that Grossman hasn’t faced stigma or challenges with her ostomy. Grossman’s individual lived experiences may very well suggest to her that ostomy stigma has been dismantled enough that ostomies too can join the ranks of unmarked, unnoticed normal embodiments. My point is that Grossman’s call for all other ostomates to “join her” in de-emphasizing ostomies, and embrace being “normal, everyday people,” only works (and even then, not with any amount of certainty) for ostomates who share her identities and lived experiences. Moreover, her assessment that “the word ostomy has become better understood and incorporated into everyday terminology,” partnered with the contrasting statements that the ostomy community has devoted the last ten years to fighting ostomy stigma, suggests that this battle is over. Ostomy stigma solved; normalcy achieved. This assessment, though, can only be made by ignoring or isolating other intersecting experiences and identities that are not represented by Grossman and by assuming that Grossman’s individual experiences can speak for all ostomy and chronic GI experiences. In sum, the normalization that Grossman suggests has been achieved for osto-
mies and ostomates is a fraught accomplishment that belies the intersectional oppression and lived realities of many ostomates.

In step with my analysis, several commenters challenged the story Grossman was presenting about ostomies and the recommendations she was making for other ostomates. That is, not everyone in the ostomy community supported Grossman’s message and her suggestion that the ostomy community had eclipsed the need to raise awareness and resist stigma through displaying the ostomy. Of the eleven comments that were left in response to the video, five challenged Grossman’s evaluation of the ostomy community and its needs. In response to Grossman’s post, one commenter addressed the never-ending fight against stigma, and specifically the self-centeredness the commenter felt was apparent in Grossman’s comments:

These pics are therefore just modelling photos of you, posted to your “ostomy themed & named” blog that you don’t want to be ALL about the ostomy but how you live life . . . I’m kinda confused [to be honest]. The awareness is never finished, erasing the stigma still has so far to go, teaching those that are vulnerable and scared about the mechanics of living with an ostomy is still vital. Yes we can live a normal life & yes we don’t want to feel singled out as “different” but that doesn’t mean we have to stop sharing knowledge, experience, negatives & images of our bags. Sadly, I think this 10yr anniversary campaign feels as though it’s more about you, than anything ostomy related. (emphasis added)

Another comment articulated the complexity of Grossman’s mandate for the community:

I agree that when it comes to awareness we can certainly do that and keep our shirts on . . . but I’m torn with the negative vibe you kinda threw out there towards those of us who choose to show “where we shit from.” I show my bag because it is part of me . . . I show my bag because I want to show other woman they don’t have to hide themselves to make society comfortable, I show my bag because it helps me accept myself, I show my bag because it DOES NOT define me.

Both responses to Grossman emphasize that there is critical rhetorical value in continuing to share images that reveal the ostomy. Building community, empowering ostomates, resisting stigma, educating others—these are the reasons commenters argue that displaying ostomies has been and continues to be an important rhetorical practice.
Conclusion

Ultimately, the complexity of visual practices, particularly along axes of gender, disability, and sexuality, raised by Grossman’s video, its responses, and the other visual stories presented in this chapter remind me of a line from Garland-Thomson’s (2009) Staring: How We Look: “Normality is the destination to which we all hasten and the stick used to drive us there” (p. 31). While Grossman (2019) argues that the ostomy community has arrived at the destination of normal and should consequently work to stay there, it’s clear that many others in the community still feel pressured by the stick to get there. The many stories and experiences explored in this book evidence that not everyone in the ostomy community feels that ostomies have been successfully normalized, nor that normalization is the ultimate goal. Indeed, the responses to Grossman’s video and the ongoing #GetYourBellyOut campaign provide just two examples that attest to the ongoing need for acts, like sharing pictures and telling stories, that resist stigma, empower people living with ostomies and chronic GI conditions, and shape how ostomies are made to mean in the everyday experiences of individuals who live with these conditions and in the public sphere.

The visual practices and stories explored in this chapter signal that “normalization” is, at the very least, a complex goal. On one hand, thousands of people have worked and are working to destigmatize and subsequently normalize ostomies through visual practices. People living with ostomies and chronic GI conditions are retooling visual practices like taking selfies to place ostomies within the public, social sphere and thus position ostomies as normal and ordinary. On the other hand, normalization is the very process by which ostomies have been deemed abnormal and problematic in the first place, which raises the question whether normality is actually the best destination. Too, normalization, as a manifestation of the interlocking systems of power that minoritize, leaves many ostomates behind in our contemporary moment. Normalization requires an embracing of privilege, when people with ostomies and chronic GI conditions, along with other minoritized groups and privileged allies, might instead work to dismantle systems of oppression altogether. For many people with ostomies and chronic GI conditions, to work toward normality is to strive for invisibility, which is perhaps what Grossman was advocating for. If normalization is the goal, then posting images that reveal ostomies and chronic GI conditions is a step toward making ostomies so ordinary that they can be simultaneously visible and invisible, seen but not stared at. Moreover, it is the collective pressure to be normal that demands that people look, act, evacuate waste, and live in particular ways.
As this chapter has also argued, normality is caught up in an array of norms and expectations, related not just to disability but also to gender, sexuality, and, no doubt, class and race. As Foucault (1995) summarized, “The judges of normality are present everywhere” (p. 304). Making sense of the visual practices being deployed as acts of resistance against stigma requires intersectional considerations that attune to the multiple systems of norms at work. As Leadley (2016) reminds us, “When one speaks of ‘normal’ bodies, one must take into account not only ability, but also the assumed cis male, heterosexual assumptions implicitly linked to thinking of the so-called ‘normal’ body” (p. 26). Indeed, arriving at normality in one capacity does not guarantee residence there.