When I was first diagnosed during my senior year of high school, I didn't really understand what was happening, and more than anything, I wanted to pretend that nothing was. Of course, left to its own devices, my disease became virtually unmanageable, which in terms of my daily life meant that I had next to no control over how frequently or urgently I needed to use the bathroom. One day, about a month after my diagnosis (and effectively a decade into having untreated symptoms), I sat in sixth-hour, senior-year Spanish class and was struck by the horrifying feeling that I needed to get to a bathroom right away. I quickly excused myself from class and literally ran down the hall to the bathroom, where I whipped open a stall door, unaware of anyone else in the room. Sheer panic and anxiety had taken over. Fight or flight initiated. But thank god, I had made it. I hadn't had an accident at school yet, but this wasn't the first close call. Although I was learning to anticipate when this urgency would suddenly appear, this whole autoimmune disease thing was still pretty new. I tried to discreetly relieve my angry intestines, knowing there was little I could do to control this situation. The memories of just that stress and fear alone would be enough to haunt me a decade later, but the story doesn't end there.

From the false privacy of the bathroom stall, I heard laughter. In my rushed entrance, I hadn't noticed two other girls in the bathroom, fiddling with their makeup and skipping class. Not just any two girls, either—two of
the most popular and, of course, most notoriously mean girls in my high school. I had friends and was well liked, but these girls were well beyond my social stratum. And they were witnessing the wrath of my disease in full force. “Oh my god. What the hell is going on in there?” “That is DISGUSTING.” “Should we go call a plumber?” All but paralyzed with shame, I flexed every muscle in my body, hoping to silence it long enough for the girls to leave. I slowly picked my feet off the floor, hoping I had done so quietly but quickly enough that the girls didn’t notice my shoes, an easy way for them to identify who was hiding behind the bathroom stall door. I held both my breath and my tears and waited for the snickering to stop. Why me? Why a digestive disease? Why did they have to be in here? After what felt like hours, the two left the bathroom, but not without a final “I can’t believe a girl could be so gross.”

This is a story that I’ve no doubt many people with gastrointestinal (GI) disease and ostomies would find relatable. It illustrates an unfortunately familiar experience for people with ostomies and GI disease: body uncontrolled in public space, stigma fully unleashed. Bathroom stories, like this one, are a hallmark of the lived experience of people having these conditions. Indeed, bathrooms present a complex space for marginalized bodies (Booth & Spencer, 2016; Kafer, 2016). I’ve heard many such stories in my time working on this research: stories of panicked searches for public bathrooms; of accidents in shopping malls because a cashier refused access to employee bathroom, the only bathroom nearby; embarrassment when a stranger assumes that a man is using the female bathroom because they see feet facing toward the toilet instead of away, when really an ostomate was just emptying her pouch. And stories like the opening one of just trying to survive a day with unruly intestines. As most GI patients will tell you, hell hath no fury like an inflamed bowel. Bathrooms become our lives.

Importantly, too, this story demonstrates some of the different ways in which stigma emerges in practices and experiences. It can emerge through nasty comments and harsh whispers and through expectations and anxiety. But, of course, this is not the only stigma that people with GI diseases or ostomies have come to know. Many people I’ve spoken with for this project have

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1. Refusal of bathroom access is such a rampant problem that states have begun passing the “Restroom Access Act,” also known as “Ally’s Law,” which requires that public places allow people with particular medical conditions, like IBD or ostomies, to use private or employee-only restrooms (Crohn’s & Colitis Foundation of America, n.d.). The law is named after Ally Bain, a woman living with Crohn’s disease, who was denied bathroom access at a clothing store while out shopping with her mom. Ally has spearheaded this legislation to ensure that people with medical needs are granted the right to bathroom access.
described the materialization of stigma in a variety of instances and ways. In their experiences, stigma emerges among stares at the local pool or eye rolls in line at the grocery store, within biased attitudes at a job interview or doctor visit, at dinner when a date abruptly excuses himself after he learns of the ostomy hidden beneath his date’s clothes, or simply in the decision to act as if someone or something doesn’t exist. Making stigma all the more dangerous is that it often manifests in subliminal ways. Indeed, stigmatization can be “overt” or subtle,” and “it can manifest in interaction, avoidance, social rejection, discounting, discrediting, dehumanization, and depersonalization of others” (Bos et al., 2013, p. 1). Stigma is everywhere, somewhere, and nowhere all at once.

As Cathryn Molloy (2019) put it, stigma is “the steady hum . . . that casts its shadow over the lived experiences of bodies and minds” (p. 54). The insidious, shadowy nature of stigma presents a variety of challenges to researchers aiming to capture and understand it, despite the “enormous array” of research conducted (Link & Phelan, 2001, p. 365). Across the academy, the methods for studying stigma are as diverse as the fields conducting the research. Stigma has been studied as a psychological, interpersonal, sociological, political, physiological, rhetorical, and economic phenomenon (Johnson, 2010; Vickers, 2000). For instance, stigma has been examined physiologically, through changes in hormonal response, heart rate, and muscle contraction (Graves et al., 2005; Himmelstein et al., 2015); socially, as reported through interviews and surveys and observed in social spaces (Hughes & Romo, 2020; Molloy, 2019; Rohde et al., 2018); and textually, as documented in tweets or archives (Johnson, 2010; Kosenko et al., 2019). No doubt, all these approaches have afforded key insights into stigma.

However, based on my own lived experience with GI stigma and my pre-existing knowledge of the ostomy and GI communities, I knew at the outset of this study that stigma doesn’t neatly fit into any one definitional or methodological box. Molloy (2019), citing Pescosolido et al. (2013), argued that stigma “originates in social relations, is diffuse in everyday life, and is

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2. Himmelstein et al. (2015) claim to study physiological responses such as cortisol stimulation as a “consequence of” stigma rather than as stigma itself. However, I argue, perhaps in conflict with their stated argument, that they study stigma as changes in cortisol. For instance, to study stigma, they informed participants that they “aimed to examine hormonal responses to shopping” (p. 369). Further, their findings suggested that participants who perceived themselves as overweight were more likely to experience changes in cortisol when responding to what the researchers deemed as a stigmatizing scenario. They did not ask participants whether they felt stigmatized; instead, they focused only on changes in cortisol as an indicator of response to stigma. Therefore, it seems that their conception of stigma and consequently their method for studying it were physiological, at least in part.
extremely difficult to combat” (p. 40). Stigma is physical, social, experiential, textual, emotional, and embodied, as scholarship has shown—but these dimensions of stigma do not emerge in isolation. Stigma is all of these, and probably more, at once. Simultaneously physical, social, embodied, discursive. Therefore, at the outset of this research, I had to answer: what method/ologies within or beyond RHM enable me to capture the diverse rhetorical practices that enact stigma and those that counter it? How can I rhetorically engage the lived experiences of ostomies, GI diseases, and stigma? And what would such an approach add to the current research in these areas?

This chapter, accordingly, expands on the discussions begun in chapter 1 regarding praxiography as a productive approach for engaging lived experiences with ostomies, chronic GI conditions, and stigma. I begin by outlining contemporary critiques of stigma research, specifically, regarding how we treat the stories of people who experience stigma. These critiques, I argue, can be addressed by a rhetorically informed praxiographic approach. Therefore, I next describe how, throughout the research for this book, I relied on what Scott and Melonçon (2018) have characterized as RHM’s “methodological mutability”—that is, RHM’s “willingness and even obligation to pragmatically and ethically adjust aspects of methodology to changing exigencies, conditions, and relationships” (p. 5). Such methodological mutability enabled me to study stigma stories by building on previous RHM scholarship to adapt a praxiographic approach that foregrounds lived experiences with stigma in ways that honored people's stories and experiences, respected their privacy, attended to my own positionality, and approached stigma as a rhetorical, and experimental, phenomenon, not an innate quality. I then illustrate my praxiographic approach through engaging three stigma stories. Through these stories and the experiences shared within them, we can begin to see how stigma is enacted in diverse ways, which not only provides insight into the rhetorical processes of stigma but points to potential interventional spaces. Finally, I argue that the praxiographic approach I forward addresses not only practical but ethical methodological concerns.

**Critiques of Stigma Research**

In chapter 1, I established stigma as a rhetorical phenomenon emergent in practices and experiences in which particular entities (like ostomies or GI disease) are made to mean not only different but deviant. Such a definition extends previous rhetorical scholarship into stigma. This theorization departs in productive ways from a significant tenet of ongoing stigma research, much
of which is happening outside rhetorical studies. In particular, much stigma research relies heavily on a simplified version of Goffman’s original definition. As chapter 1 recalled, Goffman (1963) initially defined stigma as a “mark,” “trait,” “characteristic,” or “attribute” that “is deeply discrediting”—a definition he later refined to focus on the management of information in interactions between so-called normals and the stigmatized (p. 12). Despite Goffman’s richer theorization of stigma as a social process, a significant body of scholarship continues to cite and deploy Goffman’s initial, simple, attribute-focused definition. In addition to the individualistic focus this definition circumscribes, perhaps what is most surprising about the continued use of Goffman’s definition is that within the defining of stigma as an attribute is an implicit or sometimes explicit argument that particular objects, people, identities, or characteristics inherently carry stigma or are fundamentally stigma-worthy.

Sociological researchers Bruce Link and Jo Phelan point to this very problem within stigma research in their 2001 article “Conceptualizing Stigma.” There, they argue that much stigma research has a “decidedly individualistic focus,” which positions stigma as “something in the person” instead of something more relational (p. 366). They further argue:

Even though Goffman (1963, p. 3) initially advised that we really needed a “language of relationships, not attributes,” subsequent practice has often transformed stigmas or marks into attributes of persons (Fine and Asch, 1988). The stigma or mark is seen as something in the person rather than a designation or tag that others affix to the person. (p. 366; emphasis original)

With this individualistic focus comes an impulse to study only those who are targets of stigma, which neglects the sources and actions that perpetuate stigma in the first place, according to Link and Phelan. For example, if I were to apply an individualistic focus to stigma in the story that opens this chapter, I might argue that the narrator was stigmatized because GI diseases are inherently discrediting. I might also argue that stigma emerged because the narrator’s GI practices conflicted with the accepted norms for alleviating oneself as well as the norms and accepted practices for public bathrooms. In either case, the narrator, her body, and her embodied practices violated norms, and this violation produces stigma. Little attention is given to the other characters in the story and their practices or to the larger cultural and historical context that enables the stigma in the first place.\footnote{Disability scholars have criticized Goffman’s work and the research that builds from it as failing to adequately account for historical and cultural factors that enable stigma. For a discussion of this criticism, see Brune et al. (2014).} I hope it is clear that this individu-
alistic focus risks, if not encourages, a victim-blaming approach with stigmatized individuals as the central focus and stigma itself as some fixed variable that emerges within a predetermined social script. Although Link and Phelan do not use this language, readers familiar with disability studies will quickly recognize this “individualistic focus” in stigma literature as reinscribing the “individual tragedy model” (akin to the medical model) wherein the focus is on individuals with physical or mental impairments. Such models stand in contrast to social models that recognize how physical, social, and discursive conditions “impose limitations on certain groups or categories of people” (Oliver, 1996, p. 21). Despite decades of scholarship advocating alternatives, these individualistic models persist.

For example, within the ostomy-related stigma literature, several studies define stigma at the outset using Goffman’s (1963) original definition, employ the “decidedly individual focus” that Link and Phelan (2001) critiqued, and consequently suggest that stigma is inherent in ostomies or ostomates (p. 365). For example, a 2018 study on ostomy stigma and selfies explained that “ostomates possess what Goffman (1963) describes as ‘an attribute that is deeply discrediting’ within a society” (Rademacher, 2018, p. 3860). Here “ostomy” and “an attribute that is deeply discrediting” are interchangeable. In other words, ostomates possess an ostomy; therefore, ostomates are automatically discredited. Similarly, as another recent study noted,

Goffman (1963) defined stigma as “an attribute that is deeply discrediting” (p. 12) and an “undesired differentness from what we had anticipated” (p. 14). Goffman further stated that the general public believes the person with a stigma is not quite human, and under this view, it is easy to see why people with ostomies might be stigmatized. (Frohlich & Zmyslinski-Seelig, 2016, p. 221; emphasis added)

While Frohlich and Zmyslinski-Seelig (2016) do later draw on more recent stigma research, they do not trouble the idea that is implied in Goffman’s definition: that ostomies, as an attribute, are somehow inherently discrediting. Again, the suggestion that it is “easy” to see why ostomies are stigmatized requires readers to see “ostomy” and “attribute that is deeply discrediting” as one and the same. Importantly, Frohlich and Zmyslinski-Seelig (2016) and Rademacher (2018) go on to examine how ostomy stigma is being challenged; they begin their arguments with these self-evident claims that stigma is within the essence of ostomies rather than within the social, rhetorical structures that shape understandings of ostomies. It is this use of Goffman’s simplest definition of stigma that Link and Phelan also identify and take issue with.
Moreover, a significant thread of stigma research has extended Goffman’s
definition to examine stigma experiences as psychological or psychosocial.
There are several such examples within research on ostomy and GI-related
stigma. For instance, one study described the stigma surrounding cancer, GI
disease, and ostomies as the “psychological area” of these conditions (Hurny
& Holland, 1985, p. 171). Another, more recent, study that focused on stigma
related to GI disease argued, “The nature of stigmatization lends itself well to
targeted psychological intervention, especially cognitive-behavioral strategies
that challenge patients’ beliefs and assumptions” (Taft et al., 2012, p. 458). Often
in research that takes this psychological or psychosocial approach, stigma is
parsed into more fine-grained categories including (1) perceived, internalized,
and enacted stigma (Van Brakel, 2006); (2) felt and enacted stigma (Jacoby
1994; Scambler, 1989); or (3) ascribed and achieved stigma (Falk, 2001).

Among these, perceived or felt stigma is arguably the most frequently
studied (Taft & Keefer, 2016). In effect, perceived and felt stigma are used
similarly if not interchangeably to describe an individual’s “perception that
others view them negatively due to their stigmatizing attribute(s)” (Radem-
acher, 2018, p. 3860). Perceived stigma, in other words, captures how people
with discrediting attributes anticipate stigma—but stigma that is not neces-
sarily considered real or “actual” (Taft et al., 2012, p. 452). Similarly, internal-
ized stigma emerges when a person with a particular trait, identity, or quality
embodies the stigma internally and stigmatizes themselves. This is also known
as self-stigma and, like perceived stigma, tends to be studied and discussed as
somehow fictional or “all in the head” of the stigmatized person. While indi-
vidual attitudes, perspectives, opinions, no doubt, are part of stigma experi-
ence, this discrete focus on stigma as individualistic and psychological seems
limited in methodological, ethical, and interventional scope. This approach
further replicates the well-critiqued mind/body divides and, again, risks a
victim-blaming approach.

In contrast, enacted stigma, as its name suggests, is explicitly enacted by
an outsider toward someone or something else. For example, if one person
said to another, “You are disgusting for having an ostomy,” we would call that
enacted stigma. Unsurprisingly, enacted stigma has been deemed a challenge
for researchers because it requires them to observe stigmatization in the act,
so to speak. However, framing enacted stigma as something that must be wit-
nessed firsthand, rather than reported on, suggests that perceived stigma is
somehow less valid or insufficient. Teasing out perceived and internalized
stigma from enacted stigma not only positions stigmatized individuals as
potentially questionable or unreliable but further assumes that perceived and
internalized stigma can exist in the absence of enacted stigma. In other words,
perceived and internalized stigma place the stigma as something “in the person” (Link & Phelan, 2001, p. 366), rather than a phenomenon emergent in social, historical, relational, and experiential contexts.

The story that opens this chapter highlights the very need for an approach that attends to Link and Phelan’s (2001) concerns about stigma research. Specifically, the stigma emergent in the story is not “something in the person” crying behind the bathroom stall. Instead, stigma emerges among the activity and actors within that high school bathroom. Maybe stigma is even emerging now in the act of reading such a story and imagining the physical details implied but too embarrassing to be made explicit. The “decidedly individualistic focus” of much stigma research does not capture the relational nature of the stigma enacted in that story; nor does it capture the complexity of actors involved in stigmatization (Link & Phelan, 2001, p. 366). Indeed, the story demonstrates that stigma does not—cannot—live within particular individuals, identities, or objects. It requires multiple actors, human and nonhuman alike, as well as actions or practices that give meaning to entities, bodies, and people within particular moments and contexts. Commentary, digestive waste, laughter, bathroom stalls, intestines, pre-established cultural expectations regarding bowel movements, and the bowel movements themselves—all these and more participated in the emergence and meaning-making of stigma in the opening story. Studying and theorizing stigma, consequently, requires methods and methodologies that are attuned to the complexity of stigma itself.

In addition to illustrating the necessity for Link and Phelan’s (2001) criticism of treating stigma as inherent in particular people, objects, or characteristics, the opening story also highlights the value in examining stigma “from the vantage point” of a researcher who belongs to a stigmatized group (p. 365). Though I surely do not enjoy sharing it, the story that opens this chapter is my own. I share it because it shows what my own experiences bring to this research, and it offers a window into the “vantage point” from which I conducted this research and wrote this book. Although my motivations for this work exist beyond my personal experiences (as detailed in chapter 1), there is no way for me to conduct this work outside of my own positionality as a person with Crohn’s disease. So, when I ask “how can and should I study stigma?” I ask as a rhetorician of health and medicine, as a person with a chronic GI condition, as a person who very well may need an ostomy someday, and as a person who experiences stigma. Therefore, my desire to find a way out of individualistic approaches to stigma is grounded in the type of necessary positionality that Link and Phelan call for—my positionality as both researcher and stigmatized—because in both, my data and firsthand experience with stigma
is neither inherent in some entities or people nor primarily psychological or individualistic.

According to the stigma experience detailed in my own story and in the experiences of the many other people with whom I engaged for this project, the rhetorical processes of stigma occur across a range of physical, social, textual, and embodied practices, often all at once. Therefore, I turn to praxiography and multiple ontologies theory as method/ology to capture the rhetorical process of stigmatization and the complex meaning-making practices that stage stigma. However, as I described in chapter 1, praxiography was initially designed to capture physical practices through traditional ethnographic observations. Therefore, I adapted praxiography to account for the diverse practices that staged stigma (as well as ostomies and chronic GI conditions) but that did not require me to follow people into both intimate and expansive spaces where stigma could occur. In the next section, I pick up the methodological discussions I introduced in chapter 1 to specifically detail how praxiography avoids contemporary concerns within stigma research regarding individualistic focus and vantage points.

**Praxiographic Solutions**

Praxiography, an ethnography of practices, as I alluded to in chapter 1, has been theorized considerably within RHM since Annemarie Mol first introduced it as a methodology in 2002 (Graham, 2015; Lawrence, 2020; Pender, 2018). Across this work, RHM scholars have mobilized praxiography to study how health and medical practices stage the realities of these various medical objects, bodies, and conditions. I aim to extend this work by demonstrating how praxiography provides solutions to concerns within stigma research regarding individualistic focus and vantage points of the researcher. Specifically, as part of multiple ontologies theory, praxiography moves away from perspectivalism—theories and approaches that encourage us to focus on the perspectives, perceptions, interpretations, even descriptions of a singular, stable reality.

One way that the individualistic focus critiqued by Link and Phelan (2001) has manifested in stigma research is in studies that suggest perceived stigma is somehow independent of what is called *enacted stigma*. When a divide is created between perceived and enacted stigma, research risks devaluing the stories and experiences of the stigmatized by demanding that those stories and experiences (perceived stigma) need be matched to “actual” reality (enacted stigma). Praxiography and multiple ontologies theory demonstrate that we
can avoid such divisions. Indeed, Mol might describe this divide between perceived and enacted stigma as a manifestation of perspectivalism and the highly problematic divisions between reality and perspective, or the physical realities of disease and patient’s feelings and stories (Mol, 2002; see also Pender, 2018). According to Mol, focusing on people’s feelings, stories, and experiences as perspectives enables some perspectives to be pitted against others, like the perspectives of medical professionals being privileged over the perspectives of patients (as when disease and illness are dichotomized), or when enacted stigma observed by researchers is considered more real than perceived stigma reported by stigmatized people. Stigma research that takes an individualistic focus places stigma as an inherent, static entity within individuals; advances separations between perceived and enacted stigma; and risks subjugating patients’ stories and experiences as less reliable than stigma observed firsthand by researchers.

In contrast, praxiography and multiple ontologies theory reject the idea that there are multiple points of view on a single object. Mol (2002) developed praxiography and multiple ontologies theory to resist the very idea that patients’ stories and experiences needed to be calibrated to a supposedly external, stable reality. For example, a perspectival approach would explain how a researcher could say that stigmatization didn’t occur even though a person with a chronic condition reports experiencing stigma. In this example, stigma itself remains a “single, passive object” about which the researcher and the patient had perspectives (Mol, 2002, p. 5). Praxiography, in a move away from perspectivalism, prioritizes practices and events through which objects and realities are multiple. Indeed, praxiography is ontologically focused on how practices stage realities and the entities that make up those realities. Accordingly, the focus is on practices, not perspectives. As Mol put it, “Ontology is not given in the order of things, but instead, ontologies are brought into being, sustained, and allowed to wither away in common, day-to-day sociometrical practices” (p. 6). That is, ontology is not an inherent property but a becoming: “objects come into being—and disappear—with the practices in which they are manipulated” (p. 5). Multiple ontologies theory thus avoids perspectivalism and subsequently divisions between perceptions/reality by contending that reality itself is multiple. Mol elaborated:

If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives . . . And since the object of manipulation tends to differ from one practice to another, reality multiplies. The body, the patient, the disease,
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the doctor, the technician, the technology: all of these are more than one. More than singular. (p. 5)

For instance, Mol conducted a praxiography of the disease atherosclerosis and found that it comes into being in the surgical ward as “something that can be pushed aside by a balloon” (p. 102) or as “the interaction between blood components and the vessel wall” in the hematology lab (p. 109). That is, different practices enact different entities—entities that may fall under a single name like atherosclerosis. There are not simply several perspectives about atherosclerosis; atherosclerosis is done differently in different (rhetorical) contexts.

Praxiography and multiple ontologies theory have been particularly useful in helping rhetoricians of health and medicine move toward analyses that study the practices that stage entities instead of focusing exclusively on the perspectives, language, and knowledge surrounding a particular stable object, idea, or reality. Consequently, a praxiographic approach has much to offer my research into stigma, as I work to avoid an individualistic focus and replicating divisions between perceptions of stigma and enacted stigma. Extending Mol’s work for rhetorical studies, Kelly Pender (2018) argued that praxiography provides “a much-needed alternative to perspectivalism” because it enables scholars to “[follow] an artifact across time or space to investigate the spaces through which it emerged” (p. 77). Extending Pender’s argument, I would add that the praxiographic approach guides scholars to investigate the range of entities (language, bodies, technologies, germs, cells, etc.) that come into being and become meaningful within health and medical situations, like ostomies, chronic GI conditions, and stigma. For example, rather than examine how different people perceive or discuss an ostomy, praxiography and multiple ontologies theory direct us to investigate what practices participate in the emergence and meaningfulness of that ostomy. Likewise, in a praxiographic approach, stigma is enacted in practices and experiences.

Ultimately, these praxiographic insights are helpful for my research into stigma practices, particularly in avoiding the pitfalls of stigma research identified by Link and Phelan (2001). Guided by praxiography, I attend to the ontological multiplicity of stigma, ostomies, and chronic GI conditions rather than the plurality of opinions or perspectives about these entities. I contend that stigma can be staged in multiple ways—through laughter in a bathroom, in comments made by a healthcare provider, or within something felt deeply by an ostomate—and therefore I listened to stigma stories for such enactments. Moreover, if entities like stigma, ostomies, or chronic GI conditions are done in practice, then they can be done differently in different contexts. As we’ll see in the coming chapters, praxiography cogently maps how ostomies
and chronic GI conditions are done differently across different stigma stories. Studying stigma as done in practice, I argue, provides a viable solution to the potential issues of separating perceived stigma from other forms. Relatively, stigma as done in practice places stigma itself as an ontologically multiple entity that cannot live within individuals or be inherent in particular entities, bodies, or people. Praxiography, in other words, productively addresses concerns about individualistic focus within stigma research.

However, as I outlined earlier in this chapter, critiques of stigma research extend beyond the individualistic focus. Concerns over the “vantage point” of researchers have also been identified as a pressing problem. Praxiography, too, offers insights into how engaging practices through stories can privilege the voices and experiences of the stigmatized. Relatedly, even if I were committed to ethnographically studying the practices that stage stigma, where would I look? How and where do you study phenomena that could emerge at any time and in any place? How do you study an experience that is intimately personal and often painful or embarrassing? And even if the research is conducted from an ethical, self-reflexive vantage point, what about the vantage points of the stigmatized? In considering these questions, my own vantage point was actually quite useful. As someone who has faced stigma related to GI disease, I could not imagine letting someone (an observant stranger, no less) follow me around through my day, especially into the spaces where I have felt stigma most severely: the bathroom, the doctor’s office, the bedroom. While I wanted a better understanding of the lived experience with ostomies and chronic GI conditions because I want to acknowledge and tackle stigma, I also know firsthand the deeply personal nature of these conditions and the weight that stigma can add.

Rather than exclusively privilege the vantage point of the researcher, Mol (2002) argued that praxiography enables researchers to engage with the practices and lived experiences of people with ostomies on their own terms. Therefore, I turned to stories to study stigma praxiographically. That is, I listened to stigma stories as “they tell about events [people] have lived through,” about what it’s like to live with an ostomy, chronic GI condition, and stigma (Mol, 2002, p. 20). Mol advocates that we operate in a “realist mode” in which we listen to each person (and their reports) as if they are their “own ethnographer. Not just an ethnographer of feelings, meanings, or perspectives. But someone who tells how living with an impaired body is done in practice” (p. 15; emphasis original). Understanding stigma shared through stories as entangled phenomena of bodies, diseases, and experiences “done in practice” has specific implications:
It is possible to listen to people’s stories as if they tell about events. Through such listening an illness takes shape both as material and active . . . This illness is something being done to you, the patient. And that, as a patient you do. (Mol, 2002, p. 20)

Following Mol, instead of treating the language practices presented throughout this book (e.g., blog posts, tweets, and conversations with me as well as with others) as perspectives/representations of ostomies or stigma, or as metaphors used to connect to some underlying reality, I examine patients’ language practices as praxiographic, as patients telling how living with an ostomy, disease, or other health conditions is done in practices or how experiencing stigma is done in practices.

In this approach, it is not necessary to follow people into bathroom stalls and hospitals to study the practices that stage stigma, ostomies, or GI conditions, when I could engage people’s stories about their experiences. I could listen to people tell their stories in interviews and at events where ostomates came together to chat and support one another. “What people say in an interview,” Mol (2002) explains, “doesn’t only reveal their perspective, but also tells about events they have lived through” (p. 15). Further, I could listen to thousands of public stories from the people living and sharing these experiences online. After all, social media, blogs, and public advocacy groups have become primary avenues for people with all sorts of conditions and experiences to share, cope, advise, heal, and, often, fight stigmas. Whether through participant observations, interviews, or online stories, I listened in hopes of answering “What are the events people report on?” (Mol, 2002, pp. 25–26). What is it like to live with an ostomy or chronic GI condition? What is it like to face stigma?

Engaging stories praxiographically facilitated two important methodological cornerstones for my approach: (1) treating language not as a representation, perspective, or opinion about “the ostomy” or a singular “stigma” but instead as a practice itself through which I could study how living with an ostomy and dealing with ostomy stigma is done in practice; and (2) treating people as their own ethnographers, who could share their experiences on their own terms, including or excluding details per individual discretion. By listening to stigma stories as if they tell about events, I am able to respect and lift up the embodied experiences of people living with ostomies and chronic GI conditions from their own vantage points. Who, after all, can describe better what it is like to live with an ostomy, chronic GI condition, or stigma than those with firsthand, personal experience?
Importantly, however, not every story in this book is a firsthand account of life with an ostomy or chronic GI condition. While many stories are firsthand, some are mediated or even fictional. For example, Julia’s story is a “real story,” but it is mediated through a third party, the CDC. In addition, a few stories presented are entirely fictional, such as those shared through the TV medical drama *Grey’s Anatomy*. Mol’s (2002) original praxiography and its “realist” orientation were set up to focus on firsthand accounts collected through interviews or direct observation. This, in part, enabled Mol to treat stories and experiences as tellings of events, as praxiographic data outright. I conduct this same kind of work for many of the stories in this research; as explained earlier, I conducted observations and interviews with people living with ostomies and chronic GI conditions, where I listened to and collected firsthand stories. However, I also opted to include fictional and mediated stories because I am interested in the public meanings of ostomies and chronic GI conditions, which involve all stories that circulate in the public sphere. Thus, fictional stories have much to tell us about the kinds of lived experiences that become associated with and rhetorically involved in how ostomies and chronic GI conditions are made to mean. I work to treat fictional and mediated stories in the same way as firsthand accounts by focusing on lived experience and practices that stage ostomies, chronic GI conditions, and de/stigmatization.

This kind of mixed research—that is, examining a variety of stories—required multiple data-collection strategies, some of which I’ve mentioned (see chapter 1 for details on how I navigated collecting public stories online). To collect firsthand, mediated, and fictional stories, I fused textual, rhetorical, and cultural methods with rhetorical fieldwork (see Druschke & Rai, 2018; Middleton et al., 2011). This allowed my research to be mutable (Melonçon & Scott, 2018) and responsive to the different spaces in which stigma stories show up, like in conversations with other ostomates, in doctor’s offices, on TV shows, and in public health commercials. While these data-collection strategies might seem disparate, they were productively calibrated within my praxiographic approach. Regardless of the kind of story or the space/form it took, I studied each story for two central rhetorical practices: (1) the lived experiences and practices shared, and (2) the meaning-making done through/with those lived experiences, particularly meaning-making that destabilized stigma. Praxiography provided a consistent focus across these stories and an intentional way to make sense of each and all of them. Using praxiography for RHM- and disability-studies-driven work allowed me to privilege lived experiences while critically attending to stigma's rhetorical processes.
Stigma in Practice

A praxiographic approach to stigma, as I argued in the previous sections, responds to the complex critiques of much stigma research. To illustrate the value of such an approach, I spend the remainder of the chapter exploring three stigma stories that demonstrate the diverse practices in which stigma is staged in the lived experiences of people with ostomies and chronic GI conditions.

Story 1: Disapprovals in the Bathroom

The first story was shared online by Sam Cleasby, a woman from the UK who has lived for years with GI conditions and an ostomy and who regularly chronicles her experiences on her website SoBadAss. In this post, which was circulated widely through various ostomy and GI communities online as well as by some news outlets in the UK, Cleasby (2015a) described an experience she had while out shopping with her children:

Dear lady who loudly tutted at me using the disabled loos,

I know you saw me running in, with my able-bodied legs and all. You saw me opening the door with my two working arms. You saw me without a wheelchair. Without any visible sign of disability.

You tutted loudly as I rattled the handle with my hands that work perfectly and my able voice call to my kids that I’d be out in just a minute.

My lack of wheelchair may have suggested to you that I was some lazy cow who didn’t care. Some inconsiderable bitch who was using something I wasn’t entitled to. (I actually carry a card to explain that I’m entitled to and have a disability key if you’d have cared to ask). You may have seen my face blushing as I caught your eye and assumed I was showing guilt at blagging the disabled loos.

The fact is that I have no bowel. I have a pouch form from my small intestine which can’t handle volume and so I have to go to the toilet and poo several times a day. My lack of large intestine means that my stool is totally liquid as I have no means of absorbing the fluids in food and so it’s really hard to hold it when I need to go.

I sometimes have accidents which means a large toilet that has a sink right by me means I can clean myself up when things go awry.

I hate having to use the disabled loos as I have to deal with people like you starting, nudging, tutting . . .
Whilst I’m at it, I’d like to address the cleaner in the supermarket ladies toilets I used this week. As I ran in, knees together, bursting through the door and running into a cubicle, I’m sorry that the noise of my (lack of bowels) made you burst out laughing.

I can actually take the sniggering as since I had a pouch made from my small intestine because my disease ridden colon was removed during surgery, the noise I make when I defecate is hilariously loud. Seriously, I get it. It’s comedic in its volume.

But before you ran outside the loos and called to your friend “OH MY GOD! You should hear the noise in there!!! I wouldn’t go in if I was you!!!!” Perhaps you could have noted my daughter who was waiting outside with our trolley because her mum had to leave her stranded to run to the toilet. Perhaps you could have stopped and heard me sobbing in pain because the acid in my stools has no way to be neutralized because I don’t have a large intestine and so opening my bowels actually burns my skin.

Perhaps you both could have shown a little empathy, a little compassion, a little understanding. . . .

To everyone else reading this, the next time you see someone who doesn’t “look disabled” using a toilet. Or someone busting through and crashing into the toilets noisily.

Take a moment. Remember that not all people who have the right to use disabled toilets are in a wheelchair. Some of us have a j-pouch, a lot of us have an ostomy bag that needs emptying and changing with the use of space, a skin, and a bin. And even more of us just don’t want to shit our pants in public.

Think about the nearly 300,000 people in the country who have inflammatory bowel disease . . . who need to use the toilet urgently, noisily, smellily . . . It’s an embarrassing enough thing to deal with before having to see disapproving looks.

In this story, Cleasby explained what her recent experience of using the public disabled bathroom must have looked like to another woman watching her. With Cleasby’s “able-bodied legs,” “two working arms,” and without “a wheelchair” or “any visible sign of disability,” the onlooking woman apparently had little reason to believe Cleasby was justified in using the disabled

4. A j-pouch is an internal pouch or reservoir created from the end of the small intestine. J-pouches are commonly created in patients whose colon has been removed, and usually require two or three surgeries. In between these surgeries, an ostomy is created and used; therefore, the creation of a j-pouch is one of the most common reasons people have temporary ostomies.
bathroom. The stark and honest language in this passage exposes the challenges of both living with an invisible disease and facing stigma. Through the onlooking woman’s visual practices (staring) and verbal practices (“tutting,” a British term for making a disapproving sound), Cleasby became a “lazy cow” and “inconsiderate bitch” who was using something she “wasn’t entitled to.” In the second scene, at the grocery store, Cleasby recalls another woman calling her disgusting and laughing at Cleasby’s digestive sounds. That woman also abruptly leaves the bathroom upon sensing Cleasby’s bodily noise and smell. The women’s disapproving looks, sounds (laughter and tutting), and comments reported in Cleasby’s story stage Cleasby, her body, and her chronic GI condition as undesirable and inappropriate. Cleasby’s story also poignantly demonstrates that stigma operates at the intersection of disability and gender, an intersection magnified in the space of bathrooms. Cleasby was stigmatized through stares, comments, and sounds for neither looking disabled enough to use the disabled restroom nor behaving appropriately femininely in the women’s restroom. In these ways, Cleasby’s story aligns in important ways with my own story at the opening of this chapter.

Story 2: Eager Reversals

The second story comes from an interview with a young woman, Tonya, who underwent ostomy surgery multiple times over the course of approximately a decade. As she and I chatted about what it’s like to live with an ostomy and chronic GI condition, Tonya told me many positive stories about how her health had improved with her ostomy, how having these conditions enabled her to find a huge community of friends online, and how she was grateful overall for the freedom and health that her ostomy gave her. Over the course of our conversation, Tonya began describing that one of the difficulties of living with an ostomy is the lack of education and awareness of others about ostomies and related GI diseases. She explained how so few people know what an ostomy is, what purpose they serve, and how they can save lives. She said that her own parents, even after years of supporting her through her own disease and surgeries, seemed to lack the kind of awareness Tonya hoped for. According to one story she told me, her parents want her to pursue a reversal surgery as soon as possible because they don’t understand why or how she would want to live with an ostomy:

5. Names of interview participants are pseudonymized to protect their identities. I use the real names of people who have written and published public stories online in order to credit their stories and to enable readers to find their stories, blogs, and websites for further reading.
Immediately post-op [my parents] were sort of already pushing me about when I was going to have my takedown. And that’s like their first concern with the doctor and the surgeon, and just like jumping over the fact that I’m healthy and just completely concerned with when I won’t have the ostomy anymore . . . [I tell them] after my history, I am in absolutely no rush and with my history you guys should not be in a rush either . . . My mom I guess can’t wrap her head around how her comments affect my body image . . . I just try to let it roll off.

Although she described her parents as overall supportive, I could feel the weight of these conversations on Tonya as she tried to reconcile her own positive experiences with her parents’ negative comments and desires. Tonya specifically described these experiences with her parents as stigmatizing. She further explained to me that her parents’ comments were especially painful and frustrating because she had been extremely sick with IBD prior to her ostomy surgery and her parents had witnessed the struggles that had led to the surgery. She personally approached surgery hopeful that the ostomy would enable her to regain her health, but it was clear that her parents did not see the surgery the same way. Instead, she reported, her parents’ first thought was to find out how quickly she could have the ostomy reversed instead of focusing on how the ostomy might be able to help. According to her story, her parents just couldn’t understand why she would want to have an ostomy. In these experiences, stigma was staged, according to Tonya, through her parents’ conversations with her and with her healthcare providers. By asking her doctor and surgeon when she could reverse her ostomy “immediately” after she’d undergone surgery to create the ostomy, Tonya’s parents made her feel that having an ostomy was undesirably different. In addition, they repeatedly questioned why she would want to have an ostomy and why she wasn’t in more of a rush to have it reversed. For Tonya, stigma was done in her parents’ discursive and attitudinal pressure to reverse her ostomy.

Story 3: Failed Bag Changes

In another interview, a woman named Hilary, like Tonya, told many ostomy-positive stories. However, as she began to tell me about various hospitalizations she’d experienced because of various complications with chronic GI conditions and her ostomy, she shared how some of her most negative experi-

6. Ostomy-reversal surgery is often referred to as takedown surgery or as a takedown.
ences with her ostomies have occurred in interactions with healthcare professionals (outside her GI care team) who struggled to change her ostomy bag when she was too ill to do it herself:

You would think nurses would know how to change an ostomy bag. I can’t tell you the number of nurses who have told me that it’s “so sad” I have an ostomy or who have said things like “you’re just too young to have a permanent ostomy.” Like, these are the people who are supposed to be caring for us while we are hospitalized, making us feel better, and instead, they make these kinds of mean comments. On top of it, they have no idea how to change an ostomy bag! It took three nurses one time to change my bag. At that point, I might as well have done it myself, but I was too weak to move.

In Hilary’s experiences, stigma emerged when healthcare providers failed to physically manage her ostomy properly. The nurses’ lack of knowledge and skill regarding her ostomy, which resulted in a botched ostomy-bag change, made Hilary feel, as she said, “stigmatized.” Hilary went on to summarize: “Medical professionals just really need sensitivity training.” Hilary’s story showcases, like the first two stories, the role discursive practices have in staging stigma. However, Hilary’s story also highlights that material experiences enact stigma, too, such as mishandled bag changes by healthcare providers who Hilary felt should know better. Later in the interview, Hilary described such experiences with healthcare providers as one of the two most stigmatized contexts for ostomates (the other being “anytime you are around water . . . pools, water parks, beaches”). Stigma, in this story, was done in the inability to successfully remove, empty, and replace an ostomy bag combined with what Hilary described as “mean” comments about having an ostomy.

An Ethical Case for Engaging Stigma Praxiographically

These three stories demonstrate the diversity of practices in which stigma is and can be staged and how those practices enact stigma differently. Further, the stories shared showcase the value in treating people living with ostomies or chronic GI conditions as their own ethnographers. Ultimately, in exploring lived experiences with stigma, chronic GI conditions, and ostomies, my goal in this chapter is to articulate the value in examining stigma praxiographically, an approach that foregrounds practices, ontologies, and people’s own stories to better understand lived experiences with chronic conditions and stigma. While this approach provides a way to make sense of how stigma comes into
being and is made meaningful, what many rhetoricians might be wondering at this point is how this particular theory is distinctly rhetorical. And, since I looked at stories and language practices shared within them (e.g., stigmatizing comments), how a praxiographic approach is different from textual analyses of patient stories.

Understanding stories as reports of events, lived experiences, and practices instead of as representations, Mol (2002) argued for treating people as ethnographers of their own lives. That is, Mol advocated that we listen to each person (and their reports) as if the person is their “own ethnographer.” Rather than evaluate the stories as perspectives/representations of stigma, chronic GI disease, or ostomies, praxiography can examines patients’ language practices as ethnographic data, as tellings of how living with an ostomy, disease, or other health condition is done in practice. As a rhetorician, I, of course, recognize the power and influence of language. However, I propose praxiography as a way to understand the rhetorical work in peoples’ lived experiences without subsuming all practices and activities into perspectives or representations. In his rhetorical-ontological inquiry, built on praxiography, Graham (2015) insisted, “Language is doing. It has impacts and consequences—social, political, material” (p. 84). Indeed, if language is doing, then a praxiographic study of stigma stories can account for the ways that language practices stage stigma within a “deeper ecology of practices” that make up people’s lived experiences.

In following Mol (2002) and rhetoricians who have compellingly argued that ontologies emerge through practices, I argue that the enactments of stigma in the practices described throughout the exemplar stories are not simply different perspectives on stigma. Instead, they describe what it is like to live with an ostomy and how stigma manifests differently in practices. By treating Sam Cleasby, Tonya, and Hilary as ethnographers of their own lives, these stories serve as reports of events, of the practices that stage stigma. Moreover, they demonstrate stigma’s ontological multiplicity. Stigma is done as stares in a public restroom, questions from parents, comments from healthcare providers, and failed bag changes. Each story and each of the practices that stage stigma illustrate that stigma is not something inside these individuals; instead, it emerges in actions and practices. My praxiographic approach considers each of these stories as an account of lived experiences with stigma, not as a perception of stigma that I needed to confirm through my own witnessing or triangulation with other, more objective data. The stories don’t simply provide perspectives about potential stigma; by respecting Sam, Tonya, and Hilary as their own ethnographers reporting on events, it becomes “possible to understand” stigma as “manipulated in practices,” which, as Mol argued, has the “far-reaching effect” of multiplying reality (p. 5). Stigma is not a “uni-
versal object” but is both emergent and manipulated in practices and experiences (p. 5).

My primary reason for studying stigma praxiographically is not theoretical, however. It is ethical. Praxiography, as this chapter has demonstrated, provides a robust solution to two key issues within stigma research; consequently, rhetorical adaptations of praxiography highlight the important insights that rhetoric can bring to understandings of stigma.Treating people with ostomies and chronic GI conditions as their own ethnographers enables exploration of what it is like to live with such conditions. It facilitates research into these lived experiences in a way that is not intrusive of people’s lives and that takes people’s own stories as useful data in its own right. Listening to people’s stories praxiographically respects people’s privacy, and it protects people’s autonomy to tell their stories on their own terms. In their praxiographic study of diabetes, Mol and Law (2004) emphasized this very point:

The quotes [provided through stories] . . . are not supposed to tell the reader about the specificities of the *people* uttering them. Instead, they are intended to inform us about *practices* of dealing with diabetes—practices that are so spread out that they are hard to study ethnographically for a limited number of researchers who have only limited time, and who would also prefer not to intrude for long periods into people’s lives by spending days and days with them. So, we take professionals as well as people with diabetes as *(lay)* ethnographers in their own right, taking it upon ourselves to select, translate, combine, and contrast their stories. (p. 59; emphasis original)

Of course, as Mol (2002) and Pender (2018) pointed out, people are not necessarily the best ethnographers of their own lives. It very well may be that other people involved in these stories would report different experiences or that if I had observed those experiences directly I might have noticed different things. Those discrepancies, to me, do not signal an unreliable narrator or any reason to distrust the stories on the exact terms they were presented. In fact, reliving those experiences through the stories and memories of Cleasby and my interview participants is exactly what I set out to do, because it is their lives that are impacted by those stories, and it is their lives and experiences that I hope to understand and support through this research. When it comes to engaging highly personal conditions or experiences that are diffused across space and time, stories present a viable means to study lived experiences. It is an act of care for the participants of our research (Scott & Gouge, 2019), be they people with diabetes, ostomies, chronic GI conditions, or otherwise, *and* for ourselves as researchers to employ participants as lay ethnographers of their own lives.
My study of stigma encountered the same methodological challenges that Mol and Law (2004) describe. Stigma is neither easily isolatable or predictable. As the stories shared in this chapter testify, the instances in which stigma is staged are often inaccessible and inappropriate for an outside researcher. Public bathrooms, postoperative hospital rooms, and intensive care units: these are the spaces where stigma was staged in the experiences of Sam Cleasby, Tonya, and Hilary. And, like Mol and Law, I felt following participants into these spaces in search of stigma would unnecessarily “intrude” into people’s lives (p. 59). While I could have asked for ethnographic access to such spaces, a praxiographic approach to stigma stories afforded flexibility and valued the space and autonomy of participants. Rhetorician of health and medicine Kristin Bivens (2018) has reminded, researchers in health and medicine need to “think about the needs and motivations of participants” and “prioritize the bodily experiences of both researcher and participants” (p. 147). Though Bivens made these suggestions specifically regarding consent for research studies, her suggestions for prioritizing research participants’ needs, bodies, and experiences are highly important throughout the research process. Certainly, her argument resonates with my own work, especially as she extends Ratcliffe’s (2005) concept of rhetorical listening as a research ethic for health and medical contexts. It is this ethic of listening and care that I work to extend as I build praxiography as a productive and ethical methodology for RHM and, more specifically, for studying stigma stories.

Additionally, praxiography mitigated a practical concern that I faced regarding my own ability to meaningfully study lived experiences with stigma. That is, it was and is a practical impossibility for me to follow several people with ostomies and chronic GI conditions around in order to capture stigma firsthand. Through interviews and participant observations, I listened to stories from people across the US, and through online stories, I listened to many more stories from around the globe. Had I privileged only my own ethnographic vantage point, I would have been restricted geographically, and, therefore, the people and lived experiences represented in my research, too, would have been limited by my location. Studying stigma through stories allowed me to listen to a broader community of people living with ostomies and chronic GI conditions. In this way, praxiography valued the vantage point of the very people living with chronic conditions and experiencing stigma. In other words, I believe that through praxiography I found one way to privilege and attend to what impacts those “with the most at stake” (Scott & Gouge, 2019, p. 191).

A praxiography of stories accommodates these practical and ethical challenges of researching lived experiences within health and medical contexts.
while attending to the specific challenges within stigma-related research. Through stigma stories, I am able to discern many rhetorical processes and practices that enact stigma, ostomies, and chronic GI conditions in meaningful and complex ways. It is through the experiences shared in these stories that we can begin to understand how stigma is done within rhetorical practices. This understanding, then, can inspire meaningful intervention. Kelly Pender (2018) aptly pointed out that the “turn to enactment” (a phrase credited to John Law), facilitated by praxiography, orients us toward practices that “participate in the making, and unmaking, and remaking of realities with the goal to intervene . . . rather than describe or tell” (p. 73). One problem with individualistic approaches to stigma, particularly those that focus on perceptions of stigma as separate from enacted or actual stigma, is that they have the potential to place the site of intervention within stigmatized individuals. If stigma is “something in the person,” then treating and caring for the stigmatized might focus exclusively on attitudes, opinions, and perspectives about stigma or undesired differentness like ostomies or chronic GI conditions (Link & Phelan, 2001, p. 366). In other words, the primary interventional pathway is to tell patients to have a better attitude, to think, talk about, and perceive their ostomies differently. If stigma is done in practices, however, intervention sites become the practices themselves, which moves the locus of blame and agency toward a more diverse constellation of practices and away from stigmatized peoples’ thoughts and attitudes. Toward this end, studying stigma stories as reports on lived experiences can equip rhetoricians of health and medicine to understand how people are engaged with entities like stigma, ostomies, and chronic conditions, and to use the insights of RHM to best contribute to the lives of the lay ethnographers to whom we are fortunate enough to listen.

However, finding practical points of intervention first requires rhetorical and praxiographic theorization of stigma through a range of stories. I began such work in this chapter but take it up over the course of the next several to show the different ways in which stigma is staged as well as the ways in which lived experiences and practices also work to counter stigma. As chapter 2 shows, stigma is not only staged through complex, visceral practices but is marshaled in the public ostomy stories to fuel stigma.