

WHAT DISABILITY AND LITERACY MEAN TOGETHER

ABLEIST VIOLENCE AND A DISABILITY MATERIALITY APPROACH TO LITERACY

I begin, as a way of opening space for the questions of this book, with two scenes: scenes that bring to light the clashes, conflicts, contrasts, and complications that arise when disability and literacy intersect, scenes that get at some of the many complexities of what disability and literacy are perceived to mean together—and of what, in fact, disabled people do with literacy. These scenes are public and personal, pointing to the complex micro and macro factors nested within all literacy practices, identities, and politics.

On January 30, 2013, former Democratic congresswoman Gabrielle Giffords testified briefly before a Senate Judiciary Committee on gun violence. Her argument urging stricter gun laws, however, was not the newsmaker of the day. Instead, what dominated the news was her use of language, and in particular the “handwritten notes” from which she spoke. Giffords had been shot just over two years prior by a gunman, tragically sustaining a severe head injury while speaking to her Tucson, Arizona, constituents. That shooting left Giffords with not only physical disabilities but also with aphasia, a disability affecting her ability to use language: to speak, to decipher spoken language, to read, and to write.

The *Atlantic* and the *Washington Post* reposted pictures of Giffords's "handwritten notes," initially shared on the Facebook page of Giffords's PAC Americans for Responsible Solutions. The *Atlantic* framed those notes as "pen-scrawled words deliberate, diligent, written on a surface all too familiar to schoolchildren: binder paper." "She is trapped in her injury," the brief write-up went on, "and few things make that point more powerfully than a piece of binder paper and a hand-scrawled message" (Garber). Shortly after, the *Atlantic*'s initial posting was edited to reflect that Giffords, in fact, had not handwritten the words herself, but rather, that it was her speech therapist's handwriting. I offer this example as a window into the complexity of meanings for literacy, language, personhood, and authorship in the context of disability. Giffords's disability dramatically affects both what writing studies scholars would call her literate practices—how she uses writing and reading and speaking, her handwriting, her having others handwrite—and also how the press recognizes her as a literate, or an illiterate, person.

Alleging that Giffords is "trapped in her injury" frames disability as a kind of static, individual embodied flaw demanding medical treatment, the kind of "medical model" framing that has been critiqued broadly by disability studies scholars and disability justice activists. I would argue that the media portrayal of Giffords's literacy, too, is trapped by this rigid framing of disability as injury. In the hands of Giffords, even the lined binder paper she reads from is itself taken up as a symbol of Giffords's embodied deficits, of her limiting, "trapping" "injury." In this way, Giffords is trapped in others' perceptions of her so-called infantile literate skills. Illiteracy and disability here are bound up: one signaling the other. Literate materials—the childhood paper and "scrawled" letters—"make that point," as the *Atlantic* writer Megan Garber goes so far as to say, "more powerfully" than anything else she can imagine. Marking or alleging "[a] lack of literacy," though, signifies much more than just a lack of literacy (Dolmage, *Academic* 110). Rather, alleging a lack of literacy, Jay Dolmage claims, may "be a way to insinuate a biological lack or difference, a disability, without coming out and saying it, or writing it" (Dolmage, *Academic* 110).

What else might literacy—or literate ability or literate disability—in the life of a disabled public figure like Giffords symbolize? It matters, the updates made to Giffords's story show, who did the physical handwriting of the speech notes themselves. Because political ghost-

or speech-writing is a ubiquitous and openly acknowledged practice (Brandt, *Rise*), these questions of authorship are particularly striking. Studies of disability memoir writing tell us how writing by disabled people has been used to certify humanness or personhood: that to demonstrate the ability to write is to demonstrate the ability to think and, thus, to be human (Berube). As with slave narratives that begin with statements by whites certifying the authenticity of the writing of African slaves, disability autobiographies have commonly opened with certifying context by medical authorities, family members, or other so-called able-bodied/minded authorities that the writing has in fact been produced by the disabled person: certifying authorship, certifying literate ability, certifying personhood. This brief example of Giffords clarifies how disability may call literacy into question, opening questions about how disability and literacy contrast and conflict—of what they mean, or have been allowed to mean, together.

A second scene occurred closer to home for me: a few months before I began my PhD program in rhetoric and composition, my mother had a severe hemorrhagic stroke, causing right-side paralysis and aphasia. For several months, she didn't speak at all. For someone who had always been so loquacious, this was a sea change. Then she regained a few words at a time: strange words at strange times, yes for no, no for yes. One time, *pocket* for *Kleenex* in a repeated question, "Do you have a pocket?" which yielded both frustration and laughter. After much silence, she recalled unexpected, often multisyllabic, words from *paraphernalia*, *redundant*, and *actually* to her childhood pet dog's movie-star name, Gypsy Rose Leigh. Other words were missing: her birthdate, or the day of the week to perform at the doctor's appointment that ultimately assessed her as insufficiently prepared for the hospital's inpatient intensive rehabilitation program, or her daughters' names. From the basement therapy room of the nursing home facility she ultimately called home for six months after her stroke, I thought of the possibilities and power of communicating in multiple modes. As she stuck her tongue out at me when she proved me wrong; froze out infantilizing, loud-talking neurologists and nursing staff with a sharp glare; charmed the nurses she liked with sounds, smiles, and exaggerated facial expressions, I wondered about the weight we put on language—what we expect, mark as normal or abnormal, reject out of hand.

She and my siblings dealt with changes in our roles, settled into the relative quiet—so strange after always knowing our mother as ver-

bose, as always talking, even in situations that called for silence—developed a shorthand, cried, laughed, worked gestures around words and words around gestures, came to ask for context and to look for synonyms, to narrow in on meaning. A family friend once observed that we communicated in what seemed like another language, saying though he was not following our conversation, it was clear that we were.

Literacy came into contact with her still relatively new disability—or didn't—when, at the hospital discharge and again at the nursing home intake, she refused to sign: to even make an X on the paperwork, to even hold a pen. In no small part, this is the reason my oldest sister became her power of attorney. Always more like a sketch than a signature, more like an art than a transaction, the very look, the very craft of her handwriting meant something to her. Reading and writing writ large had never been her forte. Perhaps working from something like, I later suspected, undiagnosed and unacknowledged dyslexia in a generation that didn't expect girls to go beyond the basics of education anyway, she described being passed forward, grade to grade, until she could get out. Still, the swirls of her name were sacred, and now, as she has not to my knowledge so much as held a pen, inscribed a letter, or even made an X in the decade since her stroke, they are lost.

Since my elementary school days, my mother always found the lines and scribbles of my handwriting, as she said, “appalling,” sloppy, artless. These responses reflect values around language and literacy, around penmanship and personhood, around ability and literacy, disability and illiteracy. What of the pain of handwriting when the letters no longer come quickly to mind and when one's hand moves and feels differently? What of the specter of a memory of being able to write in certain ways? What of the shift to having other people write, read, and sign on one's behalf? What does it mean to be literate when one's access to language is changed? What's “normal” or desirable about the ways of doing and being, or not doing and being, literate/illiterate after aphasia? What, I ask in this book, does it mean to be literate at all?

The questions of these two public and private scenes are questions of literacy, illiteracy, ability, disability: of the materials we use to write and read; of what feels or looks right or wrong; of the ways others perceive us, or we perceive ourselves, as literate or not; of the ways literate

norms hurt us; and of the ways we change, adapt, and transform those norms. In *What It Means to Be Literate*, I ask and explore these questions and complexities through the generous participation of people who've experienced strokes and brain injuries and now live with language-related disabilities, or aphasia. Aphasia, though it is relatively unknown, is more common than cerebral palsy, multiple sclerosis, or Parkinson's disease. Every year, roughly two hundred thousand individuals in the United States acquire some form of aphasia, affecting various aspects of their language use: speaking, listening, writing, and reading (National Institute). While this book focuses in on aphasia, the experience of disability affecting reading and writing activities and identities, as well as language use and thinking processes, is certainly not entirely unique. Individuals with Parkinson's, multiple sclerosis, or other progressive conditions may experience aphasia. Similarly, scholarship and advocacy around neurodiversity—or the varied range of “neurocognitive functioning” for individuals with autism, dyslexia, intellectual disability, depression, and more—has highlighted important diversity in language and literacy use in ways that overlap with the aphasic folks featured in this study (Hughes 2). Throughout, I aim to point to some of those resonances (and hope readers will make their own links) to experiences of disability, embodiment, neurodiversity, or even aging bodies in relation to literacy, literate norms, and what it means to be literate.

My study of aphasia and literacy began not as research at all, but as a public humanities project in which I collaborated with a speech pathologist to create multimodal composing groups for local community members with aphasia interested in telling their life stories. Because aphasia affects language, the medium for so many narratives, I suspected that aphasic people's life experiences and insights often go unheard, unobserved, and unrecorded. Accordingly, we designed not therapy, but weekly community storytelling groups to facilitate the telling of stories in life books: scrapbook-like texts that featured drawings, old photos and ticket stubs, newspaper clippings, and even locks of childhood hair. “It's *your* book,” we urged participants, and “*your* story.” In response to one participant's request that she wanted to “*write* write,” we created an aphasia writers' group that has met weekly for the past several years, focusing on the composing of any writing genre that interests participants, featuring projects from children's books to poems to resumes and cover letters. As I sat in the small Easter egg blue-green rooms of the speech and hearing clinic

in these weekly composing groups, as folks illustrated old memories and future goals on bright scrapbook pages, as our ears and eyes listened to speech and gestures alike, I learned a great deal about how individuals compose across modes and with other people, about what it means to communicate, to listen, to tell stories.

What It Means to Be Literate draws insights from those composing groups, but it also looks beyond the clinic's walls. Participating in these groups, I quickly realized I had questions about individuals' literate lives outside of the groups: at home, as part of hobbies or careers, as parents and daughters or sons or significant others. Because aphasia is an acquired disability, often experienced later in life, it intervenes into people's lifelong histories with literacy. As writing studies has established, literacy develops across the lifespan, threading in and out of people's educations, vocations, and personal lives. To explore literacy in the lives of aphasic people in this broader sense, I decided to conduct in-depth literacy history interviews. I began interviewing participants in these groups, and then snowball sampling outward, for a total of twenty-four interviewees.

In this book I offer and analyze findings from those interviews—as individuals kindly invited me into their homes, sharing their passion projects—presentations to increase aphasia awareness, binders full of homebrewing recipes, poems commemorating parents' birthdays and anniversaries. And sharing early memories of writing one's name alongside siblings doing homework or the nervous performance of a spelling bee. Of hundreds of genres of writing at home and work: lesson plans for teaching and individual education plans for special education students, inventory, and business plans. I asked about people's memories of reading and writing before aphasia and after—the scenes of their writing and reading, what made them proud and what disappointed them, when they used writing and reading to get what they need.

I'm privileged to share the literate experiences of, among many others, former special education teacher Jean, who reads books by following each word of the text with her fingertip until she falls asleep, exhausted, but committed to what she calls the task of "reprogramming" her brain. Of Judy, a former high school English teacher, who three years after her stroke explains "leaving the writing behind" as she says her brain is "squashed" and her "flair to do it" is gone. Of former computer programmer, chef, and current tai chi instructor Rose, who explains how she has adapted to "get into this whole mode" of

using speech-to-text software as she composes for the weekly aphasia writers' group. Of Jill, a former middle school teacher who sums up writing after aphasia in one word: "Bleh." It's "too much work," she elaborates. Though she now listens to audiobooks, Jill says she misses the "feel" of reading like she used to. Of John, a former Marine used to training his body, who finds that, after his brain hemorrhage and surgery, he needs to read only in the mornings and counts on daily journaling in his notebook to serve as what he calls his "auxiliary brain." Of Andrea, who returns to her work as a counselor after her stroke, and who says that writing has become a way to express herself even "better" than before her stroke. Of Bob, who after a brain tumor advocates for aphasia awareness in presentations to the Elks Club and church groups, explaining how the practice feels like "a weight off the shoulders." Of Beth, who after sustaining a traumatic brain injury when she was hit by a car the day after she submitted her master's thesis, is now reworking her writing process as a PhD student in theater: turning to design theory, Post-It notes, and movement. Even still, she struggles with herself and her "brain for not being able to get better fast enough."

These experiences reflect individuals' grappling with what I theorize as an ableist violence of literacy—the ways literacy is commonly yoked with ability, illiteracy with disability, and the ways these associations do harm to individuals' sense of themselves as being literate or doing literacy in "right," "normal," or "able" ways. The field of rhetoric, composition, and writing studies has done a great deal to uncover and critique this ableist violence of literacy; however, we need to know more about how the associations, disassociations, conflicts, and even cancellations between disability and literacy play out in everyday people's lives. In other words, we know more about the kinds of ableist stigmas and barriers disabled people face, but less about what disabled people *do* when they read, write, and grapple with literate identity. What does it mean to understand oneself as both as disabled and literate? What meanings do people ascribe to disability and literacy? How do these meanings intertwine, conflict, or compound? How do these meanings affect people's literate identities and practices—how they understand themselves as literate, and what they do with literacy? As they read and write, what materials do they draw on, and how do they use their bodies? How do these literate identities and practices engage with, bump up against, challenge, or even exceed the ableist norms and violence of literacy?

To answer these questions, I outline and take up what I call a disability materiality approach to literate lives: a critical new materialist lens that takes seriously, and learns from, the embodied, material experience of disabled writers. This disability materiality approach seeks to account for how disabled writers face social constraints in the form of ableist norms and violence, embedded in perceptions of themselves/their bodies as less than literate, resulting in their exclusion from educational opportunities, subjecting them to the scrutiny of their literacy, ability, and even personhood. At the same time, I argue that disabled people's embodied and material literate practices—the way they go about the embodied/material doing of reading and writing—may also, and frequently do, exceed and challenge expectations about and norms of literacy writ large. Specifically, I show how a focus on “disability materiality” reveals how aphasic writers take up, inhabit, grapple with, and challenge ableist scripts around (1) the body in literacy: how brains, hands, eyes, mouths, voice boxes, and more should operate to make reading and writing happen; and (2) the spaces, places, activities, tools, and materials that matter in literate practices and environments. I want to note that a disability materiality approach to literate lives seeks to draw attention to bodies and their emplacement in environments not to displace humans, or to pay more attention to pens or keyboards than aphasic people (being careful to avoid, as Remi Yergeau incisively, yet playfully, notes, prioritizing the “Socratic gusto of futons” over the rhetoricity of disabled human beings [11]). Rather, I show how taking up a disability materiality approach to literacy in fact centers the rich, complex, embodied and material experiences of disabled people as they read and write, pushing us to better account for, and counter, the ableist violence of literacy.

I first examine the important work done by scholars from rhetoric and composition, education, disability studies, and more that has begun to trace an ableist violence of literacy. These critiques have importantly brought a social model of disability lens to understanding literacy and disability, rejecting the idea of disability as an individual, medical problem, and turning attention to how society's norms in fact disable people. I then identify what a social model critique of the ableist violence of literacy needs to better account for: in particular the insights from disabled writers themselves, particularly what embodied and material knowledges and experiences they bring, in addition to the stigmas they face. I lay out a disability materiality ap-

proach to address these gaps, outlining what that approach offers to the study of literacy, and close by articulating how subsequent chapters analyze various facets, and applications, of a disability materiality approach to the literate lives of aphasic people.

THE ABLEIST VIOLENCE OF LITERACY

As rhetoric and composition studies has established, when it comes to literacy, whose uses of reading and writing get valued or promoted or supported is a social process. That process, as US history has revealed—from desperate attempts to keep literate materials from use by African slaves to the practice of literacy testing limiting voting rights to the proliferation of standardized exams—is often violent. The concept of the “violence of literacy” merits some extended attention, as it is foundational to much of the critical work done in rhetoric and writing studies. J. Elseph Stuckey popularized this phrase in *The Violence of Literacy*. “When literacy harbors violence,” Stuckey contends, “the society harbors violence. To elucidate the violence of literacy is to understand the distance it forces between people and the possibilities of their lives” (94). In this way, literacy can be understood as a barometer of ideologies, a vehicle for carrying a culture’s “ideological freight” (Brandt, *Literacy in American* 20). Since the 1980s, scholarship in rhetoric and composition and interdisciplinary fields from education to anthropology have interrogated how literacy is about much more than encoding and decoding language. Literacy is ideologically weighted: denied, measured, marked, sponsored, or not, depending on individuals’ identities and social locations. This ideological weight does violence to individuals along the lines of race (Richardson; V. Young; Kynard; Prendergast; Pritchard), class (Stuckey; Rose; Brandt), gender and sexuality (Pritchard; Alexander), and citizenship and nationality (Wan; Vieira; Lorimer Leonard).

Literate violence, then, relies on conceptions of normativity, as Eric Pritchard argues in his important work examining the meanings Black queer people make of literacy in their lives as they grapple with the damaging force of “how literacy is used in policing and reconstituting the boundaries of respectable Black gender and sexual identities” (27). I follow Pritchard’s lead in this book by pointing to the similarly damaging qualities of an ableist violence of literacy that does harm to the literate identities and practices of disabled writers. “In any work on literacy,” Pritchard astutely observes, “the very value placed on literacy in this world with regard to citizenship, economic

class, educational attainment, and other matters shows the ways in which the very word ‘literacy’ has always hailed the idea and promise of the normal” (29).

Ableist perceptions about what is “normal” and “abnormal” likewise “police” disability and literacy, perpetuating what I call an ableist violence of literacy. Ableism, of course, is always wrapped up with norms constraining race, class, gender, and sexuality (see Pickens; Yergeau), propounding violence in ways often disproportionately harmful for multiply marginalized individuals. Indeed, both literacy (Richardson; Pritchard) and disability studies (Bell; Erevelles and Minear) have been critiqued for inadequately theorizing disability in relation to race, for failing to make “substantive and lasting” “connections to other identity-based fields, particularly race/ethnic and sexuality/queer studies” (Schalk). As Julie Avril Minich notes, these gaps are “particularly troubling because disability is so highly racialized” as “unequal access to health care” and higher incidences of “environmental contamination, and state violence” more severely affect communities of color but also as “disability is often used rhetorically to reinforce white supremacy (just as it is also used to reinforce heteropatriarchy, transphobia, colonialism, and capitalist exploitation).” The way critical disability studies moves to interrogate “(dis)ability as a system of social norms which categorizes, ranks, and values bodyminds” (Schalk) provides important insight into how the ableist violence of literacy itself links ability and literacy through racist, classicist, sexist, transphobic norms, a phenomenon I trace in more depth in chapter 2 with the concept of a “normate template” for literacy.

For many of the aphasic people in this study, ableist (and relatedly racist, classist, and sexist) literate norms do violence to, even erase, literate identity as they conceptualize of their literacy practices as marking and marked by lost ability. Noting, for instance, how they write and read more slowly, get caught up on words, or no longer automatically navigate the keyboard, many aphasic people struggle to see themselves as literate at all. A disability materiality approach helps to untangle how this ableist violence of literacy relies on assumptions about what bodies should look like and do, what materials are deemed necessary for literate activity (from keyboards to printed books), and how they should be used.

Disability-focused scholarship in rhetoric and composition has done much to expose how common understandings, definitions, and

discourses on literacy popularly, medically, and pedagogically engender and maintain an ableist violence. For instance, rhetoric, composition, and literacy scholars have powerfully critiqued how disabled people have been denied recognition as authors, as reliable communicators, and even as literate subjects—doubted as both “storytellers” and “storyable” (Yergeau 21; see also Lewiecki-Wilson; Dolmage; Walters; Brueggemann; Price). As these scholars have shown, disability and literacy are often understood as incompatible, even irreconcilable; disability is taken to be a sign of illiteracy, and illiteracy to be a sign of disability, both the cause, and the result, of some kind of “biological lack” (Dolmage, *Academic* 110). These conflations have severe consequences. Disabled students are often limited to skills-based, functional literacy, marked with literate “impossibility,” and often denied literacy education altogether (Kliwer, Biklen, and Kasa-Hendrickson 167; Brueggemann; Dunn, *Learning*). Students of color and multilingual students who do not perform to the “standards” of reading and writing are more likely to be marked as disabled and illiterate, reflecting how ableism and racism rely on one another (Connor et al.). Nonliterate adults are broadly perceived as lacking intelligence, knowledge, and ability, similarly reflecting the entangled nature of class, race, and disability in defining literacy and illiteracy (Rosenberg; Branch). As these conflations circulate in educational, medical, and popular discourses, they put ability at the center of what it means to be literate, and literacy at the center of what it means to be able. With literacy and ability so intricately intertwined, disability is often understood as canceling out literacy.

An ableist violence of literacy is particularly apparent in the ways disability has been framed as a kind of other to education, and higher education in particular (Price, *Mad*; Dolmage, *Academic*; Kerschbaum et al.). The barriers, erasures, and burdens for disabled students to “prove” their needs and negotiate their own accessibility all rely on ableist and disablist beliefs: promoting able bodyminds and disparaging disabled ones (Kerschbaum et al.; Wood; Simpkins). Margaret Price notes that the very “norms” of the academe—rationality, and even presence and participation—exclude mental disability. Rhetoric and composition scholars, in particular, have examined how students with disabilities are often understood by writing teachers and beyond as someone else’s “problem.” “There are no disabled students in my classroom” is an oft-cited refrain, or “disability is a drain on limited time and resources in academia” (Vidali). In *Academic*

Ableism, Dolmage traces the ways higher education is built on its very opposition to disability, constructing “steep steps” to keep out disability and disabled students. In primary and secondary education, Christopher Kliever, Doug Biklen, and Christi Kasa-Hendrickson similarly chart how students with disabilities segregated from “mainstream” classrooms are denied “opportunities to encounter activities that foster literacy” at all, kept apart from libraries and in classrooms that lack “child-oriented reading materials such as storybooks” (172). This restriction around access to literacy education “among people with disabilities has become institutionalized as a presumably natural manifestation of organic defects thought to objectively exist well beyond the reach of social, cultural, or historical consideration” (164). Such educational policies rely on a belief in “literacy invisibility” or “impossibility,” the exclusion from being considered capable of reading and writing at all, based on beliefs about individuals’ very bodies and minds (167).

The two studies in composition that most directly focus on the literate activities of disabled people—Brenda Jo Brueggemann’s *Lend Me Your Ear: Rhetorical Constructions of Deafness* and Patricia A. Dunn’s *Learning Re-Abled: The Learning Disability Controversy and Composition Studies*—both comment on the ways disability is understood as erasing or cancelling out literacy. Dunn notes that composition studies simply “does not deal with learning disabilities,” resulting in “a crack through which a small, but significant number of college students [are] falling” (4). In fact, in 2015 the National Center for Education Statistics found that 11 percent of US college students self-reported having a learning disability, and given that many students choose not to disclose their disability or are unaware of their disability, the presence of learning-disabled college students is likely significantly higher. Likewise, Brueggemann, studying discourses around literacy education for deaf students, finds that illiteracy “is often equated with deafness” (*Lend* 28). Such an equation, an erasure of literate potential, results in deaf students’ literacy education being substantially limited to basic skills, or what Brueggemann calls “literacy as a communicative product” (34), marking individuals as “haves” or “have-nots.” Brueggemann traces how at Gallaudet University, an all-deaf university, the English literacy requirement is all about “passing” basic skills, but leaves deaf students disconnected from learning about and developing uses for English literacy in their lives, and valuable knowledge of their own writing processes.

Taken together, disability scholarship reveals how the very concept of literacy can be understood to be grounded in ableism. The big claims that have long been made for literacy's "power" and "consequences" seek to hold up literacy as a skill that differentiates humans from animals, advanced from primitive, educated from ignorant. Well-rehearsed anthropological studies of literacy attached substantial cognitive and cultural consequences to the attainment of writing and reading skills; "proper" human history commences when the advent of writing enables the recording of abstract historical and logical tracts (Goody and Watt 304). And writing, Walter J. Ong claimed, "more than any other single invention, . . . has transformed human consciousness" (78) through its ability to privatize and concretize thought. These "great divide" theories of literacy posited transformation from darkness to light, ignorance to intelligence, as individual psyches and societies proceed from orality to literacy. Such claims are founded, Stuckey argues, on the persistent belief—in spite of studies complicating the power of literacy in unilaterally increasing cognitive or cultural growth (see Scribner and Cole; Graff)—"that literacy confers special power, the power to be human. To be wanting in literacy is to be wanting in human fulfillment" (67). *Able*, here, is tacitly synonymous with *human*. To be literate is to know, and print literacy has been taken as the way to demonstrate one's knowledge in citizenship tests and standardized exams; even the most common classroom practices such as spelling tests are grounded in proving one's knowledge. An ableist violence of literacy marks out disabled people as not quite literate, not quite able, even not quite human.

On the other side of the coin, popular discourses around illiteracy are dominated by metaphors of sickness, scourge, slowness, stupidity, darkness—all linked to disability. Stuckey questions the "inchoate" measurement by which "illiteracy" is counted as evidence of the ways illiteracy is less a concrete condition, and more an instrument of the violent nature of literacy. She notes how labels of illiteracy are aggressively associative, linking with all matter of unappealing social labels. As stigmatizing characteristics, it is possible to understand both disability and illiteracy as falling under one of what Jenell Johnson calls "stigma's most insidious aspects": the way that stigma of any kind marks individuals as "bad" in a "frustratingly general" way, enabling "slippage between the many permutations of badness: worthless, evil, dirty, ugly, weak, cowardly, envious, dangerous" (465). Johnson notes that the "stigma of disability" in particular "has a history of being

read as a sign of evil and associated with weakness, criminality, asexuality” (465). To these associations with disability, I would add illiteracy. And meanings of “badness” proliferate even more as one examines the negative associations with illiteracy—a range of “antisocial behavior,” Stuckey argues, from poverty to criminality to unwed pregnancy (101). Citing Stuckey’s claim that “the face of illiteracy is less and less linguistic,” Dolmage notes how “illiteracy is now directly affiliated with immigrants, with young mothers, with inmates, with indigenous peoples, with the jobless, with those on welfare, and so on” (*Academic* 110). Peter Mortensen also analyzes how class and disability were used to mark rural citizens’ bodies in the late nineteenth and early twentieth century as “feeble-minded,” “illiterate,” and even too defective to attain literacy. A powerful stigma, “illiteracy gathers power from what it can be associated with, and it also crucially gathers definition from these affiliations; it is magnetically affiliative. Other downward comparisons stick to illiteracy” (Dolmage, *Academic* 110). These studies of literacy, disability, and education have exposed how ableist violence is perpetuated through the ongoing exclusion of students with disabilities, relying on the equation of disability with illiteracy as “something to fix” (Dolmage, “Mapping” 19). An ableist violence of literacy, thus, has done substantial harm to disabled people.

FROM MEDICAL TO SOCIAL TO CRITICAL MODELS OF DISABILITY

The important body of scholarship that has worked to expose an ableist violence of literacy has drawn upon fundamental tools of critical disability studies to do so. For roughly the past three decades, the scholarly field of critical disability studies has complicated understandings of disability as purely a medical, biological, or individual “problem.” Integral to this critique of a “medical model” of disability has been the theorization of a “social model” of disability, which argues that what “disables” people is not their bodily impairments, but rather society—specifically, that is, stigmatizing belief about what constitutes a “normal” body. The social model, then, exposes how what is often considered just “the way things are” (i.e., environments built with stairs) in fact assume a very specific kind of “normal” body/mind (i.e., individuals with two “able” legs to facilitate the walking or climbing of stairs). In this way, “disability becomes a representational system more than a medical problem, a social construction rather than a personal misfortune or a bodily flaw, and a subject appropriate

for wide-ranging intellectual inquiry that augments the medical, rehabilitation, or social work approach to disability” (Siebers, *Disability* 295). The reframing of disability not as biological flaw, but rather as social stigma powerfully rejects individual blame and responsibility around embodied variation, turning attention toward how so many aspects of our built and social environments are designed for “normal” bodies and minds, excluding all others. Disability studies, then, focuses not on how to “treat disease or disability, hoping to cure or avoid them,” but rather interrogates “the social meanings, symbols, and stigmas attached to disability identity” and “how they relate to enforced systems of exclusion and oppression” (Siebers, *Disability* 3).

A social model analysis of disability, combined with a social analysis of literate violence (moving beyond the well-rehearsed “strong text,” autonomous, Great Divide approaches), interrogates literacy and the people practicing it in ways beyond biology or individual, neutral skill. A social model analysis of disability and literacy, such as a critique of much of the framing of Giffords as infantile and less-than-literate as discussed earlier, highlights how disabled people’s use of literacy and access to literate identities are often marked as deficient, broken, and infantile—even impossible; as in need of treatment, special education, and remediation—stigmatized, even erased. A social model critique of disability-literacy tracks how this disability stigma does significant violence to literate identities and practices, to educational opportunities, even to disabled people’s very personhood. In this way, social model critiques of disability and literacy have been invaluable in tracing the ableist violence of literacy and its material consequences: providing us as a field with essential insights into how social and built environments stigmatize and exclude disabled people, particularly students. The social model of disability has not only enriched scholarship and pedagogy, it has, as activist Liz Crow compellingly puts it, without “exaggeration,” “saved lives” (2). By countering the notion that disability is a problem with disabled people and is in fact a problem with the way society fails to support, and often does serious harm to, disabled people, the social model has succeeded in “promoting disabled people’s individual self-worth, collective identity and political organisation” (2).

A DISABILITY MATERIALITY APPROACH FOR LITERACY STUDIES

While unquestionably seeking more just realities for disabled people, the social model’s focus on, many scholars and activists argue,

tracing the social construction and social stigmas creating disabling conditions may cover over disabled people's lived realities, concerns, and insights (Kafer 7; see also Shakespeare; Davis; Siebers; Mitchell and Snyder, *Cultural Locations*; Wendell), effectively "refus[ing] to engage thoroughly the materiality of disabled embodiment or en-mindment," including experiences of "pain" and "distress" (Yergeau 108).

In response to the complications of the social model, critical disability studies approaches (Minich; Garland-Thomson, "Critical"), including "cultural" (Mitchell and Snyder, *Cultural Locations*), "relational/political" (Kafer), and new materialist models (Mitchell et al.; Kupetz), have increasingly turned attention to how disability must be understood as simultaneously social and material, discursive and distinctly embodied/enminded. These approaches break down "binary understandings" of disability, expanding the "struggle for social justice and diversity" to "another plane of development, one that is not simply social, economic, and political, but also psychological, cultural, discursive and carnal" (Meekosha and Shuttleworth 50). Likewise, disability theorist Sami Schalk uses the term (*dis*)ability to highlight "how the boundaries between disability and ability are uneven, contestable, and context dependent." The disability materiality approach I develop and use in this book seeks to highlight these blurred boundaries: between ability and disability; between bodies and minds (using terms like *bodymind*, to reflect "how mental and physical processes not only affect each other but also give rise to each other," how they act as one" [Price, "Bodymind" 2]); between physical, mental, intellectual; between literacy and illiteracy.¹ In so doing, I seek to explore how these concepts not only rely on one another, but are, following Lauren Rosenberg and Stephanie L. Kerschbaum's recent powerful call "to open up possibilities for thinking about literacy and disability together," "continually taking shape and shifting in dynamic relation with one another" (276).

Specifically, I seek to build on how these models have begun to interrogate and account for how the experience of living in and navigating the world with disabled bodies itself creates a certain kind of knowledge, stemming, in no small part, from the embodied/material experience of disability itself (Siebers, "Returning"). When in *Disability Rhetoric* Dolmage defines rhetoric as deeply of the body and asks, "Are bodies things made of language? Yes. But only insofar as languages are also things made by bodies," he reflects a model of

disability that is both social and material, privileging both the ways bodies are constructed and what they construct in the world (100).

In this book I build on the critical, cultural, political, and new material extensions to the social model of disability to offer what I call a disability materiality approach. In short: medical models of disability have reduced embodied experience to a medical process of diagnosing and treating symptoms; social models have focused largely on discursive meaning. So while the social model has been such an important correction to and repudiation of the medical model, a disability materiality approach builds on the social model to link together the social and the material to more fully, justly account for disability experience and knowledge, and, as a result, to generate more tools to continue to account for, and counter, ableist violence and its damaging consequences. This approach takes up the critical new materialist assertion that “our material lives are always culturally mediated, but they are not only cultural,” and that a deeper political/social critique in fact necessitates such attention to materiality (Coole and Frost 27). A disability materiality approach is built on the fact that disability brings into bright relief how matter, which I define as including bodies and the stuff of the environments that they inhabit, is both socially constructed, or discursive, and simultaneously exceeds those constructions. That is, I argue that the new materialist commitment to “giv[ing] materiality its due” necessitates giving disabled embodiments/lived experiences their due (Coole and Frost 7). This approach, while still reframing disability “in more positive, affirming ways,” further emphasizes the need “to more tangibly recognize the materiality of disability’s active participation in the process of meaning making itself” (Mitchell et al. 2).

I want to note that while disability materiality shares much with many of the powerful approaches to new materialism and posthumanism, including several that have begun to be taken up in rhetoric and writing studies, it does not necessarily aim to decenter the human (see Boyle and Barnett). While my disability materiality approach does draw attention to nonhuman objects, to the complexity of agency and to how it is complicated by bodies and distributed across literacy-disability ecologies (see especially chapter 4), I follow the work of several disability theorists who, in new materialist work, continue to center disabled people as agents (Kupetz; Siebers, “Returning”; Pickens). The ableist violence of literacy works to question and deny disabled people’s capacity to do literacy and to be literate; I am deeply

invested, with disability rhetoric and composition scholars, in countering these pernicious ways that the agency, literacy, rhetoricity, and humanity of disabled people have been, and continue to be, denied (Yergeau 11). A significant aim of a disability materiality approach is redressing the ways that agency has been denied to disabled people by both medical and social approaches.

In *What It Means to Be Literate*, I outline and employ a disability materiality approach to studying literacy that foregrounds how bodies, environments, and social norms are “mutually transformative” (Siebers, “Returning” 39). This approach highlights “how disability makes things in the world, not just how the world makes disability” (Garland-Thomson, “Critical” 15). The knowledge that disability makes stems in no small part from the embodied/material experience of disability itself: coming from particular bodyminds. While it is possible to use many methods to take a disability materiality approach, I offer an approach to disability and literacy that foregrounds and learns from the lived experiences of aphasic writers, contributing to what critical materialists identify as a need for “a detailed phenomenology of diverse lives as they are actually lived” (Coole and Frost 27). That is why this book seeks to explore the lived experience of people navigating literacy and disability: not to identify biological or cognitive “problems,” nor solely to track how built environments and beliefs about disabled bodies perpetuate ableist stigmas, but because disabled people’s embodied literate experiences matter, and embodied experience matters to the ways people do literacy (how they read and write) and see themselves as literate, or not.

My disability materiality approach builds upon and extends social model analyses and, in turn, contributes to the study of literacy and literate lives in at least three primary ways that I discuss in what follows: (1) acknowledging the reality of bodily impairment and change, (2) understanding stigma at the level of material and embodied practice, and (3) understanding how materiality may exceed stigma.

ACKNOWLEDGING THE REALITY OF BODILY IMPAIRMENT AND BODILY CHANGE

A disability materiality approach addresses one of the primary critiques of the social model: that turning attention to disability as a social construction risks separating individuals’ bodily experience of “impairment” from the “social” disabling factors that stigmatize “impairment.” Liz Crow worries that the social model reinforces a di-

chotomy between embodied impairment and the stigmatizing nature of “disability” that “is so absolute that we are in danger of assuming that impairment has no part at all in determining our experiences” (3). This distinction “between impairment and disability,” Alison Kafer argues, is simply not “useful”: “A sharp divide between impairment and disability fails to recognize that both impairment and disability are social” (7). In this way, both the medical and social models of disability have made an artificial distinction between “impairment” as bodily and thus outside of the concern of disability experience and politics and the social factors of “disability.” The fact that “what we understand as impairing conditions—socially, physically, mentally, or otherwise—shifts across time and place” complicates this clean distinction, and, Kafer argues, “presenting impairment as purely physical obscures the effects of such shifts” (7). One particular consequence of this erasing of impairment and bodily experience is that “in its well-intentioned focus on the disabling effects of society,” the social model “overlooks the often-disabling effects of our bodies” (7). That is, “social and structural changes will do little to make one’s joints stop aching or to alleviate back pain. Nor will changes in architecture heal diabetes or cancer or fatigue” (7). In these ways, “a strict social model” may leave out “pain,” “fatigue,” and even disabled people’s choice to pursue medical care or treatment from “the project of disability politics” (7).

In the experiences of aphasic people in this study, for instance, disability materiality’s insistence on the reality of impairment turns attention to how brain injuries and the right-side weakness that often accompanies them have real impacts on how quickly individuals read and write, on headaches, on fatigue. Disability also changes; it materializes differently across lifespans, even across the day as energy might wax or wane; it shifts and morphs as bodies change—well illustrated by the disability reframing of “able-bodied” people as “TABs”—“temporarily able-bodied” (Garland-Thomson, *Extraordinary*). Likewise, what is understood as “disabling” varies in relation not just to social values, but also to material technologies. Audio books and electronic books, for instance, as I discuss in this study, open up literacy access for some and complicate it for others (based on both expectations around “normal” reading and around bodily needs such as struggles with aural comprehension). In chapter 2, I show the complexity of aphasic writers grappling with the blurred lines between impairment and disability, the material and the social, as they reflect on what it

means to feel literate. A disability materiality approach helps to account for the complexly material-discursive roles of so-called impairment and disability in people's literate experiences.

UNDERSTANDING STIGMA AT THE LEVEL OF MATERIAL AND EMBODIED PRACTICE

A disability materiality approach to literacy insists upon accounting for embodied, material experience beyond the social construction of disability. Many disability scholars allege that while attempting to reject the "diagnosis" of disability as only an embodied problem central to the medical model, the social model itself "continues to objectify disabled people because they are the targets of disabling environments" (Siebers, "Returning" 39). In this way, both medical and social models can be understood as relying on diagnoses. The "two diagnostic approaches have profound differences when it comes to their findings (one diagnoses deviant embodiment, the other diagnoses exclusionary social and built environments)" (Mitchell et al. 2). In so doing, David T. Mitchell et al. contend, "Both [models] tend to empty disability materiality of its active participation in fashioning alternative biologies, alternative subjectivities, and viable nonnormative modes of life (human, animal, organic, inorganic)" (2).

Rather than reducing materiality to a site for diagnosing ableist stigma, a disability materiality approach calls for a deeper dive into how and why materials matter.

In this study, aphasic people focus intently on what literacy looks and feels like, including if literate practices feel right or wrong. Close attention to these scenes of literate practice reveal how ableist, classist, racist, sexist, or otherwise limiting, what I trace in chapter 2 as a "normate template for literacy," norms/expectations around literacy inhere in writers' very ideas and deep-seated feelings about bodies and space. That is, doing literacy, in embodied and material practices, is central to feelings/identities around being literate or not. A disability materiality approach, then, helps to interrogate how deeply bodies and environments and materials are enmeshed with social values.

As Rosenberg and Kerschbaum importantly remind us, though, "as we read literacy through disability, and disability through literacy, neither term is a fixed referent against which the other can be defined or understood; these concepts are always in flux" (270). Their insight takes seriously the critical disability studies tenet that what is understood as disabling itself is shifting and fluid. Schalk's term (*dis*)

ability helps to “visually sugges[t] the mutable nature of these terms,” “highlight[ing] how the boundaries between disability and ability are uneven, contestable, and context dependent.” A disability materiality approach helps tune in even more closely to the flexible, context-dependent meanings of disability (and literacy). For instance, in this study, we learn how former special education teacher Jean attaches at least two contradictory meanings to literacy and disability. She both observes in her practice as a special education teacher for twenty-five years that there is no “normal” way to be literate, that students, and the teachers supporting them, should do “whatever it takes,” whatever students need, with the materials and embodied practices of literacy, enabling students to read and write in ways that fit their needs, such as covering up all but one line of text, reading alongside audiobooks, changing the lighting, reading outside, or reading aloud with others. After acquiring aphasia, however, Jean expresses an unwillingness to use technologies such as speech-to-text, read-aloud features on her iPad, or easy reader books, describing her deep desire to “write *write*” and to “get back to normal.” A very close attention to the material/social dynamics of disability and literacy, in this way, offers an important tool for “studying power, privilege and oppression of bodily and mental norms” (Schalk).

UNDERSTANDING HOW MATERIALITY MAY EXCEED STIGMA

While a disability materiality approach helps reveal how stigma may operate in powerful ways in the most mundane material and everyday embodied actions, I acknowledge with disability scholars that by equating disability with oppression, social model of disability critiques have sometimes stopped short of accounting for the unique and important embodied/material experiences of disabled people. A disability materiality approach turns attention to what disabled individuals do with their bodies, how their bodies matter and interact in the world, rather than solely what is done to them by stigmatizing discourses and their material manifestations. Thus, a disability materiality approach contributes to literacy a deeper understanding of materiality in ways that often exceed stigma: specifically, it offers a new materialist emphasis on the “mutually transformative nature of bodies, materials, and social norms” (Siebers, “Returning” 39). As I explore in chapters 3 and 4, the creative embodied and material literate practices of aphasic people reflect how disability is not located in either biology or socialized stigma put upon bodies/materials.

Disability is instead materialized in relation. This “both/and” nature of what constitutes “disability” makes vivid the new materialist conception of matter as always “becoming” through “conjoined material-discursive” “constraints, conditions, and practices” (Barad 141). The material and the discursive are always entwined and influencing one another. New materialist perspectives recognize matter not “as massive, opaque plenitude,” but rather as “constantly forming and reforming in unexpected ways. One could conclude, accordingly, that ‘matter becomes’ rather than that ‘matter is’” (Coole and Frost 10).

A disability materiality approach to literacy helps to better account for how bodies and environments transform one another. In so doing, disability materiality offers an approach to interrogating what Rosenberg and Kerschbaum call the “entanglements” of literacy and disability, in hopes of not “fixing” our understanding of either concept, but gaining more insight into how they transform one another, and “lead to new phenomena,” new ways of understanding what disability and literacy mean, and mean together (276). In chapter 4, I explore how rather than solely responding to stigmatizing discourses and environments, aphasic people in this study create new awareness of their bodily needs, develop new habits, and inhabit and interact in literate environments in ways not reducible to the constraints of ableist violence. Along those lines, while a disability materiality approach to literacy makes room for experiences of pain, it also foregrounds disabled people’s literate pleasures. Disability materiality seeks to account for literacy scholar Morris Young’s important reminder that “living a life filled with literacy is full of both pleasure and pain” (11). The creative textures, habits, and unique joys of engaging with texts through one’s specific literate body are an essential part of people’s literate experiences, and that includes disabled people’s experience. For instance, that uniquely embodied, material joy is apparent when Judy and Clara express “love” for their Kindle reading practices (engaging, as Judy points, with her eyes and ears), or when Andrea reflects on morning writing rituals that she has developed and turned into a habit after her strokes as a practice she “treasures.”

It is the task of each chapter to privilege the insights, as they stem from the inextricably entwined social, material, discursive, extra-discursive reality of both literacy and disability, of aphasic people. Each chapter carries out an analysis of a different facet of a disability materiality approach to literacy—interrogating “the conjoined material-discursive nature” at play as aphasic people read, write, and

grapple with changes to how they understand their reading, writing, and literate identities (Barad 147). Thus, I attend to literate practices and identities for the “material-discursive” “constraints, conditions, and practices” that influence them (147). This disability materiality approach emphasizes not only what ableist violence does to aphasic writers, but what they do, the knowledge they make, in the material practice of their literate lives; that is, what it means to be literate after aphasia.

In chapter 1, I provide in-depth look at my process of developing the qualitative study that forms this book. Specifically, I offer my efforts to conduct ethical, accessible research as a kind of case study in designing, redesigning, and continually working toward a research design that centers communicative disability and communicative access. In chapters 2–4, I examine three key aspects of literate practice and identity, what the individuals in this study reported about what it means to do literacy and to be literate, revealed by taking a disability materiality approach: feeling, bodies, and ecologies.

I begin chapter 2 with a fundamental claim for the value of a disability materiality approach to literacy: that the insights of aphasic writers in this study bring the physical, embodied, material nature of literacy into bright relief. This chapter extends that finding to argue that bodies and materials matter not only to the doing of literacy, but to feeling, or not feeling, literate as well. I explore the experiences of four women who before aphasia identified as literacy experts, all former or current teachers, as they grapple with the blurred lines between impairment and disability (the material and the social), and as they reflect on what it means to feel literate or not after aphasia. I show how their concern with being literate in the “right” ways operates as a kind of literate violence. Specifically, I show that that violence is perpetuated through the influence of what I call a “normate template for literacy,” a concern for upholding standards for “normal,” able bodyminds, leading to shame, frustration, and often the painful decision to abandon certain literate practices altogether.

In chapter 3, I go on to explore what bodies mean to people as they read and write after aphasia. I trace how individuals focus on, adapt, and adjust their bodies as a literate resource to do the work of reading and writing after aphasia: training, programming, and practicing. Again, I show how a disability materiality approach, an intertwined social and material analysis, exposes the complexity of disabled writers’ focus on their bodies. I examine how individu-

als' training practices can be understood to be simultaneously taking on ableist norms around bodies and literacy focused on "fixing" and "rehabilitation," what disability theory calls "compulsory able-bodiedness," and exceeding those ableist norms by engaging in creative bodily practices to adapt and transform their bodies, to develop new habits, and to get what they need to read and write. Here, a disability materiality approach helps reveal aphasic people in this study both grappling with ableist norms or normate templates, sometimes taking up those frames, and sometimes pushing back on them.

In chapter 4, I use a disability materiality approach to literacy, learning from disabled writers, to bring together and extend new materialist ecological perspectives from both literacy and disability studies. I take seriously here the material-discursive interplay of aphasic people's literate experience, informed by Mitchell et al.'s insistence that "the alternative modes of becoming that even the most severe impairments offer involve the promise of an alternative agency that reshapes the world and opens it up to other modes of (non-normative) being" (9). I argue that aphasic literacies may do much more than just chafe against the violence of ableist stigma, but instead generate new practices, "other modes of (non-normative)" literacies that push back at ableist literate norms. I show how literacy-disability ecologies turn our attention to objects and practices often overlooked or ignored by a normative gaze, analyzing how language, time, technology, and people interact, engage, and transform one another in literacy-disability ecologies. I argue that these interactions expose alternative/anti-ableist aphasic literacies that push back at ableist literate norms, including what reading and writing should look like, how long it should take, what materials it requires, how those materials should be used, and who has the potential to be, or to be understood as, an author. In the final chapter I close by highlighting the key contributions of taking a disability materiality approach to literacy theory and for lifelong learning, particularly in community literacy groups.