

Reading Defiantly: A Personal Narrative of Discovering a Disabled Self

by

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## Abstract

Disabled individuals face stigmatization because of their body's impairment (or the biological manifestation of their disability) as well as various socioeconomic and cultural factors depending on their race, sex, and sexual preference. Because of this, it is very hard for a disabled person to embrace an identity that, culturally, signals lack, incapacity, and deficiency. Growing up as a disabled child, I found embracing this part of my identity very difficult. For me, the symbol of the school bus that took me to school each weekday conceptualized the medical model of disability where disability is a tragedy and something to be fixed. It was only when I started reading fiction at a young age that I was able to reconceptualise my disabled identity through emphasizing with characters of minority in literature. Through this process, I was able to recognize my disabled identity as an aspect of my being that I could shape on my own without anyone having to dictate it to me or enforce upon me. Through theoretical discussion, autobiographical reflection, and reading response, I chronicle this time in my life and directly reflect on the importance of reading as a means of identity-making in this thesis.

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## Dedication

In memory of Lillian Joyce Kapilik—the first sharer of stories.

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## Introduction: Bodies

“All argumentation must rest on the authority of the personal narrative. Before we may begin to converse, we have to counter the awkward obstacles to our own stories.” (Baker 46)

From a young age, I became aware of the problem my disabled body proposed; or, I should say, I became acutely aware of how it didn't look like or fit in with other bodies. Building upon this reality, I became aware of how my body was unanticipated by family, friends, and even myself. Rosemarie Garland-Thomson writes that, “most disabled people are surrounded by nondisabled families and communities in which disabilities are unanticipated and almost always perceived as calamitous” (15). If my body was unanticipated, what was I? I viewed my body as separate from other bodies because others did first.

This separateness became most apparent in social situations, where strangers would stare at my body and/or wheelchair. Seeing my consternation, my mom would whisper, “Stare, stare, like a bear, I can see your underwear,” causing me to smile weakly. Nevertheless—disaster averted for the moment—I couldn't help but be fed the message that my body complicated social situations. But it didn't do just that: it also triggered an emotional reaction.

Ato Quayson refers to this emotional response of pity as “a short-circuit triggered by the representation of disability” (15). I began to wonder what else my body signalled to others and what other emotional responses it conjured up. I began to realize that not only could my body produce pity, fear, distress, and sadness in others, it also became an emblem for all these emotions. I couldn't stop or halt this process—society's reaction to my body did this on its own.

At the same time as I was figuring this out, I began to read voraciously. I was the only one of my parents' three children who didn't have to be bribed by a penny a page over summer

holidays. Searching out books and stories about disability came later—but stories referencing disability and difference in unique ways seemed to seek me out. I read *Charlotte's Web* and *Harriet the Spy*, *A Wrinkle in Time* and *The Secret Garden*, *Little Women* and *The Lion, the Witch, and the Wardrobe*. I began to realize that all kinds of bodies produced emotions in others. I realized that fiction explored what bodies meant to each other in more fulsome and open ways than what I had experienced in life. I was curious to learn more about how fictional characters related to each other. It was easier for me to witness this in a fictional setting as a reader and observer than struggle to identify the emotional reaction a stranger might be having to my body in real life. Having this more fully addressed in words on a page allowed me to better understand the role I played as a disabled person in a world that assumed I was a tragic figure based on my body alone.

Fiction was how I began to make sense of the world. I absorbed books because they made more sense to me than real life did. My understanding was expanded in fiction, where in real life there was no one to explain complicated social situations. This is why I have chosen to write my story with the help of fiction, specifically with the books I read as a child that still speak to me now. Passages from fiction are woven into my life narrative here as a reminder that I was and continue to be culturally influenced by the world I live in. It is also a reminder to me to—like in fiction—become familiar and grapple with the complications, negotiations, nuances, and subtleties that arise but may escape notice on the surface of a real life encounter. For me, fiction helps me understand the complicated circumstances in which I grew up as a disabled person heavily influenced by life and art.

Impelled by this same motivation to observe, assess, and understand the world around me, I am writing my story in full knowledge that I most often find what is occurring around and

separate from me much more illuminating and interesting than what is actually happening to me. Fiction taught me at a young age that much more happens in a scene than one originally thinks. The stance I am most comfortable in, therefore, is one of cultural observer, not active player. I include both theoretical and autobiographical reflection in my story to better demonstrate that my life is directly affected by the cultural position I find myself in as a disabled person. Mine is an autoethnographical narrative in which I, as Carolyn Ellis explains, gaze back and forth: “First [by looking] through an ethnographic wide angle lens, focusing outward on social and cultural aspects of [...] personal experience; then, [by looking] inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations” (37).

It is also my hope that, as Heather Kuttai writes, “telling my own personal story can also make bigger points about our social condition” (39). Disabled life is not lived in a vacuum but is directly affected by the social and cultural ways disability is perceived. Disability has been perceived through the dominant narratives of medical intervention as Alison Kafer explains:

disability is cast as a problematic characteristic inherent in particular bodies and minds.

Solving the problem of disability, then, means correcting, normalizing, or eliminating the pathological individual, rendering a medical approach to disability the only appropriate approach. The future of disability is understood more in terms of medical research, individual treatments, and familial assistance than increased social supports or widespread social change. (5)

Personal reflection is one of the ways to turn the conversation away from medical intervention towards systemic social change. By actively rejecting the cultural desire to solve, fix, and cure the body medically, disabled people and those reading their story can begin to see the ways disability is cast as abnormal and problematic by instilled social and cultural factors. These

factors include the words used to describe disability, the lack of agency surrounding disabled persons, and the importance of hearing a multitude of voices representing the disabled experience.

One of the foundations of disability studies as a field of intellectual inquiry and critical analysis has been the formation of two distinct models of disability: the medical model and the social model. The medical model asserts that “a medical approach to disability [is] the only appropriate approach” (5). This is how disability was first presented to me as a child. Being kept in hospital for two months suggested that I needed to be fixed in order to be released into society. What came later to me was the adoption of a social model understanding where society’s attitudes and infrastructure (rather than a person’s body or *impairment*) was what really disabled an individual. Inherent in the social model is a differentiation between disability and impairment, the former being a social conception of what disables an individual (environment, society) and the latter being the physical and biological manifestation (an inability to see/hear/walk/think) that disables an individual. I agree with Kafer’s analysis, however—as I have lived and experienced the social model for the better part of a decade—that the division between *disability* and *impairment* is not always beneficial and may, in fact, further complicate understanding: “asserting a sharp divide between impairment and disability fails to recognize that *both* impairment and disability are social; simply trying to determine what constitutes impairment makes clear that impairment doesn’t exist apart from social meanings and understandings” (7).

What Kafer proposes as a relational model—the understanding that “disability is experienced in and through relationships” (8)—is what I would like to propose as the understanding that I have both written this thesis under and as a useful tool to further recognizing the three-way relationship between reading, identity, and disability. For at no time was I reading

as an able-bodied person; when I read, I had already experienced disability and so the lens with which I read was directly influenced by my personal experience of disability. At the same time, my identity as a disabled person was also shaped by what I read which was a direct reflection of the culture of the early 1990s. In the same way that disability may mean something different to each person who has *witnessed* disability but not *experienced* it personally, so was my perception of disability largely influenced by the conceptions of disability presented by the school I went to and other places where I encountered the reality of what my body symbolized to others. Even though the models of disability may seem fairly distinct in themselves, my point here is that we each draw on different models at different times in our lives depending on who we present ourselves as and who we feel we are as our most personal selves.

### **Thesis Outline**

In the first chapter, I directly examine the words used to describe disability in order to demonstrate that words are used in provocative ways to police the relationships between people. I've always been intrigued with the question of whether the words used to describe me and my existence matched up with how I would choose to describe myself. It comes as little surprise that this is largely not the case; however, by examining how and why insults and ableist language are used against disabled people, it is my hope that people will become more aware of how their words directly impact others.

Words used in fiction directly correlate to those used in life as well. This is another reason why I incorporate fiction in my story in order to demonstrate that art and culture have a direct influence on the way people live their authentic lives. Lennard J. Davis observes that fiction uses normative methods to promote the reader's identification with the main character. He writes,

the very structures on which the novel rests tend to be normative, ideologically emphasizing the universal quality of the central character whose normativity encourages us to identify with him or her. Furthermore, the novel's goal is to reproduce, on some level, the semiologically normative signs surrounding the reader, that paradoxically help the reader to read those signs in the world as well as the text. This normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject, and so on. (10)

I would like to propose, too, that the ways in which language structures normativity in fiction occurs in life as well and that language acts as a mirror through which ideology structures real lives. It is a primary example of how different bodies are used as a measure against which people can compare, conflate, and contrast their normative qualities against others. Bringing the words used in fiction into real life, then, has a contingency to it as the normativity once attached to the main character is now assumed to exist as an entity within society—an entity, Garland-Thomson writes, “that describes only a minority of actual people” (8). By examining words, I hope to demonstrate that language is culturally constructed and is used by people to both oppress and elevate others, sometimes even simultaneously.

I next move to how disabled persons are assumed to possess an inherent lack of agency. I examine this assumption through a formative period of my life when I rode the accessible school bus to school and home each day. Fragments of my life story take place on the school bus, and while I include some fragments from the bus in other chapters, I directly relate that time to a period when I and my disabled peers had our agency taken away from us. For not only were we segregated from our able-bodied peers, our presence on the bus also signalled to ourselves and others that our lives weren't expected to amount to much. The bus was a pernicious symbol used

to stigmatize us as disabled children. Lerita M. Coleman-Brown writes, “Stigma often results in a special kind of downward mobility.... Stigma allows some individuals to feel superior to others. Superiority and inferiority, however, are two sides of the same coin. In order for one person to feel superior, there must be another person who is perceived to be or actually feels inferior” (147).

I used my time on the bus to read. I did not take this on as an assertion of self at the time, but now I see it as a way to struggle and contend with the assumptions thrust upon myself and other disabled people. Kafer writes that, for disabled people, “[people] imagine a future that is both banal and pathetic: [...] their visions assume a future of relentless pain, isolation, and bitterness” (2). By occupying space on the bus, and by doing nothing, I was unknowingly promoting this idea of my future. By eventually rejecting that idea, I was actively promoting a new way of seeing myself the way I wanted others to see me. Reading also magnified the social systems at work around me and suggested how I could either play into them or reject them, changing them into something else completely.

Finally, I explore two other important narratives related to disability. The first narrative is most accessible in mainstream culture and is employed and widely circulated in order to bolster the belief that disabled people need to be healed and rehabilitated, creating the message that disability is pitiable and tragic. This narrative is not a challenge to perceptions of disability, nor is it an opportunity to identify the systems in place which cause disability to be perceived as a tragedy. As Simi Linton explains, “By focusing our attention on the individual and eliciting sympathy or awe, [this narrative diverts] us from thinking about how to change social conditions. There were no comments on the discrimination these people faced [...]; instead [disabled people] were asked if they missed all the things they used to do” (112). By honing in on an individual’s



loss, this narrative recreates the perception that inherent to disability is a longing for a pre-disabled state.

The second narrative, however, rejects the first and allows disabled people to tell their stories honestly, provocatively, and without self-denial. The writers of these stories do so in untraditional ways and in different spaces than writers of the overcoming narrative. Rather than being seen on TV in local news stories and newspapers, these stories appear in innovative—and more inclusive—mediums such as poetry, videos on YouTube, and graphic novels. These narratives do not portray disability as shameful or inferior, but rather as simply one way of being human. They also critically examine the systems of discrimination and oppression disabled people face and that is written into our social fabric. By writing untraditionally, disabled people's stories take on new meaning as spaces where authentic disabled voices can be engaged with critically, evoking new ways of thinking about disability. I conclude my thesis by examining notions of disabled embodiment.

I want to take this opportunity to make a very important note about the language used within my thesis. I have chosen to refer to both myself and my disabled peers as “disabled people” not only to highlight the fact that we are disabled by society, but, as Linton writes, because “I identify as a member of the minority group—disabled people—and that is a strong influence on my cultural make-up, who I am, and the way that I think” (118). I use the term as an expression of identification—not oppression—to acknowledge that we are a specific grouping within society. I realize that not every disabled person would choose to describe themselves in this way, but it is my belief that everyone should choose the terms used to describe themselves. My language choice has, in fact, changed within the last four years through my experience as a graduate student. Being a “person with a disability” allowed me to examine what I wanted that

term to mean for me. For example, it allowed me to question my association with disability and what that meant for me personally. I now, however, feel most comfortable establishing myself as disabled because being disabled makes up the biggest part of my identity. I also see this change in language as a political decision I have made to identify myself by my potential flaws rather than by how society would wish to label me as.

In paying particular attention to the language of disability, I also wish my story to pay close attention to the ways language helps to enforce exchanges of power. As Jeanette Robertson and Grant Larson write, “language and terminology have the power to influence and determine the meaning or value placed on people by the terms used to describe them” (2). Most of all, I wish to portray that language is at its most powerful when the author has the freedom to provocatively disturb the social structures in which language is embedded.

Ultimately, what I wish to display through the dissemination of my story is that, as Douglas C. Baynton writes, “Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write” (31). I want to write my disabled history, and have others realize that—whether they are aware of it or not—they are also a part of the history of disability. We all take part in the oppression of others in the words we use, the perceptions we have of others, and the voices we choose to listen to. We have not been trained to challenge ableism or other systems of oppression. But by recognizing these systems at work, we can call them out. We can push the boundaries; we can write our own stories in protest. As Audre Lorde writes, “silence has never brought us anything of worth” (8).

We also need to celebrate and mourn the histories that are to come before and after us. We need to embrace those who choose to write truthfully about disability and ask ourselves where we fit in. We have to grapple with even the most uncomfortable of truths. We have to

realize that encounters with painful truths happen everywhere, both in public and in private, and that we need to recognize their importance. We need to recognize that they can happen even on a gently rocking school bus, in a child first learning the allure and comfort of words on a page, as she begins to see herself.

### **Interlude: Story**

I yearn to hear stories about disability. I seek them out, conducting independent searches like a private investigator looking for a case to sink their teeth into. I hastily find them in obscure literary corners on the internet and snatch them up, anticipation coursing through my veins as I await their arrival in generic cardboard boxes. I tear into them, taking note of their size and cover as we become intimately acquainted. I want these stories to consume me.

For so long, disability has been my personal story. In hearing and reading other disabled people tell their story, I have found the validation I have so long searched for. I have found belonging and a sense of community in their stories that is hard to replicate in social situations. I take solace and comfort in their familiar words, diction, and cadence, recognizing experience and personal knowledge where it meets my own. I wrap myself in their warmth, wishing I could stay within them instead of having to encounter the next person who dismisses disability as nothing but a tragedy. I want to bring these stories out as arsenal, point to a passage, and say to them, “See? See right here? This is my experience that you so easily dismiss—this is my life!”

Through others’ stories of disability, I slowly became acquainted with my own. I began to recognize its edges, the trajectory of its narrative. But what follows is not your average story about disability, or at least the one you are most familiar with. It is not meant to inspire, or scintillate, or make others feel secure in their able-bodiedness. It is not your parents’ story, or your grandparents’ story, or even that of a loving sibling of a disabled person. It is not linear, but

instead dips and dives into the spaces where I became most aware of my disabled existence. It is not an easy read, and it was not easy to write. It may bite at times. But it is not to be underestimated. It was written for a reason.

## Chapter One: Words

“In [...] words, we find the making of the meaning of people” (Titchkosky 3)

This chapter opens with a creative reimagining of how the word “disability” creates and shapes societal conceptions of what it means to live with disability. I then look theoretically at how words surrounding disability are problematic in their consistent negativity and propagate notions of fear and disgust when they are used as a form of oppression. I examine how, with the help of ableist tendencies within society, this oppression gets turned back onto the disabled person in their perception of themselves. I also use excerpts from Madeleine L’Engle’s 1962 children’s literature novel *A Wrinkle in Time* and personal autobiographical reflection throughout this chapter to further demonstrate that language has a direct impact on how we perceive disability and other means of difference and how our perceptions manifest in different situations. Finally, I use Alison Kafer’s re-negotiation of the word “crip” to suggest how words can be strategically reclaimed to enhance political understanding.

### Interlude: Lose the Word

Words are funny things.

If I could change the English language, I would change the word “disability” into a nonsensical sound like “ugh” or “argh.” “Argh” sounds like it would be a pain in the ass some days but wouldn’t pack the punch “disability” has. “Disability” has a story behind it. There is pain, there is hurt, there is confusion. There is tragedy. There is the association with “ability,” which can only lead to the anticipation of its opposite—incapacity, inability, etc. Put “ability” on one end of a spectrum and “disability” on another and I can guarantee that people want to be closer—if not dead on—to “ability” rather than “disability.”

Another good thing with “argh” is that the word doesn’t take itself too seriously. You could almost say it with a smile. But “disability” is a rock in your gut, a bug in your shoe—you might as well be close to tears when you say it. The word is not a happy camper. Any hope that comes with the slight inflection of “dis” is lost by the time you hit “-ity.” The word itself should be followed by a sad face emoticon. The label of disability, after all, shapes our idea of disability. Maybe if we change the word, our social perception of it would change as well.

So what of the people who have this word perpetually tied to their ankles, strapped to their tongue? “Hi, I have a disability, can I talk to you for a minute?” is not a conversation most people want to be a part of. Neither do most people want to be the person referred to in the plea, “Could I bring my disabled friend along?” Just bring up “disability” when making a reservation at a restaurant and people will hang up.

No, “disability” is too sad of a story. The word can stall a conversation, bring people’s eyes to their shoes when there’s a sunny sky outside. It doesn’t take much—“disability” is a hole you stumble upon, a stray rock on the path, an unexpected patch of construction on a rush hour-free highway. You can’t help but notice, but you pretend not to. Five syllables never held so much anxiety and fear.

### **The Problem with Words**

As a child, I noticed there was a problem with words right away: the problem was that the words others used to describe me weren’t any of the words I would use to describe myself. People kept telling me I was these labels that were attached to me, but I either never believed them or the words didn’t stick to the person I knew I really was. For example, in the hospital I was given a diagnosis that was a foreign concept to me. The diagnosis only described my body, not who I am. And yet I have been forced to drag around these words my entire life, a weight

that has never lessened. These words are burdensome and sterile—doctor’s words—and yet whenever anyone meets me these concrete medical terms are the ones they are looking for in order to make sense of my body. These words are attached to me, for better or worse, and yet they do not describe me as a person. They only describe my disability.

What’s most frustrating is that my state of being was based on words I didn’t have a say in choosing myself. A statement like “quadriplegia resulting from meningoencephalitis” was supposed to sum up my entire embodied existence from birth to death. But “quadriplegic” fell flat in my mouth; “meningoencephalitis” sounded perverse, dangerous. These words identified me as in a constant state of being disabled, sick, and broken. But what if I am as a person capable in many ways but my body is not? Which words can portray *that* state of being?

What was concealed from me as a child that I know now for certain is that words are part of the problem. Words are used culturally to distinguish one person from another based on a very primitive understanding of not who they are but by what their body is capable of doing. Anyone who does not live up to social standards of bodily ability has fallen short of a very cruel and prescriptive standard within society. And why? All because of words.

The reality is that in society today, words are used to distinguish one group of people from another. When a person or a group of people is associated with a certain word, a large part of their being becomes tied up in that one word. Again, these words aren’t often chosen by the person themselves but rather by people with the power and authority to project that word onto others, often for the purposes of categorization within a medicalized setting. Tanya Titchkosky writes, “Words on disability are themselves a doing, are themselves a way of knowing” (7). This “way of knowing” a person by the words used to describe them is a pervasive way within able-bodied society of presenting what others think they should know about a disabled person first

while placing secondary importance on what that disabled person would actually choose as terms to describe themselves. Words are also a way of ensuring that the perception of whether a person falls within an acceptable level of normality is prioritized, as if this were the most important thing to know about a person.

Words are used to normalize bodies in order to categorize whole groups of people. Eli Clare writes that, “Depending on the time and place, priests, scientists, freak show managers, philosophers, charity workers, and doctors have all claimed to be the reigning experts on disability” (7). The people Clare identifies here have determined and continue to determine the words used to describe disabled people with little to no input from actual disabled people. These words are specifically chosen to create a sense of distance between societal notions of what constitutes a normal body or mind and the types of bodies disabled people actually inhabit. As well, words retain their power as long as they are used. Through the widespread cultural adoption of ableist terms and the linguistic notion of animacy which Mel Y. Chen defines as “a quality of agency, awareness, mobility, and liveliness” (2), this illusion of distance will continue to exist within the language used to describe us. These words will continue to create misunderstanding, misrepresentations, and even feelings of disgust towards a group of people who have had no choice in the language used to describe them. Finally, they will produce what Sianne Ngai calls “ugly feelings” in disabled people because of the emotions imbued within these words. And yet these words will stick with us our entire lives, even though they say much more about the speakers’ insecurities and fears about their own bodies than the actual feelings disabled people—and not just their bodies—produce.

Clare has explored how words applied to disabled bodies are damaging especially when viewed through the lens of the cultural prioritization of cure. Notions of cure wreak their own



kind of havoc as there is a turning to and wishing for an entirely different kind of body, a wrestling between what is and what could be. Clare notes that “defect” is a word that is often hurled at disabled people as if we are broken and in need of fixing. The words take on an angry quality as they are used to distinguish a certain group of people from another. He writes, “Entire body-minds, communities, cultures are squeezed into *defective*. And then that single blunt concept turns, becoming *defect*. Bullies hurl it as an insult. Strangers ask it out of curiosity. Doctors note it in medical files. Judges and juries hear it in testimony. Scientists study it as truth. Politicians write it into policy. *Defect* and *defective* explode with hate, power, and control” (25).

In order to fully encapsulate the damage and hurt that words can do, one has to examine the relationship between the speaker of these kinds of words and the person they refer to. The power is not balanced in this relationship, as damaging words are often spoken by a person with enough sociopolitical power to believe they are superior to others. Here, the application of the linguistic study of animacy as proposed by Chen is important as “Animacy underlies language and serves in specific ways to inform words and their affective potency” (30). As Chen explains, words used to specifically order animate material enforce a social hierarchy. For example, a perception exists that able-bodied persons are “naturally” more animate as they are able beings; disabled persons, being unable, are believed to be less animated. When animated words are used to describe able-bodied persons and less animated ones are used to describe disabled persons (“disability” being a perfectly adequate example), this hierarchy is maintained and unchallenged. Spoken words that maintain this order are themselves an activating force through which the strength of the hierarchy survives and is passed on through language.

Animated language is just one way language is used politically to demonstrate and shore up uneven power dynamics. Chen writes, “Words more than signify; they affect and effect.

Whether read or heard, they complexly pulse through bodies [...], rendering their effects in feeling and active response” (54). Using ableist terms is a way to ensure words signify and maintain the assumption that one body can and should be able to do the same things every other body can do. Ableism and animated language feed into each other as they both perpetuate notions of a skewed social hierarchy at the expense of disabled people, especially when used to cause verbal hurt or insult: “Linguistic insults vividly demonstrate that language acts to contain and order many kinds of matter [...]; they also show that language users are ‘animate theorists’ insofar as they deploy and rework such orders of matter” (13).

### **Reading Response: *A Wrinkle in Time***

*School. School was all wrong. She'd been dropped down to the lowest section in her grade. That morning one of her teachers had said crossly, “Really, Meg, I don't understand how a child with parents as brilliant as yours are supposed to be can be such a poor student. If you don't manage to do a little better you'll have to stay back next year.”*

*During lunch she'd rough-housed a little to try to make herself feel better, and one of the girls said scornfully, “After all, Meg, we aren't grammar-school kids anymore. Why do you always act like such a baby?”*

*And on the way home from school, walking up the road with her arms full of books, one of the boys had said something about her “dumb baby brother.” At this she'd thrown down the books on the side of the road and tackled him with every ounce of strength she had, and arrived home with her blouse torn and a big bruise under one eye. (L'Engle 7-8)*

Meg Murry doesn't know how great she is, and that's what makes her so endlessly endearing as a protagonist. She thinks she's at the bottom of the social hierarchy, but she doesn't belong there. She's caught up in the stories other people tell about her and her family, so much

so that she starts to believe them as truth and underestimates her worth. She wears these stories like a cloak, convincing herself this is who she really is until she's caught up in them fully and can't escape.

She's constantly comparing herself to others and convinces herself that she's done something wrong. Her mind spins and spins like the hurricane outside her window, dragging her deeper and deeper into paranoia. She thinks that if something in her could be fixed, things would be better. Things would be different; she wouldn't cause others (and herself) so much pain. She's so deep into seeing herself as the problem that she can't comprehend that other people have problems too, because hers seem so much bigger, life-dominating, all-encompassing. She thinks she's the problem because other people tell her she is.

She doesn't know how smart or intuitive she is. She doesn't know that being strong and standing your ground are really hard things to do and should be rewarded instead of punished. She doesn't know that the braces on her teeth make her human. She doesn't know that all her flaws make her into the person she's scared to recognize in the mirror. But she can't see herself because she's too afraid to look.

### **Fear as Oppression**

Sara Ahmed describes the relationships of negotiated power as impressions people make on one another: "*We need to remember the 'press' in an impression.* It allows us to associate the experience of having an emotion with the very affect of one surface upon another, an affect that leaves its mark or trace. So not only do I have an impression of others, but they also leave me with an impression; they impress me, and impress upon me" (6). Typified by Clare's admonitions about the terms defect and defective and insults such as Charles Wallace being referred to as Meg's "dumb baby brother," these power negotiations between an oppressed

person and their oppressor are felt by both parties involved. It is not a meaningless exchange, but one mediated by two persons in two different situations. In one situation, the oppressed person is being actively oppressed by language. In the other situation, the oppressor is using language as a means of oppression to maintain the status quo and a sense of desired social hierarchy.

In other words, part of what is being exchanged between oppressed and oppressor is an element of fear. While fear might seem like an unexpected response, contact with a disabled person can bring up deep, repressed feelings people have about their own bodies. If a disabled person is being called out by an oppressor because their body varies from the norm, then the oppressor is likely to have some insecurities about their own body's vulnerability. Rosemarie Garland-Thomson writes that, "the physically disabled body becomes a repository for social anxieties about such troubling concerns as vulnerability, control, and identity" (6). A disabled body is nothing if not uncontrollable. Whether a disability happens slowly or quickly, the process of becoming disabled is feared because it is ultimately a letting go of control over one's body and life circumstances. When up against this fear, a person's emotional response is as telling as their verbal response.

However, Ahmed is clear to point out that, "the other is only felt to be fearsome through a misreading" (63). Such a misreading happens because of the perceived vulnerability someone projects onto someone with a disability because of the insecurities they might experience if they experienced the same level of vulnerability. A misreading also takes place because of the beliefs an able-bodied person has about their own body. Personal fears and anxieties may manifest themselves in verbal speech including a heavy reliance on well-known clichés, an over-exaggeration of their initial emotional response, or a complete denial of their own insecurities. Often a combination of all three occurs at different intensities. Whatever the case, contact with a

disabled person can result in the verbalizing of an ableist or de-animating response. The important thing to note, however, is that nothing the disabled person does causes this reaction. Rather, it is the perception a person previously holds about a disability that will most often dictate their reaction.

### **Interlude: Drool**

I feel at first as if a mistake has been made, as if I am not supposed to be here. But as I look around me on the school bus that takes all the disabled children to school I realize that I am, for better or worse, one of them. My body is non-conforming like theirs and I sit in a wheelchair. My speech is slurred like theirs too. Our mouths don't work like everybody else's and so sometimes we drool, or our arms or legs shake uncontrollably. I realize that this is what disabled children look like.

Looking around I notice my friend Amy. Amy has beautiful big blue eyes and long wavy blonde hair the colour of straw. She is beautiful. But I wonder, what makes her different from anybody else? What makes *me* different from anybody else? Is it just the fact that we are in wheelchairs, and that we sometimes drool and shake? And if it is because of that, who made up that stupid rule?

I know some people think drool is gross, but I don't. I probably did before I started drooling myself, but now I know that drool is drool. Sometimes it happens. It isn't anything to be grossed out about.

But sometimes people are. When the bus stops to pick up someone else, a mother comes on the bus and points out that a kid's chin is dripping in drool. She sounds disgusted. Am I disgusting when I drool, even if no one sees me doing it, even if I have the ability to wipe it away myself?

Drool isn't disgusting. You just wipe it off, after all. It doesn't leave a stain.

### **Language can Signal Fear**

Language can also produce disgust. Some words associated with disability become directly related to an individual, and therefore what becomes disgusting is not the act the word describes but the person the action refers to. For example, a particularly nefarious word is “retard.” Retarded—once again, a word sprouting from medical lexicon—has been used to refer to a person who is considered slow in body, mind, or both. In recent cultural history, however, the word has been used to describe a whole population of people that are generally considered to be mentally and/or physically slow. These types of words with a damaging history within the medical system have somehow spilled out into the cultural consciousness and are now used as common parlance. As Clare describes, “diagnostic language slips and slides over the decades” (39). Diagnostic language is especially damaging as none of the words’ history have been erased but are used precisely because of their notorious history. I don’t wish to dwell on the complicated circumstances of “retard” becoming a culturally appropriate word to use within daily life; I bring it up as an example of how words have the power within them to demonize a group of people. “Retarded” is a word that emphasizes the distance between one group of people from another because of the fear able-bodied and -minded people associate with possessing a different kind of mind.

### **Reading Response: *A Wrinkle in Time***

*“Don’t worry about Charles Wallace, Meg,” her father had once told her. Meg remembered it very clearly because it was shortly before he went away. “There’s nothing the matter with his mind. He just does things in his own way and in his own time.”*

*“I don’t want him to grow up to be dumb like me,” Meg had said.*

*“Oh my darling, you’re not dumb,” her father answered. “You’re like Charles Wallace. Your development has to go at its own pace. It just doesn’t happen to be the usual pace.”*

*“How do you know?” Meg had demanded. “How do you know I’m not dumb? Isn’t it just because you love me?”*

*“I love you, but that’s not what tells me. Mother and I’ve given you a number of tests, you know.”*

*Yes, that was true. Meg had realized that some of the “games” her parents played with her were tests of some kind, and that there had been more for her and Charles Wallace than for the twins. “IQ tests, you mean?”*

*“Yes, some of them.”*

*“Is my IQ ok?”*

*“More than okay.”*

*“What is it?”*

*“That I’m not going to tell you. But it assures me that both you and Charles Wallace will be able to do pretty much whatever you like when you grow up to yourselves. You just wait till Charles Wallace starts to talk. You’ll see.” (L’Engle 13-14)*

People are afraid of what they do not understand. People do not understand a person who they think has not hit all the normal life markers, and speech is a big one. Babies who do not speak at a normal time or take too long to develop into the tendency are thought to have something wrong with them, something unnatural or abnormal. Charles Wallace is not a normal person, and Meg and her parents know this. But instead of having that be okay—instead of accepting that what’s normal for others might not be normal for all—people have to comment and judge the situation in order for them to feel justified in their normality.

At the same time, the fact that Mr. and Mrs. Murry independently diagnose their children—even if it is as gifted instead of as intellectually disabled—is troublesome as in doing so they succumb to finding an explanation for deviant childhood behaviour. Meg and Charles Wallace’s development could be accepted as is, but instead the Murrays subject them to tests to confirm that, like their parents, they are not only average but exceptional. Tests like these, independent of the circumstances they are used under, have sociopolitical consequences as they rank the perception of what is considered as normal. The Murrays, in their investigation into their children’s above-average intelligence (even if society doesn’t perceive them the same way), live by the same societal presumption that intelligence can be quantified. The contradictions of disability in this passage move against each other but also reveal that disability is a strong measure against which behaviour is culturally ordered and attaches itself to certain bodies, especially during childhood.

### **The Production of Disgust**

The once lauded colonial pastime of the freak show brought to North American popularity by the infamous Barnum brothers is one example of producing and perpetuating notions of fear, disgust, and worse towards one group of people by another. Attendance was virtually guaranteed by the varied and voyeuristic display of exotic bodies and races. People came because of the freedom to gawk at a group of people exploited for their very ability to be gawked at. For freak show attendees didn’t just want to see difference—they wanted to judge it and deem themselves “the most human” based on the perception of their own true humanity. Garland-Thomson writes, “Freaks are above all products of perception: they are the consequence of a comparative relationship in which those who control the social discourse and the means of representation recruit the seeming truth of the body to claim the center for themselves and banish



others to the margins” (62-63). They were disgusted by what they saw, and so much the better: they were able to leave the freak show happier than they came, bolstered by viewing what they were not.

While the performative nature of disgust has paled since the popularity of the freak show, I would like to argue that it is still a prevalent response to disabled persons. While fear is common, disgust takes the response of fear one step further as disgust is, as Sianne Ngai writes, “never ambivalent about its object” (335). In other words, there was no room for ambivalence when attendees at a Barnum brothers show viewed the people on display. They didn’t look to the performers to establish a human connection; they looked to them to obscure it. They weren’t just scared by what they saw. They were terrified by it.

The aesthetic nature of disgust may also reveal why disabled bodies can sometimes produce these reactions. “Aesthetics,” as defined by Tobin Siebers, “is the domain in which the sensation of otherness is felt at its most powerful, strange, and frightening. Whether the effect is beauty and pleasure, ugliness or pain, or sublimity and terror, the emotional impact of one body on another is experienced as an assault on autonomy and a testament to the power of otherness” (25). The aesthetics of an othered body are more likely to produce disgust as opposed to appreciation or even envy. Disabled bodies are not appreciated or envied. They are, instead, a last resort which many people reject outright based on aesthetics alone.

The visceral nature of disgust also produces a comparison between bodies: the disabled body represents a state of vulnerability that is often assumed (or hoped) not to actually exist. Siebers writes, “Taste and disgust are volatile reactions that reveal the ease or disease with which one body might incorporate another. The senses revolt against some bodies, while other bodies please them” (1). If the disabled body is viewed as not being pleasurable—or, what’s more, is

perceived to be defined by pain—then the aesthetic response of disgust might be a logical one for an able-bodied audience. And it might be logical because people often see their self-worth tied up in their bodies and by the pleasure their bodies bring to themselves and others.

While disgust may indeed seem like a particularly harsh emotion to have, I would like to point back to the choice of words able-bodied people employ in order to create distance between themselves and disabled people: Defective. Weak. Cripple. Handicapped. Abnormal. Gimp. Even at a basic linguistic level, these words do not promote inclusion, equity, or community between peoples of diverse bodies and minds. They promote, rather, exclusion, difference, and judgment on them. Whether disgust is involved or not, these words are testaments to the fact that nobody who uses them would wish to have a disabled body as their own. Indeed, the words attached to disabled bodies carry within them potent feelings and judgments about the body. This, in turn, has a direct influence on how disabled people perceive themselves and their value in the world.

**Reading Response: *A Wrinkle in Time***

*Meg knelt at her mother's feet. The warmth and light of the kitchen had relaxed her so that her attic fears were gone. The cocoa steamed fragrantly in the saucepan; geraniums bloomed on the window sills and there was a bouquet of tiny yellow chrysanthemums in the center of the table. The curtains, red, with a blue and green geometrical pattern, were drawn, and seemed to reflect their cheerfulness throughout the room. The furnace purred like a great, sleepy animal; the lights glowed with steady radiance; outside, alone in the dark, the wind still battered against the house, but the angry power that had frightened Meg while she was alone in the attic was subdued by the familiar comfort of the kitchen. Underneath Mrs. Murry's chair Fortinbras let out a contented sigh.*

*Mrs. Murry gently touched Meg's bruised cheek. Meg looked up at her mother, half in loving admiration, half in sullen resentment. It was not an advantage to have a mother who was a scientist and a beauty as well. Mrs. Murry's flaming red hair, creamy skin, and violet eyes with long dark lashes, seemed even more spectacular in comparison with Meg's outrageous plainness. Meg's hair had been passable as long as she wore it tidily in braids. When she went into high school it was cut, and now she and her mother struggled with putting it up, but one side would come out curly and the other straight, so that she looked even plainer than before.*

(L'Engle 16-17)

Encouragement to conform to societal standards of beauty are all around us. Shiny, “taut” bodies honed by the gym and diet medication are envied; big, fleshy bodies with wide hips and thighs are not. They are thought to be “lazy” bodies—couch potatoes—unproductive in their own way. The more a body can do, the more it is worth. If your body can perform and be beautiful, you're in. If not, you might as well not have one. For the body is meant to perform, to be seen, to be commented on.

Meg is, understandably, envious of her mother's beauty. Her own plainness is, in fact, contrasted by her mother's looks as readers wonder whether Meg will make a similar transition. Once again in this passage, ideas about normality and exceptionalism are contrasted to reveal what Meg can become if only she follows her mother's path. The conventional narrative of becoming beautiful in adolescence convinces Meg that if she is not beautiful, she is not worth as much. The feelings one has about one's own body can powerfully shape the perception one has of one's self.

## “Ugly Feelings”

The impact words have on disabled people can create ugly feelings such as disgust, judgment, and a general othering of one group of people by another to create distance. Rather than turning this ugliness onto others, however, it has been my personal experience that the disabled person will turn those feelings inward and onto themselves. It is a doubled response to the resistance we feel against ourselves in the first place: we’re hurt by others’ remarks and attitudes, and yet we can’t deny them. So instead of banishing or rejecting those feelings, we take them in as an ironic means of preservation—for, as in any situation, one needs to build resilience to any kind of persecution in order to not get hurt over and over again. It is a way of telling ourselves, *instead of being hurt by your words, I will add them to the others I’ve heard already and pretend they don’t hurt me anymore*. This, in my experience, is the sad reality in which many oppressed peoples live. In order to preserve our intangible humanity, we guard ourselves against further hurt by accepting that we are already hurting and, before someone else has the chance to hurt us, bracing ourselves for another onslaught of judgment couched in language. It is a constant state of denial and resistance that is set up on an already shaky foundation, and so it fails almost every time.

Ngai’s helpful analysis of these kind of ugly feelings is, on the one hand, a much-needed validation that they occur, and on the other, a call for acknowledgement from others that they are, in fact, real feelings. It is also a call to acknowledge that ugly feelings can and do provide insight into the cultural imagination and that they do not deserve to be ignored based on the argument that only happy—and therefore productive—emotions are worthy of interrogation. Ngai writes about this inverse: “Something about the cultural canon itself seems to prefer higher passions and emotions—as if minor or ugly feelings were not only incapable of producing

‘major’ works, but somehow disabled the works they do drive from acquiring canonical distinction” (11). Note, ironically, the use of “disable” as a verb; it seems that any kind of ugly feeling, in the cultural imagination, devalues those particular emotions at the same time that it devalues why one would feel those emotions in the first place. It is as if, in the very power relationship in which one uses a word to devalue others, their power also comes from a refusal to recognize or acknowledge that their words will cause harm. It is a devaluing of both an individual and their emotional response.

It is also this sense of our emotions not being valid that causes us to feel bad that we are even having them—and so we are, as a result, in a state of arrested agency. However, to Ngai, it is the very having of emotions that is important:

My exclusive focus [...] is on the negative affects that read the predicaments proposed by a general state of obstructed agency with respect to other human actors or to the social as such—a dilemma I take as charged with political meanings *regardless of whether the obstruction is actual or fantasized*, or whether the agency obstructed is individual or collective.... The evidence here would suggest that the very effort of thinking the aesthetic and political together [...] is a prime occasion for ugly feelings. (3; emphasis added)

If these ugly feelings are indeed happening and are indeed valid, then surely the state that causes them to be felt is valid as well, even if the person or persons causing them may think otherwise. Recently, bullying has been acknowledged as a significant form of abuse and a significant factor in the rapid de-escalation of a person’s self-worth. Homophobia, xenophobia, misogyny—all inform the worst kinds of bullying, and yet we still see examples of this in our daily lives. A concept that hasn’t been as widely accepted—and yet one that, I would argue, is just as

important—is ableism. Ableism is alive and well in society. The words spoken to us are an ableist response to the world in which we live. And yet, the fact that these words are said to us, and the fact that we feel badly about them, are not widely called out often enough to condemn ableism as a harmful problem within society. It is a hard state to prove that you are actively oppressed by ableism when that oppression isn't as obviously recognized as other forms of oppression (racism, sexism, homophobia) are.

### **Interlude: Encounters with Strangers**

I was not bullied in school. I was generally liked, as a matter of fact, especially in elementary school. High school was a different story, but I was still not bullied. This strikes me as curious every once in a while. Why, being so different, was I not “called out” for it, like so many other people who are minorities are in adolescence? And because I wasn't bullied, does that mean that my difference was accepted by others? Or did people just not want to hurt my feelings for whatever reason? If I hadn't grown up going to a predominately white and affluent school, would I have been bullied more?

These questions leave my head spinning sometimes, wondering about the intersectionalities of oppression and why I did not face outright bullying. Did it have something to do with my being female, and therefore seeming fragile? I may have an answer, or at least a partial one: bullying and overt oppression does not always take place in verbal form. Sometimes a lot more rides on what is not said. Silence is also a form of oppression.

In other words, it was by what was not said aloud that I felt ostracized growing up and throughout adolescence. No one came up to me and said “you're broken” or “you're disabled and therefore worth less than me,” but they didn't have to. People's actions, or oftentimes their inactions, spoke more to me about what they thought of me. They didn't have to say anything.

We all grow up in an ableist society, and so I already knew what they thought of me. I could catch them staring or whispering, or worst of all, I could imagine what they weren't saying. By not approaching me, by not inviting me over—this said as much as their words ever could.

I have two examples of when people actually did say something. But it wasn't what they said that was important. It was in what they didn't say, but assumed.

My best friend is also in a wheelchair. We were in a coffee shop one day when it became obvious that we had an audience. A woman came up to us and said, "I just had to come over here and tell you how pretty you are. It's just so sad you're disabled." This woman wasn't outwardly aggressive towards us. She wasn't angry or scared, only confused. In her mind, prettiness and disability weren't possible. You either have to be one or the other. She thought she had paid us a compliment, in fact. She thought by acknowledging our outside appearance, and by validating it, she could justify nullifying our disability. She actively placed more importance on one part of our existence than another. She thought that since we were disabled, which is not a valid existence, at least we were pretty. This could *possibly* validate our existence. But being disabled and pretty wasn't of much use to anyone.

Around the same time, I was in Shoppers Drug Mart when I was approached by two people who asked if they could pray for me. I immediately knew what they were up to. My body was a problem to them. Why would someone want to be in a wheelchair? To them, I needed to be cured. I needed their hands on me to pray out everything that was wrong with me, so I could know the all-encompassing pleasure of walking. Perhaps I was feeling extra charitable towards these people, who I knew had a skewed picture of me but they didn't know it yet, and so I said yes. Maybe I wanted to give them the benefit of the doubt. Whatever the reason, I thought it couldn't hurt. I'm not anything except a nice disabled person, after all.

I said something about “being fine with being in a wheelchair.” In other words, I didn’t need prayer for *that*. I should’ve known they wouldn’t listen.

After my body was prayed over—everything they actually said was a blur—I politely excused myself. But I felt betrayed in a way. Didn’t I know, their words said, that what I needed prayer for the most was my brokenness? It wasn’t even spiritual or emotional strength, but physical strength. I needed to be able to walk, to be normal. To them, being able to walk was the only way they knew of being a normal human.

Even if I wasn’t bullied, I got the message that I wasn’t like everybody else. The only thing that possibly redeemed me were my looks, but to be truly pretty I would have to not be disabled. In both these circumstances, I wasn’t threatened by these people. I didn’t think they hated me—they might’ve even liked me. They just knew better than me. And they wanted me to know it.

### **Reclaiming Words**

To paraphrase Titchkosky, words attach meanings to bodies. Perhaps it is the perceived vulnerability of disabled bodies that makes words so easy to attach to them, or maybe it is because words reveal the fear that exists within an able-bodied person of becoming disabled. Whatever the case, the cultural realities of both ableism and animated language only reinforce and maintain the social hierarchies which exist in society today. These hierarchies are used to oppress, shame, and belittle disabled people. All because of words.

Because of language’s potency, the ugly feelings infused into hurtful words are then instilled within the disabled person themselves. It is hard, after all, to separate the words used to describe one’s disability from the words one would use to describe one’s self. Damaging words



rub off onto the person they are meant to damage. Ugly feelings can quickly turn into a belief about one's self.

Disabled people are meant to enforce the social hierarchy as much as anyone else, and it is only in our response to these words that they hold power. It is at the level of words that one has to cut off the signifying power with which words are imbued and then distributed into cultural life and imagination. It is at the level of words that a change needs to be made.

Alison Kafer has started this conversation: "Claiming crip," she writes, "[...] can be a way of acknowledging that we all have bodies and minds with shifting abilities, and [that we can continue the process of] wrestling with the political meanings and histories of such shifts" (13). "Cripple" is a word that has historically labelled disabled people. It has also been a way to label the disabled community as it also cripples the people that care for us. Like the word "queer," "cripple" has been used historically to oppress the very people the word is meant to describe. What Kafer argues for in the process of "claiming crip" is to incorporate that damaging history into and throughout the acceptance of disability as another normal way of being. It is a call to respond to oppression by not cowering or turning away from it but, rather, to accept and challenge it, turning it into a political response. Claiming crip can be a way to lift the experience of disability out of its tragic, non-normalizing existence into an all-encompassing experience that is confrontational and political. It is a position that is fed up and pissed off with the oppression disabled people have faced and continue to face through the propagation of hurtful words and labels that only generate fear and misunderstanding. Claiming crip is a way to demand a politics of supporting disabled persons instead of wishing their bodies and minds could be changed through cure. To end with Kafer: "[Using the term crip] to make people wince suggests an urge to shake things up, to jolt people out of their everyday understandings of bodies and minds, of

normalcy and deviance” (15). If we can jolt people awake, maybe we can get them to realize that we aren’t going anywhere.

## Chapter Two: Agency

“One can transform a place by reading in it.” (Manguel 152)

This chapter opens with an introduction to how the world of the accessible school bus I inhabited each day shaped my perception of myself as a disabled child. I then theoretically explore the narratives surrounding disabled children as passive and complacent and my yearning to change them to ones of agency and defiance. I rely on Alberto Manguel’s *A History of Reading*—which Manguel describes as “the history of the act of reading . . . . Ultimately, perhaps, the history of reading is the history of each of its readers” (22)—to situate myself as a conscientious and observant reader. This identification as a reader allowed me to develop my personal sense of agency and power over the physical space of the school bus which demanded a relinquishing of that same power. Reading also allowed me to challenge interpretations of preconceived conceptions of disability and difference I was taking from both the texts I was reading and the reality I was living. I use excerpts from E.B. White’s 1952 children’s literature novel *Charlotte’s Web* and personal autobiographical reflection throughout the chapter to demonstrate that being a reader allowed me to identify with characters within literature who experienced agency and power that I lacked in reality. Finally, I examine how literature provided the mirror through which I could perceive my wants and needs most accurately reflected back at me.

### **Interlude: Learning the Rules**

I had a love-hate relationship with the school bus that picked me up each weekday morning and took me to elementary school. While I tended to like the soft-spoken man driving the bus, I detested the extra “teacher’s aide” (as we called them in the ’90s) who was all too

quick to jump when any of the children under her care dropped something, coughed, or generally looked askance in her direction. The bus was the first time I learned that people felt most comfortable when disabled people were monitored. With this inconvenient knowledge I also came to realize that, at the age of five when I spent two months in the hospital and came out in a wheelchair, I had been adopted into this community—the disabled community—and that this was the treatment disabled people were usually given. Not only that, I was also especially susceptible to monitoring as a disabled child as I quickly became aware that there were certain rules I was expected to follow. These rules included eating in a different room from everybody else and going to physical therapy instead of physical education because the regular gym class was held in the basement at school. The biggest surprise to me was that I had needs different from my able-bodied friends, and that these needs were apparently special. They included being picked up by the school bus each day and monitored while you sat there, bored out of your mind.

I don't know when I first made the decision to bring a book as my companion. I tried a Barbie Doll first, even though I had, for the most part, grown out of dolls. But my friend, Amy, brought one on the bus and so I tried it, thinking that was what a disabled child did on the bus. I didn't take to it, or at least it didn't take to me. I was still bored. Also, when I played, I knew I was being watched by the TA, and that creeped me out. I wanted to play in peace, just like any other kid.

### **Choosing Another Narrative**

Whatever agency I had seemed to wane and thin after I became disabled. I accepted my lot without much complaint. I didn't know I was supposed to wail at the emotional pain of it all: as James Overboe writes, "For the most part, the diseased, the disabled, or the traumatized are expected to undergo some form of rehabilitation in order to achieve normality. If normality

cannot be achieved, then they must ‘make sense’ of their lives in order to find underlying meaning for, or purpose to, their tragic existence” (275). On the bus, where I was given no alternative but to accept that I was indeed disabled, I had virtually no interest in getting my normality back. Just figuring out how to be disabled was enough to keep me occupied at the time.

On the bus, for example, I realized I had no choice over how I wanted to be seen by others. I had no narratives to cloak myself with—to preserve my human-ness—other than the “disabled as broken” narratives Overboe alludes to. The normative narratives of agency, power, and defiance were taken away because of my tragic existence and replaced with ones associated with passivity, weakness, and complacency. By becoming a reader and opening myself up to narratives I could see myself within, I was able to reject the ones predetermined for me and reclaim the ones I wanted for myself.

In the predetermined narrative of a disabled life, my disability became *a thing* other people feared. My disability represented a tragic story of loss: something had been taken away from myself, from my family, and from those who knew me best. I had no idea this was happening, of course; I was just living my life. I found being monitored a nuisance, but in actuality it was fear that fueled that decision; *I* was feared. My body, unbeknownst to me, was a signifier of what the majority of people *did not want to have happen to them*.

I was forced into a tragic—and therefore passive—role and unfortunately had no choice but to adopt it for myself instead of replacing it with another. My body was swathed in loss, having been stained by the past and what had once been. I wasn’t a whole person; my body was cut in two: a nostalgic *before* body and an incomplete *after* one. Alison Kafer has renegotiated this sense of “selves,” putting them in a cultural context: “fears of disability [...] are often bound

up in a kind of *compulsory nostalgia* for the lost able mind/body, .... with a cultural expectation that the relation between these selves [the lost and present] is always one of loss, and of loss that moves in only one direction” (42-43). By being placed in a situation where my body was only allowed to be viewed by a certain group of people and not by wider society, my body and my self became two separate things over which I had little control. If I had any agency at all in my *after* body, few people—if any—could see it. I was having trouble seeing it myself.

**Reading Response: *Charlotte’s Web***

*“Where’s Papa going with that ax?” said Fern to her mother as they were setting the table for breakfast.*

*“Out to the hoghouse,” replied Mrs. Arable. “Some pigs were born last night.”*

*“I don’t see why he needs an ax,” continued Fern, who was only eight.*

*“Well,” said her mother, “one of the pigs is a runt. It’s very small and weak, and it will never amount to anything. So your father has decided to do away with it.”*

*“Do away with it?” shrieked Fern. “You mean kill it? Just because it’s smaller than the others?”*

*Mrs. Arable put a pitcher of cream on the table. “Don’t yell, Fern!” she said. “Your father is right. The pig would probably die anyway.”*

*Fern pushed a chair out of the way and ran outdoors. The grass was wet and the earth smelled of springtime. Fern’s sneakers were sopping by the time she caught up with her father.*

(White 1)

Fern Arable was my first exposure to active narration; I was drawn to her immediately. I liked her because she asked questions that made people uncomfortable, and yet she asked them anyway. She didn’t censor herself for the sake of others. Her personal sense of justice was more

important to her than the possible consequence of a reprimand. I was always scared of being reprimanded, of being told that this was just the way things were and nothing I could ever do would change that. Fern, however, didn't care what other people thought. She knew she would be challenged, and yet that didn't stop her. She stood up for herself and what she knew to be true.

### **Discovering Agency**

Whether I eventually chose to read because of a latent agency within myself, I cannot say for sure. Because I did it, though, suggests that I refused to just “sit there” on the bus and fulfill my role as the tragic and passive disabled child with no choice but to be (and act) disabled. Expectations placed upon me as a disabled child did not require me to “do” anything at all on the bus. But I wasn't comfortable with this—I wanted to do something, to be active. My dislike of being monitored, too, shows that I (unconsciously) rejected that particular “special need” to be watched just in case something should happen, that I should require anything from medical attention to an item being picked up. These assumed needs distorted the image of myself that I wanted to have: that I could be responsible for my own body in how I behaved and in what I chose to do. Being monitored stripped me of the confidence I needed in order to be comfortable with who I was and how I chose to handle my time. Surveillance made me think I needed approval, and that I was unable to approve my own choices. The prescription of “just in case” didn't match with the self I saw myself as—I wanted to be the sole person responsible for my own body.

And so, whether or not I felt its full force, I did at least have some agency within me. The act of bringing a book with me, even as an initial refusal of boredom, shows that I was actively looking for a solution that did not fit the predetermined narrative I was supposed to accept. This decision ended up having unanticipated consequences. Alberto Manguel describes reading as an

act of direct agency: “What took place, took place in the book, and I was the story’s teller. Life happened because I turned the pages” (150-151). Everything that had happened to me previously—becoming disabled, being sent to school on the bus, and being viewed negatively—was something I had no control over; in reading, I finally did. I chose to wield that power by coming back to books and literature again and again. It wasn’t an act I performed half-heartedly, either: “Reading, then,” Manguel writes, “is not an automatic process of capturing a text in the way photosensitive paper captures light, but a bewildering, labyrinthine, common and yet personal process of reconstruction” (39).

The reconstruction of my narrative, I am now sure, is what initially hooked me on literature. After all, I already knew that I was not a fan of the real world I inhabited when I read: the world of the school bus, that is. I did not like being segregated from my able-bodied friends. I did not like being monitored. What’s more, I did not like being complacent in how I spent my time. I did have disabled friends on the bus, but they did not read as I did. It was just not for me, the “sitting there”-ness the school bus offered.

For, even if I did not have the tools and resources available to me to change anything about it at the time, I recognized that the world of the bus was inherently wrong—and not just for me, but for my friends as well. We should not have been segregated from our able-bodied classmates. We should not have been monitored because of the perception of us as vulnerable individuals, as requiring extra care and surveillance. Finally, we should have been given the option of choice.

Without being completely aware of what was happening at the time, I was actively engaged in two worlds: the world of the bus, which I did not like, and the world of literature and books, which I did. Manguel teases out the important juxtaposition between the place of reading



and the place of the page, writing that, “both share the same hermeneutic quality, both tempting the reader with the challenge of elucidation” (166). In other words, I wanted to “figure out” the two places I inhabited. I was reading my world as if it were text; I was challenging its interpretation.

**Reading Response: *Charlotte’s Web***

*“Please don’t kill it,” she sobbed. “It’s unfair.”*

*Mr. Arable stopped walking.*

*“Fern,” he said gently, “you will have to learn to control yourself.”*

*“Control myself?” yelled Fern. “This is a matter of life and death, and you talk about controlling myself.”*

*Tears ran down her cheeks and she took hold of the ax and tried to pull it out of her father’s hand.*

*“Fern,” said Mr. Arable, “I know more about raising a litter of pigs than you do. A weakling makes trouble. Now run along!”*

*“But it’s unfair,” cried Fern. “The pig couldn’t help being born small, could it? If I had been very small at birth, would you have killed me?”*

*Mr. Arable smiled. “Certainly not,” he said, looking down at his daughter with love.*

*“But this is different. A little girl is one thing, a little runty pig is another.”*

*“I see no difference,” replied Fern, still hanging on to the ax. “This is the most terrible case of injustice I ever heard of.” (White 2-3)*

Not so long ago, a similar justification of euthanasia was used against disabled people. They were assumed to be weak, to need “extra” care, and to be unable to develop as quickly or fully as others, especially if they were disabled at birth. Fern questions this logic, and in doing so

grotesquely juxtaposes the treatment of livestock to an (able-bodied) child. As hurriedly as Mr. Arable replies, readers are left to wonder at the possibilities of *what if*—indeed, the disabled body largely constitutes a gaping *what if* statement that is largely glossed over in Mr. Arable’s reply. His admonition for Fern to control herself also signals that a certain “reining in” of emotions is most appropriate. As readers, we are left with the impression that a logical response is preferable to an emotional one and that Fern’s emotionality is uncontrollable and dangerous.

### **Looking for an Alternative**

In the same way that I read Fern as capable and intelligent, I was being read as the opposite: as a disabled child. Tanya Titchkosky explains, “Disability is made viable as a metaphor to express only that which is unwanted and that which is devastatingly inept” (5). I did not want to be “read” the way Titchkosky suggests; the bus ensured, however, that I was. I secretly held the opinion that neither I nor anybody else on that bus deserved to be read that way in the first place, but as far as I could see we weren’t given a choice in the matter.

I wanted an alternative. I did not want to accept that narrative as predetermined. I did not want to have that reality continue for me in the future. Kafer writes that, “How one understands disability in the present determines how one imagines disability in the future; one’s assumptions about the experience of disability creates one’s conception of a better future” (2). I wanted disability, and by extension myself, to be read differently because I wanted a better future than the one being on the bus signaled. Titchkosky’s observations about the configuration of disability suggest that I was expected to be satisfied with what I was given. Sitting on the bus enabled me to imagine a future where this would not be my reality, where I did not have to comply with such low expectations of myself and other disabled people. Books provided the portal through which I

could imagine a future where I didn't conform to the social rules governing the bus and, by extension, the rules governing life outside its bright yellow walls.

### **Interlude: Reading as Knowledge**

I come from a long line of readers. My Grandma Joyce, even as her eyes failed her in her old age, read vociferously. At our family cabin, she would sit in her chair in the corner where all the action was and everybody could see her, lamp perpetually on and never without a book close by. Even if she fell asleep—which she did often—that light was still on, a book collapsed towards her as if in protection.

My mom once told me that Grandma Joyce would read after a long day caring for her six young children, the house a mess and her husband just home from work. “How was your day?” he would ask. “It’s better now,” she would reply without looking up from the page.

Similarly, I have a vision of my mom curled up in a chair like a cat, feet propped under her, with a book in her lap and tea in hand. She always read in the living room, the sun shining in from the bay windows. I envied that she had all this knowledge from reading stored inside her. I wanted that knowledge stored deep down inside of me, too.

I don't see this as a coincidence.

### **Accessible Futures**

As a disabled child, I didn't feel at all powerful. The opposite, in fact: I felt power consistently being taken away from me, and I became silent. I lived under the popular assumption that, as Ato Quayson writes, “disability [is] an individual affliction to be borne silently by the [disabled] person” (3). I also realize now that silence is, of course, the “natural” reaction to any kind of oppression; as Audre Lorde writes, “In the cause of silence, each one of us draws the face of her own fear—fear of contempt, of censure, or some judgment, or

recognition, of challenge, of annihilation. But most of all [...] we fear the very visibility without which we also cannot truly live” (19-20). In many ways, my silence was borne out of the fear of not knowing what to do and feeling incapable of doing it even if I knew what it was.

But in another way, I was waiting for something, too, which, if not empowering or powerful, is at least not complacency. I yearned for another existence, and yet I didn’t even have the words to express what that existence might be. I now see that I was striving for my version of the “more accessible futures” which Kafer describes as “thinking through how to get to an ‘elsewhere,’ to other ways of being that might be more just and sustainable.... I am yearning for an elsewhere—and, perhaps, an ‘elsewhen’—in which disability is understood otherwise: as political, as valuable, as integral” (3). My yearning was to make my existence meaningful. On the bus, I didn’t feel meaningful; I felt lost, unmoored, temperamental, powerless.

Whether or not I realized it, I did have a decision to make: I could accept the lowered expectations as they were laid out in the physical space of the school bus—being monitored, bored, and complacent—or choose another way. I didn’t know what that other way was, or could be, at first. At some point, I decided to read. For, I realized, the space of the bus wasn’t just physical but cultural as well: if I could decide how I wanted to be viewed on the bus, then my hope was that I could choose how to be viewed outside of it as well.

Manguel observes, “However readers make a book theirs, the end is that book and reader become one.... [I]nvisibly, unconsciously, text and reader become intertwined, creating new levels of meaning, so that every time we cause the text to yield something by ingesting it, simultaneously something else is born beneath it that we haven’t yet grasped” (173). Reading gave me an active presence. As I became one with what I read, I revealed a power I was unaware

of: I was making meaning within myself, not as I was on the bus, but in who I chose to see myself as.

**Reading Response: *Charlotte's Web***

*She closed the carton carefully. First she kissed her father, then she kissed her mother. Then she opened the lid again, lifted the pig out, and held it against her cheek. At this moment her brother Avery came into the room. Avery was ten. He was heavily armed—an air rifle in one hand, a wooden dagger in the other.*

*“What’s that?” he demanded. “What’s Fern got?”*

*“She’s got a guest for breakfast,” said Mrs. Arable. “Wash your hands and face, Avery!”*

*“Let’s see it!” said Avery, setting his gun down. “You call that miserable thing a pig? That’s a fine specimen of a pig—it’s no bigger than a white rat.”*

*“Wash up and eat your breakfast, Avery!” said his mother. “The school bus will be along in half an hour.”*

*“Can I have a pig too, Pop?” asked Avery.*

*“No, I only distribute pigs to early risers,” said Mr. Arable. “Fern was up at daylight, trying to rid the world of injustice. As a result, she now has a pig. A small one, to be sure, but nevertheless a pig. It just shows what can happen if a person gets out of bed promptly. Let’s eat!” (White 4-5)*

Fern won her battle. Rather than conforming to the expectations placed upon her as a girl child—similar to the ones expected of me on the bus—Fern broke out of her own narrative. She saw injustice in her world, and she strove to do something about it. She *demand*ed her father do something about it, to change the way he normally did things. Deep down, I wanted to do the

same thing—to demand my right to be my own person—I just didn’t know how to go about doing it.

### **Recognition of Self through Reading**

With little idea of what I was actually doing, I was choosing to live my life—as *I* saw it—through text. Manguel describes this process: “To say that an author is a reader or a reader an author, to see a book as a human being or a human being as a book, *to describe the world as text or a text as the world*, are ways of naming the reader’s craft” (168, emphasis added). I perceived myself as having no agency or power in my reality, but Fern Arable had these in spades; and so as I immersed myself in the world of *Charlotte’s Web*, I identified with Fern and her unwavering sense of justice. Since the world I saw myself in I perceived as unjust, I chose to ally myself with the world as written by E.B. White in 1952 instead.

This world appealed to me in many ways. Most importantly, I was “reading” (and analyzing) relationships between the Arables where characters’ sense of meaning or being changed according to their actions *and was not predetermined by their perceived status or cultural importance*. In other words, Fern was a child, and was seen as such by her parents and brother. But once she demanded to be seen differently, they had no choice but to grant her wish, as “inappropriate” as it may have originally seemed.

Manguel writes that, “the act of reading serves as a metaphor to help us understand our hesitant relationship with our body, the encounter and the touch and the deciphering of signs in another person” (169). My relationship with my body was strained and deeply complicated because it was implied that my body had betrayed me in some way. More than that, no one seemed to want my kind of body as their own and, in fact, I was segregated from others because of it. The relationship I had with my body as a child was confusing and frustrating and would

take years for me to become comfortable and satisfied with—it would take even longer to love it. I could no more identify the feelings towards my body at that time than say what I wanted from it. Reading and identifying with Fern, then, whose body was, at least, “acceptable,” enabled me to forget for a moment the complications and assumptions my own body carried.

The world of *Charlotte’s Web* suggested that there was a choice in the world, and that I didn’t have to live by the narrative predetermined for me. Realizing this helped me to re-capture the power I assumed had been taken away from me. I came from a line of readers, and I would choose to read books that presented a choice rather than the unfairness and chaos of the world that I, and my mother and grandmother, had been born into. I could attempt to bring those meanings I was making through literature into my own life.

If I did have a choice between the world of the school bus and the “accessible futures” (borrowing from Kafer) that I yearned for, I had little idea of how to bring those futures into my reality. I yearned to see myself as productive, as important and vital, but most of all as being able to change reality through questioning it as Fern did. But I had no tools to disrupt the narrative I was living out on the bus. I was trapped, ironically, because of narrative’s ability to entrap us within its hold, as Audre Lorde describes: “we share a commitment to language and to the power of language, and to the reclaiming of that language which has been made to work against us” (20-21). By reading, I slowly learned to use that power to my own advantage.

### **Interlude: Reading as Performance**

Why did I read on the bus? Here’s why: unbeknownst to me, my reading was a performance. I read to break myself out of the chains of what a disabled child was capable of. I read because I wanted to appear to do *something*, I just didn’t know what, at first. And so I read.

I wanted out of my head.

We had to fill out book reports. I would bring these onto the bus with me to fill out. Of course—as I was also just learning acceptable penmanship—my writing was slanted, sloppy, and virtually unreadable as the bus lurched and growled towards school. I don't know why I did this particular act, but I remember how it was commented on. It even made some people laugh. “How will anyone be able to read what you wrote?”

Maybe I didn't want them to. Maybe they were my secrets.

### **Learning Defiance**

I was reading the two places I inhabited at the same time. As much as I realized that on the bus I was not expected to do much, I did something anyway. I read to be different. I read to entertain myself, to be entertained by something. I read to stave off boredom. But also, I read precisely *because* I knew it was not expected of me. I read as an act of defiance.

Manguel writes that, “While [...] the readings of a text are not infinite—they are circumscribed by conventions of grammar, and the limits imposed by common sense—they are not strictly dictated by the text itself” (183). I imbued my own experiences, frustrations, and lived realities into the text itself, creating my own re-writing and interpretation of it. My defiance of the lived reality of the school bus actively changed the way I read text by turning reading into a political decision. Through reading, I was able to see myself more clearly as my wants, needs, and desires were reflected back at me and filtered through the literature I chose to read. I wanted this to be the image myself and others had of me rather than the image of the static disabled child governed by the similar social systems that existed on the bus to school and beyond it.

What I did not find in my world on the bus, I searched for within literature. In this way, the two “readings” produced—the actual reading and the one I re-created—not only juxtaposed



the other but imbued each other with meaning. Manguel addresses this directly when he writes about two particular ways of reading by a segregated group:

In the first, the readers, like imaginative archaeologists, burrow their way through the official literature in order to rescue from between the lines the presence of their fellow outcasts, to find mirrors for themselves.... In the second, the readers become writers, inventing for themselves new ways of telling stories in order to redeem on the page the everyday chronicles of their excluded lives.... (233)

In this configuration, Fern's story tied into mine and vice versa. I so wanted to see myself in her that the mirror of her own defiance reflected the defiance I wished I could enact in my own world. But I didn't have to drastically change any social systems at the moment, even if I knew how: just by reading, I was defying my own narrative. The constraints of being tainted by tragedy and low expectations were slowly becoming looser and looser with each page I read. I was making futures happen, even if they were not yet my own.

### **Desirable Futures**

Disabled futures are both unimaginable and undesired by most people, while desired futures are absent of any trace disability. Kafer writes that that the futures of disabled people are harmfully tainted by their desired absence:

If disability is conceptualized as a terrible unending tragedy, then any future that includes disability can only be a future to avoid. A better future, in other words, is one that excludes disability and disabled bodies; indeed, it is the very *absence* of disability that signals this better future. The *presence* of disability, then, signals something else: a future that bears too many traces of the ills of the present to be desirable. (2)

In Kafer's configuration, then, my body represents this "ill" present. In this light, my move from the world of the school bus to one in books is understandable. My body represented what people did not want to have happen to themselves. If bodies like mine continued to exist into the future, then it was inevitable that others' bodies *would* become like mine. This deep tension radiating from my own body prompted my decision to swap worlds for one where my body wasn't an issue anymore, one where it didn't cause distrust and fear in other people.

The world of literature, and specifically *Charlotte's Web*, represented an alternative world where disabled bodies *could be* desirable: as Kafer writes, "We lack such futures in this present.... There is no recognition that one could desire disability, no move to imagine what such desire could look like" (45). In moving to a world of literature governed by different rules than those that existed in my reality, I was hoping to find bodies like mine and, what's more, ones that were desired. Even if no body exactly like mine was depicted in *Charlotte's Web*, the important thing was that I was *reading myself in Fern's actions, narratives, and choices*. I had found a place where my own thoughts were reflected. If my choice was between this world or the world that the school bus represented, it's no surprise that I chose the former.

For, in many ways, the bus provided the manifestation of a disabled non-future: if nothing was ever expected of us, if we kept having things done for us without our consultation but believed to be done for our own good, if we were kept separate and segregated from our nondisabled peers, family, and friends. The physical space of the school bus became, for me, not only a cultural space epitomizing others' perceptions of me but a political one as well. It became political in that in it I re-imagined the literary spaces I inhabited as ones that provided many futures—and most importantly, futures that were desirable.

## Searching for Disability

Kafer has asked, “Where do we find disability and where do we miss it?” (149). I am suggesting here that disability and its likeness, for me, was found in literature. The process of recognizing it took time and clarity, and I do not believe that the very first time I picked up *Charlotte’s Web* I immediately identified with Fern and saw my internal struggle with agency reflected in her. However, I did start reading at a very formative part of my life, which I was also likely not aware of at the time. I possessed little to no actual agency within my life once I became disabled. Once I entered the world of the school bus, I did not like it but I didn’t see myself as having any power to change it. I was bored, but I didn’t have a choice in the matter; I acted as I thought a disabled child was supposed to. I was complacent, with no complaints except internal ones. I thought I was trapped within the grips of this world forever, forced to see my body as others chose to see it.

Aided by my mother’s and grandmother’s choices, however, I was lured into literature as another option. There, I found a part of myself reflected and written back to me. There, my body didn’t matter so much because I could relate to others’ lives without having to differentiate my body from theirs. I found defiance in characters like Fern and I wanted that sense of agency for myself. I wanted the choice to have a story like hers, to not only question and comment on the world but to have a chance to mold and shape it.

## Reclamation

Reclaiming the future I wanted for myself, and seeing myself *in* that future, started with reading. The decisions—or lack of decisions—that brought me to this point were based on me becoming a disabled child. The complacency which I loathed for myself but which I did not see as having an alternative to was the very situation that allowed me to discover literary worlds. I

existed, however, in the world of the school bus, which was a social world of its own: there were rules about how I conducted myself and, by the very situation of being on the school bus, rules which governed my necessity to be there. These rules dictated that I did not have a choice in the present or the future. My body was a threat of sorts to those who viewed it, and so I was kept with others who had bodies similar to myself. Of course, as it turns out, it was never our bodies that were important in the first place, but what they represented; as Tobin Siebers writes, “Medicine and charity, not social justice, are the answers to the problems of the disabled body, because the disabled body is thought to be the real cause of the problems” (25).

Even this I did not see as something I could change on my own. I saw the error in it, but I did not know how to correct it. I was experiencing an intense feeling of incapability—a feeling that never leaves me, even now—but as Audre Lorde reminds us, “The enormity of our task, to turn the world around.... I must be content to see how really little I can do and still do it with an open heart” (10). Eventually, I turned away from my reality and instead immersed myself within the world of literature. There, I found portions of my reality mirrored back at me in ways where I could see myself more clearly where I was not a tragic figure, but possessed agency, power, and defiance. The predetermined rules that existed for me in reality were, now, not enforced upon me. My body did not dictate who I could and couldn’t spend time with anymore; I was not governed by social expectations of who I was and what I could do. I got to make up the rules as I went along; I was free from a narrative that I did not want for myself or anyone else. I had freed myself by reading defiantly.

### Chapter Three: Voice

“[T]he woman [writes] her own life in advance of living it, unconsciously, and without recognizing or naming the process.” (Heilburn 11)

This chapter opens with an exploration of the physical and social spaces I encounter as a disabled woman, and how these spaces shape narratives of disability. I turn to recent examples of the overcoming narrative of disability in mainstream media which highlights the idea of disability as loss in order to portray that disability is only useful when it is being overcome or triumphed over. I then contrast these configurations of disability with untraditional narratives written by disabled writers—Georgina Kleege, Harilyn Roussu, Heather Kuttai, and Simi Linton—that depict and accept failure in order to explore and contend with disability as a political identity. I also examine how mediums like graphic novels, poetry, and video by artists Ellen Forney, Vassar Miller, and Maysoon Zayid can refigure depictions of disability in innovative ways. I use excerpts from Louisa May Alcott’s 1868 children’s literature novel *Little Women* and personal autobiographical reflection throughout the chapter to demonstrate that reconfiguring preconceived notions of disability and identity are essential to shifting cultural conversations. Finally, I reflect on the case of Tracy Latimer who was murdered in 1993 by her father to further demonstrate that narratives of disability are negotiated throughout culture based on the physical and social spaces one is allowed to exist within.

#### Physical and Social Space

As a disabled woman, I have had to learn to fit my body into the spaces I encounter. This has not come naturally as a process and has been a slow—but necessary—evolution. I have also learnt over time that the spaces I encounter most regularly have contributed to the way others see

me. This includes the schools I went to, the jobs I have had, the houses I have lived in, and the places I search out to feel the most comfortable: coffee shops, bookstores, restaurants, theatres. My level of familiarity with these places is fraught with complexity as the most important—indeed, the deciding factor—of whether I frequent these spaces is the accessibility and inclusivity which they provide. For most of my life, if a space wasn't accessible in a wheelchair, I couldn't inhabit it. A surprising number of spaces are, thus, off limits to me. I imagine that in the average North American city a mere two-thirds to one half of spaces are literally inaccessible to the disabled population—or at least to those of us who require no stairs, first-floor access, and/or a ramp. This is not acceptable in 2018, but the reality is that physical accessibility is only the starting point. If there are two-thirds to one half of spaces in my city that I can enter, half of these are still not spaces I would choose to inhabit.

Part of this has to do with further requirements for full physical access such as a big enough washroom and doorways wide enough to manoeuvre a wheelchair through. But other aspects of a space are much more personal and differ from person to person. For example, another barrier to inclusion are the attitudes I will encounter in others who also frequent the space. I have to ask myself, are they the kind of people I would choose to surround myself with? Will I feel silently judged by them because of my disability? Will they treat me with the respect that I, like any other person, deserves? Will they respect my need to change the physical space around me if I need to, such as moving a chair or table?

What I am getting at here is that spaces control the narratives of the people who inhabit them. If all the above answers are a “yes,” I am much more likely to inhabit a space. These are spaces I feel most comfortable in as my physical and emotional needs are met. Inaccessible buildings limit the people who can inhabit them, and therefore the narrative of the space does not

include the stories of disabled people. While it is important to create physically inclusive spaces, providing emotional access is just as—if not more—vital in ensuring full inclusion. The attitudes existing in physically accessible buildings that create hostile or inhospitable environments are just as important as whether there is an accessible entrance into the building.

In the same way, spaces that restrict a certain group of people project a specific narrative or story onto those people. Sara Ahmed writes that, “fear works to align bodily and social space: it works to enable some bodies to inhabit and move in public space through restricting the mobility of other bodies to spaces that are enclosed or contained” (70). The accessible school bus which I was so familiar with as a child is an example of such a containment. Because of our disabilities, we were confined to that bus while other more mobile (read: non-disabled) children were able to get to school in whatever way they and their parents chose. They were allowed to move within public space. We weren’t. We were restricted to one choice, and it was a choice made on our behalf.

These enclosed or contained spaces don’t just have a structural component to them. While the physical space of the school bus was designed with disabled people in mind, the space didn’t make its inhabitants feel welcomed or included but rather segregated and marginalized us from our able-bodied peers. In other words, having our physical needs met did not ensure that we felt welcomed into the space. This either/or scenario left us with the impression that a space could only be physically or socially inclusive, but not both. This tension created by a structural space that was not socially inviting caused ambivalence to be felt by those who inhabited it. It set the tone for us as disabled children at the start of our day: by being physically marginalized at the outset, it was difficult once at school to negotiate the feeling that we were socially marginalized as well.

What's more, the people who inhabited that bus, me included, were assumed to fit into a restrictive story about disability. We were supposed to be weak and passive because of the limitations disability supposedly placed on our lives. We were, in fact, assumed to not have a good life. When we no longer needed that space of the bus, we were expected to have not much of a life at all. It didn't matter that we weren't asked if we wanted to fit that narrative. Just by being on that bus, restricted by our mobility, we fit it. By our placement there, we were being told that by having physical access—without the social consideration of being surrounded by our able-bodied peers—our needs were met.

In being told our physical needs were more important than our social ones, we were essentially told what we needed and how we needed it. We weren't given a choice. If we still weren't happy despite being accommodated, that was just too bad. Our bodies' needs were given priority over our social needs to connect, appreciate, and effectively communicate with society as a whole regardless of the diversity of our bodies. In a vital way, we were voiceless, relegated to a space that nullified our access to seeing our bodies and selves as worthy of full inclusion. We were given what we were given, with no means of accessing more.

### **Interlude: Speechless**

My worst nightmare of the last five years has been one in which I can't speak. In it, my mouth is full of a substance I can't rearrange my lips around, and so I just keep spewing it out uncontrollably. My dreamworld is potent with misunderstanding. Sometimes I cry around my speechlessness, becoming all the more misunderstood. I wake up, still sad, and something else. I realize it is fury.

Now I wonder, is this why? Does my worst nightmare in adulthood harken back to my suppressed fears from childhood?



My subconscious has certainly reinterpreted that time as such, anyway. That dream always terrifies me, as well as infuriates me. I wake up, repeatedly having to remind myself that I can, in fact, speak.

But I am always haunted by not being able to. What if I were given a choice, or *more* of a choice? I wonder if just *more* is actually what I needed. It's not as if, in my dream, someone is preventing me from speaking. I am preventing myself.

Did I feel this way at the time? Is that when my nightmares really started—in life?

### **Narratives of Disability**

The previous two chapters have established that two major problems exist within society as they pertain to disability: that the words used to describe disability fail in and of themselves and that disabled people are assumed at the outset to have little to no agency. These two problems collide and collapse into one another, forming one big problem: how stories about disability and disabled people are told. Many stories are still not told by disabled people directly, but by news outlets who shape their stories in a particular way for their audience. Simi Linton describes her search for stories about disability and the predilection media outlets have to shape them in a particular way:

There was the occasional human interest story that told a tragic tale and described the plucky determination of the “handicapped” man or woman, the “sufferer,” the “victim” of some tragic condition. The story’s main focus was on what had already happened—the cause of the injury or condition. The agonizing birth, the catastrophic accident, or the family medical history. Yet to uplift us, the article would somehow demonstrate the triumph of the human spirit. . . . Another story would tell us of someone who had achieved something seemingly extraordinary—going to college, becoming a lawyer—

accomplishments it would appear were reserved for more robust people. The story inevitably included the word “despite...,” followed by the name of the individual’s condition, in the first sentence. We would be told, implausibly, that the successful woman or man had “overcome disability.” (111-112)

These stories converge in the way disability is portrayed to society through the stories that are most widely told and accepted. “Overcoming narratives,” Tanya Titchosky writes, “are a familiar everyday strategy invoked to deal with the dangers of disability imagined as lack. Perhaps such stories are even a way to accumulate resources against such lack, since these stories suggest that in the face of disability there is always at least one promise—we can overcome” (180). The overcoming narrative is particularly pervasive as it is based on the assumption that disability isn’t a normal or natural part of life *unless* it is being overcome. It is because of this assumption that the narrative is so popular in the first place as disability is bypassed in favour of another more acceptable narrative of striving to achieve a state of being better than the one preceding it. It also makes the experience of disability more palatable to those who haven’t felt it for themselves, as if disability is just a stepping stone to finding the courage within to nullify it, thus making oneself more acceptable to others through its denial.


For example, three stories in local newspapers in the United States have featured the overcoming narrative in the past few months. Two feature amputees—one as a spirited band leader, Robby Powers, and one a triathlon athlete and mentor, Sidney Smith—and another features a disabled hunter able to shoot a buck with specialized equipment funded by friends and family, Mitchell Benson. The titles of the articles alone either mention overcoming disability specifically or use a popular trope of disability narratives to establish “disability-as-loss” as the main factor and emphasizing point of the article: “Marching band member uses passion to

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## Deer hunter overcomes disability to shoot a buck with specialized crossbow equipment

By Brad Dokken on Nov 12, 2017 at 5:59 a.m.

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Mitchell Benson of Moorhead shot this deer with a crossbow mounted on an apparatus that attaches to his wheelchair Oct. 8 near Karlstad, Minn. Benson's younger brother, Matthew (left), helped him with the hunt. (Submitted photo)

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**Figure 1.1** Graphic appearing in *Grand Forks Herald* Nov. 12, 2017 featuring Mitchell and Matthew Benson overcome disability”; “Double amputee who trains for triathlons and mentors others with disabilities receives Utah’s Ace Award”; “Deer hunter overcomes disability to shoot a buck with specialized crossbow equipment”). All three articles feature the disabled person’s story of disability in the first few paragraphs, further emphasizing that the story of “what happened” is the most important part of the person’s narrative. Quotes like “lost his legs but not his spirit” (Smart) and “Amputate or die” (Jennings) provide the traumatic element to living with a disability, while Dokken emphasizes how many hours of care Benson receives as well as contrasts his acquirement of a job with the anniversary of his accident. Finally, the articles feature a photo highlighting its subject’s disability (peculiarly, in what can only be a gross formatting faux pas which only further de-humanizes disabled people, the Grand Forks article

*cuts off the head* of Benson but features his brother, Matthew, propping up the head of the killed buck).

The three type of stories Linton references directly correlate to the three examined articles: the agonizing birth of Robby Powers, the catastrophic accident of Mitchell Benson, and the family medical history of Sidney Smith. Alison Kafer also writes that, “In our disabled state, we are not part of the dominant narratives of progress, but once rehabilitated, normalized, and hopefully cured, we play a starring role: the sign of progress, the proof of development, the triumph over the mind or body” (28). In this way, the stories of Powers, Benson, and Smith work together to demonstrate that—even in 2018—our cultural narratives of progress only feature disabled individuals *after* they have proven themselves to be as normal as everybody else.

As a result, authentic disabled voices are silenced in favour of more palatable ones such as those existing through narratives where a disabled person’s physical ability to overcome their physical limitations are given priority. Disabled voices have still been heard, although not as often as they should be. Instead, overcoming narratives presented as a “feel good” story are popular because of the feelings they produce in readers. As a result, those wanting their voices heard have dismissed the “disability-as-loss” message of overcoming narratives where their stories serve as a normative reading, instead favouring traditionally unexplored mediums including poetry, graphic novels, and interactive media like YouTube. In these open-ended mediums, the primary concern of the disabled person is able to shift from ensuring their physical needs are met to concerns about their social wellbeing and notions of identity and autonomy. Whereas overcoming narratives are usually featured in local newspapers where their ultimate goal is to provide a “slice of life” perspective to able-bodied audiences, the mediums disabled writers and artists choose to work within are instead able to open up a more nuanced dialogue

about what it means to live with a disability. The stories laid out in the following chapter have refused to fit into a prescribed narrative, instead favouring ones that are best able to display the messy, complicated, and complex nature of living with a disability and connecting emotionally to bodies and the general diversity of human existence. Rather than succumbing to a popular narrative which supports and validates the perception and views of the audience hearing it rather than the person actually living it, these creators have chosen to instead share their narratives in non-traditional ways which empowers and amplifies their non-conforming life experiences. The spaces of text and video where these voices exist are also unique and provocative whereby they challenge, contrast, and expand readers' perception of the type of story they expect to hear.

**Reading Response: *Little Women***

*“I hate to think I’ve got to grow up, and be Miss March, and wear long gowns, and look as prim as a China aster! It’s bad enough to be a girl, anyway, when I like boys’ games and work and manners! I can’t get over my disappointment in not being a boy; and it’s worse than ever now, for I’m dying to go and fight with Papa, and I can only stay at home and knit, like a poky old woman!”* (Alcott 5)

So writes Jo March. But, as Jo learns, non-conformity is one of the ways people of minority have to adopt in order to survive the daily competitive nature of society as a coping mechanism of sorts. If we were the same as everybody else, our sense of being would be constantly changing based on who the rest of society wants us to be. Through non-conformity, we can take aspects of ourselves we value and present them to others who might not have seen anything like it before. We can take in the world’s messaging to us while choosing to ignore, share, or critique it.

## **Desiring Disability**

On the bus, our experiences as disabled children were tainted by the all-consuming identity of disability. If we weren't allowed to be in the same spaces as our nondisabled peers because of our bodies and "special" needs, then we were characterized by what made us different and nothing else. We were assumed to need to travel this way for the good of others and ourselves, to stay within the parameters of our difference. We were assumed to need to be treated differently, to have our minds made up for us, and to require a modification of the system according to our physical needs. But this was the problem, as well-meaning people assumed what we wanted, and what was best for us, instead of actually asking us what we wanted. We were perceived as bodies needing special attention and vigilance, living lives separate from others who were able. We were viewed as not capable of having desires, choices, and imaginations that were not limited by our disabilities.

Too often, this is the story that gets told about disability. It is not a complicated or nuanced tale. Our bodies and behaviours speak more about our experiences and realities than we were ever allowed to. It is our defining characteristic, as Tichkosky writes: "The hope that people are more than that which conditions them is actualized in the overcoming story by making disability into nothing but a negative condition, almost an inhuman condition. All people should, then, be more than that which conditions their existence" (184). In the reality of our bodies' difference, we are assumed to have one identity which is clear to everyone. It is made clear by how we are treated, the spaces we are obliged to inhabit, and by the amount of responsibility and choice we are given.

If disability is our one true identity and defining characteristic, then our placement on the bus both confirms and problematizes it. For no one chooses to be put on the bus. No one *desires*

to be placed on a bus for disabled children; rather, it is a placement that is made. No one desires it because the bus becomes a symbol in and of itself, as Jonathan Mooney writes: “The [...] bus as a symbol of special education says as much (or more) about that culture—its values, beliefs, fears, aspirations, and injustices—as it ever did about people with disabilities” (17). But we are placed on the bus for a reason. We are there because we do not conform to the parameters of normality that society ascribes to. We are so non-conforming, in fact, that our condition can’t be ignored. Rather, it has to be eradicated in order for us to get our humanity back.

This is the kind of storyline that gets repeated over and over again in the overcoming of disability. The body’s brokenness needs to be fixed and rehabilitated before one can truly overcome the brokenness to get to the next—and better—state of being where disability isn’t as much of a problem anymore. This either/or scenario also plays into the appeal of the overcoming narrative as it does not let one sit with disability for long before desiring it to go, and stay, away. And it is in the very grappling with disability and finding it undesirable that the overcoming of it is achieved: the desire to not be one thing, but another. To work towards that other state is what is rewarded and lauded by society above all else.

Alison Kafer presents what might be the antithesis to the overcoming narrative: “I desire [...] futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being” (45). The language of desire that Kafer uses is uncommon within society today. The narratives disabled people exist within are usually not ones where disability is desired, cultivated, or appreciated. The popularity of the overcoming narrative to mass audiences virtually guarantees that disability is not a desired way of being in the world. Stepping outside the overcoming narrative, however, opens up numerous ways of describing, and

even desiring, the reality of disability. It is through these voices, freed of society's desire for able bodies, that one can reimagine disability and its desirable aspects.

Interestingly, what Kafer desires does not have anything to do with her physical needs. Rather, what she desires most is *the connection* between disabled people and non-disabled people. In other words, Kafer recognizes that we desire emotional connection over our physical needs. In recognizing this desire within ourselves, we can begin to express the importance of our need for emotional support over physical support. It is here where we can truly see ourselves—not in what we desire physically but in the social landscape, in how we wish to connect with others and how others can connect with us.

### **Interlude: Body as Beautiful**

I want to want my body. On good days, I do.

I love its non-conformity. I love how my toes hide and curl against each other and how they twitch against confinement. How my chicken legs lack muscle but are covered in a variety of shape-shifting moles. How the one on my knee looks like an eye staring up at me. How my hands curl inward when I'm anxious like a turtle gone to hide in its shell. How the curvature of my spine is a conclave swimming pool, my shoulder blades the diving board. How, if I had a back massage every day, I would never want for anything else.

How my knees knock and bruise each other senseless. How I want to keep my leg spasming after working them hard just for the sense of relief when they end. How my voice warbles and wobbles like I'm sputtering underwater, always chasing the next deep breath.

How the curves and bumps and twistedness make my body unique. On good days, this is a good thing. Why would I want to see what everybody else does in the mirror? My body has a sense of humour, a graciousness to it. It is endlessly contradictory.



On bad days, I wish my body was not the punch line of a joke.

### **New Narratives of Disability**

If in dominant narratives, such as overcoming narratives, disabled people grapple with the physical aspects of rehabilitation and overcoming the limitations of one's body, non-traditional narratives of disability take on the emotional awareness one acquires when learning how best to live with disability without nullifying, ignoring, or overcoming a valuable aspect of one's identity. Written by Georgina Kleege, Harilyn Roussu, Heather Kuttai, Simi Linton, Ellen Forney, Vassar Miller, and Maysoon Zayid, these narratives turn from others' concerns about their bodies and physical health to concerns about finding oneself and one's identity. In other words, instead of attempting to overcome disability's hold on the body, these voices explore the emotional landscapes of presenting one's self as a disabled person and finding connection with our bodies and with the people around us. Their narratives turn political when they become concerned about their emotional lives within an ableist world rather than their physical lives as encumbered by disability. While many of their stories examine how they fit into certain spaces, these stories are more about emotional fit in that they attempt to find their selves in their cultural surroundings rather than a physical fit as concerns support for their bodies.

### **Reading Response: *Little Women***

*I felt angry at first, and then I didn't care, for a governess is as good as a clerk, and I've got sense, if I haven't style, which is more than some people have, judging from the remarks of the elegant beings who clattered away, smoking like chimneys. I hate ordinary people!* (Alcott 363)

As Jo finds, talking back is a way of gauging how the world looks and demanding a change. Being satisfied with everything is a static existence, and this includes how we are treated

by others. To talk back, we need to redirect our perspective from what we expect of people to what we demand of them. Even if it is not aloud, talking back is a healthy way to engage with a world that often does not function the way we want it to.

### **Talking Back**

Helen Keller is nothing if not a formidable figure of disability. Keller is, in the cultural imagination, used as a prompt to be grateful for what you have because it could be much worse. But such a standard is hard to live up to in reality. Blind professor and writer Georgina Kleege, in her 2006 creative nonfiction work *Blind Rage: Letters to Helen Keller*, explores her ambivalence to this mythic cultural character who had a large impact on Kleege's development as a young blind girl. Kleege writes:

[T]he most important thing you need to know about me, and the reason for my letter, is that I grew up hating you. Sorry to be so blunt, especially on such short acquaintance, but one of the advantages of writing to a dead person is there's no need to stand on ceremony. And you should know the truth from the start. I hated you because you were always held up to me as a role model, and one who set such an impossibly high standard of cheerfulness in the face of adversity. "Why can't you be more like Hellen Keller?" people always said to me. Or that's what it felt like whenever your name came up. "Count your blessings," they told me. "Yes, you're blind, but poor little Helen Keller was blind and deaf, and no one ever heard her complain." (1)

In her writing to Keller, Kleege explains and works through her ambivalence towards the normative narrative of Helen Keller's life as it was presented by society. Kleege writes vulnerably, beseechingly, and humbly about her own existence as a blind person and the enormous expectation of living a venerable life as Keller did. Asserting her agency by talking

back to such a venerated figure, Kleege asks questions that explore another element of Keller's humanity—an element that went virtually ignored when Keller was alive. People wanted to know about Keller's achievements, her triumphs, her tenacity for life in the face of adversity. Kleege, rather, wants to know just as much about Keller's failures. This is where a normative and traditional reading of disabled people breaks loose from the constraints of what overcoming narratives do. For, instead of focussing on the successes of a disabled person who is able to do x, y, and z—basically, by negating disability and proving oneself to be a productive individual—untraditional narratives of disability are able to focus on the messiness and, yes, the failures that are part of living a disabled life. But instead of judging those failures as being unnecessary and a waste of time, these narratives are able to explore a different understanding of what failure is and why we should experience it at some point in our lives. As J. Halberstam writes, “Under certain circumstances failing, losing, forgetting, unmaking, undoing, unbecoming, not knowing may in fact offer more creative, more cooperative, more surprising ways of being in the world” (2-3).

Most of all, untraditional narratives of disability explore how failure and a general acceptance of our body and mind's limitations can cultivate a positive outlook on our bodies and selves by encouraging the letting go of normative standards. Letting go of these standards is a way, unfamiliar to mainstream society, of viewing bodies as being capable of different things and *still valuing those bodies*. Where Helen Keller was perceived to be a success in living a normal life *despite* her disability, Kleege is much more interested in the ways Keller *failed* to see herself as successful in life and in her disability. The untraditional narrative thrives on the unpacking of powerful binaries which continue to exist, largely unquestioned, within society. So able/unable, sick/well, good/bad bodies, male/female, static/political, and success/failure are all

pairings ripe for exploration within the untraditional narratives disabled people choose to create and share with each other and society.

The able/unable binary has a tricky extra component to it. When disabled people succeed where they are not supposed to, basically encompassing the whole trajectory of the overcoming narrative, they are seen as inspirational. Success and disability are thought to be mutually exclusive. And so even in small aspects of daily life, the banality of a life with disability becomes inflated with importance. And so while we are just living our lives, the stories others ascribe to us have us overcoming insurmountable odds *just by living*. Like Kleege, disabled activist, writer, and psychotherapist Harilyn Roussu actively takes up the well-known trope of providing inspiration to others and scrutinizes it in order to tease out its assumptions, truths, and failures. She writes in her 2013 book, *Don't Call Me Inspirational: A Disabled Feminist Talks Back*, “frankly, I’m not inspirational. I’m damn boring, if you ask me, which you rarely do.... [But] I’ll tell you why I am inspirational: I put up with the barriers, the barricades, the bullshit you put between us to avoid confronting something—probably yourself—and still pay the rent on time and savor dark chocolate. Now that takes real courage” (25). By pointing to a popular stereotype of disabled people, Roussu rejects it as having nothing to do with her personal experience and reveals herself—as a disabled person—in a different light. The overcoming narrative would simply place Roussu within the narrative itself without asking permission, endlessly reproducing it as it was reproduced for Helen Keller, and stripping her of authenticity. But when a disabled person in this position has the agency to reject those constraints, together with the voice to actively fight against it, then the strength of the overcoming narrative relinquishes some of its grip on the people who are often forced to succumb to it.

Writer and three-time Paralympic medalist Heather Kuttai also disentangles a strong binary about becoming a disabled mother in her 2010 autoethnography *Maternity Rolls: Pregnancy, Childbirth and Disability*. Where most people advised Kuttai against becoming pregnant and raising her own children with an able-bodied partner, Kuttai examines the strong messages girls receive about becoming mothers and why disabled women are often discouraged from undertaking such a natural part of life. What Kuttai comes to realize is that her identity as a girl and as disabled became interwoven at the time of her accident, making it hard for her to see herself as female. She writes, “While I could not feel my legs, while I was experiencing excruciating pain in the places I could still feel, surrounded by strangers in a strange place and knowing instinctively that something was terribly wrong with me, my most prevailing thought was how I did not want that dress to be mutilated by a pair of scissors.... In my mind, that dress meant I was a girl. In that moment, the idea of losing that identity was somehow more tragic than what by body was experiencing” (14). As the identity of being disabled trumped her identity as a girl by being more prominent to her and everybody else, the messages she received from others was that her disability also precluded her from being a natural mother because of her unfeminine body. As disability comes with an assumption of asexuality due to the cultural stigmatization of disabled bodies combined with the prescriptive nature of female beauty, Kuttai found herself surprised by her own femininity when she became pregnant, writing, “when I was obviously pregnant, my body was open for public presentation, and therefore no one could deny my sexuality and femininity, not even me” (31). She describes the harmful messaging she received from doctors and those worried for her baby’s health, writing that “I believe my ultrasound experiences were larger social, political, and bioethical issues concerning the lack of worth we have for disabilities and how we want to avoid them at all costs” (60). As she emphasizes how

personal experience can expand social awareness, Kuttai opens up a dialogue about the harmful lessons disabled women internalize about their own bodies. By offering herself as an example, Kuttai demonstrates the misconceptions of the medical institution and of society at large who falsely feel they have the final say on who has the ability to successfully conceive, sustain, and nurture children as “what constitutes a competent and healthy mothering body” (57).

While writer and activist Simi Linton’s memoir *My Body Politic* does demonstrate the importance of physical access, she also spends a lot of time negotiating the spaces disabled people are provided access to but still find barriers within. She writes, “[My] injury was a sudden cataclysmic event, and the paralysis in my legs was instant. Becoming disabled took much longer” (3). As she contrasts the physical work of disability with the emotional work of adopting disability as an identity, she demonstrates that the sense of “becoming disabled” comes with time and an increasing familiarity with social situations; it is not, Linton explains, an automatic process. The political agency with which Linton is able to navigate her life as a disabled woman is learned, not through society’s assumption that disability is a life not worth living, but through investigating one’s personal relationship with disability and negotiating the potential self-worth that comes with identifying with that group. She also rejects the normative spaces disabled people often find themselves within, such as medical institutions, in favour of a more open understanding of the spaces where disability can exist. For example, she writes,

There, on the corner, facing me, was a man sitting tall in a sporty black wheelchair. Wavy blonde hair fell down his bare back. He wore only tattered jeans and leather sandals. He was not alone. Three women swirled around him, dancing and skipping. Each woman held a container of yogurt, and each, with gusto, was throwing handfuls of the stuff at him. He answered them. He scooped up the cream from his naked chest and off his sun-

burned shoulders, and lobbed it back. There was yogurt in their hair, running down each and every chest, dribbling down one woman's thigh, another's forearm. It lingered in bellybuttons, between toes, and in the spokes of his wheels. Wet, white yogurt pooled on his lap.... He swivelled his chair back and forth, doing a kind of wheelchair twist. He snaked in and around them, and they jumped to get out of his way. (42)

In this telling moment, Linton's encounter with a free-spirited young man who was not acting in the way disabled people usually do turns into a desperate want to occupy a similar space devoid of the seriousness disability often imposes. It is a recognition that disability can, and should, be present in *all* desirable aspects of life and not only within the enclosed and contained spaces where disabled people can often be found.

Sometimes the physical space of the page on which disability is written needs to be re-evaluated in order for disability to be portrayed realistically in a medium that is true to the non-normative author and their experience. Such is the case with *Marbles: Mania, Depression, Michelangelo, & Me*, cartoonist Ellen Forney's 2012 graphic memoir of bipolar disorder. Here, the text of disability is so completely removed from the overcoming narrative that the page which depicts her story prominently features black space, visuals, and a stark contrast between the words on the page and the negative white space of the gutters. In this medium, Forney chooses to detail her life with bipolar. Not only is the medium of the graphic novel more accessible to numerous disabled people (those with learning disabilities or low vision, for example), the choice of the medium is able to say much more about the subject matter than a straightforward overcoming narrative ever could. The graphic novel captures visual moments in time, whereas the overcoming narrative's primary concern is with the moment at which one becomes disabled—returning to Linton, “The agonizing birth, the catastrophic accident, or the

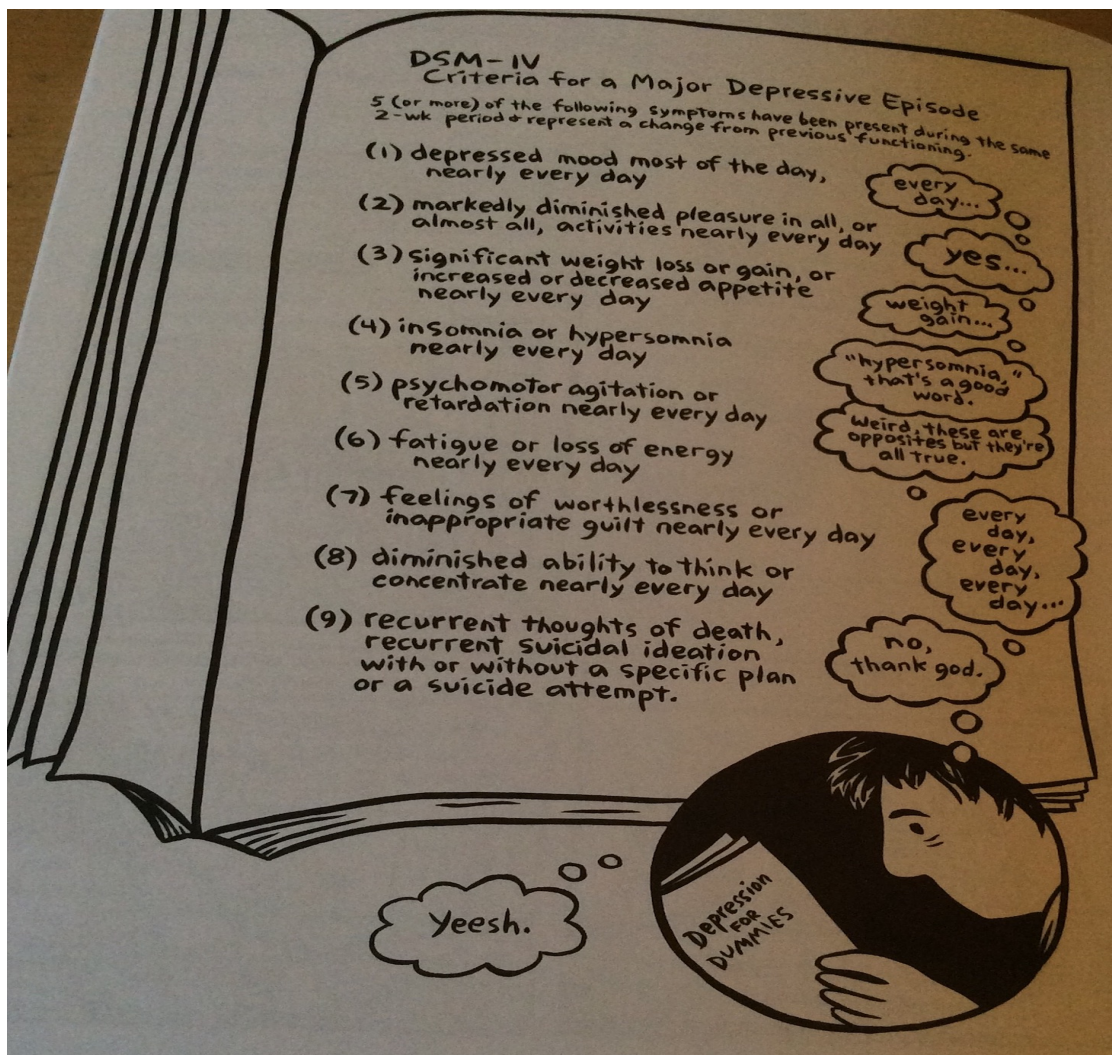


Figure 1.2 Page 86 of *Marbles, Michelangelo, & Me* by Ellen Forney

family medical history” (111). The graphic novel is also able to experiment provocatively with time, capturing non-linear events that might not happen chronologically but make up a complete story. Popular overcoming narratives, however, follow a fairly stringent linear path and are from one distinct point of view, whereas Forney’s graphics are allowed to jump between multiple points of view on any given page.

Take, for example, the graphic on page 86. The point of view is of a page from *Depression for Dummies* that lists the criteria for a major depressive episode taken from the Diagnostic and Statistical Manual of Mental Disorders, fourth edition. In the graphic of the page,



nine criteria are listed—with the stipulation that “5 (or more) of the following symptoms have been present”—ranging from “depressed most of the day, nearly every day” to “recurrent thoughts of death, recurrent suicidal ideation with or without a specific plan or a suicide attempt.” Not only do readers “see” Forney reading the book, but also, on top of the graphic of the page are Forney’s own overlaid thoughts (“every day”; “no, thank god”). On the surface of the page an interaction takes place as Forney’s own symptoms of a major depressive episode are described back to her. Forney, an artist, is interacting with the bible of diagnostic disorders *that is relied on by doctors to diagnose aspects of disease in others*. It is hard to imagine a medium that could have such a clear depiction of Forney coming face-to-face with her disability. The overcoming narrative, in fact, would vehemently resist such an interaction from occurring. The intellectual space Forney has opened up in her graphic memoir allows a level of communication about and interaction with disability, disease, and illness that the overcoming narrative deliberately ignores. It is as if, in the negative white space between Forney’s graphics and the page, a whole new dialogue of disability between reader and author is being written which has never been witnessed before.

Poetry, too, allows for disability to be represented both non-linearly and without a stringent narrative pattern. In 2011, Jennifer Bartlett, Sheila Black, and Michael Northern edited a collection exploring disability poetics. *Beauty is a Verb: The New Poetry of Disability* features both new and established work by disabled poets. Poet Laureate Vassar Miller (1928-1998) edited the first anthology of poetry about disability, entitled *Despite this Flesh*, in 1985. Her poem “Dramatic Monologue in the Speaker’s own Voice” first appeared in her seminal collection *If I Had Wheels or Love* in 1991. She writes,

I am either a monster  
in search of a horror movie to be in,

or else I'm a brain floating in a body  
 whose sides I must gingerly touch while you glance  
 discretely away. (53)

Such a visceral portrayal of the disabled body—especially when used to evoke such a culturally familiar genre as the horror movie—would never exist within an overcoming narrative, except maybe as a further delineation of what the disabled person has overcome. However, Miller's words evoke a sense of embarrassment *on the part of the viewer* and not within the disabled person themselves. For the overcoming narrative, most importantly, *relies on* the disabled person's earnest willingness to not be considered disabled anymore. The disconnect between the brain and the body, too, evokes an unnaturalness which the overcoming narrative also supports—never seeing the compatibility between the body and the mind but rather a clear-cut differentiation where the body must be rehabilitated, at the very least, in order for the body/mind balance to be successfully achieved. It is in the negative space surrounding Vassar's words on the page where the potential of the disabled body becomes tangible, real, and vibrant.

In addition to new and challenging mediums that haven't seen many positive depictions of disability, videos uploaded to YouTube at alarming speeds become not only viral but provide *the* cultural reference to a society that relies on snippets and sound bites to reconstruct the world around them. Palestinian Muslim and disabled activist and comedian Maysoon Zayid gave a TED talk entitled "I Got 99 Problems ... Palsy Is Just One" in late 2013, a time when the audience she encountered were more accustomed to hearing versions of the overcoming narrative. Zayid is provocative and challenging, even directly confrontational at times—but, most importantly, her sense of humour indicates that she doesn't take herself too seriously. She starts, "I'm not drunk, but the doctor who delivered me was. He cut my mom six different times in six different directions, suffocating poor little me in the process." While such a blunt opening

may come off as crass on the page, Zayid's confident and humorous delivery shares similarities with the kind of frank dialogue Kleege felt she needed to have with the venerable Helen Keller. Also like Kleege, Zayid uses the cultural significance of icons like Muhammad Ali—a figure complete with his own overcoming narrative as one of the greatest athletes of all time, an achievement complicated by a diagnosis of Parkinson's disease later in life—and Latina hip-shaking heartthrob Shakira to make a comparison to her own body: "I'm like Shakira meets Muhammad Ali." In making claims like this one, Zayid places herself securely within the cultural imagination where the overcoming narrative is often used as an attempt to erase or eradicate oneself from the same position. For Zayid's desire isn't to fix or cure her body spasms. Instead, through her comedic delivery, she is able to use them as an in-your-face demonstration of difference and the acceptance—even embrace—of that difference. In other words, she isn't embarrassed or shamed by her body; instead, she puts it on full display.

If Forney's graphics and Miller's words recreate the page in order to portray disability's innovative and malleable nature, then Zayid's TED talk lessens the need for the page to construct a narrative altogether. While Zayid's body is the main vehicle with which she rejects the overcoming narrative—purely in her direct approach—it also evokes not-too-long-past decades when disabled people were paraded and their bodies used as a prompt for charitable giving. Paul Longmore writes, "During the 1980s and 1990s, these four major disability-related telethons [the United Cerebral Palsy Associations, the Muscular Dystrophy Association, the National Easter Seals Society, and the Arthritis Foundation] aired nationally at various times during the year. The charities claimed to reach an audience of more than a quarter of a billion people in the United States and Canada" (502). However, telethons were never meant to actually raise the profile of disabled people as social beings. Rather, they were a preliminary form of the overcoming

narrative. The parading of disabled children on telethon stages was meant to evoke pity and signal tragedy, strengthened by a social and collective gaze. According to Longmore, telethons provided the opportunity to

gaz[e] at people with disabilities [...] as an organized public or semipublic event. It is communal, planned, and, in the end, ritualized. It carries greater social weight than does individual staring partly because, unlike those momentary encounters, collective gazing is not a casual singular occurrence. Rather, it happens as one of a long series of events produced by social institutions [...] designated as appropriate areas for dealing with people defined as physically or physiologically anomalous. Over time, these displays become formalized. This ritualization reflects the power dynamics between nondisabled and disabled people in both the institution and the larger society. It also expresses the institution's, and more broadly society's, dominant ideology of disability. (503)

Above all else, telethons loudly communicated the contentious message that disabled people couldn't take care of themselves. They were encouraged to fit into the overcoming narrative because, in doing so, their efforts to overcome disability spoke louder than their disability did. And that effort to overcome deserved celebration.

On stage, Zayid's body isn't accompanied by the messaging of telethons. She isn't paraded, isn't used to evoke charity. While the spectacle of disabled bodies in and of themselves are used in a myriad of ways, Zayid clearly has agency. She is there of her own will. The spaces disabled bodies take up in their narratives, as we have seen, do not have to conform to the overcoming of disability. Through mediums which place the disabled person—and not just their bodies—at the centre of their own narratives, disability is not negated or ignored but is identified as essential and valuable. The overcoming narrative, too mired down in its own commitment to

repackage the experience of disability as palatable, does not require disability to evolve or change in any way. Rather, it demands that it doesn't.

### **Interlude: Community**

Dear Tracy,

You were thirteen years old when your father killed you. I was eight. I do not remember the day you died, or when I was first told about you, but I have always thought we could have been friends in another time and place. You lived in Saskatchewan with your family, me in Manitoba. You had Cerebral Palsy. I have a lot of friends with Cerebral Palsy. You were the oldest of four siblings. Me, the oldest of three.

We lived pretty similar lives. I know a similar bus took us both to school and back every day. How did you feel being on it, Tracy? Did you feel special? Or did you feel different, judged for your disability?

Your father has said he loved you so much he killed you. But I do not think that is love. I think your father wanted you to be normal, and that intense yearning is what made him do what he did. He wanted you to be normal so much that he could not stand you being disabled, and so he said he killed you out of love. What do you think, Tracy? Do you think your father loved you?

I looked you up on Wikipedia today, Tracy. You were not there, only your father. How does it feel to have your life be defined by what your father did to you? Have you forgiven him? Me and a lot of other disabled people can't. We can't because he ended your life too soon, Tracy. He thought your life was not worth living. But wasn't it?

Your mom mentioned you enjoyed music. Did you smile and laugh, move your head to the beat? Did it help you forget some of your pain? Your father hated needles, but did you realize they came with the game plan? I bet you got used to them. I know I did. Your father hated seeing

you like that. He assumed you were in constant pain, but were you really? Did you enjoy being alive?

You were supposed to have another operation soon but your father did not want that for you. What did you want, Tracy? I'm sure this wasn't your first operation. But did you mind them as much as your father did? Would you have been willing to risk it, to stay alive?

I'm sorry you're dead, Tracy. I wish your father had loved you enough not to want to change you. Because that's what he wanted, and that's not love. That's selfish love, that's love that justifies a narrow prescription of what life should look like from the outside. But you were different, Tracy. Your differences were beautiful. I think you knew that. I wish your father knew that.

But we know that, and we're all here, Tracy. We know that your life mattered and that what your father did was wrong. We remember you.

Love always,

Kate

### **Spaces of Disability**

Robert Latimer killed his daughter Tracy in the fall of 1993. While the story shored up support to Latimer and his family over what was considered a "mercy killing" in response to Tracy's pain and discomfort with Cerebral Palsy, the disabled community has rallied against Latimer and the support he has received in the last twenty-five years. Ruth Enns writes,

Organizations of disabled citizens have objected to the predominantly negative presentation of Tracy inside and outside the courtroom but their objections have been met with at best patronizing pats on the head and at worst outright hostility. The reasons they

oppose leniency for Robert Latimer have not been adequately investigated or understood by fellow Canadians. (8)

Tracy's experience was summed up in the apparently painful body she inhabited with no thought given to her emotional wellbeing. The "space" she took up was traditionally defined by her physical needs. She was assumed not to take any pleasure in having a disability at all. She was a victim of being written within the typical narrative of disability, a narrative based on the assumption that living disabled means living without pleasure.

Latimer's violent actions wrote Tracy out of her own life. He was accepted, along with his intense hatred of disability and everything that caused his daughter to be identified as a tragic figure, while Tracy was rejected. Latimer assumed that his daughter was in such pain that she would be better off dead in order to be saved from the unbearableness of it. No one will know the level of pain Tracy was in except, of course, Tracy herself. But the assumptions Latimer cloaked himself within and thought to be true were, in the end, a justification for how he treated his daughter. Tracy unfortunately didn't have access to a narrative where disability could be anything short of a horrifying existence, and the people who placed her there were the people that supposedly cared for her the most. They rendered Tracy powerless, not allowing her to exist outside of a disabled existence that wasn't tragic and painful.

**Reading Response: *Little Women***

*Now, if she had been the heroine of a moral storybook, she ought at this period of her life to have become quite saintly, renounced the world, and gone about doing good in a mortified bonnet, with tracts in her pocket. But, you see, Jo wasn't a heroine, she was only a struggling human girl like hundreds of others, and she just acted out her nature, being sad, cross, listless,*

*or energetic, as the mood suggested. It's highly virtuous to say we'll be good, but we can't do it all at once....* (Alcott 469)

Narratives attach themselves to people unwittingly. We are so caught up in the spaces we find ourselves in that, before long, we are defined by those spaces. Breaking those chains is hard to do. It's not done all at once, or all in one day. But slowly, surely, we need to break those chains in order to feel comfortable with ourselves; in order to revel in our rebellious nature. Then, maybe, others might follow suit.

### **Sharing Stories**

In choosing untraditional forms of narrative expression, disabled people have demonstrated that they do not need to rely on narratives that may be more comfortable or might confirm society's beliefs about bodily capacity. Rather, a rejection of the overcoming narratives and other narratives that negate the disabled experience can seem hollow and superficial in comparison to the vulnerability and openness with which disabled voices have chosen to express themselves. The spaces these voices create are not primarily concerned with their bodies' defectiveness but with the ways they can live emotional lives in the full knowledge that disability is simply another way of living.

Against this reality, it is no wonder that disabled people choose untraditional means of expressing themselves in order to reject the lives imagined for them. As the tragedy of Tracy Latimer shows, her father rendered her powerless, first through invalidating her life, and second by ending it. Through untraditional narratives, disabled people take back the spaces they are banished from. Robert Latimer wasn't familiar with these spaces and no doubt assumed they didn't exist and never would. But the very people who treat their assumptions as truth do it for the comfort they find within their own humanity, bolstering themselves against the "otherness"



of disability. Narratives that are able to reconceptualise disability's worth and value expand these boundaries, threatening the beliefs people like Latimer hold.

### **Conclusion: Embodiment**

“I have come to believe over and over again that what is most important to me must be spoken, made verbal and shared, even at the risk of having it bruised or misunderstood.” (Lorde 17)

### **Interlude: Sex Ed**

I am on a beach reading under a red and white striped umbrella. At my father’s suggestion, I am touring the crude and scintillating world of the books of John Irving. I am twelve years old.

Masturbation is a common theme. Not only do I not know what masturbation is (I could only, under duress, hazard a guess), I am pretty sure females don’t do it and, what’s more, my naked prepubescent body has only been viewed by my caregiver parents and doctors.

John Irving was my rebellious act, my way to read (straight male) sexuality. It had never dawned on me that my body could be sexual, or that it could make me or someone else feel pleasure. I did not think my body could be desired by anyone. While my female friends were being led down basement stairs and under bleaches at recess by cute boys, I pretended not to notice or care.

I knew enough to know that I was a long way from doing the illicit things I read about in books. I found them fascinating, even if they did seem like some faraway fantasy. Their very illicitousness gave them allure. I felt like I was privy to a life other than my own.

This covetousness of other’s sex lives was partially because, as a disabled kid, I was fed the message that I wasn’t supposed to be sexual. I wasn’t even taught sex ed in high school as I wasn’t a part of a “regular” gym class. Having missed the boat on that one, I never had anyone

explain what an erection was to me, nevermind what masturbation was. Clearly, I wasn't supposed to be having sex.

Thank goodness for books. Even if it was a fantasy, at least I knew it was one worth having.

### **Embodiment as Rebellion**

My story of disability has been nothing short of volatile. The barbs within it still hurt, and still present themselves to this day. But in the following conclusion I want to depart from my story just a little bit in order to ask an important question. This question was first presented in *Interlude: Body as Beautiful* in the previous chapter and it remains the most vulnerable part of myself I have shared. The question is this: How do I become comfortable in a body that has been clearly deemed as inferior? While I have argued that disability and the disabled body is a social construction, I still have a body, and I still have to live in it. Moving forward from my story, how can I comfortably live within this body that has been socially constructed but is still, for better or worse, the physical vessel in which I live my life?

Tanya Titchosky writes that, “We perform the meaning of our embodied existence by the way we narrate the intersections of human diversity in the midst of which our bodies appear” (6). Our embodied natures as disabled people become proliferated through the stories we choose to tell and others choose to tell about us. But, again, the stories I tell about disability do not portray the everydayness of what it means to live with a disabled body. Rather, my stories portray the sociality of what it means to live a disabled life ruled by the constructs already prevalent within society. Words are imbued with conceptions of the body as they mirror our perceptions of people, but what I would like to suggest is that embodied identity lives within the

body itself. It is an identity mediated by and through others, yes, but it starts and ends with the body.

I don't know whether I always knew this. The pull of ableism is so pervasive that I thought once I had proven my body's worth to both myself and others—not in the sense of physical ability, but in terms of my worth as a disabled person—I would accept it and others would simply follow suit. But this has been an ongoing struggle, especially as I age, as the physicality of my body seems to have splintered into multiple directions away from the ideal. The transcendence of the body that Susan Wendell talks about is a reality disabled people face as, similar to the overcoming narrative referred to in the last chapter, it provides a promise that people are not only *and can be separated from* the materiality of their body. Wendell writes that, “transcendence of the body lies [...] in the rational (as opposed to pathological) desire to make one's happiness, or at least one's sense of self, independent of illness, pain, weakness, exhaustion, and accident” (166). The embodiment of disability exists *in direct juxtaposition* to this desire; however, the negation of one's happiness because of disability goes directly against critical disability studies thought. What does it mean, therefore, to embody an identity that is not pleasurable by society's standards?

This is where disabled embodiment is difficult to grasp, I think, for most and where disabled people themselves struggle with presenting the positive aspects of living with disability. Like anyone, we have good days and bad. In wishing to live a more embodied disabled life, I have had to incorporate “disability days” into my schedule—days where, no matter what I do, my body and mind are working against me and I just have to give up and let it happen. I see this as a direct provocation to society's working definition of what it means to be human, to not have a choice but to succumb to a body and mind indifferent to the wishes of its owner. This is where

I see the embodiment of disability as most potent: in its rejection of the notion that bodies are meant to do, perform, or embody anything specific.

There is a sense of pleasure, too, I would like to argue, in rejecting such a widely-held and normative belief. Wendell writes that, “the body or body parts are taken to be symbolic forms in a culture” (168). The rebellion against the disabled body as a symbolic form, and the acceptance of it as rather a real embodied existence, is a kind of perverse pleasure in a world that demands conformance to social rule and regulation. The rebellious nature of the disabled body, in and of itself, provides the pleasure through which one can appreciate the disabled form. In other words, it is through the body’s refusal to constrain itself to the standards and rules of bodily normality that the disabled body can be appreciated for its beauty.

I am not saying that the disabled body eludes social regulation; in fact, just the opposite. But I have found that I feel the most embodied as a disabled person when I rebel against the very standards or symbols that are used against my body. For example, I feel most embodied when disabled beauty is seen as another way of being beautiful; when experiences of disability are prioritized over medical knowledge; when disability is adequately represented throughout culture and ceases to be a specialized field. The rebellion lies in refusing to perceive the world as it has always been seen, and in finding new ways of seeing it.

For me, my first act of rebellion as a disabled person was in choosing to read. As Pamela Paul writes, “Books are how cautious kids get to experience a kind of secondhand rebellion, a safe way to go off the rails” (15). In fiction I came across concepts that were brand new to me, many of them unfamiliar because of the insulation that comes with living with a disability. But I brought these experiences, too, into my embodied being. Fiction became just as much a part of my life as disability did. I fused the two worlds together, grateful that fiction was able to

introduce me to things I would not have encountered in my disabled life. Through fiction I was able to, as Titchkosky writes, “[uncover] how [to] constitute a sense of the world” (1). By rebelling against what was expected of me as a disabled child, I was able to feel my most embodied self: I rejected expectations placed on me and found an environment where I could figure out who I really was.

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