MAKING BODIES MATTER: DISABILITY NARRATIVE AFTER THE ADA

DISSERTATION

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ABSTRACT

The disability rights movement aims to shift the definition of “disability” from something like “a set of pathologies located in individual bodies and causing inability to perform certain tasks or meet certain standards” to something like “a set of contingent interpretive, institutional, and systemic practices that disable people with allegedly anomalous bodies.” In the political history of this movement, the passage of the Americans with Disabilities Act in 1990 was the single most important moment in forcing that shift in the mind of the public at large. Partly as a result of this relatively recent movement toward understanding disability as an identity and as a primarily social rather than a primarily medical or physiological phenomenon, disability is often represented a value-neutral or value-positive part of disabled characters’ and narrators’ understandings of themselves in contemporary narrative texts created by both disabled and nondisabled artists. Disability in such texts functions as a mode of expression, an object of contemplation, or both, demonstrating that disability has taken on a positive valence for artists working in various media and genres. For this project I have selected texts in a range of media (novels, memoir, graphic narrative) that deal with different disabilities (Tourette syndrome, autism, blindness, and chronic illness). At the same time, these texts are unified in being interested in identity formation and in being published by
major publishers and thus being widely available for popular consumption.

*Making Bodies Matter* accomplishes two goals: First, *it identifies new objects of study*, characterized by a shift in attitudes and practices toward disability that has become prominent since 1990. Second, *it develops a new methodology* for disability studies—a field often focused on lesser-known contemporary and older art and primarily focused on political readings—increasing its aesthetic dimension by using the principles and methodology of rhetorical narrative theory. I take the Americans with Disabilities Act of 1990 as a starting point for the project because of the way it reframed disability in the law and, to an extent, in the popular imagination. I show that one defining feature of contemporary literary treatments of disability is that disability is often framed as a positive identity rather than an awful fate or symbolically loaded physical signifier. Disability in contemporary literature, including relatively popular works, is a complex phenomenon, matter-of-factly represented and potentially illuminating for everyone.
For Micah, without whom I never would have started

And for Lesley, without whom I never would have finished
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Introduction – Making Bodies Matter

The interdisciplinary field of disability studies understands disability as an identity marker, and work in the field approaches disability as a social phenomenon whose meaning is largely determined by its context. Disability studies scholars aim to increase disabled people’s access to education, employment, and independent living, meaning that the field has an openly political agenda. What, then, would happen, if by some incredible sea change, disabled people achieved the degree of access and equality the field seeks? Such an achievement is neither imminent nor even likely within this generation, but given such a state of affairs, would there be any work left for disability studies to do? If the field’s usefulness were only political, then perhaps there would not. But since disability is an identity marker that has played a significant role in history, psychology, politics, philosophy, education, art, and literature, we can reasonably conclude that though the field’s aims include political outcomes, its significance is not exclusively political.

In the interest of the field’s ongoing vigor regardless of the political or cultural context, I want to better articulate disability’s value as an aesthetic and poetic resource in contemporary (post-1990) literature using the vocabulary and methodology of narrative theory. The result of this articulation will be an increased appreciation for disability
aesthetics, as well as a better-developed understanding of the way embodiment affects the creation and reception of stories—a significant benefit to narrative theory.

This project fits into an existing body of disability studies criticism that articulates textual deployments of disability and what those deployments reveal about broader cultural beliefs concerning disability. Disability studies scholars have interrogated texts from all literary periods, seeking to understand what disability signifies to people living in different historical and literary moments. Reading Victorian fiction with an eye to its representations of disabled women, Martha Stoddard Holmes marshals evidence from Charles Dickens, melodrama, and Charlotte Mary Yonge’s novel *The Clever Woman of the Family*, identifying the general trend whereby the “ritual exclusion” of disabled women “at the end of so many courtship plots serves not only to purify the plot of the specter of the fallen disabled women but also to remove the equally potent threat of the sexual and potentially reproductive disabled woman, a figure whose dangers were amply suggested by contemporary social science and medical texts” (224). Stoddard Holmes has published a book on the status of disability in Victorian fiction, and she along with many other critics discovers in literary history a pattern of devaluing representations consonant with the historical treatment of disabled people.

Other readers have tried to discern shifts in understandings of disability by looking at the history of criticism. For example, in a 2005 essay about Benjy Compson in William Faulkner’s *The Sound and the Fury*, Maria Truchan-Tataryn takes issue with a unilateral critical tradition that assumes Benjy’s narration and characterization are basically realistic of people with developmental disabilities. Truchan-Tataryn contrasts
this static critical history with the history of readings of Faulkner’s racialized characters like Dilsey, a black servant, and Caddy Compson, the young woman near the center of *The Sound and the Fury*: “[E]ven though Faulkner’s once subversive treatment of Dilsey and Caddy today betrays persistent racism and sexism, new generations of readers are able to reframe the meaning and relevance of these major characters. Little equivocation, however, surrounds the representation of Benjy as an idiot” (165). Readings of Benjy continue to herald him as simultaneously human inasmuch as he uses language and inhuman inasmuch as he is an “idiot”; for Truchan-Tataryn this impasse highlights “the failure of Faulknerian scholarship to query the particular socio-political investments served by the assumption that this configured mentality reflects a lived experience of people with developmental disabilities. Unlike…the portrayal of race in Dilsey and gender in Caddy, Benjy’s disability marking is rarely historically contextualized” (165).

More recent literature reflects shifting cultural attitudes toward disability. David Mitchell and Sharon Snyder find Katherine Dunn “defin[ing] the experience of disability within a more complexly human constellation of tropes and perspectives” because of the way she troubles “the false opposition of ‘freaks’ and ‘norms’” in *Geek Love*, which was a National Book Award finalist in 1989 (157). Dunn’s panoply of outlandish genetically modified characters who operate a traveling family circus would perhaps have been merely objects of wonder and exhibits in freak shows in an earlier literary moment. In *Geek Love*, however, “Dunn…uses the freak to allegorize an array of bodily conditions that act as the host for numerous cultural pathologies” and anxieties about “normal” bodies and the compulsion toward standardization that so oppresses “normals” (158).
Aware of the historically contingent nature of our preferences for certain kinds of bodies and also of the eugenic heritage of some of our notions of typicality, artists and critics have in some cases begun to use disability in subversive ways. Yet just as disability is still contested in the world outside art, disability is still often represented negatively or ambivalently.

My aim in this project is twofold: (1) to identify new objects of study for disability studies in literature—namely, texts characterized to differing extents by new attitudes and practices toward disability that have become more prominent since 1990 (the year the Americans with Disabilities Act was passed), and (2) to develop a new methodology for disability studies in literature—a field often focused on lesser-known contemporary texts or older texts, and frequently consisting of political readings to the neglect of issues of aesthetics and poetics.¹ This project aims to increase the scope and depth of literary disability studies’ engagement with issues of form by using the principles and methodology of narrative theory (chiefly but not exclusively rhetorical narrative theory) to interpret the texts in my corpus. I argue that narrative theory and disability studies are mutually beneficial. Narrative theory clarifies the importance of stories for disability studies’ activist aims. Meanwhile, disability studies insists in various ways that narrative theory take into account the constant and consequential fact of creators’, characters’, and audiences’ embodiment.

¹ That said, there have recently been welcome contributions to disability aesthetics and poetics—most notably, Tobin Siebers’s Disability Aesthetics, Ann Millett-Gallant’s The Disabled Body in Contemporary Art, and Michael Davidson’s Concerto for the Left Hand: Disability and the Defamiliar Body.
I take the Americans with Disabilities Act as a starting point for the project because of the way the act reframed disability in the law and in the popular imagination. My texts are drawn from a range of media (three novels, one memoir, and one graphic narrative) that deal with different disabilities (Tourette’s syndrome, traumatic brain injury, autism, blindness, and Huntington’s disease). While they are diverse, these texts are unified in their interest in issues of identity, and also in being issued by major publishers and thus being widely available for popular consumption. Additionally, selecting texts in a range of media that deal with a range of disabilities makes two important things clear: first, that the principles of narrative theory apply equally to a variety of texts; and second, that for as much as no two disabled people are alike, there are sufficient common experiences, insights, and ways of thinking to constitute a unified field of “disability studies” (and disability identity) rather than a more fragmented collection of “disabilities studies” (and the absence of such an identity).²

In order to begin, I need to discuss just what I mean by disability, which I will do by discussing the political status of disability in the period 1970-1990 (the former date marking the formation of an advocacy group called the Rolling Quads, and the latter marking the passage of the Americans with Disabilities Act). I will then explain what disability’s shifting status means about how people already think and how we are encouraged (at least on paper, by federal legislation) to think about disability. Having

² Mark Haddon’s *The Curious Incident of the Dog in the Night-time*, the subject of Chapter 2, is the only British text I discuss; the rest are American. Though the UK’s disability rights movement differs in substantial ways from the American movement, there is also substantial overlap. Moreover, Haddon’s novel is massively popular among American readers, and it trades in conceptions of autism common to the UK and the US.
staked out a definition of disability, I will provide an overview of narrative theory as I conceive and utilize it in this project. Then I will return to the two aims for the project I just described, explaining the mutual benefit my project brings to disability studies and to narrative theory. I conclude the introduction with a thumbnail sketch of each chapter that follows.

A partial political history of disability, 1970-1990

The disability rights movement (DRM) is built on the assumption that disability is created by institutional, architectural, and attitudinal arrangements as much as, if not more than, by properties of human bodies. This way of thinking about disability is called the social model, and it is both the foundation for the field of disability studies and a foundational insight for the disability rights movement. Joined with the social model, the recognition that disabled people are frequently denied their rights generates what can be called the minority group model of disability. According to this explicitly politicized version of the social model, the social construction of disability produces a minority group similar to racial, ethnic, or gendered minority groups.

While people with and without disabilities had been advocating for disabled people’s rights to participate in American society for some time prior to the DRM, cross-disability alliances and a moment of political receptivity to the social model did not arise until around the 1960s (Longmore 109). The DRM emerged amidst the broader American civil rights movement and the advent of concerted political action by disabled people.
Like other minority groups, the DRM successfully put pressure on legislators in order to achieve the civil rights that disabled people had long been denied.

In the 1960s and ‘70s, several centers for independent living (CILs) formed in American cities like Berkeley, Houston, and Boston. These centers were coalitions of disabled people and their advocates who lobbied for independence (functionally and with respect to controlling and directing resources and services) for people with disabilities. Ed Roberts, who founded the Berkeley CIL, had polio and afterward was quadriplegic and used an iron lung. While attending the University of California at Berkeley, Roberts lived in an empty wing of the university’s hospital. Other disabled students lived there as well, and they soon formed an informal coalition known as the Rolling Quads. As their concerns broadened and their conviction deepened that disabled people have the same rights to independence that everyone else does, the Rolling Quads began to think about what kinds of accommodations and support systems would be required for disabled people to live independently in the community, within and outside the university. They founded the Physically Disabled Students Program at Berkeley, and in 1972 they took their conviction that independence was a right that could and should be ensured for disabled people beyond the university setting by founding the first CIL in America. Today there are hundreds of CILs across the country, and they are organized nationally as the National Council on Independent Living. Collectively, these CILs are the driving force of what has come to be called the Independent Living Movement (ILM).³

³ In 2010 the Ed Roberts Campus, a center for disability rights education, training, policymaking, and advocacy, opened in Berkeley.
In 1973, the year after the Berkeley CIL was founded, Richard Nixon signed into law the Rehabilitation Act of 1973, which included the civil rights statute that spawned the unified disability rights movement. Section 504 of the Rehabilitation Act states:

No otherwise qualified individual with a disability in the United States…shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

This section is significant because it frames disability as a civil rights issue, assuming that various kinds of disabilities are often used as a basis for discrimination. Included under “any program or activity receiving Federal financial assistance” are schools, including colleges and universities, libraries, and other socially and culturally important entities and programs. As historian Paul Longmore puts it, Richard Nixon left Americans with disabilities an unintended legacy, a legal weapon he had been unaware of and surely would have opposed as too expensive. In one of American history’s ironies, Richard Nixon had signed into law a major civil rights statute that the new generation of disabled people would use to fight discrimination, perhaps most importantly in higher education, and to gain equal access to American society. (Why I Burned My Book 105)

The Rehabilitation Act, combined with the Architectural Barriers Act of 1968, inserted disability into the discourse of civil rights and laid a foundation for both the Individuals with Disabilities Education Act (IDEA)\(^{4}\) and the ADA.

Before the ADA, however, disability rights advocates had to fight to ensure that Section 504 would actually be implemented. In April of 1977, the American Coalition of Citizens with Disabilities was formed, with the primary aim of seeing Section 504

\(^{4}\) Formerly the Education for All Handicapped Children Act, of 1975 which entitles all disabled people to “a free and appropriate public education” in the “least restrictive environment.”
implemented, especially in employment situations involving Bureaus of Vocational Rehabilitation. The coalition organized sit-ins at Department of Health, Education, and Welfare (HEW) offices in nine American cities, most notably San Francisco, where over one hundred people occupied the federal offices for more than three weeks until Joseph Califano, then secretary of the Department of HEW, signed 504’s regulations into law (Why I Burned My Book 107, 111).

Longmore points out four important features of the 504 sit-in that make it the pivotal political action leading to implementation of the ADA: It framed disabled people’s problems as primarily social rather than medical, especially by way of extensive media coverage showing disabled people as political agents demanding their rights. It aligned disability with other civil rights movements and causes. It created crucial alliances across disability lines, making the movement newly cohesive. And finally, it constructed a positive public image of disabled people (109-110).

With a newfound national consciousness and cohesion, advocates continued lobbying for disabled people’s rights to functional independence and their access to educational, vocational, recreational, and other opportunities that nondisabled Americans often take for granted. The denial of such opportunities fosters a kind of disability in itself. The Rehabilitation Act, and especially Section 504, provided a political context in which activists could continue to voice claims about disability rights that they had been making for years, but with no political precedent to support their endeavors. In the opening section of the ADA, Congress says they find that “historically, society has tended to isolate and segregate individuals with disabilities, and…some forms of
discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” Further, they find that this discrimination persists “in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services.” However, because people with disabilities had not historically been considered “a discrete and insular minority,” they had not had the kind of legal recourse that other minority groups had as a way of claiming and ensuring their rights. Consequently, the ADA set out “(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; (2) to provide…enforceable standards addressing [such] discrimination; [and] (3) to ensure that the Federal government plays a central role in enforcing the standards” (ADA).

By an overwhelming majority, Congress passed the ADA. At the signing ceremony on July 26, 1990, President George H.W. Bush proclaimed, “[W]e rejoice as this barrier falls…Let the shameful wall of exclusion finally come tumbling down.” By legislating against disability-based discrimination, the federal government subscribed to a minority group model of disability, as many scholars of disability have pointed out.5 Here I am intentionally sidestepping complicated questions surrounding this minority group model, as well as issues connected with the specifics of the law’s implementation, since my project is focused on attitudes revealed in contemporary (post-1990) literary texts,

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5 For example, Harlan Hahn, “Accommodations and the ADA: Unreasonable Bias or Biased Reasoning?” in Backlash Against the ADA, ed. Linda Hamilton Krieger.
Regardless of the way the ADA has been interpreted and upheld in its intent. Suffice it to say that in the period between 1970 and 1990, political activity relevant to disability both reflected and furthered the tendency to view disability as a sociological, architectural, civil rights issue relevant to nondisabled people. Federal legislation addressing the built environment, institutional conventions, public policy, and exclusionary attitudes unsettled assumptions about disability’s meaning. At issue are assumptions that the disability experience is static or determined by a particular form of embodiment. Instead, this period in American history—along with the narratives to which this period gave rise—has helped clarify how individuals, institutions, and whole societies actually construct disability to a significant degree.

What is disability?

In saying that disability is constructed, I am assuming that while events, phenomena, and agents exist apart from interpretation, they do not necessarily matter apart from interpretation. For example, when I see the high fence surrounding my neighbor’s back yard, it is a collection of visually and structurally congruent pieces of wood arranged in a rectangular shape that marks off (or rather, identifies) certain space. I could say more about the physical properties of the fence, but suffice it to say that the

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6 I will address these questions to an extent in my conclusion, though in rather general terms. Linda Hamilton Krieger’s collection Backlash Against the ADA: Reinterpreting Disability Rights takes on these questions head-on, from the perspective that the ADA has been severely curtailed in the years since its passage. Case law reveals that an overwhelming majority of plaintiffs filing suits under the ADA lose their cases. See also Ruth Colker, The Disability Pendulum: The First Decade of the Americans with Disabilities Act (2005).

7 For her help in making decisions about what terms to use here, I am grateful to Stephanie Smith McHenry.
fence would exist, and all the things I have just mentioned would still be true, regardless of my presence near or any relation I might bear to the fence. However, the fence does not matter until it has some effect on me (or someone) or on the way I (or someone) think about some aspect of myself, my life, or the world I live in. In this case, my neighbor’s fence prevents me from seeing his yard from ground level and also prevents me from moving freely onto his property. His fence matters to me because it affects my perception of and engagement with the space surrounding my home and, by implication, my understanding of what kind of attitude my neighbor has toward his property and the way he wants me (and others) to relate to it.

The neighbor’s fence also matters because there are laws dictating that the neighbor has a privileged relationship to what the fence encloses—namely, that it is his property. Thus, my neighbor can do things to the space the fence encloses that I cannot. If I do something to the property—say, plant a tree on the grass or burn a message into it—there will be consequences. These consequences are not, strictly speaking, the result of anything about the property itself, but about the institutional and discursive factors that bear on the property and make it matter in a certain way. However, depending on what kind of relationship I have with my neighbor, how zealous I am about burning messages into his grass (or grass in general), and other factors, those contextual elements will have varying degrees of impact on my life and my relationship to both my neighbor and his property.

Both this contextual dimension of being and mattering and the relational one I discussed in the previous paragraph are relevant to thinking about disability. In the
section on disability politics I touched on the political factors that have shaped
disability’s meaning in an American context, and in the following paragraphs I will
discuss the conceptual and ethical status of disability in the field of disability studies.

Most disability studies scholars and disability rights advocates posit a distinction
between disability and impairment—a distinction predicated on the difference between
phenomena and their significance that I have just discussed. On this account, disability is
the result of an interpretation, a socially derived way in which the existence of certain
bodily features is made to matter. The goal of making this distinction is to show that
while one can have any number of things be true of one’s body, those things can matter
differently depending on what situation or context that person exists in and how people
interpret her or his body. If certain properties of human bodies are only disadvantageous
given a certain social arrangement, then changing the arrangement changes the extent to
which those bodies are “unable” to participate in some activity or another. For example,
if a woman has one arm, that simply means she has one arm. Since the majority of
humans have two arms, the argument goes, having one is an impairment. Strictly
speaking, though, having one arm is simply a fact about one’s body. The woman with one
arm is only disabled insofar as certain activities or conventions of a society require that
one have two arms, and so her one-armedness matters because it inhibits her participation
in conventionally defined practices—in ways that call attention to that bodily feature.

The most important function of the distinction between bodily features and
disability is that it destabilizes the value of various bodily features and makes possible a
range of meanings that human bodies might be assigned in diverse contexts. Depending
on one’s life situation and culture, a bodily feature might be a non-factor, a disadvantage, an advantage, or a source of insight or pleasure. In a culture where people walk several miles a day for water, a person with a chronic illness producing fatigue would be disabled, whereas in an urban center with good public transportation, the same physiological property may not disable a person at all. Some bodily features might even mean different things in different moments. A nurse with persistent nausea, for instance, might be disabled insofar as his nausea affects his ability to do his job, but might find it an advantage insofar as it improves his bedside manner with ill hospital patients. He may say something like, “For as much as my illness gets in the way of my work sometimes, I’m glad I have it for the sake of these patients.” This statement reveals that in at least some cases, the meaning of a bodily feature vacillates according to its influence on certain functions or relationships.

Lennard Davis has put pressure on the impairment/disability distinction itself, questioning the extent to which impairment is self-evident, as well as the value of placing disability as one among many identity markers like race, gender, and sexuality. Davis argues that the concept of impairment “relies heavily on a medical model for the diagnosis of the impairment…Particularly with illnesses that did not exist in the past, the plethora of syndromes and conditions that have sprouted…we have to question the clear line drawn between the socially constructed ‘disability’ and the preexistent and somatic ‘impairment’” (*Bending Over Backwards* 23). For Davis, to call something an

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8 Incidentally, there has been fruitful work at the intersections between disability and other identity categories. See, for example, Suzanne Bost’s *Encarnación: Illness and Body Politics in Chicana Feminist Literature*. 
impairment is already to have fitted it into a social framework that makes assumptions about what human bodies are or should be. Ultimately, Davis wants to scrutinize the distinction because in his view both impairment and disability are identified and named against the backdrop of an illusory concept of the ideal body. Further, the project of campaigning for equality among all people aims at an ideal of autonomy that may not be as self-evidently desirable as most advocates have suggested. Davis says, “Politics have been directed toward making all identities equal under a model of the rights of the dominant, often white, male, ‘normal’ subject,” and this is a misguided effort (30).

Instead, Davis advocates a mode of thinking about bodies that he calls “dismodernism”:

In the dismodernist mode, the ideal is not a hypostatization of the normal (that is, dominant) subject, but aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence. This is a very different notion from subjectivity organized around wounded identities [as under identity politics]; rather, all humans are seen as wounded… Protections are not inherent, endowed by the creator, but created by society at large and administered to all. The idea of a protected class in law now becomes less necessary since the protections offered to that class are offered to all. (30)

I agree with Davis to a significant degree, especially with regard to two of his presuppositions: first, the fact that all humans are “wounded” (in the sense of having needs and requiring protection and provision from others as a result) and should be seen as such; and second, that it is possible to imagine the kind of universally considerate, interdependent social arrangement he imagines. If all humans are wounded, then it follows logically that all humans are in need of some kind of services or accommodations, in some area of life or other.
Under this paradigm, thinking about disability is necessary to understanding what it is to be human. By necessary, I mean that we cannot reckon with humanness without reckoning with disability. Try as some might, we cannot thwart the radical contingency of our bodies, as evidenced by congenital disability, temporary disability due to injury, acquired illnesses, and most of all, death. The fact that we continue trying to elide our frailty is curious in its own right, as Tobin Siebers has pointed out:

The briefest look at history reveals that human beings are fragile…And yet the vision of the future to which we often hold promises an existence that bears little or no relation to our history. The future obeys an entirely different imperative, one that commands our triumph over death and contradicts everything that history [and, I would add, experience] tells us about our lot in life. (Disability Theory 7)

Davis’s claim about humans’ “woundedness” alongside his assertion that our common wounded state should lead to the pursuit and provision of accommodations leading to “functionality” points toward the same paradox that Siebers identifies here. In each case the tension hinges on what it is about humans that makes us at once aware of our limitations, fearful that we will not have what we need and want, and eager for certainty and peace of mind about our futures. Both Davis and Siebers want to destabilize the notion of “normal,” posit a new account of humanness that acknowledges our fragility, and also lay claim to universal human rights.

While both are committed to the rights of disabled people, Davis and Siebers ultimately disagree about the means to achieving those rights. Davis scrutinizes definitions of humanity and identity that depend on membership in ethnic groups or gender categories, while Siebers is deeply critical of definitions that depend on rationality

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9 Chapter 4 is a case study of the havoc this tension between fantasy and reality causes.
as a criterion for humanity, specifically because of the problematic position of people with significant intellectual disabilities under such a definition. In their proposed alternatives, we find one conception of humanity that assumes interdependence and need without providing a particularly clear foundation for the right to having those needs met (Davis’s), and another, Siebers’s, which I find even more problematic. Siebers urges that “another universal and metacritical concept of the human that moves beyond the eighteenth-century use of rationality as the determining factor for membership in the human community is urgently required if people with disabilities are to attain the respect due to them and if we are to make progress as a democratic society.” He proposes the following as a new definition: “Humanness is defined by the aspiration to be human but in a paradoxical way that includes as part of that aspiration the requirement that one concede to other human beings the status of human being in order to be recognized as human oneself” (93). It is not only the tautological quality of Siebers’s definition that leads me to object to it. It is also flawed in its attempt to address the very problems that occasion it. Siebers says that to be human is “to aspire to be human.” This is a highly abstract cognitive function, and in fact the only kind of creature that could aspire to be human would be a human with well-developed cognitive faculties. It is difficult to imagine a person with a significant cognitive impairment understanding the notion of aspiring to be something one already is, for example. (This is not even to mention the basically unimaginable task of aspiring to be human.) To “concede to other human beings the status of human being” is equally problematic, for then a person with a mental illness
such that she viewed all other beings as animals or, say, robots, would be, on this definition, non-human.

While I understand the rationale behind these two conceptions of humanity and human rights and am deeply sympathetic to their aims, I think more work needs to be done in order to provide a foundation for a progressive definition of disability that securely grounds an egalitarian disability rights agenda. Such work is beyond the scope of this project; however, I want to point out briefly that in the absence of some normative moral standard, it becomes difficult to make strong claims about human rights. This is perhaps especially true in a world that, as Siebers points out, has since at least the eighteenth century so prized rationality as a baseline criterion for being human. How can we arrive at an understanding of humanity on which to base claims about the inherent rights of all individuals? In some cases, such an understanding would not be necessary: it is not at all an ethical given that all people deserve rights—or at least not the same rights.\(^\text{10}\) For the purposes of this project I will assume the appropriateness of the field’s agenda and ideals even as I acknowledge that I am dissatisfied with existing attempts to provide a defensible justification for them.

My working definition of disability in the project builds on feminist philosopher Susan Wendell’s.\(^\text{11}\) I will assume that disability is any persistent inability—the cause and perpetuation of which involves the interaction of biological, social, and experiential

\(^{10}\) I find it difficult to justify a commitment to universal human rights successfully apart from an explicitly theistic account of humanity. Such a justification for universal human rights bears on disability politics and disability studies because it provides a foundation on which to insist upon those rights even in the absence of a social consensus that they ought to be extended and defended.

factors—to participate in at least one necessary or highly valued part of life in a given society. This definition preserves the distinction between being and mattering, including under the heading “disability” only those impairments which are made to matter and not the brute facts of someone’s body. It also acknowledges that disability is constructed as an experience by institutions, interactions, and attitudes in a given environment, and that that experience can be both positive and negative. Sometimes being “left out” of certain activities can be pleasurable and generative, and the shared experience of being categorized or treated a certain way in a society often creates new communities of people—in this case, the disability community, which is open to all who have had the experience of disability in our (American) social arrangement. Finally, the definition requires that in order to count as an identity marker, disability must be “persistent,” a word that admits some flexibility. I would consider a lengthy recovery from injury a temporary disability that would bring one into the disability experience. However, I would not consider the momentary experience of getting soap in one’s eye a disability. The possibility of temporary but not momentary disability also brings another needed qualification to Davis’s description of “dismodernism”—namely, that we are not all “wounded” all the time (except insofar as we are always imperfect in various ways, which seems to me something different from being wounded), just as we are not all healthy all the time.

A fluid but not entirely constructivist view of disability such as this one makes clear the importance of stories about bodies: they take the stuff of bodies, which simply are, and communicate something about how and why those bodies matter. Bodies are and
have been assigned all kinds of significance, roles, and value in different cultural and historical contexts, and those assignments have substantial effects on the nature and quality of people’s lives. Because people have told and do tell stories about bodies, and because those stories often bear significant consequences both for individuals and for societies, carefully thinking about these stories is a worthwhile endeavor. This leads me to the central question narrative theory asks: what are stories, how do they work to create meaning, and for whom? In this project, I am exclusively concerned with how stories construct meanings of disability. As I will explain below, I work from the perspective of rhetorical narrative theory, into which I incorporate ideas developed in other strands of contemporary scholarship on narrative.

**Narrative Theory**

I should clarify at the outset that, in developing a narratological approach to literary disability studies, my primary impetus is not a dispute with the conclusions prior critics have drawn about texts involving disability. Rather, my interest in developing a new methodology for the field stems from my sense that disability studies in literature is at a point where its continued vitality depends on its demonstrating that it can improve and nuance literary studies at large—in addition to continuing to expose insidiously discriminatory treatments of disability in literature. In this project I have selected texts that approach disability as a multifaceted aspect of identity that affects every area of a disabled person’s life. My claim that these texts' approach is progressive comes from a consideration of these narratives as communicative acts that involve an exchange
between an author and an audience situated in a particular place and time. In other words, my claim about these texts’ perspective on disability comes from my readings of them through the lens of (especially, but not exclusively) rhetorical narrative theory.\textsuperscript{12}

The rhetorical approach to narrative, developed by Wayne Booth, James Phelan, Peter Rabinowitz, and others, thinks about stories primarily as communicative acts. Phelan’s definition of narrative, which I will assume throughout the project, is “somebody telling somebody else on some occasion and for some purpose(s) that something happened” (Experiencing Fiction 3). Whatever else stories might be—entertainment, latent instructions, reflections of cultural values alive at the time of the work’s production—they consist fundamentally of one or more tellers expressing to one or more audience members that some event has come to pass.\textsuperscript{13}

The “occasion” and “purpose” parts of this definition are especially important for this project. Though there may be other, relevant occasions for the texts I analyze, the primary occasion I want to keep in mind is the post-ADA, increasingly disability-aware

\textsuperscript{12} There are multiple branches of narrative theory, including cognitive, rhetorical, and what might be called “contextual” or “ideological.” I draw on all three of these branches in the present study, but I employ the cognitive and ideological insofar as they throw light on the rhetorical functions of the text in question. For example, in Chapter 4 I draw on psychologist Jerome Bruner’s idea of narrative as a conceptual framework—not a rhetorical approach as such. However, part of what drives Bruner to the conclusion that narrative is a cultural tool for sense making is his understanding of the rhetorical uses to which narrative is put in our efforts to organize our experiences: we persuade ourselves that our experiences mean a certain kind of thing and not another. Similarly, in Chapter 3 I use Dorrit Cohn’s idea of consonant and dissonant narration to explore the progression of Stephen Kuusisto’s Planet of the Blind. Cohn is not a rhetorical narrative theorist. However, as I use it, her model is helpful as a way of describing Kuusisto’s rhetorical self-presentation to his authorial audience: I was this way, and here is what that was like. I am now another way, and here is what it is like.

\textsuperscript{13} I want to emphasize that the rhetorical model insists that narrative is communication, but does not in any way exclude considerations of cultural or historical context or of the functions of a given narrative. To the contrary, consideration of context and rhetorical purpose are crucial aspects of understanding authorial agency and audience response. See Phelan, “Chicago Criticism, New Criticism, Cultural Thematics, and Rhetorical Poetics” in Experiencing Fiction.
contemporary world. At the same time, I want to remember that there is plenty of room within a legal or discursive context to think in diverse ways about a given issue. While the ADA and other disability rights legislation have improved disabled people’s everyday lives substantially and have changed how many people think about disability, that does not mean that disability is a static entity in the world or in literary narratives. For this reason, I aim to allow each of my primary texts to have its own say about disability, even as I note a general trend toward a more progressive understanding of disability than we find in earlier, pre-ADA narratives. Moreover, in each text it will be important to consider not only the authorial “occasion” of the post-ADA world, but also the narratorial occasion for telling of the story. In a memoir like Kuusisto’s *Planet of the Blind* (Chapter 4), the occasion for author and narrator are quite similar. In contrast, novels with character narrators can involve substantially different occasions for author and narrator (see Chapter 3 especially).

As I approach each novel, memoir, or graphic narrative, I ask, “What is disability’s status in this text?” In asking that question I set myself the task of tracing disability through the narrative progression in order to find out what stance the implied author, narrator, characters, and authorial audience take toward disability—and what each of those parties thinks of the others’ stances. In order to do this, I need to understand the component parts of narratives as well as the impact of the temporal progression of a narrative on its treatment of people, events, and ideas.

Phelan helpfully summarizes the specific dynamics of the narrative transaction as
a recursive relationship…among authorial agency, textual phenomena… and reader response. In other words, for the purposes of interpreting narratives, the approach assumes that texts are designed by authors in order to affect readers in particular ways; that those designs are conveyed through the words, techniques, structures, forms, and dialogic relations of texts as well as the genres and conventions readers use to understand them; and that reader responses are a function of and, thus, a guide to how designs are created through textual and intertextual phenomena. At the same time, reader responses are also a test of the efficacy of those designs. (Experiencing Fiction 4)

At different points in this project I will focus particularly on one of these three elements—authorial agency, textual phenomena, and reader response—but, because all three are necessary ingredients in the construction and experience of narrative, I will attend to all three of these factors in each of the chapters that follows, though different chapters will foreground different factors.

When discussing authorial agency, as in Chapter 3, I focus primarily on the implied author, which is the consciousness and value system that readers reconstruct on the basis of their encounters with the narrative text. The implied author concept is important because of the way it allows us to think about intentionality and the presence of a central organizer of textual phenomena. Yet at the same time, the fact that it is an implied author leaves room for textual phenomena (and their implications) that may not have been consciously placed there by the flesh and blood author. Positing an implied author also leaves open the possibility that the perspective offered in a narrative text might not align with a flesh and blood author’s perspective on an issue or character. In general, accounting for the implied author’s perspective reveals a textually-grounded baseline perspective from which to begin discussions of the issues a given text raises.

However, as I show in my discussion of The Curious Incident of the Dog in the Night-
time, tracing the implicit values articulated in narrative texts sometimes reveals inconsistent perspectives toward a given issue within a single text. In such cases, the tension within the implied author’s perspective might help us explain contentious audience responses to the narrative in question. Given contemporary controversies about disability (and especially autism), it should come as no surprise that narrative representations sometimes reflect such contestation in ways we can identify within the narrative itself.

I am primarily interested in the way authors manipulate textual phenomena in order to create certain impressions or effects; my goal is to understand the way the authors of my chosen narrative texts shape their material in order to achieve certain rhetorical purposes. In each of the following chapters I attempt to describe the kind of agency authors exercise with respect to disability and what kinds of responses the texts in question invite, authorize, and disallow. After describing the texts’ rhetorical design and purposes, I offer aesthetic and ethical evaluations of the way they represent disability against the backdrop of the contemporary (post-ADA) world. For Wayne Booth and subsequent rhetorical narrative theorists, a thorough engagement with a literary text first requires understanding (granting the text its presuppositions, making an effort to follow its rhetorical cues, reading in the authorial audience) before one can overstand (critically assess the work, reject its implicit worldview, and make judgments as flesh and blood readers) (Booth, *Critical Understanding* 197).

Chapters 2 and 4 are especially focused on textual phenomena; in them I attempt to describe the ways in which disability affects and is viewed by characters, both fictional
and historical. In Chapter 2 I pay particular attention to the way Lionel Essrog and other characters interpret his Tourette’s syndrome, as well as what role Tourette’s plays in the construction of the narrative as a whole. In Chapter 4 I am interested in the way Stephen Kuusisto as narrator of his own life thinks differently about the experience and meaning of his blindness at different points in his life.

I discuss reader response, the third element in the narrative transaction, in Chapter 5. The text in question—Steven T. Seagle and Teddy Kristiansen’s graphic narrative It’s a Bird...— is a semi-autobiographical story about Seagle’s family history of Huntington’s disease, and also about Superman. Over the course of the narrative progression, Seagle responds both to his family’s responses to and (lack of) discussions about illness, and also to the myth of Superman and his invulnerable body and endurably iconic status. I discuss the way Seagle’s developing understanding of his family and himself depends on the Superman story via a process I call “narrative analogizing.” Likewise, in Chapter 3 I discuss Peter J. Rabinowitz’s taxonomy of audiences in order to account for the layered experience Mark Haddon offers in The Curious Incident of the Dog in the Night-time. This is a more straightforward discussion of audience than the one found in Chapter 5, where I explore ways of thinking about an audience within the narrative world. However, I do extrapolate from the character Seagle’s responses to illness and to Superman more generally in order to identify the implied author’s perspective on the way disability leads us to reconsider broader cultural assumptions about human bodies, as well as the way the Superman story offers a means for dealing with our bodies’ vulnerability.
Another important aspect of Phelan’s rhetorical model that I alluded to above is the centrality of judgments and progressions to the experience and interpretation of narrative. Thinking about narrative progression means understanding that we experience narrative in time. That is, time elapses as we experience narrative (reading a book, watching a film, etc.), and we respond to the content of a narrative based on the way and order in which that content comes to us. Whatever else it might be, experiencing a narrative is a temporal process (*Experiencing Fiction* 3). Further, that process consists of our initial, ongoing and revised, and final judgments about what is happening (interpretive judgments), whether we approve of various elements of what is happening and how we are learning about it (ethical judgments), and whether we are pleased with what is happening and how we are learning about it as a piece of art (aesthetic judgments). Each type of judgment can influence the others, and the point in the narrative progression at which we make judgments can affect both the execution of those judgments and their effect on one another.

For instance, the first part of *Planet of the Blind* largely represents blindness as a significant trial, and some audience members might make a positive aesthetic judgment of Kuusisto’s prose as well as an interpretive judgment that blindness is in fact a misfortune. However, by the end of the narrative progression, while readers will probably retain their positive aesthetic judgments about Kuusisto’s prose, the new way Kuusisto has begun to talk about blindness will lead them to revise their interpretive judgments about the earlier portion. Namely, readers are led to the conclusion that had the younger Kuusisto—the “experiencing-I” of the first part of the book—stood in a different
relationship to his blindness, his experience of it would have been substantially different. However, the educational, social, and cultural environment did not offer him a different relationship to his blindness, and he did not develop such a relationship through his own ingenuity. The possibility of another way of being blind is evident in the dissonance between the beauty of the prose and the sadness of the experience in the first part.

Similarly, my other chapters trace the structure and effects of the narrative progression in my example texts, thinking about how the progression relates to the developing conception(s) of disability offered by the text as a whole.

Rhetorical narrative theory captures the interrelated importance of major aspects of narrative production and reception. The way narrative texts characterize disability reflects something about the way their creators think about disability, but we must pay careful attention to textual cues and how they add up in the context of a progression to present some picture of disability. That picture will partly determine audience response, though preexisting audience assumptions and biases will obviously affect how those audiences interpret and evaluate the narrative in question. For instance, positive aesthetic judgments about the execution of the narrative progression can temper negative ethical judgments about the way a given author represents a disabled character. Or, a reader’s negative ethical judgment of a character whose attitude toward disability is reprehensible might diminish her positive aesthetic judgment of the narrative as a whole.

The recursive account of experiencing narrative also nicely connects to disability studies’ claim that disability is not simply a matter of bodily facts. Rather, disability affects characters’ and audiences’ interpretations of events and texts, the way they
evaluate ethically salient situations, and their senses of aesthetics. Considering the relationships among bodies, ethics, and aesthetics leads me to a discussion of the overall benefits of my project for understanding these primary texts in particular, both for narrative theory and for disability studies.

**Bodies and Stories: Mutual Benefits**

I have explained that narrative theory provides an effective methodology for reading contemporary disability narratives. However, this project aims to accomplish more than simply performing a new reading of literary narratives by way of an interpretive framework it simply had not yet occurred to anyone to apply to those narratives. Beyond that useful methodological intervention, narrative theory benefits disability studies by highlighting and systematically explaining the importance of stories in the endeavor of building compassionate, ethical, and just human communities, which is the activist goal of disability studies as a field. The more stories we have and understand that represent disability as a valuable aspect of identity, the close we will be to having those kinds of communities.

Meanwhile, disability studies benefits narrative theory by highlighting the influence of our bodies on the kinds of stories we tell and the ways we tell them. More fundamentally, disability studies insistently reminds all disciplines that we do *everything* from within our bodies. Narrative theorists have long been quick to point out that narratives unfold in space and time, and disability studies provides the further reminder that our constant boundedness in space and time has primarily to do with our bodies. As
physician and literature scholar Rita Charon puts it, “Combining both functions of occupying space and keeping time, [our] bodies by virtue of their materiality exist within both dimensions, and we are hard-pressed to think of one aspect without the other, no blade without the sheath, no needle without the thread” (34, emphasis in original). By focusing simultaneously on bodies and stories, we can understand both better.

Charon’s recent essay “The Novelization of the Body, or, How Medicine and Stories Need One Another,” explores the mutually beneficial relationship between disability studies and narrative theory in the context of narrative medicine. In contrast to approaches to medicine that focus solely on pathologies and symptoms, Charon offers an approach to clinical practice that situates patients and their experiences in their bodies as they exist in space and time—that is to say, in stories. Such a situated medical practice both fosters connection between doctor and patient (demonstrating the importance of stories to bodies) and yields knowledge about ourselves and about others as we pay real attention to our bodies (demonstrating the importance of bodies to stories).

On the connection between doctor and patient, Charon remarks that when physicians invite patients to narrativize their embodied experiences, patients encounter physicians as stewards and sharers of their stories rather than as invaders of their bodies, their homes. In turn, as physicians digest and retell those stories, the new,

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14 I am fully aware that Charon is focused on the ill body and not the disabled body, and that the two are different. However, I think her insights in this particular essay can be generalized without much trouble. The language of doctor and patient in the claims I am citing here could easily be about any two persons communicating about their embodied stories. Moreover, I do not detect any privileging of the doctor position in Charon’s insights except insofar as one visits a doctor in order to seek some insight into and amelioration of bodily conditions that one could not otherwise attain—in the absence of a certain type of training in interpreting the body. Other debates about the institution of medicine (and the hierarchy of its structures and discourses) vis-à-vis issues of disability are outside the bounds of this study.
collaboratively-authored stories “become powerful hypothesis-generating acts, enabling the writer to give expression to half-formed impressions that can often lead to clinically useful perceptions” in the context of medicine (41). More generally, sharing stories together, the two parties “accrue not only knowledge of self and other through this recognition [that the body is the home of the self] but also knowledge directly of the relations to others at these personal membranes through the agency of bodies” (47).

In Chapter 2, I argue that Lionel’s story of his experience of Tourette’s from youth to adulthood makes possible for Lionel, other characters, and readers an understanding of what it means for Lionel to have Tourette’s. This type of narrative understanding could not come exclusively from a clinically oriented book like *Understanding Tourette’s*, which Lionel receives from his mentor and which focuses on symptoms and pathologies (and which, incidentally, Lionel finds unhelpful). Rather, in order for Lionel, other characters, and readers to understand Tourette’s well, we must incorporate the bodily facts that signify “Tourette’s” into an awareness of Lionel’s life and experiences. Similarly, in Chapter 4 I show that Stephen Kuusisto’s story of blindness yields not only an understanding of his experience of blindness but also a broader aesthetic of blindness—a paradigm that opens a multifaceted understanding of blindness and facilitates a sympathetic connection between Kuusisto and others, both readers and people in his life, based on his story.

On the knowledge that reflecting on our bodies can provide, Charon (in part quoting Carrie Noland) writes,
Instead of a reductive or essentialist or dismissive approach to the bodily state, we might grow in our deep knowledge of self and other through a careful and respectful hearing out of sensate, kinesthetic, corporeal phenomena. As we learn from recent scholarship on sensuous lived experience, “anthropologists, archeologists, and dance ethnographers have been exacting in their approach to understand just how the body’s experience of itself might play a role not only in the emergence of subjectivity but, further, in the process of meaning construction in which cultures are involved” (Noland 12). (39-40)

What Charon and Noland are saying is that thinking about the way embodiment affects experience is an essential part of understanding both human subjectivity and processes of meaning making among human cultures. For instance, as I discuss in Chapter 3, fraught as his understanding of autism might be, Mark Haddon is interested in The Curious Incident of the Dog in the Night-time in how Christopher Boone experiences the world and organizes his experience given that he is autistic. And in Chapter 5 I draw on Jerome Bruner’s insights in “The Narrative Construction of Reality” and Acts of Meaning and Mark Turner’s in “Double Scope Stories”—insights quite similar to Charon’s and Noland’s above—to examine how Steven Seagle’s family history of embodiment leads him to engage with cultural products like Superman. If Huntington’s disease were not a factor in his family history and a potential influence on his own body, Seagle’s response to Superman would not be the same.

No matter how deep our understanding of one another’s embodied experiences, we exist in a world that operates on more than interpersonal connections. We live with institutions, built environments, public policies, and other influences that mediate our relationships with our bodies and with one another. In my conclusion I explore the current socio-political context of disability as a way of making a further plea for the
importance of careful attention to well-crafted stories about disability. Understanding stories about disability is an important part of the future of disability rights, and not just part of the process of studying the mutually beneficial relationships between narrative theory and disability studies.

Looking ahead

Each of the chapters in this project focuses on one or two primary texts and uses concepts from narrative theory to articulate disability’s status and function over the course of the narrative progression in the primary text(s). Consequently, the project demonstrates the usefulness of narrative theory for engaging disability in narrative, drawing out the values the implied author, narrator, characters, and authorial audience hold with respect to disability. This accomplishes the project’s second major goal: developing a new methodology for disability studies in literature.

As for the selection of texts, I have intentionally chosen texts in a range of media and genres: fiction, nonfiction, and something in between; novels, memoir, and a graphic narrative. The texts also deal with different kinds of disabilities: Tourette’s syndrome, traumatic brain injury, autism, blindness, and chronic illness. My selection criteria are intentionally broad, since the project is meant to demonstrate the usefulness of narrative theory for interpreting all kinds of literary texts that deal with all kinds of disabilities. Moreover, I aim to identify trends in the representation of disability in contemporary texts, not just those in a particular medium or genre, or those that deal with a particular
kind of disability. Based on my earlier argument that disability is an identity marker primarily because of its social components, which are common to disabled people living in a given social arrangement, one would not expect to find radically different treatments of different kinds of disability. Arguably, the key differences among the texts I discuss are the result of their authors’ and narrators’ different rhetorical purposes and strategies, not of the different disabilities their authors, narrators, and characters have.

Chapter 2, “Ubiquitous Invisibility, Visible Ubiquity: Disability in Contemporary Fiction,” contrasts two novels: Brady Udall’s *The Miracle Life of Edgar Mint* and Jonathan Lethem’s *Motherless Brooklyn* (from 2001 and 1999, respectively). I show that *Motherless Brooklyn* is an example *par excellence* of a contemporary narrative text in which disability takes on a broad range of meanings and remains a central interest at the level of plot, theme, and aesthetics. Meanwhile, in *Edgar Mint* disability recedes to a vanishing point after catalyzing the plot, a disappearance made especially noticeable in contrast to the novel’s sophisticated and poignant representations of family, friendship, and ethnicity. Since both novels were published in 2001 and since they bear significant similarities—both feature disabled, twenty-eight-year-old, orphan narrator-protagonists with self-chosen missions centering on mysterious older male figures in their lives—they make for a useful pairing as examples of different ways of engaging disability in narrative. Moreover, the differences in these texts’ representations of disability demonstrate that disability’s meaning and aesthetic potential in contemporary literature are anything but monolithic. This chapter demonstrates that even though the ADA has been in force for twenty years, disability can be and is still engaged differently in
narrative texts—sometimes favorably, and sometimes only instrumentally to catalyze a plot.

Chapter 3, “Implying Authors and Reading Minds: Mark Haddon’s The Curious Incident of the Dog in the Night-time,” uses Wayne Booth’s concept of the implied author and Peter Rabinowitz’s taxonomy of audiences as a way to account for the controversy surrounding Haddon’s massively popular 2003 novel and its autistic narrator-protagonist. Autism’s meaning within the novel is unresolved, and even if the flesh and blood Haddon has a well-established and singular understanding of autism, the tension in the text makes Curious Incident an ongoing site of debate in what have come to be called “the autism wars”—a debate among parents, autistic people, advocates, and researchers that centers on the meaning, diagnosis, and appropriate rhetorical, scientific, and affective responses to autism. This chapter shows that disability is contested even within single narrative texts, complicating the simple binary between “good” and “bad” disability narratives that Chapter 2 might suggest on its own.

Chapter 4, “Consonance and Dissonance in Stephen Kuusisto’s Planet of the Blind” uses narrative theorist Dorrit Cohn’s distinction between consonant and dissonant self-narration to explore disability’s shifting meaning within the context of an individual life, as told in a literary memoir. At the time of writing Planet, Kuusisto considered blindness a positive and productive way of being, whereas blindness throughout much of his life prior to the time of writing was a source of insecurity, shame, and self-protection. Once the status of blindness on the level of the book’s plot (involving what Philippe Lejeune calls the “experiencing-I”) aligns with the status of blindness in the author’s mind
at the time of writing (at the level of the “narrating-I”), the affect and tone of the book shift dramatically as Kuusisto turns toward his conclusion, at which point he has embraced blindness and his identity as a confidently blind man. This chapter makes clear that the shift in disability’s meaning initiated by the ADA has affected actual people’s interpretations of themselves as disabled people, highlighting the practical effects of the legislation and its ideological (and psychological) implications.

Chapter 5, “Growing Up, Graphically: Cultural Narratives and the Haunted Body in It’s a Bird...,” turns to another medium, the graphic narrative. In this autobiographical text, a comics artist grapples with his psychological “baggage” concerning Superman, whose invulnerable, inviolable body he first encountered while his grandmother was dying of Huntington’s disease, a degenerative and incurable neurological disorder. Rather than being primarily a Superman comic, It’s a Bird... is fundamentally a meditation on the tenuousness of cultural myths about physical bodies in light of those bodies’ undeniable frailty. Far from using disability as a metaphor for misfortune or evil, as other superhero comics have done, It’s a Bird... uses one of the most iconic figures in American culture to explore our collective anxieties about our bodies. Over the course of the narrative progression, the protagonist, Steve, engages in a process I call, building on the work of Jerome Bruner, Mark Turner, and Gilles Fauconnier, “narrative analogizing”—synthesizing aspects of the Superman story with his own life experiences—in order to make peace with his family history, his body, and also the Superman story he formerly spurned.
The conclusion, “The Role of Stories in the Future of Disability,” highlights the complexity and controversy that still surrounds disability as evidenced by the texts discussed in each chapter and, by extension, the project as a whole. It then turns outward toward the broader social world, citing evidence from current events that reveals that though disability’s legal status has changed, its status in the contemporary world does not always reflect the kind of liberating change the pioneers of the ADA envisioned. Consequently, narrative representations of disability have a substantial role to play in the ongoing shaping of disability’s meaning within the wider culture.
Chapter 2—Ubiquitous Invisibility, Visible Ubiquity: Disability in Contemporary Fiction

Introduction: Constructing Disability

Whatever kinds or pieces of art we like, we like for reasons, even if we cannot always explain those reasons. Even such an intuitive pronouncement as, “Well, I just like it,” is a reason, based on the standard (albeit ill-defined) of the subjective impression an encounter with a work of art makes. But where do those standards and impressions come from? Do we bring the standards to works and then judge works by the way they do (or don’t) measure up? Is it possible for us to take on different values than those we hold in our everyday lives as we engage with an artwork, so that our standards for good art are not the same as our standards for, say, good friends? If so, how do such shifts take place, and does making them affect how we think after we stop engaging directly with the artwork?

According to rhetorical narrative theory, we can answer these questions in this way: Our pre-existing preferences and standards for narrative come from any number of places—our backgrounds, social circles, personalities—and as audience members, we bring those idiosyncratic prejudices to every text we encounter. However, when we engage with a narrative, it is possible for us to take on different ways of thinking than we use in our everyday lives. We do this by choosing to participate in the authorial audience,
which is an audience position we construct and enter based on the implicit and explicit
norms and values exhibited, endorsed and disapproved of by characters, narrators, and
the overall (authorial) perspective we infer from the text. The authorial audience position
we infer from the text is, as it were, a blueprint for an “ideal” audience experience.
Moreover, the authorial audience’s values and preferences may be similar to or quite
different from flesh and blood readers’, and the distance between the two can make entry
into the authorial audience easier or more challenging for some flesh and blood readers.
For instance, a reader committed to philosophical materialism must make some effort to
enter into the authorial audience of Toni Morrison’s Beloved, which grants and
anticipates the existence and agency of supernatural beings like ghosts. Depending on the
skill with which the implied author invites readers to enter the authorial audience and the
extent to which they enter into that audience, a narrative text may affect our
understanding of a type of person, a time in history, or a topic that appears in the
narrative. While the materialist might not leave his encounter with Beloved believing in
the supernatural, he may leave the text with a better understanding of why some people
do hold such beliefs and what effect that belief has on their lives.

Fictional texts both offer their audiences encounters with myriad types of
characters and reflect their creators’ attitudes toward those characters and the situations
they encounter. Different fictional texts contain comparable characters who face
comparable situations, and these texts’ implied authors offer different perspectives on
those types of characters and situations. Often creators of fictional texts choose to engage, via their characters and events, issues that are significant or vexed in the world outside the fiction. Consequently, an audience’s engagement with a fictional text may entail an engagement with significant real-world issues. Such engagements result in an understanding of one perspective on the issue, and can potentially provoke further reflection on and conversation about the issue beyond the immediate experience of the text.

For example, for an audience unfamiliar with disability, Jonathan Lethem’s novel *Motherless Brooklyn* (henceforth *Motherless*) has the potential to advance a general agenda of valuing disability positively—a goal which, aimed at or not, Lethem achieves via the way he not only represents but also utilizes disability in the construction of the novel. In this chapter I explore Lethem’s engagement with disability initially by contrasting Lethem’s text with Brady Udall’s *The Miracle Life of Edgar Mint* (henceforth *Edgar Mint*). While Udall engages matters of ethnicity and family life in poignant and realistic ways, his treatment of disability—in this case, a traumatic head injury with long-term effects—is curiously understated in comparison. I will explain the role disability plays in the narrative progression of *Edgar Mint* and thus explain in formal, rhetorical terms why disability studies scholars are likely to object to it on ideological grounds.

As I will show, *Motherless* constructs an authorial audience that, among other things, trusts and sides with the Lionel Essrog, a Tourettic detective and the novel’s

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15 I discuss the implied author in the introduction and in Chapter 3. The term belongs to Wayne Booth, and for my purposes I define the concept as the consciousness and value system that readers reconstruct on the basis of our encounter with the narrative text.
narrator-protagonist. Essrog is thoughtful, sincere, and an accurate judge of character; even his naïveté about romance and organized crime are endearing. Throughout the novel Essrog is in control of our understanding of events and characters, and from start to finish he proves trustworthy and likeable. Additionally, Essrog is a skillful narrator, lyrical and engaging, and his disability plays a substantial role in the way he tells his story. *Motherless*’s authorial audience trusts and sides with Essrog not *despite* or *irrespective of* his disability, but at least partly *because of* it.

Many disability studies scholars have explored the representation of disability in literature and have insightfully explained the role disability plays in literary texts. As this earlier scholarship has demonstrated, disability in literature can reflect, reinforce, or challenge disability’s role in culture more generally. There have, however, been comparatively few scholarly efforts to investigate the representation of disability in formal terms—that is, in terms that begin with the aesthetics of disability narrative rather than the politics of disability studies. In this project I begin with those formal elements and ultimately draw conclusions about how the texts in question engage disability. While I am committed to the agenda of disability studies as an openly political field, identifying formal properties of texts that might advance and impede that agenda both demonstrates the usefulness of rhetorical narrative theory—a benefit to narrative theory—and shows

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16 An early and notable example is *Images of the Disabled, Disabling Images*, ed. Gartner and Joe. Other examples include David Mitchell and Sharon Snyder’s *Narrative Prosthesis: Disability and the Dependencies of Discourse*, Martha Stoddard Holmes’s *Fictions of Affliction: Physical Disability in Victorian Culture*, and G. Thomas Couser’s *Signifying Bodies: Disability in Contemporary Life Writing*. Also see the Introduction.

17 A recent and important exception that I will mention below is Tobin Siebers’s *Disability Aesthetics*, which focuses primarily on visual and performance art, not narrative.
disability studies scholars and students some ways that narratives can construct and invite audiences into a particular way of engaging with disability—a benefit to disability studies.

“Wheels within wheels”

Motherless Brooklyn and The Miracle Life of Edgar Mint were published just two years apart (1999 and 2001) by American authors of the same generation. Both feature disabled, orphan narrator-protagonists with self-chosen missions that center on formative older male figures in their lives. Lionel Essrog and the eponymous Edgar Mint are both twenty-eight years old when they tell their stories of solving Frank Minna’s murder and finding a particular mailman, respectively. Both narrate their formative years from the perspective of their adult selves. In each text there is thus a “narrating-I”—the person telling the story—and an “experiencing-I”—the self as character over the course of the narrative progression.18 In addition to these global similarities the novels have odd local correspondences. For instance, both books include scenes of a tormentor attempting to force the protagonist to eat feces in response to an involuntary or unwitting insult. By all accounts, Lethem’s and Udall’s contemporary disability narratives form a natural pair.

On the other hand, I may just be finding “wheels within wheels,” the phrase Lionel’s mentor, the small-time criminal Frank Minna, uses to “sneer at” what he perceives as unfounded “notions of coincidence or conspiracy” (Motherless 74). Minna

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18 The terms “narrating-I” and “experiencing-I” are Philippe Lejeune’s and were originally applied to life writing. I explore these concepts more fully in Chapter 4, where I apply them to Stephen Kuusisto’s Planet of the Blind.
chides Lionel and the other three orphan boys who work for him for being “idiots of connectivity, overly impressed by any trace of the familial in the world,” encouraging them to “doubt [themselves] any time [they] imagined a network in operation. We should leave that stuff to Minna…only Frank Minna was authorized to speculate on the secret systems that ran Court Street [in Brooklyn] or the world” (74). By virtue of their youth, inexperience, and backgrounds, the four teenagers are, in Minna’s mind, unqualified to make pronouncements about the way things are. As far as Minna is concerned, the facts of these boys’ lives preclude them having interpretive authority. He would probably say the same of Edgar, who as an orphan desperate for “traces of the familial” resembles the Brooklyn orphans. Both Lionel Essrog (with his Tourette’s syndrome) and Edgar Mint (who sustained brain damage after his head was run over by a mail jeep when he was seven years old) might act as storytellers and stewards of information, but to those like Minna, people like them are at some level—though, as I will explain, not entirely—deficient narrators.

This way of thinking is not unlike the still-regnant paradigm of disability I discussed in the Introduction—an essentially medical paradigm that interprets bodily difference primarily as lack or deficit, and under which human wholeness corresponds to a standard of bodily wholeness. On this account Lionel Essrog and Edgar Mint are by their very nature deficient storytellers and stewards. Any conclusions people like Lionel and Edgar might draw, or any wisdom they might attempt to generate would be suspect—or would at least need to be qualified or corroborated by some more authoritative voice.
Disability matters and functions quite differently in each of these novels. I will spend the majority of this chapter discussing *Motherless Brooklyn*, which is an example of a contemporary narrative text in which disability takes on a broad range of meanings and remains a central interest at the level of plot, theme, and aesthetics. In contrast, in *The Miracle Life of Edgar Mint*, even though Edgar is a sympathetic narrator-protagonist whose voice is uncontested and reliable from start to finish, this text participates in some of the more restrictive conventions of disability representation. As a result, disability in *Edgar Mint* is largely inconsequential, which means almost by definition that what I can say about the novel *qua* disability narrative is quite limited. Consequently, I refer to *Edgar Mint* primarily to draw a contrast with and launch my discussion of Lethem’s *Motherless*. My central aim is to argue that in *Motherless* Tourette’s syndrome remains central not just to the plot, but also to the thematic and aesthetic heart of the novel, and that it is therefore a valuable example of contemporary disability art in addition to being particularly fertile ground for new work in disability studies.

*Edgar Mint’s dealings with disability*

One way of utilizing disability in a narrative progression—the changes in events and characters, and audiences’ evolving responses to those changes—is to have bodily difference catalyze the plot and then recede as the narrative progresses. In this utilization, according to David Mitchell and Sharon Snyder, disability provides an easy symbol of difference, but does not require that the narrative engage disability as such: “[W]hile stories rely upon the potency of disability as a symbolic figure, they rarely take up
disability as an experience of social or political dimensions” (48). This operation, which Mitchell and Snyder term “narrative prosthesis,” is precisely the kind that Udall performs at the outset of *Edgar Mint*, in which the advent of disability absolutely and explicitly summons the tale. The novel opens,

If I [Edgar] could tell you only one thing about my life it would be this: when I was seven years old the mailman ran over my head. As formative events go, nothing else comes close; my careening, zigzag existence, my wounded brain and faith in God, my collisions with joy and affliction, all of it has come, one way or another, out of that moment on a summer morning when the left rear tire of a United States postal jeep ground my tiny head into the hot gravel of the San Carlos Apache Indian Reservation. (13)

By Edgar’s very clear admission, the moment when he became disabled is the central event of his life—more central than the sad story of his family, his migrant lifestyle, the unspeakable horrors he endured in his school years, his closest friendships, his involvement in the LDS church, or anything else. His description of the accident and its immediate aftermath occupies the first twenty-some pages of Udall’s novel. Remarkably, however, after that Edgar’s disability becomes little more than a set piece. Frequent references to Edgar’s “lumpy” head notwithstanding, the massive head trauma that supposedly deeply influenced the rest of his life hardly figures in his telling of that life. Indeed, even the opening chapter, which recounts the accident, is called “The Mailman,” focusing attention on another’s action rather than on disability, or the experience of disability, itself. It is not the case that Udall represents disability *as such* in an offensive or ethically problematic way. Rather, Udall is more interested in disability as a catalyst and an ever-present symbol of Edgar’s distinction than he is in the experience of disability as such.
In narrative theoretical terms, disability in *Edgar Mint* is a backdrop for rather than the substance of any of the novel’s global instabilities (unstable situations between characters, between a character and his environment, or within a character) and tensions (gaps in knowledge, beliefs, or judgments between either the narrator or the implied author and the authorial audience) (Phelan *Narrative As Rhetoric* 218). Edgar does not have to learn to negotiate a disabled identity, except insofar as his appearance makes him a target for persecution; but this means that disability’s primary significance is as an explanation for why he is treated poorly by other characters. The authorial audience’s interest in Edgar’s disability is similarly not in disability as such, but in his conflicts with other characters (which are sometimes based on his appearance) and his self-chosen mission in its wake (finding the mailman and reassuring him that all is well).

One might object that I am faulting Udall for failing to do something he never meant to do—that *Edgar Mint* is constructed largely as a fantastical novel and thus it is quite unlike Lethem’s comparatively realistic detective novel. Perhaps the difference in genre accounts for the different ways disability functions in each text, especially when we consider that Udall has explained that he “write[s] for the emotional experience of it, for me as the writer and for the reader” (Toffoli, “Interview With Writer Brady Udall”). If Udall did not mean to engage disability as such, then surely I cannot censure him for it. I grant that there are genre differences between the novels. The problem, as I see it, is that although plenty of moments in *Edgar Mint* are fantastic and implausible—perhaps most notably, Edgar’s too-easy survival of a leap from a fifty-foot cliff onto waiting rocks—
the novel deals realistically with other serious social issues like adoption, race, and the cycle of poverty.

For instance, *Edgar Mint* is rife with unsubtle commentary about the Native American experience in the contemporary United States. One of the most significant bits of commentary on ethnicity coincides with a significant moment in *Edgar Mint*’s plot: the visit of “[t]he great Native American poet Vincent DeLaine, some famous guy we’d never heard of. *Native American*, they said, like it meant something. I still wasn’t sure what the difference was between a *Native American* and a regular Indian” (202). Edgar describes DeLaine’s visit in a way that creates substantial tension between what he perceives as an idealized “Native American” and being a “regular Indian” at a place like Willie Sherman School on a reservation near Globe, Arizona:

> The first poem Vincent DeLaine read was something about stealing horses and ponies neighing and the blood of the horses on the grass. Vincent DeLaine read his poem in a strange voice with an exaggerated singsong to it, the way white people talk when they want to make fun of Indians, the way we sometimes heard the cooks or the teachers imitating the students…Sometimes Vincent DeLaine raised up his arms and yelled some of his poems in a loud, angry voice…With his green Town Car and his own pretty lady friend and such nice clothes, I didn’t see what he had to be mad about. (203-204)

After the reading, the students gather outside, where the bully Nelson Norman confronts Edgar for having accused Nelson of stealing contraband from the principal’s office. As Nelson “began to pound [Edgar] into the mud, his great fists landing on [Edgar’s] head and back like heavy stones dropped from a great distance,” Edgar’s friend Cecil shoots Nelson with three arrows, the last striking him “dead center, the easiest shot ever made” (206-207). Cecil’s attack lands him in prison, while the accusations against Nelson
occasion his removal from the school, which leaves Edgar with no friends and no antagonist at Willie Sherman. This chain of events nudges Edgar toward becoming a Mormon and, eventually, moving to Utah to live with a white Mormon family. During the assault, “Vincent DeLaine, the Native American poet, emerged from the auditorium just in time to see me being carried off to the infirmary…and Nelson laid out on the side of the road, two arrows sticking out of him. Vincent and his assistant practically dove into the Town Car before it fishtailed off” (208). The juxtaposition of the sterile and artificial-seeming poetry reading with the chaos and grimness of life on the reservation, combined with the persistently elongated and formal references to DeLaine as “Vincent DeLaine, the Native American poet” demonstrate at least some interest on Udall’s part in matters of ethnicity as a social phenomenon.

The students at Willie Sherman have no category for a “Native American” like DeLaine, hence their laughter when they begin to hear his “singsong voice;” “but immediately [they] quieted down when he looked up from his book and glared into the darkness. He wore a tomato-red shirt, a necklace with beads and animal claws, and braids that lay rigidly on his shoulders like brightly polished billy clubs. He was not, we finally understood, trying to be funny” (203). As he goes on to read poems “about Indians getting butchered, about the sorrow of old women, about the coyote and the eagle and the crow and a bunch of other animals walking around talking to each other,” Edgar notices DeLaine growing visibly upset. Yet for Edgar, the evidence of DeLaine’s own wealth and comfort makes the poet’s expressions of contempt for a cruel world ring hollow; Edgar “didn’t see what he had to be mad about” (204). Moreover, DeLaine soon flees the
present manifestations of violence that are, presumably, the after-effects of the past problems for which the poet just expressed his sympathetic contempt.

Ethnicity (and class) also surfaces in discussions and examples of relationships between Native Americans and white people—especially but not only Mormons, who send missionaries to the reservation and sometimes arrange for orphans to be adopted by Mormon families. As she and Edgar watch some missionaries, Prissy, an older Native American girl, explains to Edgar, “Them guys are called the Elders…They talk to you about Jesus Christ and all that…And if you join up with them, join their church, they’ll send you to live with a rich anglo family somewhere. Utah, mostly…The only problem is it’s you the Indian and everybody else anglos. They’ll ask you stupid questions” (188-189). As Edgar tries to imagine that strange world, he encounters a female tourist and her son.

They were looking at the cavalry bell when the boy turned and saw me. He had rust-colored hair and freckles that covered his face and arms like he’d been splashed with tomato juice. He came up to me and looked me over, put his face close to mine. “These Indians stink,” he said. His mother turned, took off her sunglasses, and smiled at me. (189)

In response to the insult, Edgar “took a few steps back, snatched a rock out of the dirt, and drilled [the boy] in the belly with it.” The woman cries out, “He hurt my son!” as a school employee named Raymond comes out and makes a show of “whack[ing Edgar] over the head a few times with his magazine. ‘No Edgar! Bad! Very bad!’” However, as the tourists drive away, Raymond asks Edgar, “‘What’d you hit him with?’ ‘Rock,’ I said. ‘You get him solid?’ ‘Pretty good in the stomach.’ He patted me on the back, ‘That’s the way’” (189-190). In this short scene, the implied Udall demonstrates his awareness of
and interest in the complexities of race in the United States. Specifically, he demonstrates an understanding of the nuance present in cases in which a member of a minority group apparently plays to the expectations of the dominant group, but actually subverts those expectations. Raymond wholeheartedly approves of what Edgar has done, but must make a show of disapproval in order to satisfy the white tourists’ expectations that they should not be held responsible for their ill treatment of Edgar and those like him.

However, no similarly complex scene involving disability—by itself or in connection with race or ethnicity—appears anywhere in *Edgar Mint*. While the logic of race relations in the contemporary United States is dramatized, the logic of disability and its potential connections with race are not.

Disability studies scholars have observed that representations of disability obey an unspoken imperative according to which the disabled person must either be killed or cured. Interestingly, Edgar inhabits one and then, for all practical purposes, the other: after the “formative event” at the age of seven, his “heart quivered to a stop, [his] lungs shut down and [he] became an inanimate object” until, having been resuscitated and spent months in a coma and then in recovery, he is “back in the world,” apparently hardly worse for the wear (24, 29). Apart from being unable to write by hand, Edgar ultimately suffers no ill effects, and yet, because of the sheer implausibility of what happened to him, he is henceforth an otherworldly figure onto whom others map their ideas of destiny.

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20 One thorough treatment of this representational heritage is Lois Keith’s “Punishment and Pity: Images and Representations of Disability, Illness and Cure” in *Take Up Thy Bed and Walk: Death, Disability, and Cure in Classic Fiction for Girls*. 

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and divinity. For example, the doctor who revived him says Edgar has “some kind of
destiny to fulfill. That’s the only explanation [for the fact that he’s alive and all right],”
and he also interprets Edgar’s particular injury to the head as signifying something about
the mystery of the human person (67, 77). Further, Edgar himself reports that he “could
not be killed” and yet that because of his accident, “wherever I went…ruin would follow,
sooner or later” (210). And one of the Mormon evangelists tells Edgar, “God has spared
you for some larger purpose…He has saved you from death to do a specific work, I am
sure of it” (227).

Disability and divinity have a long and complicated relationship. In various
theological traditions, disabled people have been read and constructed as both less and
more than human, by turns smited and specially endowed by God or other divine agents.
Edgar is received into and quickly internalizes an interpretative grid according to which
his physical and relational suffering single him out for some particular purpose. The
Mormon Elders cannot discern his purpose for him, but because he is marked by his
uniqueness, physical and otherwise, they are confident in assuming that purpose exists.
That assumption and the ease with which the Elders make it is rooted in a theological
tradition according to which, as Nancy Eiseland puts it in The Disabled God, “disability
denotes an unusual relationship with God and that the person with disabilities is either
divinely blessed or damned: the defiled evildoer or the spiritual superhero” (70).²¹

²¹ Eiseland traces disability through biblical texts as well as contemporary denominational treatises. My
disagreements with Eiseland’s treatment of the Bible are significant, but her basic claim—that disability’s
status both in texts and in practice has been ambivalent and has left many disabled people and their loved
ones in a marginalized position within the Christian church—is so accurate as to be almost self-evident. For
an interesting treatment of disability in the Hebrew Bible that uses a disability studies framework, see
Moreover, it is this sense of purpose that motivates Edgar’s plans and action for the rest of the novel, though those plans and that mission are not connected to his disability as such—but only to the significance the marker of disability carries in his mind and others’.

Ultimately, Edgar Mint’s narrative progression relies on Edgar’s unlikely survival of a series of catastrophes and adverse circumstances. The authorial audience’s response to Edgar is predicated on our sympathy for his circumstances; our agreement that there is something special about him; our ethical approval of him even as he makes many poor decisions (we can let him off the hook to a large degree because of his environment and upbringing); and our judgment that his retelling of his life story is aesthetically successful. Edgar is first the child of an alcoholic mother; then a near-fatally wounded hospital patient; then the object of a doctor’s obsession; then a target for abuse at a school on a Native American reservation; then the adopted child of a crumbling family; and finally, an adult living with the old woman who long ago hoped to be his adoptive mother but was thwarted. In other words, the narrative is built on Edgar’s cyclical experiences of suffering, which he eventually survives via his obsessive recording of those events on a typewriter and his abiding sense that he is alive for some great purpose. Ironically, however, the event that precipitated Edgar’s ominous sense of his own purpose in the world—his becoming disabled—recedes into obscurity.

_Motherless Brooklyn and Dynamic Disability_


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In contrast to its presence in *Edgar Mint*, disability is prominent in *Motherless Brooklyn* and its world in which context is, indeed, everything. Lionel Essrog’s Tourette’s syndrome means different things to different people at different times and in different places. Importantly, however, Lionel is in control of the discourse about Tourette’s for the duration of the novel. Sometimes that means Tourette’s is the focus of the discourse; sometimes it means Tourette’s is interpreted thematically and applied to parts of Lionel’s world; and at all times it means that the storyworld is textured and inflected by Tourette’s. In these ways, *Motherless* engages dynamically with disability and takes it up as a way of being in the world that is inseparable from the disabled person. To the extent that Tourette’s is a metaphor or symbol in this novel, it is so wide-ranging in its symbolic attachments as to exceed any easy categorization—and that is part of what makes *Motherless* such a remarkable book. I will begin this section by discussing Lionel as a character-narrator, and then I will turn my attention to the impact of Lionel’s embodiment on the narrative progression.

Lionel’s body’s impact on his narration and characterization raises an interesting question for narrative theory. In many texts the nature of the narrator’s body is never mentioned. In fact, non-character narrators are literally disembodied, only voices. Narrative theorists have made the important distinction between character (intradiegetic) and non-characterized (extradiegetic) narrators. However, the obvious effect of Lionel’s body on his narration suggests that further theoretical reflection is needed on the various
degrees to which narrators’ embodiments are made explicit, as well as the ways in which embodiment affects narration.  

For example, perhaps we could add to the designation of an intradiegetic narrator some questions regarding that narrator’s embodiment. Existing treatments of intradiegetic narrators do take into account where such narrators stand in time relative to the diegesis (roughly, main storyline), as well as whether such narrators are also participants in the stories they tell. We could add to these considerations the question of whether there is any information about the narrator’s body that may be salient in our interpretation of his or her storytelling. So, when thinking about Lionel, we might take into account both that he is “neither fat nor particularly muscular; but large, bearlike, and so harder for the bantamweight Tony or anyone else to bully,” and that he has Tourette’s (82). With these considerations in mind, we might look for any indications throughout the narrative of that embodiment affecting how Lionel thinks about himself, how other characters interact with him (and what assumptions about bodies might underwrite those thoughts or interactions), and so on. I suggest that adding considerations of narrators’ embodiment—disabled or otherwise—will often produce useful insight into a given narrative text, as I am demonstrating here in my reading of Motherless. In this case we find evidence that Lionel, some of his associates, and Lethem have a category for disability as an integrated, not-exclusively-medical facet of identity. Scholars of other aspects of identity have dealt

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22 I think embodiment’s effect on narration is quite different from something else that can be called “narrating embodiment.” Rita Charon, Robert McRuer, Elaine Scarry, Rosemarie Garland Thomson, and many others have addressed the question of representing the body. I am talking instead about the ways in which the nature and effect of a narrator’s embodiment might lead narratologists to revisit and revise our various taxonomies of types of narrators.
with the way attending to, say, ethnicity and sexuality in narrative reveals both characters’ and authors’ attitudes toward those aspects. The same is true of disability, but the scholarly treatment of narrators’, characters’, and even authors’ embodiment in narratological terms has yet to be thoroughly developed. The present discussion of *Motherless* is one example of thinking about the way embodiment affects characterization and narrative progression.

The novel’s backdrop of Tourette’s allows us to take pleasure, as Lionel often does, in locating “ticcishness” in unexpected places. Probably the most memorable instance is Lionel’s discussion of the musical artist Prince. In Prince’s music Lionel finds a translation of the “feelings of claustrophobic discomfort and expulsive release” that he experiences himself. Lionel first heard the song “Kiss,” which “lived entirely in that territory [of discomfort and release], guitar and voice twitching and throbbing within obsessively delineated bounds, alternately silent and plosive. It so pulsed with Tourettic energies that I could surrender to its tormented, squeaky beat and let my syndrome live outside my brain for once, live in the air instead” (192-193). Lionel began to gather Prince’s whole discography, eventually discovering the song “How Come U Don’t Call Me Anymore,” which he characterizes as “featur[ing] the Tourettic abruptness and compulsive precision, the sudden shrieks and silences, that made Prince’s music my brain’s balm” (193). When I read this passage, I can’t help picturing (and enjoying picturing) Lionel in a car or his Brooklyn apartment singing and dancing to Prince, reveling in the kinship he feels with the eccentric musician’s Tourettic aesthetic.
Throughout *Motherless*, Lionel proves himself a fair and largely charitable judge of the people around him. In fact, only once does he openly and specifically express sustained dislike for another person. Speaking of the sanitation officer Loomis, Lionel says, “He was permanently impressed by the most irrelevant banalities and impossible to impress with real novelty, meaning, or conflict. And he was too moronic to be properly self-loathing—so it was my duty to loathe him instead” (122). By this point we have covered approximately forty percent of the novel’s pages, and the sudden expression of open enmity comes as quite a shock. Yet just a page later, Lionel explains his disdain.

After Lionel tics Loomis says, “Jesus, Lionel, you crack me up. You never quit with that routine.” Then Lionel explains,

Here, finally, was what I most hated in Loomis: He’d always insisted, from the time we met as teenagers to this day, that I was elaborately feigning and could keep from ticcing if I wanted to. Nothing would dissuade him, no example or demonstration, no program of education…As far as he was concerned, my Tourette’s was just an odd joke, one going mostly over his head, stretched out over the course of fifteen years. (123)

In a world of lies, deception, and manipulation, Lionel reserves his (strongest) negative judgment for a man who interprets his Tourette’s as a farce kept up for humor’s sake.

Significantly, the main reason for Lionel’s disapproval of Loomis is that Loomis refuses Lionel’s right to define his own identity. Loomis rejects the possibility that something like Tourette’s could be a natural part of Lionel’s identity, and he instead frames Lionel’s tics as part of a joke.

For his part, Lionel understands his Tourette’s and its development quite well, both in terms of the trajectory of the syndrome’s manifestations in his life and the
significance it has for him and for others. From a book Frank Minna gave him, Lionel learns some of the science and social history of Tourette’s, some helpful and some not. He sarcastically recalls reading that “[m]y constellation of behaviors was ‘unique as a snowflake,’ oh, joy, and evolving, like some microscoped crystal in slow motion, to reveal new facets, and to spread from its place at my private core to cover my surface, my public front. The freak show was now the whole show, and my earlier, ticless self impossible to recall clearly” (82). Even here Lionel reports having begun to think of Tourette’s as an inextricable part of his identity. Both this awareness and the regrettable side effects steered Lionel away from drugs and medical interventions. He discovers that “chemicals slowed my brain to a morose crawl, were a boot on my wheel of self. I might outsmart my symptoms, disguise or incorporate them, frame them as eccentricity or vaudeville, but I wouldn’t narcotize them, not if it meant dimming the world…to twilight” (83). As his tics move from motor—kissing, tapping, smoothing—to verbal, other people continued to view Lionel as “merely crazy;” but as his narration shows, Lionel himself incorporated his behaviors, precisely as he said he had the option to do instead of medicating (84).

For Lionel, then, Tourette’s is a part of his identity that affects others and him in different ways at different times. It is not the case, as Joshua Kupetz (to my knowledge, the only other critic to have offered a disability studies reading of Motherless) argues, that the book Understanding Tourette’s Syndrome is the catalyst for Lionel’s “recontextualization” of Tourette’s. Kupetz says Lionel uses the book to create
a tentative causality for his actions and recasts them (and himself) as pathological...In effect, Lionel establishes a medicalized narrative for his development, but because that narrative is dominated by a single (and in this case stigmatizing) trait, it cannot fully account for the multiplicity of his personality as it develops or for the various presentations of Tourette’s syndrome. (17)

To the contrary, as Lionel says, “With the help of Minna’s book I contextualized my symptoms as Tourette’s, then discovered how little context that was” (82). Kupetz acknowledges this statement from Lionel, but goes on to argue that because Lionel relies on the “organizing power” of the label to explain himself, and also because he likens other things to Tourette’s, Lionel ultimately “succumbs to the power of medical discourse” (17).

I do not think this is at all what Lionel is doing. In this passage Lionel resists a primarily medical account of Tourette’s, an explanation of disability in terms of pathology, in two specific ways: First, he rejects drug treatment, saying, “I might outsmart my symptoms...frame them as eccentricity or vaudeville, but I wouldn’t narcotize them, not if it meant dimming my world (or my brain—same thing) to twilight” (83). Second, he mocks the book’s discourse, importing the tone and language of Understanding Tourette’s Syndrome, which tells him his “constellation of behaviors was”—and this is presumably a direct quotation from the volume on Tourette’s—“unique as a snowflake,” following the direct quote with a clearly tongue in cheek aside: “oh, joy” (82).

By the time he has reached adulthood and looks back on the experiences of his younger self, Lionel cannot separate himself from his tics, so thoroughly that he claims,
“[his] earlier, ticless self [is] impossible to recall anymore” (82). Lionel has, in fact, consciously taken on disability identity. The short chapter “(Tourette Dreams)” reads as follows:

(in Tourette dreams you shed your tics)  
(or your tics shed you)  
(and you go with them, astonished to leave yourself behind) (131)

One available reading of this short reflection is that Lionel feels bound to his tics in a way he would like to resist, and he is unpleasantly surprised to find that his dreaming self identifies more with his tics than whatever else constitutes his “self.” Yet the persistently ambivalent and largely positive, generative influence of Tourette’s throughout the novel forecloses this interpretation. This chapter, all (including the title) contained within parentheses, rather reveals that the disabled self is always disabled, and as I have already mentioned, to remove disability is to compromise identity. The whole chapter, including the title, being in parentheses further emphasizes that the question of what Lionel would be like without Tourette’s is immaterial. That Lionel ubiquitously refers to Tourette’s—a “medical” term—does not mean he has pathologized himself. Tourette’s is the signifier Lionel chooses, but as the novel demonstrates from start to finish, the signified is constantly shifting, even influencing other signifiers so that Tourette’s as a sign carries far more meaning than a monolithically medicalized term.24 In this way Tourette’s is both

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23 In narrative theoretical terms, the adult Lionel who narrates the novel is the “narrating-I,” and the younger version of himself is the “experiencing-I.” These terms are Philippe Lejeune’s. I introduce them first in the Introduction and lean on them in my reading of Planet of the Blind in Chapter 4.

24 Here I am using the language of structuralism, an approach to language (and other cultural practices) that involved taking concepts like, for instance, “tree” as “signs” comprised of a signifier (the word “tree”) and
constantly present and constantly changing, affecting Lionel in different ways at different times, but at all times very much a part of his identity. The meaning of Lionel’s Tourette’s frequently shifts depending on where he is, who else is present, and what he is doing; but regardless of those changes, the adult Lionel thinks of Tourette’s as a part of his identity in that it affects both how he acts and how he interacts with people and environments.

Lionel is aware of many advantages Tourette’s presents, especially those that serve him well as a detective. Even as a series of people in his life “looked at [him] like [he] was crazy,” Lionel discovers that having Tourette’s gives him a very specific edge on most of the rest of the world (107). In one of the more incisive passages in the novel, Lionel says, “Tourette’s teaches you what people will ignore and forget, teaches you to see the reality-knitting mechanism people employ to tuck away the intolerable, the incongruous, the disruptive—it teaches you because you’re the one lobbing the intolerable, incongruous, and disruptive their way” (43). Lionel then recounts an experience he had sitting on a bus “a few rows ahead of a man with a belching tic,” who “sat at the back of the bus, and only when every head faced forward did he give out with his masterly digestive simulacra” (43-44). At first people look back at the man, but once “it was clear to everyone he was the source…the other riders hummed or coughed

signified (the concept of a tree). While there are many problems with this approach to language—such as how these signifier/signified pairings relate to referents evoked in a given discursive context—those problems are precisely what create the force of my claim that to say “Tourette’s” does not necessitate a pathologized understanding of his symptoms and all the contextual, social, and relational features that together constitute the meaning of Tourette’s in Lionel’s (and the novel’s) world.

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reprovingly, quit giving him the satisfaction of looking, and avoided one another’s gaze”

(44). Whether or not the man had Tourette’s is immaterial, for Lionel says,

The point is, I knew that those other passengers would barely recall [the experience] a few minutes after stepping off to their destination. Despite how that mechanical froglike groaning filled the auditorium of the bus, the concertgoers were plainly engaged in the task of forgetting the music. Consensual reality is both fragile and elastic, and it heals like the skin of a bubble…A Touretter can also be the Invisible Man. (44)

In other words, being the kind of person whose very nature tends to unsettle people puts one in the position of discovering what kinds (or degrees) of wrinkles in the expected and familiar people will overlook and what kinds (or degrees) demand some kind of response or action.

Such moments of highlighting the pleasurable aspects of disability are common in contemporary disability memoir. I describe some examples from Stephen Kuusisto’s *Planet of the Blind* in Chapter 4. However, they also appear in another of Kuusisto’s books, *Eavesdropping: A Memoir of Blindness and Listening*, where he says that because he is blind he listens uniquely:

In reality I cannot see the world by ear, I can only reinvent it for my own purpose. But admitting this may make me lucky. I am free to daydream for survival or amusement. Even when I listen to Manhattan traffic I’m drawing my own pictures of New York—the streets are crowded with Russian ghosts and wheels that have broken loose from their carriages. (xi)

Similarly, in *Sight Unseen*, Georgina Kleege includes a section called “Blind Phenomenology” in which she describes getting very close to paintings and the pleasure such a close-up view brings. Kleege writes, “While my too-close vantage point makes representational paintings seem abstract, with abstract works I sense not only movement
and energy but depth and form. The sprays of paint on a Jackson Pollock canvas become a dense, webby mass. Ad Reinhardt’s flat planes of color resonate afterimages, vibrate with ghosts of form” (94-95).

Given its relatively common occurrence in disability memoir and fiction, it seems that this type of calling out of pleasurable aspects of disability is an identifiable rhetorical move in disability narratives. Grouping and defining examples of this move is useful for rhetorical approaches to narrative, since calling attention to disability as a pleasurable experience creates a positive impression of disability for audiences and contributes to audiences’ sense of the character/narrator/author. Naming and defining this trend would also be useful for disability studies, especially since those working in the field are eager for examples of value-positive understandings of disability. So, I would like to propose that instances in narrative texts of calling attention to pleasurable experiences that depend on disability be called “disabled pleasure,” where “disabled” refers to the explicit recognition that one’s identity includes disability.

Of course, however someone might think of or take pleasure in his own embodiment, he always also lives in a social context that operates according to certain conventions with which his body may or may not cooperate naturally or by choice. Tourette’s is no exception, and in fact is a kind of embodiment that social scientists have discussed as exposing and challenging conventional boundaries of social spaces. According to Kat Kleman Davis, Jeffrey Sasha Davis, and Lorraine Dowler, “Touretters’ actions may be ‘out-of-place’, but the individuals are also located ‘in place’. They go about their daily lives like anyone else…Yet their bodies resist, crossing boundaries, and
acting out through movement, becoming ‘out of place’ and challenging ableist conceptions of space (Parr, 1997). The Touretter is then divided, simultaneously ‘in place and ‘out of place’” (110). For Lionel the ability to be in place and out of place is always both an asset and an inconvenience. In his line of work, attention to people’s reactions and quirks is a crucial part of being a good detective, though at times his tics are certainly inconvenient.

Thinking of Tourette’s as a form of embodiment that alternately fits into and challenges social spaces and conventions makes clear the appeal of this particular disability for Lethem as a novelist. In Lionel, Lethem has created a character whose effusion of words and ideas generates mimetic, thematic and aesthetic appeal: mimetic because Lionel both inhabits and interrogates social conventions; thematic because Lionel’s experiences with disability represent a range of possible ways of framing and experiencing disability in a social/cultural context; and aesthetic because, as Lionel puts it, his words and gestures “course over the surface of the world, tickling reality…[c]aressing, nudging” (1). These observations about Lionel’s embodiment and its impact on his interpretation and narration of his world carry an important corollary. That is, if Lionel is aware of disability’s impact on his identity and way of thinking, then we would expect to find evidence of that awareness both in Lionel’s retelling of his story (the diegetic level of the novel) and on any reflections on why he tells the story the way he does (any metadiegetic remarks Lionel might make). With this in mind I turn to the progression of Motherless, thinking of it as standing in clear contrast to Edgar Mint,
where the advent of disability catalyzes the plot, but then disability disappears from both the diegesis and the discourse.

Like any good detective novel, *Motherless Brooklyn* contains its share of implausible car chases and coincidences, and yet it also pays careful and complex attention to disability. Lionel is a skillful investigator, reporter, and interpreter, not to mention a capable and likeable narrator. Unlike Edgar Mint, though, much of Lionel’s appeal and skill both as a detective and a storyteller throughout the novel has centrally and insistently to do with his Tourette’s syndrome. From beginning to end, disability is central to Lethem’s novel.

The novel opens, “Context is everything” and continues in a breathless, lyrical explanation of Tourette’s:

Dress me up and see. I’m a carnival barker, an auctioneer, a downtown performance artist, a speaker in tongues, a senator drunk on filibuster. *I’ve got Tourette’s*. My mouth won’t quit…my Adam’s apple bobbing, jaw muscle beating like a miniature heart under my cheek…the words rush out of the cornucopia of my brain to course over the surface of the world, tickling reality like fingers on piano keys. Caressing, nudging. They’re an invisible army on a peacekeeping mission, a peaceable horde. They mean no harm. They placate, interpret, massage. Everywhere they’re smoothing down imperfections, putting hairs in place, putting ducks in a row, replacing divots.” (1, emphasis in original)

From the outset Lionel characterizes his Tourette’s as an overflow of plenty, a playful and pleasurable operation, a form of care, a fact of life, and often—but not always—a beneficent or felicitous impulse. He also points out in the first sentence that what his body means depends on where he is, and in whose presence. With Frank Minna and the other Minna Men, for instance, Tourette’s could be advantageous: his head jerks and compulsiveness meant that
[Gilbert] Coney and the other Minna Agency operatives loved doing stakeouts with me, since my compulsiveness forced me to eyeball the site or mark in question every thirty seconds or so…A similar logic explained my popularity at wiretap parties—give me a key list of trigger words…and I’d think about nothing else…while the same task invariably drew anyone else toward blissful sleep. (4)

Minna liked to take Lionel out on stakeouts because, as he reports, of “my effect on his clients and associates, the way I’d unnerve them, disrupt some schmooze with an utterance, a head jerk, a husky ‘Eatmebailey!’ I was his special effect, a running joke embodied” (57). In the context of meetings, Lionel’s Tourette’s keeps “clients and associates” on their toes.

Kupetz takes issue with this passage about Lionel’s effect on Minna’s clients. He says, “Lionel’s development in this context [of small time crime in Brooklyn]…relies in large part on others’ presuppositions about a small-time mob enforcer, their lack of knowledge about Tourette’s syndrome, and their perception of him as resolutely different. Minna’s use of Lionel to gain advantage over clients and associates relies on Lionel’s ability to upset his perceived virtual social identity (Goffman, 1990)” (16). In other words, Lionel develops as a character as he learns to define himself against these Brooklynites’ stereotypical assumptions about what makes a “good” enforcer, their ignorance about Tourette’s, and their ability to recognize Lionel as different. Instead of being allowed to define himself, his identity is dependent on the way others interpret and respond to him. Kupetz goes on to conclude;

Because Lionel’s actual social identity departs from the clients’ presumptions about him, Lionel causes anxiety. Ironically, both Lethem and the reader are complicit in this same dynamic—Lethem seems to rely on the reader’s assumptions about the conventions of representing a private detective and a thug, and he manipulates those representations by attributing Tourette’s syndrome to
Lionel. Ultimately, then, the recontextualization of Lionel, both in the narrative and through the process of reading that narrative, has much to do with dominant assumptions about normalcy and stereotypes, many of which the contrasting representation inadvertently reaffirms. (16-17)

Kupetz is obviously correct that Lionel’s actual social identity causes other people anxiety and that Lethem (and Lionel) are quite concerned with the conventions of detective fiction. But instead of thinking of Motherless as reaffirming stereotypes about normalcy, I would argue that the novel’s generic conventions actually facilitate a dynamic representation of disability.

First, the very fact that Lethem is entrenched in genre fiction in some ways requires that he play to the genre’s conventions such that subverting them has an effect—in this case, raising the question, “What would happen if the conventional ‘thug’ in a detective novel had Tourette’s?” And for Lethem via Minna, the answer is, “Potentially, he’d be better at his job.”

Second, Motherless Brooklyn is a basically realistic novel, in that it gives us little reason to suspend or alter what we think of as normative physical or social features. Pertinent here, in narrative theoretical terms, is what Marie-Laure Ryan calls the principle of minimal departure, which dictates that audiences “project upon these worlds everything we know about reality, and we will make only the adjustments dictated by the text.” In this novel’s Brooklyn, it makes sense that Minna’s clients and associates

25 In Chapter 3 I ask and answer a similar question about Christopher Boone, the autistic detective and narrator-protagonist of Mark Haddon’s The Curious Incident of the Dog in the Night-time. I think the answer there is more complex and ultimately less favorable in its assessment of disability.
26 Marie-Laure Ryan, Possible Worlds, Artificial Intelligence, and Narrative Theory (Indiana University Press, 1991), p. 51. The basic idea is that we assume that the alternative possible worlds of fiction are like the actual world unless we’re cued to think otherwise. In order to account for anachronisms—Ryan’s
would, like many readers, have assumptions about a mobster’s thugs, and also that they would be unlikely to have much experience with Tourette’s—not to mention thugs with Tourette’s. So the important considerations when reading this portion of the novel are not, as Kupetz has it, what other characters think of Lionel and his Tourette’s, but rather how Lionel interprets what other characters think in light of his self-understanding. These are the important questions not only because of the appropriately conventional (if stereotypical) elements of genre, but also because, within the constraints that Lethem as the final creator of the text has placed on him, Lionel controls the narrative discourse. This control means that Lionel can frame and respond to any aspect of the storyworld however he pleases. The way Lionel stands in contrast to what the clients and associates expect from a thug does not reaffirm stereotypes. In fact, Minna begins the process of revising those stereotypes by leveraging Tourette’s as a professional advantage, and

example is that there wouldn’t be computers in the world of Lewis Carroll’s *The Jabberwocky*—she adds, “A proposition of the type ‘x’s exist,’ where x refers to a species, will be transferable from AW [actual world] to TRW [textual reference world] if:

1. x’s existed in AW in the stage of its historical development that corresponds to the stage at which TAW is shown, and
2. the appropriate environment for x’s is set up in TAW [text actual world].

Moreover, a proposition of the type ‘x exists,’ where x refers to an individual or geographic location, will be transferable to TAW if it fulfills both (1) above and

3. the text names as member of TAW at least one individual or geographic location belonging to AW” (53).

I have for some time thought that disability studies might be able to apply some scrutiny to the principle of minimal departure. For example, is it valid for us to assume that, in the absence of any indications to the contrary, characters and narrators are nondisabled? Lennard Davis raises a similar question in *Enforcing Normalcy* (p. 156).

I think the difference between my conclusion about how stereotypes work in *Motherless* and Kupetz’s is the result of the difference between Kupetz’s *a priori* political reading and my *a posteriori* rhetorical one. Kupetz is reading *Motherless* from a disability studies perspective, but it seems to me that this perspective prevents him from adequately accounting for the structure of the novel: Lethem works within a set of self-imposed generic constraints, within which certain characters engage in stereotypical thinking about disability. At the same time, Lethem also challenges, via Lionel’s skillful management of the narrative and his comments on people and situations, some stereotypes about disability.
Lionel’s understanding of Tourette’s—which is not ultimately consonant with Minna’s—continues those revisions.

The two most significant indicators of Minna’s at least partially positive view of Tourette’s are his giving Lionel a book called *Understanding Tourette’s Syndrome* and his request for Lionel to tell him a joke just before his death. The former demonstrates his sense that Lionel might benefit from understanding himself as a disabled person, and the latter shows that Minna stakes the discovery of his killer on Lionel’s Tourettic tendencies.

Just before he flees Brooklyn on fear of being hunted down by the mobsters who have recently discovered he and his brother have been stealing from them, Minna stops at St. Vincent’s to let the four boys know he is leaving. Apart from saying he is “going out of town for a while,” Minna gives no information about his destination or the reasons for his departure. Before he leaves, he gives Lionel the book (the first time Lionel has ever seen Minna touch a book) and says, “Take a look…Turns out you’re not the only freak in the show…Meaning to get that to you…But I’ve been sort of busy” (81). As unceremonious as this act of gift-giving might be, it indicates that Minna has been thinking about Lionel in the period leading up to his flight, and also that his view of Lionel’s Tourette’s goes beyond thinking of him as a human curiosity. At some level, Minna cares about Lionel, and he knows that Lionel may gain something from knowing that he is part of a community of people who share similar eccentricities. Moreover, Minna relies on his awareness of Lionel’s obsessive thoughts to ensure that his killer will be found out.
Minna dies after being stabbed by an unknown assailant in a car trailed by Lionel and Gilbert Coney. Lionel and Gilbert find Minna in a dumpster, fatally wounded, and rush him to the hospital. They urgently ask Minna what happened: “Frank, what happened? … Who? Who did this?” Minna’s reply to Lionel is strange: “You know what I want out of you, Freakshow? Tell me a joke. You got one you been saving, you must.” Lionel is surprised, but is able to contextualize the remark: “Minna and I had been in a joke-telling contest since I was thirteen years old, primarily because he liked to see me get through without ticcing.” This alerts us to the fact that in Minna’s mind there is a connection between Lionel’s Tourette’s and the significance of joking. Lionel tells a joke, but before they arrive at the hospital Minna requests another, specific joke from Lionel. He says, “You know that Jewish joke you told me? The one about the Jewish lady goes to Tibet, wants to see the High Lama … That’s a good one. What’s the name of that lama? You know, at the end, the punch line.” Lionel replies, “You mean Irving?” To which Minna says, “Yeah, right. Irving…That’s who.” Confused, Lionel says, “You’re saying it was someone named—Dick! Weed!—Irving who did this to you?” Minna quietly whispers “something that sounded like ‘remember’” in the din of the hospital before being whisked away by doctors and nurses (25-35).

Lionel later reports the “Jewish joke” in question. I quote it almost in full because of the significance it carries for the plot of Motherless in general, and in particular for what Lionel does with the joke:

A Jewish mother—Mrs. Gushman, we’ll call her—walks into a travel agency. “I want to go to Tibet,” she says. “Listen, lady, take my word for it, you don’t ant to go to Tibet. I’ve got a nice package tour for the Florida Keys, or maybe Hawaii—
“No,” says Mrs. Gushman, “I vant to go to Tibet….Sell me a ticket for Tibet!” … So she goes to Tibet. Gets off the plane, says to the first person she sees, “Who’s the greatest holy man in Tibet?” “Why, that would be the High Lama,” comes the reply.” “That’s the man I vant to see,” says Mrs. Gushman. “Take me to the High Lama.” “Oh, no, you don’t understand, American Lady, the High Lama lives on top of our highest mountain in total seclusion. No one can see the High Lama.” “I’m Mrs. Gushman. I’ve come all the way to Tibet, and I must see the High Lama!” … So Mrs. Gushman checks into a hotel at the base of the mountain and hires sherpas to take her to the monastery at the top. All the way up they’re trying to explain to her, nobody sees the High Lama—his own monks have to fast and meditate for years before they’re allowed to ask the High Lama a single question. She just keeps pointing her finger and saying “I’m Mrs. Gushman, take me up the mountain!” … The monks go [to announce to the Lama that Mrs. Gushman has arrived] and come back and they’re shaking their heads in confusion. “We don’t understand, but the High Lama says he will grant you an audience” … The monks are whispering and they open the door and the High Lama nods—they can leave him alone with Mrs. Gushman. And the High Lama looks at Mrs. Gushman and Mrs. Gushman says, “Irving, when are you coming home? Your father’s worried!” (88-89)

Only later do we discover the joke’s significance and the reason Minna requested this particular joke at this particular moment.

The joke comes back to Lionel while he is sitting in the zen studio where Minna encountered the man who eventually killed him, investigating a lead. While listening to a Buddhist monk discuss his arrival in New York to spend time with “Jerry-Roshi,” the zen master at this studio, Lionel thinks, “I vant to go to Tibet! The joke insisted itself upon me again… I vant to speak to the Lama!” (199). The joke continues to run through Lionel’s mind until he realizes that “[Jerry-]Roshi looked like Minna. Your brother misses you, Irving. Irving equals Lama, Roshi equals Gerard. Roshi was Gerard Minna. I couldn’t say which got me there, his profile in front of me or the joke’s subliminal nagging…Of course, the joke had been designed to get me there sooner, spare me figuring it out while in the belly of the whale.” In other words, Frank requested the joke
because he knew Lionel would remember and return to it. When he did return to it, Frank knew Lionel would eventually discern that Frank’s brother Gerard was directly responsible for Frank’s death. In essence, then, Frank relied on Lionel’s Tourettic impulses to ensure that Gerard would be exposed.

It is unlikely that Lionel is making more of this joke’s importance than is warranted. This is for at least two reasons: Lionel is a reliable reporter, and his description of Minna’s last moments leaves room for reasonable doubt about what he might have said. Minna said something that sounded like “Remember,” but Lionel does not report with certainty that Minna definitely said the word. Further, it makes sense that Minna would continue speaking cryptically, only obliquely indicating who was responsible for his death. He did not know where the microphone he had been wearing or the receiver Lionel had held were, and he did not know who else was present in the hospital. Moreover, the chances that a randomly selected joke that Minna requested just so happened to involve someone’s identity being veiled—not to mention veiled by a new religious identity—and a family member being aware of that person’s true identity are remote at best. Thus we conclude that Minna does not think of Lionel purely as an oddity or a professional convenience. Rather, Minna relies on Lionel’s eccentricities to ensure that the truth about his death will come to light.

At the same time, Minna does think of Lionel’s tics as “evidence of life’s unpredictability and rudeness and poignancy…In this way, Minna licensed my speech” (57). This symbolic reading of disability might not sit well with disability studies scholars. Indeed, just a few moments ago I pointed out and criticized the subtle
metaphorical operation in *Edgar Mint*, citing such metaphorizing as an indication that Udall’s novel does not really engage with disability as such. The difference in *Motherless* is that everything readers learn about Frank Minna comes from Lionel, a significantly perceptive and intelligent man. Lionel spent most of his time in St. Vincent’s Home for Boys, where he grew up, devouring every book in the library; his references to the titles of several books, especially detective fiction, are evidence of his fluency with literature. Further, Lionel often makes shrewd, self-aware, and humorous observations about the events of the plot. For example, when he and fellow Minna Man Gilbert Coney are trailing Minna in a car, they fall too far behind within a block of beginning their pursuit. Lionel remarks, “We were back in the game, a notion exhilarating and yet pathetic by definition, since we’d lost them in the space of a block” (15). Similarly, later in the novel Lionel encounters some woefully incompetent “muscle” attempting to frighten him on someone else’s behalf. Describing their tactics (after nicknaming them Pinched, Chunky, Pimples, and Indistinct), Lionel simultaneously reports and critiques the men’s efforts: “‘Listen,’ said Chunky, now trying to reason with me, as his gang’s morale and focus…were dwindling. ‘We’re here on behalf of the big guy you’re talking about, see? That’s who sent us.’ He offered the morphic resonance theory: ‘So if he scares you you ought to be scared by us, without us having to hurt you’” (151-152). In these two instances Lionel demonstrates a high degree of awareness regarding others’ reasoning, and he pokes gentle fun at human folly, including, in the case of the car chase, folly involving himself. When Lionel offers us something Minna says about his Tourette’s, he
does not do so un-self-consciously, and he does so in the context of a novel full of his own interpretations.

One particular instance of folly demonstrates that Lionel the narrator and Lethem the implied author do not think primarily in terms of correspondences between Lionel’s disability and certain outcomes in his life, as if there were some mystical connection between bodily state and all events and outcomes. In the early pages of the novel, Lionel has already provided significant discourse on his Tourette’s and others’ responses to and interpretations of it, some of which I have already discussed. While Lionel has discussed some inconvenient aspects of the syndrome, he has in no way linked it to a certain fate. Then, reporting on the failed chase I mentioned above, Lionel says, “We were wedged in, unable to follow and brave the stream of crosstown traffic if we’d wanted to try. It felt like a straitjacket. It felt like our fate overtaking us, Minna’s losers, failing him again. Fuckups fucking up because that’s what fuckups do” (16). Significantly, in this case, Lionel calls attention to a failed action, but it is in no way connected to his Tourette’s syndrome. This is not to say there is something inherently wonderful or remarkable about not connecting disability to a failed car chase; but it does demonstrate that in *Motherless Brooklyn*, disability’s meaning is not deterministic. Thus it is at least potentially, and as I am arguing, actually, the kind of new disability art Mitchell and Snyder seek: “The study of disability must understand the impact of the experience of disability on subjectivity without simultaneously situating the internal and external body within a strict mirroring relationship to one another” (58, emphasis in original). That is, progressive work in disability studies in general and literary disability in particular should
explore the way disability affects subjectivity, but it should not do so reductively. In this case, Lionel’s subjectivity cannot be reduced to, but is always affected by, his disability.

If disability is not deterministic in *Motherless Brooklyn*, then what is it? The answer is complicated, both because disability functions in so many internal and external ways that *don’t* mirror each other, and because Lionel’s verbal and physical tics are so ubiquitous as to be impossible to pin down. Yet the very sprawling character of Tourette’s in this novel is what I want to highlight in order to demonstrate that Lethem, via Lionel, has liberated disability from its often monolithic and strict mirroring signification—that is, that Lethem has begun to explore disability’s fuller potential to a substantial degree.

When Lionel does liken Tourette’s to other things, he does so in ways that reflect on both Tourette’s and the thing being compared to it. After speaking with two Italian mobsters and trying to sort out their connections with other pieces of the Minna puzzle, Lionel reflects,

> Conspiracies are a version of Tourette’s syndrome, the making and tracing of unexpected connections a kind of touchiness, an expression of the yearning to touch the world, kiss it all over with theories, pull it close…The second gunman on the grassy knoll wasn’t part of a conspiracy—we Touretters know this to be true. He was ticcing, imitating the action that hard startled and allured him, the shots fired. (178)

In this reflection Lionel invites readers to reconsider both people with Tourette’s and conspiracy theorists such that the two fold into the same category: any of several types who seek connections in the world where there may or may not be any—any of several types who may or may not be seeking wheels within wheels. Importantly, Lionel’s
equating conspiracy theories with Tourette’s syndrome only runs in one direction: all conspiracy theorists have Tourette’s, but people with Tourette’s are not necessarily conspiracy theorists. Here disability’s explanatory power predominates, just as it does in Lionel’s later explanation of insomnia as “a variant of Tourette’s—the waking brain races, sampling the world after the world has turned away, touching it everywhere, refusing to settle, to join the collective nod” (246). In fact, Lionel connects insomnia to conspiracy theories, gathering them both under the heading “versions of Tourette’s”: “The insomniac brain is a sort of conspiracy theorist as well, believing too much in its own paranoiac importance—as though if it were to blink, then doze, the world might be overrun by some encroaching calamity, which its obsessive musings are somehow fending off” (246-247).

Finally, very near the end of the novel, Lionel addresses precisely the kinds of claims he has been making about phenomena as diverse as conspiracy theories and insomnia, making a kind of meta-gesture toward his broad claims regarding such phenomena. He says,

> Assertions are common to me, and they’re also common to detectives…And in detective stories things are always *always*, the detective casting his exhausted, caustic gaze over the corrupted permanence of everything and thrilling you with his sweetly savage generalizations…Assertions and generalizations are, of course, a version of Tourette’s. A way of touching the world, handling it, covering it with confirming language. (307)

The “of course” here refers back to Lionel’s earlier acknowledgment that all his tracing of connections is in fact part of his Tourette’s: “Have you noticed yet that I relate everything to my Tourette’s? Yup, you guessed it, it’s a tic. Counting is a symptom, but
counting symptoms is also a symptom, a tic *plus ultra*. I’ve got meta-Tourette’s” (192). This claim requires readers to read everything Lionel reports under the banner of Tourette’s. All the scene setting, remembering, reporting, and interpreting Lionel does from start to finish of *Motherless Brooklyn*—*everything* happens in the context of Tourette’s. Context is everything. We are at every moment in the hands of a reliable, likeable narrator, but we also must always remember that he is a narrator with Tourette’s, and that there is no such thing as “Lionel-without-Tourette’s,” no part of him that is not affected and inflected by the syndrome, usually explicitly so.

“Neuronovels” and the Discourses of Disability

In his 2009 essay “Rise of the Neuronovel,” Marco Roth explores the genre of the “neuronovel,” defined as novels in which “the mind becomes the brain” in response to contemporary neuroscience. The genre springs from the current and ongoing dominance of neuroscience as the privileged discourse in explaining human consciousness and behavior (see, for instance, popular neuroscience books like Daniel Dennett’s *Consciousness Explained* or Steven Pinker’s *How the Mind Works*). Neuronovels adopt the perspective that empirical science will ultimately explain us to ourselves entirely. Within the genre of the neuronovel Roth locates two subtypes: “hard” neuronovels like Ian McEwan’s *Saturday*, in which “the neurologically abnormal [in this case, the thug Baxter, whom the neurosurgeon Perowne has provisionally diagnosed with Huntington’s disease] are foils more than actual characters; their main purpose is to be defeated by normals of the better sort [i.e. Perowne];” and “soft” neuronovels like *Motherless*
Brooklyn, “in which the author inhabits a cognitively anomalous or abnormal person and makes this character’s inner life the focus of the novel, soliciting our sympathies.” The latter category “load[s] almost the entire burden of meaning and distinctiveness onto their protagonists’ neurologically estranged perceptions of our world.”

In trying to represent neurological difference that is simply a matter of course alongside the impulse toward eccentric interiority common to modernism, soft neuronovels “[attempt] a synthesis between…American realism, ending with the ‘research novel’…[and] the novel of consciousness, of interiority, of linguistic play and estranging description.” However, Roth argues that this synthesis ultimately fails. While the “modernist desire to gather and combine the heterogenous voices of entire regions and nations…led to novels open to the whole range of human language, from curses to visionary lyricism,” the neuronovel’s tendency to label or diagnose in scientific terms means that “[w]hen Lethem puts his words into the mouth of a Tourettic character, the very act of medicalization marginalizes the experimental impulse, marking any remnant modernism as a case for abnormal psychology.” Instead of simply experimenting with language in a way that potentially gestures toward all readers, “[t]he [neuronovel’s] reader is presented simultaneously with an effect and a diagnosis of its cause; the writer indulges in some fancy language or rare perceptions, and then hastens to explain why, on medical grounds, this is allowed” (emphasis added).

But it seems to me problematic to suggest that attributing to a character a scientifically- or medically-derived neurological difference is inconsistent with engaging in innovative writing practices. From the claims above, Roth can fairly be taken as saying...
that neurological differences (like Tourette’s in *Motherless*) and linguistic experimentation are mutually exclusive categories. On this account, Joyce’s attempt in *Ulysses* to inhabit the consciousness of the apparently nondisabled ad man Leopold Bloom evinces the novelist’s desire to “gather and combine the heterogeneous voices of entire regions and nations.” By contrast, Lethem’s attempt to inhabit the equally interesting consciousness of Lionel Essrog would have to be seen as one that marginalizes experimentation and is at root an excursion into “abnormal psychology.”

I think we can reframe neurological differences in such a way that we both acknowledge problematic metaphorical operations that have been performed on them and uphold the possibility of neurologically different characters being emotionally accessible to all types of readers. On the one hand, my non-Tourettic brain obviously does not work like Lionel’s. But for at least three reasons, this does not mean that I cannot locate any generalizable meaning in Lionel’s condition beyond the strictly biological fact of his having Tourette’s:

First: *Authors frequently employ bodily difference (neurological or otherwise) to multivalent ends—even if, from a disability studies perspective, some ends are better than others.* We need to consider authors’ rhetorical aims authors in representing neurologically different characters. In some ways, placing *Curious Incident* in the same category as *Motherless Brooklyn* makes tremendous sense: here are two novels about neurologically different characters trying to solve mysteries that have to do with their pasts (obviously *Edgar Mint* fits in the same family of texts, and Chapter 3 of this project is about *Curious Incident*). However, these novels have different rhetorical purposes with
respect to neurological difference. Udall’s is purely instrumental; Haddon’s is in service of constructing a specific network of relationships among readers, the narrator, the authorial audience, and the implied author (again, see Chapter 3); and Lethem’s is character-driven, interested in keeping us very close to Lionel’s subjectivity and his ways of interpreting the world and his circumstances simply because he, his story, and his way of telling are compelling. Further, knowing as we do that Haddon is not autistic and that Lethem does not have Tourette’s means that whatever identification they might feel with their protagonists (Lethem has said repeatedly that of all his characters, Lionel is most like him) grows out of difference rather than (autobiographical) similarity.²⁸

Second: Authors frequently employ bodily (neurological or otherwise) difference to metaphorical ends in particular. I made this point in my discussion of Edgar Mint. Suffice it to say here that no kind of disability carries a deterministic meaning, including but not only when it appears in a literary text. Just because neuroscience is the reigning discursive king in its purported ability to explain humanness does not of necessity mean that novelists who engage neurological difference do so with the same intellectual assumptions and commitments as others who write on the subject. Brady Udall’s Edgar, for instance, surely sustained some kind of neurological damage, but that distinction plays almost no role in our understanding of Edgar’s voice, perspective, or character in general beyond the metaphorical role of catalyzing the plot and distinguishing him as a unique individual in the storyworld. And for as much as Lethem links Lionel’s verbal

²⁸ For an interesting discussion of the phenomenon of authors identifying with characters, see Richard Walsh, The Rhetoric of Fictionality (Ohio State University Press, 2007), Chapter 7, “Narrative Creativity: The Novelist as Medium.”
eccentricity to Tourette’s, both he and Lionel metaphorize Tourette’s to various ends throughout the novel, which presumably gives readers license to do likewise.

Third and finally: Neurologically typical readers may be able to identify with neurologically different characters, because biology is not the same as ontology. As I mentioned above, asserting a categorical difference between neurological typicality and neurological difference is not the only way to think about neurology. In fact, contemporary thought—scientific and otherwise—on autism suggests that the condition exists on a spectrum. Autistic advocates point out that it would actually make more sense to think of all human cognitive functioning as a spectrum, rather than creating a separate spectrum called “autism.” At what point and according to what criteria, for example, does someone go from “extremely neurologically atypical, but neurologically typical” to “nearly neurologically typical, but autistic”? Some cases are admittedly more straightforward, but my point is that insofar as all humans share characteristics qua human, there is no reason not to conclude that neurologically different characters in fiction are ontologically unlike neurologically typical readers. Again, my non-Tourettic brain is not like Lionel’s. However, I do have compulsive tendencies about the order in which I prepare for bed at night: brush my teeth, wash my face, use mouthwash, stretch, use the toilet, fill my water glass, check my alarm clock (several times). I identify strongly with Lionel’s urges to do things a certain way or in a certain order.

Somewhat different but probably more important, I would hazard that most people who read this novel identify with Lionel’s tendency to interpret the world through the lens of his personality and experiences. Is not our tendency to relate everything to
ourselves, after all, a basic human tendency? Think of all the times you have been in a conversation and had someone say, “I had an experience like that once…” or “I’m that way, too!” or “I do that all the time!” Just because Lionel clearly and uniquely has Tourette’s syndrome does not mean that readers of this novel (Tourettic, neurologically typical, or otherwise) will resist drawing correspondences between themselves and Lionel.

Skepticism toward neurological difference as such in literature is based on a particular (but not unavoidable) way of thinking about neurological difference. Roth, for one, seems to believe that neurological difference is so ontologically significant that it makes generalizing from or relating to a neurologically different character basically impossible for any reader who does not share a given character’s difference. In order for Edgar Mint to be emotionally accessible to readers, his physiological distinction must remain vague and in the background, even as the specifics of his ethnicity and familial history are laid bare. In *Motherless Brooklyn*, Jonathan Lethem provides an alternative to a deterministic understanding of disability: an emphatically and unambiguously Tourettic character-narrator in a familiar genre, who self-consciously incorporates the way his brain works into his readings of people and the world, as well as the way he tells his story.

Nearing his conclusion, Roth curiously suggests, “[T]he neuronovel tends to become a variety of meta-novel, allegorizing the novelist’s fear of his isolation and meaninglessness, and the alleged capacity of science to explain him better than he can explain himself.” That is, as science’s explanatory power and cultural capital increases,
novelists fear that the subtleties of human existence and interaction might come to be explainable in scientific terms, and thus they will become obsolete. And so, in an “if you can’t beat ‘em, join ‘em” sort of gesture, novelists attach themselves to scientific discourse as they create fictional worlds. For Roth, this is evidence that “the new genre of the neuronovel…appears as another sign of the novel’s diminishing purview.” The better way forward, but not the one most novelists take, is this: “Surely the way for a novelist to be a neuroscientist today is still to anticipate rather than follow the discoveries of brain science. It would be no surprise if a novelist could still describe and mimic traits of cognition that neurology can’t yet experimentally confirm.” To my mind, though, incorporating neuroscientific insights and discoveries in fiction need not mean that science is always the best way to explain human nature—especially not in “soft” neuronovels. By highlighting, reflecting on, and utilizing Tourette’s in his world making and self telling, Lionel affirms and front loads his neurological difference while remaining a likeable and emotionally accessible character. In constructing such a character-narrator, Jonathan Lethem creates a new kind of neuronovel in which neurological difference enables experimentation but is not simply “abnormal psychology.” *Motherless Brooklyn* affirms and engages disability as a way of being, a kind of human experience simultaneously unique and understandable to a broad readership.

**Conclusion: The poetics of disability**
My central claim has been that *Motherless* offers a dynamic account of disability by virtue of the way the implied Lethem incorporates disability into Lionel’s characterization and narration, as well as the narrative progression at large. Lethem’s methods contrast with other, static and/or instrumental uses of disability exemplified by *Edgar Mint*. By way of conclusion, I want to address more directly the idea of a poetics of disability. I want to begin by asking whether there are particular formal devices that belong primarily or exclusively to disabled creators of narrative texts or to disabled narrators in such texts.

While the embodiment of a creator of a fictional text may factor in a poetics of disability, such a poetics should *not* rest on drawing correspondences between certain formal elements and certain types of embodiment, whether authors’ or characters’. That is to say, there is no essential connection between disability (or certain disabilities) and certain formal devices, though certain formal devices might be more useful or intuitive for certain kinds of (disabled) creators or narrators who want to achieve certain effects. Thus, while we might be able to identify a catalog of devices prevalent among disability narratives and call them, collectively, disability poetics, it would not be the case that these devices are only available to disabled creators and narrators, or that disabled creators and narrators are bound to use them. So, for instance, when Lionel filters the world through the lens of Tourette’s—or perhaps better, when he covers the world with Tourette’s as he reads and interprets it—there is nothing about his *style* that identifies his narration as “disabled.” Lionel identifies aspects of the world that he calls “Tourettic,” but these are correspondences of content, not of form. Moreover, the creator of any
narrative text could conceivably use any formal device in order to achieve her desired effects.

At least one disability studies scholar has tried to draw strong connections between formal devices and forms of embodiment. In an essay on poet Larry Eigner, Michael Davidson identifies some ways in which Eigner’s poems convey something about the nature of his embodiment. Davidson says that being aware of Eigner’s embodiment—Eigner had cerebral palsy and had control only over the movement of his right index finger, with which he typed all of his poems—enriches our understanding of the poems’ form. Such enrichment is similar to, for example, taking into account the possibility that “William Carlos Williams’s development of the triadic stepped foot in his later career [was]…a typographical response to speech disorders resulting from a series of strokes” (119). Davidson’s mention of Williams and his longer discussion of Eigner come in answer to the question, “What would happen if we subjected a poetics of embodiment to the actual bodies and mental conditions of its authors?” The way Eigner arranged lines on the typed page and the form of Williams’s line are compelling examples of a poetics of disability.

Interestingly, though, Davidson’s other examples of the poetics of disability have to do with matters of content: Elizabeth Bishop’s mentions of suffocation and claustrophobia as a response to asthma; Robert Lowell as a poet with depression “for whom personal testimony was accompanied by hospitalization, medicalization, and family trauma;” and Robert Creeley’s lines “to look at it is more / than it was” as more meaningful with the knowledge that the author has only one eye (119). These are two
different kinds of relationships between disability and poetics: on the one hand, a
relationship between embodiment and form, and on the other, a relationship between
embodiment and content (or thematics).

Seeing, then, that disability can influence either the content or the form of
narrative and lyric texts, I offer two related claims about disability poetics: First, a lyric
or narrative text’s creator’s, narrator’s, or character’s disability might influence the form
of the text, but it does not necessarily do so. Second, it is more common for disabled
embodiment to influence content than form. This is because form is not inherently tied to
any kind of embodiment, and also because creators of narrative texts choose whether to
avail themselves of various formal resources depending on their rhetorical aims. Thus, if
a disabled creator or narrator were not interested in calling attention to her disability at
some point in the text, she could avoid doing so: her mode of embodiment would not
necessitate her making certain formal choices in her text.

What, then, would comprise a poetics of disability? I would suggest that any
poetics has primarily to do with an artwork’s rhetorical aims, which will influence its
content, its ethical dimensions, and its aesthetics. Thinking rhetorically about disability
poetics helps scholars in disability studies avoid the pitfall of reductive readings that only
focus on the way disability is represented in a given text compared with the progressive
political agenda of the field. Instead of criticism whose assessments fall into the basic
categories of “good” and “bad” representations of disability, we can generate
contextualized criticism that creates a fuller picture of how disability is used to different
ends in different periods and genres. For instance, in the foregoing reading of Edgar
Mint, my rhetorical methodology allowed me to compare Udall’s treatment of disability with his treatment of other cultural issues that were significant during the moment in which the novel was published. Meanwhile, in Motherless, Lethem’s use of Tourette’s goes beyond being “good” according to a disability studies agenda. It also reflects the flexibility of disability as an aesthetic resource for the creator and narrator of a narrative text.

In his 2010 book Disability Aesthetics, Tobin Siebers points out that “[t]he consideration of aesthetic works from the perspective of disability is a relatively new field” that “has so far approached its subject matter straightforwardly, tracking the history of representing people with disabilities in art, literature, and film, most often with respect to detrimental prejudices and stereotypes” (84). While this is “important work,” Siebers points out that it is limited in that it “misses the opportunity to consider a more vital resource for imagining disability because it accepts that the work of art represents its object transparently and mimetically” (284). To the contrary, artworks create the worlds they represent, and consequently their audiences engage with whatever persons or events populate those worlds on the terms the creator has set by creating the world in the first place: “Works of art summon into being what they only pretend to represent. This is how and why art changes our perception of the world” (85). I would suggest that disability narratives like Motherless Brooklyn change the way we perceive disability because they incorporate an understanding of disability that has developed over the last forty years, especially the last twenty, and then use that understanding as part of the way they summon their worlds into being.
Chapter 3—Implying Authors and Reading Minds: Mark Haddon’s *The Curious Incident of the Dog in the Night-time*

**Introduction: A major incident**

Mark Haddon’s novel *The Curious Incident of the Dog in the Night-time* (2003) has become a flashpoint for debates about representations of autism and disability. At the book’s center is Haddon’s fictional construction of autistic subjectivity. The nature of this fictional subjectivity has drawn praise and blame for Haddon, the roots of which I aim to uncover this chapter. Responses to *Incident* have varied so widely for at least two reasons. First, readers cannot seem to agree about how Haddon thinks of autism and its relationship to storytelling. Second, readers have not adequately addressed the way Christopher as character-narrator interprets and narrates his experiences in comparison (and contrast) to the way Haddon as implied author constructs fifteen year-old Christopher as an autistic person. Thus, there remains disagreement about *Incident’s* ethics and the (related) nature and extent of its aesthetic accomplishments.

Joining the conversation about *Incident* by way of rhetorical narrative theory—specifically, the distinction between the flesh and blood author and the implied author, Christopher’s rhetorical situation as ostensible creator of the novel, and distinctions
among types of audiences—advances the discussion of the novel beyond its current state by allowing us to synthesize and improve on existing popular, disability studies, and literary studies readings. In this chapter I begin by providing some necessary context about autism discourse and the present “autism wars.” Then I discuss what I refer to as Haddon’s “symptomatic” representation of autism before turning to those aspects of Christopher’s character that exceed symptomatic representations. These dual tracks Haddon lays, further textured by distinctions among authorial, narrative, and ideal narrative audiences, suggest that Incident is an excellent example of disability’s shifting and contested roles and meanings in contemporary literature. I conclude by situating this chapter and this novel in the broader context of literary disability studies and the ethics of representation, showing that while we may not seek out Haddon (or any author who does not actually have a given identity or condition) for strictly empirical knowledge about autism (or whatever identity or condition), we do approach literary texts in order to try on different perspectives toward people unlike ourselves and situations unlike our own. Incident in particular offers two different accounts of autism that correspond to contemporary attitudes, and thus the novel is an important part of the contemporary conversation about autism.

Before I begin, a brief summary of the novel: Christopher lives with his father in Swindon, England. As far as he knows at the novel’s outset, his mother died of a heart attack two years ago. One night Christopher discovers his neighbor’s dog Wellington impaled with a pitchfork on the neighbor’s lawn. Having concluded that Wellington “was probably killed with the fork because I could not see any other wounds in the dog and I
do not think you would stick a garden fork into a dog after it had died for some other reason, like cancer, for example, or a road accident,” Christopher sets out to find the killer (1). After a few days of investigation, Christopher learns that his father killed the dog because of tension between his father and the neighbor, Mrs. Shears. Christopher then learns that that tension had to do with the fact that Christopher’s mother had an affair with Mr. Shears, the neighbor’s husband. In fact, Christopher’s mother is not dead at all: she left Swindon with Mr. Shears and moved to London. Because of his confusion and a felt inability to explain the situation to his son, however, Christopher’s father told him that his mother had died of a heart attack. Afraid of his father, whom he now mistrusts and views as a murderer, Christopher leaves home to reunite with his mother in London. The novel follows Christopher’s journey, which is as much about him finding his way in the world as it is about him finding his way to London.

On the one hand, the implied Haddon’s understanding of autism and therefore his construction of Christopher as an autistic character are deeply rooted in the clinical, medicalized accounts made famous and popular by psychologists like Simon Baron-Cohen and Uta Frith. Another way of saying this is to say that the main indicators of Christopher’s autism are “symptomatic.” By this I mean two things: first, that the affective and behavioral indicators of Christopher’s autism are typical “symptoms” of autism; and second, that the signposts of autism in Incident are themselves indicative of a medicalized understanding focused on autism’s distinguishing features as pathology. Even though the words autistic, autism, and Asperger’s never appear in the novel, typical “symptoms” of autism (e.g., perseverance, literal-mindedness, and above all, the inability
to imagine others’ mental states), as explained by Baron-Cohen and Frith, are everywhere in the novel. In fact, readers’ ability to identify Christopher as autistic without the presence of such words speaks to the prevalence of this view of autism, defined by characteristics people have come to think of as hallmark “symptoms.”

At the same time, Christopher’s explanations of his own behaviors, tendencies, and preferences exceed a strictly symptomatic characterization and reveal an important crosscurrent in the implied Haddon’s treatment of autism. As I will discuss, Christopher’s rhetorical self-awareness as the creator of “a murder mystery novel,” as well as his frequent lying despite the avowal that he is unable to lie, cast him as far more complex than some other aspects of the novel (and its contexts of reception) would suggest. Ultimately, I argue that the implied author Haddon simultaneously offers both what I will call a “symptomatic” characterization and a more dynamic, less stereotypical version of autism.

**Autism discourse and the autism wars**

In his now-canonical book *Mindblindness: An Essay on Autism and Theory of Mind* (1995), Cambridge psychologist Simon Baron-Cohen describes autism as “the most severe of all the childhood psychiatric conditions. Fortunately,” he goes on to say, “it occurs only rarely.” He describes some common markers of autism—saying that “social and communication development are clearly abnormal…and the child’s play is characterized by a lack of the usual flexibility, imagination, and pretense”—before offering the following suggestion: “The best way to get a sense of what a child with
autism is like, if you have never met one, is to read extracts of [pioneer autism researcher Leo] Kanner’s (1943) descriptions of the children in whom he first identified the syndrome” (60-61). Baron-Cohen’s characterization of autism as a severe psychiatric condition, and his highlighting of what was in 1995 a fifty year-old list of descriptions as a way of understanding autism, is emblematic of clinical approaches to autism. On this account, the best way to understand autism is to understand its symptoms (not, as one might think, to meet an autistic person). In 2003, Frith likewise characterized autism as “a subtle yet devastating neurological abnormality” made more distressing by its invisibility—the possibility that it can “hide” behind a child’s “doll-like image” (1).  

Symptoms in the abstract are not easily placed on a spectrum; they are most readily understood categorically: you either have this symptom or you do not. Consequently, an understanding of autism rooted in a medical model might lead one to think in absolute terms about the presence of autistic “symptoms.” Creating an autistic fictional character under the same paradigm often becomes a similarly totalizing exercise: Can my autistic character understand figurative language, or not? Does he abhor physical touch, or not? Autistic people and their supporters often call this type of clinical paradigm “neurotypicality,” which refers to an account of cognition and information processing defined by non-autistic people and their expectations about human behavior and cognition. Neurotypicality stands in contrast to “neurodiversity,” a paradigm that places all cognition and information processing on a spectrum that includes both autistic

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29 It should not escape our notice that neither Baron-Cohen nor Frith mentions autistic adults in his/her respective introductory descriptions of autism. See Scott Michael Robertson, “Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges.” *Disability Studies Quarterly* 30 (2010).
and non-autistic people. Under the neurodiversity paradigm, some version of which most
disability studies scholars (myself included) endorse\(^\text{30}\), autism should be understood and
researched, and autistic people should receive support and services as necessary; but
autistic people should not be cast as a separate type of human being than non-autistic
people, and autism should not be interpreted as always and only a deficit and
misfortune.\(^\text{31}\) In other words, under a neurodiversity paradigm, autism is a characteristic
that manifests itself in various ways, not a symptom of some limiting condition.

With all of that being said, clinical psychologists—constrained as they are by the
presuppositions and parameters of their fields, and contrary to some vitriolic treatments
of their work—certainly understand that autistic individuals are, in fact, individuals. For
instance, in discussing the social patterns and struggles of autistic people, Frith points out
that since “[s]ocial behavior and emotional relationships involve many different
components…it is difficult to define social competence even in normal individuals” (98).
Further, *Autism* includes a chapter on the particular abilities of autistic people, such as the
ability to focus on elements of events or items—which in some cases leads to the

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\(^\text{30}\) I should point out that not all autistic people and their supporters advocate a neurodiversity perspective,
and that there is no party line for neurodiversity advocates’ goals. At its simplest, neurodiversity is the view
that neurological differences exist among people, and that those differences should be understood and
respected along the same lines as other forms of human variation. In this way, the rhetoric of neurodiversity
is of a piece with other forms of civil rights rhetoric. For a humorous example of skepticism toward
neurotypicality, see “The Institute for the Study of the Neurologically Typical,” www.int.autistics.org. For
an account of neurodiversity that extends beyond autism and into other neurological differences, see

\(^\text{31}\) Ongoing conflict—or dialogue, depending on how you interpret the organizations’ interactions—
between Autism Speaks and the Autistic Self-Advocacy Network (ASAN) offers a recent and lively
example. On my campus an Autism Speaks event marking “Autism Awareness Month” touted autism as an
ominous killer and notorious ruiner of marriages. The event prompted a counter-demonstration by ASAN,
whose members demonstrated with posters featuring slogans that played on Autism Speaks’s name and its
tendency to speak for autistic people in problematic ways—for example, “I can speak for myself” and, “I
have autism. Listen to me.”

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development of specific skills that require such focus (e.g., musical aptitude), and in others yields deep understanding of the object of an autistic person’s sustained attention (e.g., understanding a poem or a machine).³²

Psychologists, then, do understand autism as a condition affecting individual persons, however much they might pay attention primarily to symptoms and treatment. But whether owing to that primacy or to some other factor(s), popular understandings and representations of autism have been predicated on the centrality and totalizing nature of certain hallmark characteristics—symptoms—of autism. Where a more person-first or humanistic understanding of autism might result in more nuanced or dynamic representations, the preference for symptoms in popular scientific literature (and therefore in journalism and other popular media outlets) has produced a corresponding preference in literary representations. In most cases, this means that autistic characters: a) are savants of some kind, ideally in a way that involves numbers, b) are mostly if not entirely incapable of understanding humor or emotion, especially other people’s humor or emotion, and c) usually stand to benefit nondisabled people by their presence in those nondisabled people’s lives, a presence often enforced by some familial bond and/or exceptional circumstances.³³

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³² For another account of the benefits of autistic cognition, see Matthew K. Belmonte, “Human, But More So: What the Autistic Brain Tells Us About the Process of Narrative” in Osteen, Autism and Representation.

³³ Stuart Murray, “Contemporary Sentimental: Fiction and the Narrative Fascination of the Present,” “Hollywood and the Fascination of Autism,” and Understanding Autism. As I mentioned in a previous footnote, the canonical example before Christopher was Rain Man’s Raymond Babbit. Marcus in Nick Hornby’s About a Boy is another example.
Autism has also taken the national stage, and not only because of Jenny McCarthy’s two highly publicized memoirs of parenting an autistic child. At the end of a long and controversial nomination period, on June 22, 2010 Ari Ne’eman was confirmed as the first autistic person on the president’s National Council on Disability. Ne’eman is the founder and president of the Autistic Self-Advocacy Network (ASAN) and was officially diagnosed with Asperger’s syndrome in 2000. Many in what Melanie Yergeau calls the “autism community”—“mainly comprised of parents and practitioners who view autism as a pathology in need of eradication”—objected to Ne’eman’s appointment, suggesting that his high-functioning autism and separation from people with more pronounced forms of autism left him ill-suited and naïve about the real needs of autistic people and their families. Meanwhile, those in the “autistic community”—which Yergeau classifies as “autistic people and supporters who adopt a social model of disability, a model that regards disability as socially constructed, a matter of societal discrimination”—vigorously supported Ne’eman, arguing that he would help others recognize the need to let autistic people speak for themselves in politics and public discourse.

This very public controversy nicely embodies the present state of what have come to be called “the autism wars,” a debate among parents, autistic people, advocates, and researchers that centers on the meaning, diagnosis, and appropriate rhetorical, scientific, and affective responses to autism. At the center of the conflict are rhetoric and representation, concerns and ideas about who ought to speak about autism, with what kind of language, and in what venues. Haddon’s novel is a part of these “wars,” and its
massive popularity, which probably has as much to do with its engagement with autism as such as with any of its properly literary characteristics, solidifies it as a key site for continuing debates about autism and representation. In fact, *Incident* is all the more apropos of the autism wars because Haddon seems to offer simultaneously “autism” and “autistic” characterizations of his protagonist.

**A note on authors and audiences**

In addition to the discursive and cultural context in which the novel emerged, my argument about the dual tracks Haddon lays in *Incident* also depends on the construct that Wayne Booth famously named the *implied author*. In *The Rhetoric of Fiction* (1961), Booth described the implied author:

As he writes, [the flesh and blood author] creates not simply an ideal, impersonal ‘man in general’ but an implied version of ‘himself’ that is different from the implied authors we meet in other men’s works…it is clear that the picture the reader gets of this presence is one of the author’s most important effects…Our reactions to his various commitments…will help to determine our response to the work. (70-71)

Readers simultaneously discern and create the implied author as our “intuitive apprehension of a completed artistic whole; the chief value to which *this* implied author is committed, regardless of what party his creator belongs to in real life, is that which is expressed by the total form” (73-74).

I believe in the utility of the implied author as a way of preserving our ability to speak about intentionality while acknowledging that authors and narrators are different from one another, and further that authors might sometimes *mean* to do something but
not succeed in doing it. In a case like Incident, the implied author concept is especially useful because of the different messages the novel communicates about autism. While the book is a major part of the present autism wars, the author is not. The flesh and blood Haddon’s attitude toward and beliefs about autism are not particularly important in autism discourse, presumably because regardless of his opinions about autism, the book has a life apart from its author—being, as it is, a book that has generated widespread discussion about autism that far exceeds Haddon’s ability to steer or correct it to any significant degree. The novel’s implied author seems to hold at least partly conflicting views about autism, which makes Incident grist for people who take different positions in the conversation—even if the flesh and blood Haddon has only one or even neither of these views. Drawing out the implied author’s views of autism thus goes some way toward clarifying why Incident is a significant part of present debates over autism. Ultimately I do not think the implied author’s view can be resolved as either strictly symptomatic or strictly not, and for this reason I speculate that this novel will continue to be part of the autism wars and, in future generations, may be viewed as a microcosm of the debate between neurotypicality and neurodiversity.

Building on Booth’s rhetorical approach to narrative in his essay “Truth in Fiction,” Peter J. Rabinowitz theorized four audiences for any fictional narrative. The actual audience includes those actual people reading the text. The authorial audience is the hypothetical readership about whom the author makes assumptions regarding their “beliefs, knowledge, and familiarity with conventions. His artistic choices are based on these assumptions…and to a certain extent, his artistic success will depend on their
accuracy” (“Truth in Fiction” 126). For example, if some historical event superintends the events of a text (say, the Napoleonic wars in War and Peace), an actual reader’s engagement with and appreciation for the story hinges at least in part on her awareness of that event such that she can enter into the authorial audience. As Rabinowitz points out, “If historically or culturally distant texts are hard to understand, it is often precisely because we do not possess the knowledge required to join the authorial audience” (127). While we can engage with a text without thorough knowledge of relevant background phenomena, our involvement in the authorial audience corresponds in degree to our awareness of those phenomena. In the case of Incident, the authorial audience is the audience that adopts the implied Haddon’s perspective on and understanding of autism, which it would construct based on the cues embedded in the text—including cues that point to ideas, events, people, and places outside it. The narrative audience is the group of readers who share assumptions and knowledge with the narrator about the world in which a story takes place. In fairy tales, the authorial audience probably does not believe in goblins, but the narrative audience does. Entering the narrative audience is what prevents readers from concluding that anyone who sees goblins in a narrative world is delusional, while simultaneously deriving morals about our actual world from tales about goblins. Finally, the ideal narrative audience is “the audience for which the narrator wishes he were writing…[who] believes the narrator, accepts his judgments, sympathizes with his plight, laughs at his jokes even when they are bad” (134). Some narrators are not reliable in their interpretation of events (for instance, Humbert Humbert in Nabokov’s Lolita), and so we can enter the narrative audience that believes all the characters exist,
but resist entering the ideal narrative audience since we reject the narrator’s judgments about the events of the plot. The ideal narrative audience is ideal “from the narrator’s point of view” (134).

Rabinowtiz’s distinctions are especially useful in cases where the operative beliefs in the narrative world may be different from those in the world outside the text. As I will demonstrate, because Incident’s implied author is of two minds about autism, its authorial audience is similarly conflicted. Further, however, the novel’s narrative audience (which believes that Christopher wrote the novel it is reading, but also knows that his teacher Siobhan acted as an invisible editor) and its ideal narrative audience (which only concerns itself with Christopher’s reporting and interpretation) highlight the tension within the authorial audience. After discussing the implied author and authorial audience of Incident, I will discuss the tension among its audiences.

Incident’s symptomatic account of autism

Immediately after the book’s opening chapter, Christopher explains his difficulty understanding facial expressions. He understands smiles and frowns to mean happiness and sadness, but when his teacher Siobhan showed him simplified sketches of faces meant to depict subtler emotions, Christopher says, “I was unable to say what these meant.” In order to better navigate the social world, he says, “I got Siobhan to draw lots of these faces and then write down next to them exactly what they meant. I kept the piece of paper in my pocket and took it out when I didn’t understand what someone was saying. But it was very difficult to decide which of the diagrams was most like the face
they were making because people’s faces move very quickly” (3). Within the first three pages of *Incident*, then, we see that Christopher struggles to understand others’ emotional states based on the observable cues their faces provide. It is this struggle to interpret others’ emotional and other mental states that lends the title to Baron-Cohen’s *Mindblindness*. Briefly, Theory of Mind is the ability to “infer the full range of mental states (beliefs, desire, intentions, imaginations, emotions, etc.) that cause action…[H]aving a theory of mind is to be able to reflect on the contents of one’s own and other’s minds. Difficulty in understanding other minds is a core cognitive feature of autism spectrum conditions” (“Theory of mind” 74), and an underdeveloped Theory of Mind is thought to be the most salient indicator (“symptom”) of autism.34

In *Incident*, Christopher describes participating in one permutation of a Theory of Mind test. A schoolteacher

sat down at a desk next to me and put a tube of Smarties [a British candy comparable to M&Ms] on the desk, and she said, “Christopher, what do you think is in here?” And I said, “Smarties.” Then she took the top off the Smarties tube and turned it upside down and a little red pencil came out and she laughed and I said, “It’s not Smarties, it’s a pencil.” Then she put the little red pencil back inside the Smarties tube and put the top back on. Then she said, “If your mummy came in now and we asked her what was inside the Smarties tube, what do you think she would say?”…And I said, “A pencil.” That was because when I was little I didn’t understand about other people having minds. (115-116)

Here Christopher very clearly explains not only the test, but also its meaning.35 I will discuss the significance of Christopher referring to his own difficulty understanding “about other people having minds” later. Here Haddon cues readers to the presence of

34 In addition to *Mindblindness*, see, e.g., Baron-Cohen, Leslie and Frith, “Does the autistic child have a ‘theory of mind’?” and Baron-Cohen, “Theory of mind in normal development and autism.”
35 See note 40 below, on James Berger’s shrewd reading of Christopher’s explanation of the Smarties test.
autism by having Christopher describe a canonical psychological test from autism research, even using the phrase “other minds,” but without ever naming autism (or Theory of Mind). For the implied Haddon, it seems that autism is equivalent to its symptoms as described in popular scientific literature.

Additionally, Christopher mentions that he “cannot tell jokes because [he does] not understand them.” More specifically, while he can understand, for example, the rhetorical operations of a joke that depends on wordplay, he says, “If I try to say the joke [‘His face was drawn but the curtains were real’] to myself, making the word mean the three different things at the same time, it is like hearing three different pieces of music at the same time, which is uncomfortable and confusing and not nice like white noise” (8). Conveniently, here Christopher also discloses his distaste for multiple or overabundant sources of external stimuli, another symptom that often marks autism.

Moreover, Christopher claims to be unable to understand, or at least unwilling to tolerate, figurative language. He defines a metaphor as “when you describe something by using a word for something that it isn’t.” Christopher objects to metaphors: “I think it should be called a lie…when I try to make a picture of the [metaphor] in my head it just confuses me because imagining an apple in someone’s eye doesn’t have anything to do with liking someone a lot and it makes you forget what the person was talking about” (15). Haddon here represents Christopher’s literal-mindedness as so pervasive that he willfully avoids and actively denounces all instances of figurative language—the more imprecise, the more distasteful.
Finally, Christopher demonstrates interest and talent in mathematics and science, which he uses as a lens for interpreting other events in his life that are more difficult for him to understand—namely, other people and especially their thoughts and feelings. He numbers the chapters in his book with prime numbers, which he likes because they are “like life. They are very logical but you could never work out the rules, even if you spent all your time thinking about them” (12). He imagines that he would be an excellent astronaut, which he would like because it would require him to be alone and to spend long periods of time in a small space, both of which he enjoys. Christopher firmly believes that “logic can help you work out the right answer” in most situations, whereas “intuition can sometimes get things wrong. And intuition is what people use in life to make decisions” (65).

Each of these characteristics is unambiguously given to Christopher as a marker of his autistic identity: he is not partly unable to understand humor or interpret ambiguous facial expressions, but categorically so. As I have already mentioned, the symptoms as well as their totalizing nature can be traced to popular scientific accounts of autism.36

Haddon builds Incident’s narrative progression and its readerly dynamics on the foundation of symptomatic autism. It is not only Christopher’s characterization, but also the experience of reading in the authorial audience that depends on the assumption that Christopher is symptomatically autistic and readers are not. In the first few chapters Haddon introduces many of Christopher’s “symptoms,” including those discussed above,

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36 For more on the binary logic of autism in Incident, see Gyasi Burks-Abbott, “Mark Haddon’s Popularity and Other Curious Incidents in My Life as an Autistic,” in Osteen’s Autism and Representation.
in order to establish Christopher as a specifically autistic character. In these chapters Haddon is at pains to show that Christopher’s investigation of Wellington’s murder will not proceed primarily by his inferring things about people’s motivations and attitudes based on their behaviors and speech, because Christopher cannot infer people’s motivations and attitudes based on their behaviors and speech. Readers are cued to recognize almost immediately that *Incident* will be an unconventional mystery novel.

Further, and more important, it quickly becomes clear that part of the authorial audience’s role in successfully reading this novel will be to solve another mystery—one Christopher is not aware of and in which, consequently, he does not participate. Haddon’s story features a narrator-protagonist with a restricted capacity for Theory of Mind trying to solve a puzzle about a murdered dog. However, because that puzzle involves his complicated family history, the narrator-protagonist actually embarks on a journey of self-discovery by investigating the puzzle, a fact of which he becomes aware, albeit in a very particular way. As the case Christopher is trying to solve unfolds, he discovers and reacts to revelations about the relationship between his parents and his role in that relationship. For readers of Haddon’s *Incident*, the story of Christopher’s family eclipses the mystery of Wellington’s murder by approximately a quarter of the way through the novel, when he first learns of his mother’s affair with Mr. Shears. Because of the way his brain works—that is, because of his symptoms—Christopher does not reflect explicitly on his reactions and thoughts in the way other narrators or characters might. For the authorial audience, the mystery to be solved is: What do Christopher’s actions and utterances over the course of his discoveries reveal about his understanding of and
response to those discoveries, given the knowledge that he will almost certainly not articulate those understandings and responses himself?

Readers solve this mystery by making inferences about Christopher’s mental and emotional states. This means that to read in Incident’s authorial audience hinges on Theory of Mind—both recognizing Christopher’s struggle to use it as a hallmark trait of autism, and being able to make inferences about both Christopher’s and others’ states of mind. For example, after Christopher learns about the affair between his mother and Mr. Shears, he explains a deceptive, counterintuitive math problem in order to make the point that, while “logic can help you work out the right answer” when intuitions lead you astray, it is ultimately important to remember that “numbers are sometimes very complicated and not very straightforward at all” (65). Shortly thereafter, he quotes a description of Sherlock Holmes: “His mind…was busy in endeavoring to frame some scheme into which all these strange and apparently disconnected episodes could be fitted.” Christopher then likens himself to Holmes by saying, “And that is what I am trying to do by writing this book” (74).

For as much as Christopher decries proper novels, supernaturalism and human illogic based on emotion, and for as much as he is describing the mystery of Wellington’s murder as complicated, knowing that Haddon (not Christopher) has constructed these self-reflexive asides is a clue to the mystery of Haddon’s Incident. Specifically, in these moments Haddon shows readers that Christopher is trying to understand his experiences and organize them into a coherent narrative. Moreover, he acknowledges that the process of understanding and explaining events and people is complicated. However, this is a
conclusion readers can reach only by making inferences about emotional responses that Christopher articulates by discussing something complicated and confusing that he does understand. The implied Haddon has constructed a character with a compromised Theory of Mind and a narrative situation in which readers can only enter the authorial audience if they successfully exercise their Theory of Mind to interpret that character’s actions, understanding that he cannot do so for himself.

**Beyond the symptomatic**

Though the implied Haddon’s conception of autism is largely symptomatic and posits a corresponding authorial audience, *Incident* does not uniformly represent autism this way; and as I mentioned above, the tension between the symptomatic and that which exceeds it is part of what makes the novel so compelling and such a provocative part of the autism wars. The two most important aspects of *Incident*’s narrative progression that exceed a symptomatic understanding of autism are: 1) that Christopher insists throughout the novel that he is writing a murder mystery story based on his experiences investigating Wellington’s murder, and 2) that, as he says, “I do not tell lies…because I can’t tell lies” (19).

“It is perhaps telling that while Christopher typically follows such summary comments about himself with illustrations and further description of the point at hand, in this instance he changes the subject and begins to talk about his mother.
In Haddon’s opening chapter, Christopher describes the scene of his neighbor’s dog’s murder in a style that plays on hard-boiled detective fiction, in a voice reminiscent of Dashiell Hammett’s Sam Spade or Raymond Chandler’s Philip Marlowe:

It was 7 minutes after midnight. The dog was lying on the grass in the middle of the lawn in front of Mrs. Shears’s house…The dog was dead. There was a garden fork sticking out of the dog. The points of the fork must have gone all the way through the dog and into the ground because the fork had not fallen over. I decided that the dog was probably killed with the fork because I could not see any other wounds in the dog…But I could not be certain about this. I went through Mrs. Shears’s gate, closing it behind me. I walked onto her lawn and knelt beside the dog. I put my hand on the muzzle of the dog. It was still warm…I stroked Wellington and wondered who had killed him, and why. (1-2)

The stage is set, then, for a whodunit. But instead of launching into the investigation, as in a conventional detective novel, the next chapter opens this way: “My name is Christopher John Francis Boone. I know all the countries of the world and their capital cities and every prime number up to 7,057” (2). Christopher then moves to the discussion I addressed above about interpreting facial expressions—a usually-indispensable skill for the detective, and as I mentioned, a predictable marker of autism—before launching back into the investigation (the opening of the next chapter): “I pulled the fork out of the dog and lifted him into my arms and hugged him. He was leaking blood from the fork holes. I like dogs. You always know what a dog is thinking” (3). Unlike the first chapter, this one does not carry on in the style of hard-boiled detective fiction. Mrs. Shears emerges from her house to find Christopher and Wellington on the lawn. As she screams in confusion and anger about her skewered dog, Christopher says, “I put my hands over my ears and closed my eyes and rolled forward till I was hunched up with my forehead pressed onto
the grass” (4). Needless to say, here the novel parts company with conventional detective fiction. At this point, attentive readers know that Christopher is in the initial stages of a murder investigation, and also that he is autistic—a combination that both fits with and complicates the character of the hard-boiled detective.38

At the outset of the next chapter Christopher says, “This is a murder mystery novel. Siobhan [his teacher] said that I should write something I would want to read myself. Mostly I read books about science and maths. I do not like proper novels…but I do like murder mystery novels. So I am writing a murder mystery novel.” Further, he says he is writing this particular murder mystery novel “because [the events of the plot] happened to me and I find it hard to imagine things which did not happen to me” (4-5). Christopher explains that he likes murder mystery novels because they are like solvable puzzles, and also because there is less metaphorical and abstract discourse in them than in “proper novels,” which he dislikes.39 Thus, we now know that we are dealing with an autistic detective who is also allegedly writing, as part of an assignment or school activity, the allegedly true story we are reading.

Christopher is aware of the rhetorical necessities and the relational challenges to his production of a successful detective story that also renders his experiences as a coherent narrative, including the experience of writing the book we are reading. It is the entirely retrospective nature of the narrative that points to the first major way Incident

38 For more on the hard-boiled detective as a character type, see, e.g., Moore, Lewis D. Cracking the Hard-Boiled Detective: A Critical History from the 1920s to the Present.
39 There are also uncomfortable echoes here of the autistic mind as a puzzle. The Autism Speaks logo is a puzzle piece, for example. Additionally, I want to note the way an emphasis on detection (and the protagonist as detective) links Incident and Motherless. I discuss this connection and its potential significance in the conclusion.
exceeds symptomatic autistic narrative: Christopher’s conscious shaping of a narrative according to principles of narrative design that he would not be able to perform if his symptoms were as totalizing as they seem to be in the novel’s opening pages. This contradiction of strictly symptomatic autism presents itself at both the local and the global levels.

At a local level, Christopher understands that other people have a different attitude about his writing project than he does, and this understanding is evident in Christopher’s attempts to chronicle his detective work. Autistic scholar Gyasi Burks-Abbott points out that though Christopher is allegedly unable to infer other people’s mental states, he frequently does so. For instance, “Christopher shows a particularly keen ability to infer another’s intentions when he finds the manuscript [i.e., the early portions of his murder mystery novel] that his father has hidden from him” (292). Burks-Abbott then cites Christopher’s narrated thoughts after he has recovered the manuscript: “I was happy because Father hadn’t thrown my book away. But if I took the book he would know that I had been messing with things in his room and he would be very angry…I reasoned that…I could carry on writing in another book that I would keep really secret and then, maybe later, he might change his mind and let me have the first book” (93-94). Christopher is able to infer these thoughts because he knows “people can change their minds (something the theory-of-mind hypothesis suggests that autistics cannot comprehend), [and] Christopher is able to separate what he knows…from what his father
knows” (Burks-Abbott 292). The desire to write his story motivates Christopher to imagine his father’s perspective and adjust his actions accordingly.\footnote{James Berger points out that Christopher obviously understands inferencing about others’ mental states given his clear explanation of the famous “Smarties Test,” which tests the extent to which children understand the localization of knowledge in individual minds. “Alterity and Autism: Mark Haddon’s Curious Incident in the Neurological Spectrum.” Autism and Representation. 271-288.}

At a global level, Christopher conceives of his project not only as an attempt to explain how he solved the case of Wellington’s murder, but also as a story about his family. Since he is retrospectively narrating his experience of uncovering the truth about his family, statements Christopher makes about his novel as a whole should be interpreted in light of both the murder investigation and the story of his family.

\textit{Incident} begins as a murder mystery novel, but it is ultimately a story about Christopher’s negotiation of significant revelations about his family history and his responses to those revelations. The novel’s global tension—the gap between what readers know and what the narrator and author know—has centrally to do with Christopher’s understanding of and response to his family situation. At the novel’s conclusion, Christopher acknowledges as much, proclaiming that after he finishes his education he “will become a scientist. And I know I can do this because I went to London on my own, and because I solved the mystery of \textbf{Who Killed Wellington?} and I found my mother and I was brave and I wrote a book and that means I can do anything” (221). Thus, as the tension has developed and resolved, the scope of the text has widened such that Christopher thinks of himself as not only having written a murder mystery novel, but also having demonstrated his ability to accomplish significant things in narrating the experiences that solving the mystery catalyzed.
Over the course of the narrative progression Christopher has utilized the conventions of detective fiction, which he knows well, and also occupied the role of the detective in order to establish stability for himself in light of his new knowledge. This conscious shaping of experience required making inferences about other minds as well as the imposition of narrative structure on the disparate elements and chaos of life. Christopher is far from being overwhelmed by an inability to synthesize the information he receives over the course of the narrative. To the contrary, Christopher demonstrates a persistent interest in deploying the sense-making abilities a strictly symptomatic understanding of autism would refuse to grant to an autistic character-narrator.

“I do not tell lies...because I can't tell lies.”

Christopher insists that he is unable to lie—not because, as his mother had told him, he “was a good person,” but rather because he is literally unable to do so. He defines lying as “when you say something happened which didn’t happen,” then points out that lying is also not pleasurable, since “there is only ever one thing which happened at a particular time and a particular place. And there are an infinite number of things which didn’t happen at that time and that place. And if I think about something which didn’t happen I start thinking about all the other things which didn’t happen…even writing this makes me feel shaky and scared” (19). Having explained his inability to lie, Christopher confidently avers, “And that is why everything I have written here is true” (20).

Christopher also balks at what he perceives as other people’s untruths. As I have already mentioned, he objects to “proper novels” partly because they present as actual
events “things which didn’t happen.” More important, though, is Christopher’s reaction to his father’s confession of having committed Wellington’s murder. After the confession, Christopher says, “I had to get out of the house. Father had murdered Wellington. That meant he could murder me, because I couldn’t trust him, even though he had said, ‘Trust me,’ because he had lied about a big thing” (122). Later that night, as he is leaving the house, Christopher wonders whether his father is “asleep downstairs or whether he [is] waiting to come in and kill” him (123). And much later, after Christopher has arrived at his mother’s home in London but is visiting his father in Swindon, his suspicion remains: “I had to go to Father’s house…so I pushed the bed against the door in case Father tried to come in. And sometimes he tried to talk to me through the door, but I didn’t answer him. And sometimes I heard him sitting on the floor outside the door quietly for a long time” (217). Obviously his father feels remorseful and confused and wants to connect with his son; but Christopher’s fear, predicated equally on his father’s actions and his subsequent lies about them, still dominates Christopher’s impressions.

More important than his reactions to others’ lies are Christopher’s proud assertions and performance of his own truthfulness. Throughout *Incident* Christopher appeals to his ability to follow the letter of the law, especially in cases where his father asks him to do or refrain from doing certain things. When he finds out that Christopher has been investigating Wellington’s murder by talking with Mrs. Shears and other neighbors, Christopher’s father confronts him:

OK, Christopher. I am going to say this for the last and final time. I will not tell you again…You are not to go asking anyone about who killed that bloody dog. You are not to go asking anyone about who killed that bloody dog. You are not to
go trespassing in other people’s gardens. You are to stop this ridiculous bloody
detective game right now…I am going to make you promise, Christopher. And
you know what it means when I make you promise. (50)

Before promising his father that he will in fact do everything he asks, Christopher
clarifies what it means to make a promise, saying that when you promise, “[y]ou have to
say that you will never do something again and then you must never do it because that
would make the promise a lie” (50). Later Christopher reviews the series of things his
father has asked him not to do while talking with another neighbor, Mrs. Alexander. He
wonders whether she has any information that might help him solve the mystery of
Wellington’s murder, and he reasons that “asking [Mrs. Alexander] about Mr. Shears
wasn’t any of these things” his father had asked him not to do (56). Christopher then
says, “[I]f you are a detective you have to Take Risks” as he describes his decision to ask
Mrs. Alexander about Mr. Shears. He goes on to describe his interaction with her in terms
of being a detective: when Mrs. Alexander asks, “Why are you asking me about Mr.
Shears,” Christopher says he “didn’t say anything because [he] didn’t want to be
investigating Wellington’s murder and that [i.e. because he was investigating] was the
reason [he] was asking about Mr. Shears” (57, my emphasis).

As their conversation progresses and Mrs. Alexander realizes Christopher is
misinformed about his mother’s departure, Christopher notices her demeanor changing.
He asks her, “Why did you say ‘I think you know why your father doesn’t like Mr.
Shears very much’?” When she does not reply, Christopher

asked her the same question again, because in a murder mystery novel when
someone doesn’t want to answer a question it is because they are trying to keep a
secret or trying to stop someone from getting into trouble, which means that the
answers to those questions are the most important answers of all, and that is why the detective has to put that person under pressure. (58-59, my emphasis)

Christopher very recently promised his father that he would no longer play “this ridiculous bloody detective game,” but here he explicitly casts himself as a detective, which by his own standards means that the promise to his father has become a lie. On a strictly symptomatic account of autism, literal-mindedness would be inviolable, and thus Christopher’s desire to be a detective would have to be constrained by more general principles of truth telling. Yet in this case the desire to play the role of detective trumps the commitment to truth telling. Surprisingly, Christopher reaffirms his truthfulness within the same conversation with Mrs. Alexander. After she tells him that his mother and Mr. Shears were having an affair, Mrs. Alexander asks, “You won’t tell your father about this conversation, will you?” He replies, “No. I promised” (61).

Eventually Christopher’s father discovers that Christopher has been writing a book (the murder mystery novel we are allegedly reading) about his investigations of Wellington’s murder and takes the book away. After school one day Christopher comes home to an empty house and begins thinking about the book. He says, “I wanted to get my book back because I liked writing it. I liked having a project to do…especially if it was a difficult project like a book…Also I still didn’t know who had killed Wellington and my book was where I had kept all the clues that I had discovered” (91). Christopher decides “to do some detecting and see if I could find it. Except I had to keep listening really hard all the time so I would hear his van when he pulled up outside the house so he wouldn’t catch me being a detective” (91). He knows his father took the book because he
had violated his promise by talking with Mrs. Alexander, and so he knows that to recover the book and continue the investigation would constitute further violation of his father’s trust; otherwise, why would he have to search for the book while his father was not home? And even if he could justify his search by pointing out that he never promised not to look at or write in his book, the continued search eventually leads Christopher to his father’s room, about which he says, “I didn’t know whether I should look in there because he had told me before not to mess with anything in his room” (92). When he finds his book, Christopher says, “I didn’t know what to do. I was happy because Father hadn’t thrown my book away. But if I took the book he would know I had been messing with things in his room and he would be very angry and I had promised not to mess with things in his room” (93-94). Obviously at some point Christopher did recover the book, because most if not all we have read up to this point was contained within that book. In this case as in the conversation with Mrs. Alexander, Christopher’s commitment to the investigation leads him not only to lie, but also to act self-consciously in a way that exceeds the autistic “symptom” of literal-mindedness.

In addition to these specific instances that exceed the symptomatic, Christopher progresses as a character in comparable ways. When he arrives in London at his mother’s house, he goes to bed in “a pair of yellow shorts which were Mother’s,” something he would typically not do because of his antipathy toward the color yellow. Earlier in the novel, for instance, Christopher explains that he puts red food coloring in foods he likes apart from their yellow color. He explains that he is comfortable wearing the shorts because of extreme fatigue from his travels to London. Just a few days later, Christopher
wakes up and looks out a window. He is in the habit of determining what kind of day it is by looking for consecutive passing cars that are one color, which he views as no more arbitrary than an office employee thinking a day is bad because it is raining (what difference could the weather make if you work inside?). This day, however, “I saw 5 red cars in a row and 4 yellow cars in a row, which meant it was both a **Good Day** and a **Black Day**, so the system didn’t work anymore” (205). While a strictly symptomatic character could conceivably make these kinds of concessions—especially the later, since it is based on a logical inconsistency—their placement at the end of the narrative progression amidst the tying up of loose ends suggests that the implied Haddon does not view autism as strictly symptomatic. Rather, he constructs a character whose habits and preferences change, especially in light of major life changes.

**Other authors, other audiences**

Consideration of *Incident’s* authorial, narrative, and ideal narrative audiences further highlights the ambiguity of autism’s status in the novel. While the narrative audience takes all the events of the plot as true, it also recognizes an important cognitive difference and a difference in aesthetic priorities between Christopher and others, especially his teacher Siobhan. The narrative audience is interested in the mystery story, but like both Siobhan and the authorial audience, it is also interested in the story of Christopher’s family and his impact on the family in a way that Christopher is not—at least not consciously. The ideal narrative audience, meanwhile, knows about Siobhan’s influence on the novel—because Christopher tells them—but that knowledge does not
affect its sense of what is most important in the book. The ideal narrative audience takes Christopher at his word when he says that his having solved the mystery of *Who Killed Wellington* and thus his ability to do anything he wants are the novel’s key conclusions, not any of the information about Christopher’s past or his family. Thus, the narrative audience is closer to the authorial audience’s symptomatic view of autism because it is more conscious of autism and its impact on a whole family, while the ideal narrative audience sidesteps those concerns in its close association with Christopher, who is not self-conscious about autism. The juxtaposition between these two audiences is part of what troubles the authorial audience’s symptomatic view. This is not because the ideal narrative audience has a view of autism that *exceeds* the symptomatic, but rather because members of ideal narrative audience do not think about autism *at all*.

We can think of Siobhan as an embodiment of the authorial audience, since she is engaged in both a symptomatic understanding of autism, based on her role as Christopher’s teacher, and one that exceeds the symptomatic, based on her personal relationship with Christopher. The institutional setting of a segregated school and “special” education provides a symptomatic framework for Siobhan’s engagement with Christopher, since part of the premise of special education is that some students have recognizable characteristics that preclude their participation in the “regular” school system. At the same time, her friendship with Christopher leads her, as I discuss below, to engage with Christopher outside the context of their “institutional” relationship.

Siobhan’s primary role in the novel is to guide Christopher toward a) engaging in conventionally appropriate social interaction and b) producing a conventionally
structured story. Every time Christopher mentions Siobhan, he describes her performing an action that could be classified as having one or both of these as its aim; at times her suggestions are ostensibly directed to the latter while ultimately aiming for the former. The first goal is initially reflected on the novel’s second page, as Christopher describes his difficulty interpreting facial expressions with reference to a school activity. She attempts to help Christopher build a mental log of possible facial expressions he might encounter. This brief passage, discussed above in the section on symptomatic autism, signals to the narrative audience that Siobhan has some role in instructing Christopher about how to navigate a world he struggles to interpret. The second goal is first mentioned just a page later: Christopher is explaining that the book we are reading “is a murder mystery novel” written by him. However, Siobhan has told him

the book should begin with something to grab people’s attention. That is why I started with the dog. I also started with the dog because it happened to me and I find it hard to imagine things which did not happen to me. Siobhan read the first page and said that it was different. She put this word into inverted commas by making the wiggly quotation sign with her first and second fingers. She said that it was usually people who were killed in murder mystery novels…She said that this was because readers cared more about people than dogs, so if a person was killed in a book, readers would want to carry on reading. (5)

In both of these moments, the ideal narrative audience is willing to accede to Siobhan’s advice, trusting that there is merit to what she says while maintaining along with Christopher that, in fact, animals are just as interesting as people, if not more so. However, the narrative audience lends Siobhan’s advice more credence, agreeing to a greater degree than the ideal narrative audience that people—or at least person-like agents—are more important and interesting than their non-human counterparts. Siobhan’s
input on the book extends beyond matters of content to matters of form. Specifically, she
tells Christopher “that when you are writing a book you have to include some
descriptions of things.” When Christopher suggests putting pictures in the book as a form
of visual description, Siobhan tells him “the idea of a book [is] to describe things using
other words so that people [can] read them and make a picture in their own head. And she
said it [is] best to describe things that [are] interesting or different” (67). Here, the ideal
narrative audience agrees with Christopher that the ensuing description of his garden is
relatively uninteresting and more of a distraction from than a contribution to the book’s
success.

Similarly, Siobhan later reads a portion of the book describing Christopher’s
conversation with a neighbor in which he learned that his mother had an affair with Mr.
Shears. Christopher reports that he took that portion of the book to Siobhan “so that [she]
could read it and tell [him] if [he] had made mistakes with the spelling and the grammar”
(74). Siobhan approaches Christopher and asks him not about the technical execution of
the section, but its impact on Christopher based on her awareness of all that his
conversation with the neighbor signifies:

“Did it make you sad to find this out?”
And I [Christopher] asked, “Find out what?”
And she said, “Did it make you upset to find out that your mother and Mr. Shears
had an affair?”
And I said, “No.”
And she said, “Are you telling the truth?”
And then I said, “I always tell the truth.”
And she said, “I know you do, Christopher. But sometimes we get sad about
things and we don’t like to tell other people that we are sad about them. We like
to keep it a secret. Or sometimes we are sad but we don’t really know we are sad.
So we say we aren’t sad. But we really are…If you do start to feel sad about this, I
want you to know that you can come and talk to me about it. Because I think talking to me will help you feel less sad. And if you don’t feel sad but you just want to talk to me about it, that would be OK, too.” (75).

The ideal narrative audience does not get sidetracked thinking about the psychological impact this revelation has on Christopher. Rather, like Christopher, it is trying to piece together the clues Christopher has gathered so far in solving the mystery of Wellington’s murder. Christopher’s ideal narrative audience views him as a detective not personally invested in his case—like Sherlock Holmes, to whom Christopher explicitly connects himself in the previous chapter. Christopher has spent the entire chapter following the discovery of his mother’s affair talking about Sherlock Holmes, concluding with “two interesting facts about Sherlock Holmes” (74). In his mind and the ideal narrative audience’s, information about his past is instrumental to solving his case, but not important in other respects.

The Sherlock Holmes chapter is not the only moment when an extended discussion of some seemingly unrelated item follows an important revelation about Christopher’s past and/or his family. After he discovers a cache of letters that lead to the conclusion that his mother is still alive, Christopher begins a chapter about the Smarties test, discussed above and performed by Siobhan’s predecessor at the school. As far as the ideal narrative audience is concerned, in this as well as the Sherlock Holmes chapter, Christopher’s observations about detective fiction and human cognition are the point of the chapters, not as unintentional revelations of his own feelings or desires but simply as such. For the ideal narrative audience, the descriptions of Sherlock Holmes and human cognition and behavior are the “interesting or different” descriptions, as are Christopher’s
disclosures of his past and of the way he thinks. However, all of those are subordinate to the main diegetic level of the narrative: the murder mystery novel about Wellington’s death and Christopher’s pursuit of his killer. Yet since the narrative audience registers the cognitive difference between Christopher and others, which Christopher never directly articulates (and this, I suggest, is why words like Asperger’s and autism never appear in the text), that audience is alert to different registers of meaning in the novel in the same way as the authorial audience. Like Siobhan, the narrative audience is interested in both the murder mystery and the story of Christopher’s family. Much of that interest comes from the authorial and narrative audiences’ sense that Christopher’s autism prevents him from reflecting on his experiences in the way those experiences beg to be reflected on.

As we have seen, however, Christopher exceeds strictly symptomatic characterization of autism, and the authorial audience picks up cues that indicate as much. Simultaneously occupying the narrative and ideal narrative audiences leads the authorial audience to an ambivalent understanding of autism comparable to the implied Haddon’s.

**Critical context**

The conversations and controversy surrounding Haddon’s novel parallel broader cultural conversations and controversies about autism (and disability) in that they center on how members of contemporary culture ought to understand autism. Autistic readers, family members of autistic people, literary critics with varying degrees of familiarity or experience with autism—and those who fit into more than one of those categories—have
participated in these conversations. Some have found in Incident traces of themselves or their family members, both with specific reference to autism and with reference to the more universal experience of finding one’s way in a complicated world.41 Others view the novel as one more in a long series of misguided, stereotype-laden fictional treatments of autism.42 Some read it as an instructive account of how autistic people both resist and utilize narrative as a mode of cognition.43 Meanwhile, still others basically ignore autism and herald Incident as a consummate postmodern genre-blending hybrid text that incorporates elements of detective fiction, the bildungsroman, and experimentation in perspective.44

In Incident’s popular reception, Mark Haddon has been heralded as “a wise and bleakly funny writer with rare gifts of empathy,” who “illuminates a core of suffering through the narrowly focused insights of a boy who hasn’t the words to describe emotional pain,” a writer “to be congratulated for imagining a new kind of hero.” Incident, the response typically goes, is “a triumph of empathy,” “[h]eart-in-the-mouth stuff, terrifying and moving,” “full of cheeky surprises and tender humor.”45 Countless book clubs have selected and discussed Incident, which has been a Today Show Book and is at the moment the seventy-ninth most popular book in Amazon.com’s “Literature

41 See Burks-Abbott, below
42 The best treatment of stereotypical autistic characters in fiction—of whom Rain Man’s Raymond Babbit was the example par excellence before Christopher came along—has come from Stuart Murray. See especially his “Contemporary Sentimental: Fiction and the Narrative Fascination of the Present,” “Hollywood and the Fascination of Autism,” and Understanding Autism.
43 See Fleißmann and Zunshine, discussed below.
44 See Stefania Ciocia, “Postmodern Investigations: The Case of Christopher Boone in The Curious Incident of the Dog in the Night-time”
45 These praises all come from the paratexts in the Vintage paperback edition.
and Fiction” category. Informal reader reviews on websites like Amazon are overwhelmingly positive, as were many reviews, such as Jay McInerney’s in The New York Times, which calls Incident’s narrator Christopher Boone “one of the strangest and most convincing characters in recent fiction.” Still others recommend Incident as a useful primer on autism: many parents, aunts and uncles of autistic children comment on similarities between Christopher and their loved ones, and courses preparing educators to interact with and teach autistic students regularly list the novel as required reading.

Not every response to the book has been positive, however. In particular, autistic and non-autistic neurodiversity advocates are often deeply critical. Stuart Murray, whose Representing Autism has influenced subsequent studies of literary autism, praises Haddon’s novel for going some distance in representing life “from within the logic of autistic agency.” At the same time, though, Murray says Incident “constructs an idea of the Asperger’s teenager, complete with ritualized mannerisms, love of logic and mathematics, limited emotional range, and a lack of socialization skills, that coheres into a stereotype” (“Contemporary Sentimental” 39). Similarly, Gyasi Burks-Abbott points out, writing in Mark Osteen’s important collection Autism and Representation, “Even though Curious Incident is not about autism per se… and Haddon himself disavows any conscious attempt to enter the flow of autism discourse… the author’s singular portrayal of autism, a portrayal that fails to capture the nuances and complexities of the autism

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46 As of 30 April 2010 (http://www.amazon.com/dp/1400032717)
47 I do not wish to point fingers at specific courses offering the novel as a primer on autism. Suffice it to say that some savvy Googling proves the point. For an example of book club participants’ sense that this book would be “[g]reat for anyone who wants insight on how these minds work,” see http://www.bookmovement.com/app/readingguide/view.php?readingGuideID=80.
spectrum, serves to perpetuate stereotypes” (291). Like Murray, Burks-Abbott points to Christopher’s talents in mathematics, his perseveration and literal-mindedness, and his alleged inability to interpret and grant autonomy to other minds as indicators of Haddon’s stereotypical perspective of autism. These and other disability studies-minded readers see in Haddon’s construction of a fictional autistic person a conception of autism obviously steeped in the popular scientific accounts I have already mentioned. The problem, these critics point out, is that books like *Incident* reinforce the unhelpful and largely false notion that all autistic people have the same “symptoms,” have them in ways that can be used as heuristics for understanding them as people, and have them in a monolithic way rather than in varying degrees.

 Literary critics, meanwhile, have attended to *Incident* as an unproblematic instance of autistic storytelling. Consequently, at least two have made inferences about the extent to which autistic people can(not) produce and interpret engaging literary narratives based on Christopher’s narration and/or utilizing narrative as a mode of cognition. Surprisingly, but perhaps necessarily, since considering Haddon’s function as implied author would complicate any uncomplicated assertions about autistic people, these scholars’ readings often leave Haddon entirely out of the picture. For instance, Stephan Freißmann rightly points out the “discrepancy between the narrator’s discourse and the inferences readers make on the grounds of this discourse,” but does not account for Haddon as the ultimate origin of the narrative discourse (396). In fact, Freißmann does not mention Haddon anywhere in the essay except at the outset, when he names the
book for the first time and identifies its author. Though he acknowledges that *Incident* is fictional, Freißmann builds his argument on the following highly problematic foundation:

Through a close reading of the narrator’s report of the events [of the novel, this paper] discusses the functions and limits of narrative as a tool in everyday cognition as far as the ordering and representation of experience and the formation of knowledge are concerned. *The narrator’s being autistic highlights the problems that occur when some of the mental abilities of the experiencing consciousness are impaired.* (395-396, emphasis added)

Here Freißmann begins by positing narrative as a mode of human understanding, and then states that he will use the fictional Christopher as a test case for the effect of autism on narrative cognition. However, he goes on to do so *without* acknowledging that Christopher is a fictional autistic character created by a non-autistic author.

Lisa Zunshine makes a similarly problematic move in her discussion of the relationship between autism and narrative production and reception, though she does acknowledge Christopher’s fictionality. Zunshine describes Christopher’s “mind-reading profile” (his ability to make inferences about other people’s minds) before referring to *Incident* as a whole as “a much-needed reminder about the complexity of the issues involved in the relationship between autism and storytelling.” She concludes the section by calling *Incident* “a novel authored by a child with a compromised Theory of Mind (even if this child is himself a fictional character)” (12). Like Freißmann, Zunshine apparently thinks of Christopher, fictional though he may be, as a valid test case for autistic people’s ability to produce and interpret narrative. Zunshine is careful to point out that autism is not monolithic, and that autistic people are often if not usually able to
understand and enjoy fictional narratives. However, like Freißmann, she does not take Haddon into account in her brief reading.

For the most part, these three kinds of readings of *Incident*—popular, disability studies, and literary—have remained basically separate. However, synthesizing them by way of rhetorical narrative theory, as I have done here, and accounting for the novel’s implied author and its different audience positions increases our knowledge of why *Incident* appeals to so many readers, what is objectionable about Haddon’s representation of autism, and what *Incident* accomplishes as a work of fiction, both according to and, apparently, in spite of Haddon’s design.

**Conclusion: A more than incidental question**

All the way to the end of the novel, the implied Haddon’s understanding of autism remains both symptomatic and beyond symptomatic, as does the authorial audience’s. While Christopher does change as a character and does tell his readers about those changes near the end of the novel, his evaluation of the events of the plot does not include any substantial discussion of his family history or new family dynamics. And based on the rest of the novel, it is reasonable to suspect that the absence of this information results from Christopher’s autism. As I mentioned earlier, the novel closes with Christopher reporting the circumstances of his new life living with his mother and sometimes staying with his father before reporting his life plans. He says he will go to university and become a scientist and then affirms, “I know I can do this because I went to London on my own, and because I solved the mystery of *Who Killed Wellington?* and I found my
mother and I was brave and I wrote a book and that means I can do anything” (221).
There is no reflection on the fact that his mother, once presumed dead, is not only alive but now his primary caretaker. Christopher does not discuss anything about the relationship between his parents or any revision of his memories required by the revelation of what actually happened between them and in the period of her absence from his life. Indeed, for Christopher the changes in his life are entirely circumstantial.

What indications the implied Haddon does provide that Christopher recognizes the significance of changes in his life seem more like improvements in Christopher’s symptoms than changes in his understanding of his identity and family. Christopher’s willingness to wear yellow shorts (connected to the symptom of eccentricity about sensory input) and the breakdown of his system of evaluating days based on traffic patterns (connected to the symptom of struggling to understand other people’s moods and the effect weather has on them) are the only signs that he has changed as a person. Whereas a more dynamic and self-aware character would gesture at least obliquely to the psychological impact of learning that his mother is alive when he thought she was dead, Christopher only reports changes in behavior and circumstance, offering none of the reflection a different narrator might provide. Yet because of the awareness he has demonstrated and the fact of changes in Christopher’s behavior, the authorial audience remains alive to a characterization of autism that exceeds the symptomatic.

Employing the rhetorical model of narrative to read *Incident* throws new light on the novel because it reminds us that Christopher is a fictional character created by an actual author. At the same time, distinguishing the actual author and audience from the
implied author and authorial audience allows us to identify a complex understanding of autism within the novel from the more univocal discourse that has frequently surrounded (and been attributed to) it. In this chapter I have attempted to draw together insights from previous popular, literary, and disability studies readings, and to demonstrate that Incident at once offers and exceeds a symptomatic account of autism. These two understandings of autism are emblematic of controversy and conversation about autism in contemporary cultural discourse more generally.
Chapter 4: Consonance and Dissonance in Stephen Kuusisto's Planet of the Blind

Introduction: Consonance, Dissonance, and Disability Identity

In his 1998 memoir Planet of the Blind, Stephen Kuusisto traces his journey from shame about to “claiming” disability. Because of the conventions of many disability memoirs and the broader cultural attitudes toward and critical history of disability that I described in the Introduction, readers might be tempted to interpret Kuusisto’s memoir as a story of “overcoming.” The end of Planet, when Kuusisto has come out as a blind man, is using a guide dog, and has begun to describe his life as particularly enjoyable, might suggest that Kuusisto has somehow “gotten past” his disability. In Lennard Davis’s view, the individualistic nature of most memoirs—not just disability memoirs—leads to precisely this kind of reading. Davis has argued that “by narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story, as we have seen in so many films treating the subject of disability” (Enforcing Normalcy 4). For Davis, this tendency makes the genre of disability memoir problematic for anyone interested in highlighting the social production of disability and working to redress political wrongs committed against disabled people.

48 The phrase “claiming disability” is Simi Linton’s. I will use both “claim” and “embrace” to talk about self-identification with disability, the former because it connotes action and decision toward disability, and the latter because embracing as an action connotes positive feelings toward its object.
Meanwhile, others object to disability life writing on opposite grounds, suggesting that the genre’s politics subsume its aesthetics and thus that it is likely to be substandard art. This is part of a broader accusation against disability studies and identity studies in general. Such accusations come largely from individuals and organizations who claim academic work in the United States is no longer based on rigorous inquiry or actual knowledge, but rather on “frantic social programming” that “begin[s] with the end in mind.” That end is proving the assumption that the people whose identities are the object of study are always assumed to be “oppressed and down-trodden, victims of an insert-terrible-adjective-here system and insert-another-terrible-adjective-here society,” and thus that some ameliorative benefit will come from indoctrinating readers and students with the baldly political messages of the so-called field of “study” (Alger). In short, disability studies is merely “the latest PC fad” in academia (Allen). Thus any artist with disability studies sentiments (which Kuusisto has long had and which he frequently blogs about at planet-of-the-blind.com) is prone to prioritizing his agenda qua activist over his craft qua artist. We end up, then, with a corpus of self-important texts of questionable artistic merit.

I will grant that putting an overtly political agenda front and center in any area of inquiry does run the risk of reducing the thoroughness with which one might consider states of affairs and events, especially those that might complicate the agenda in question. To the extent that I love eating ice cream, I may be inclined at least some of the time to find other explanations for my elevated risk of diabetes. At the same time, however, all thorough intellectual inquiry is committed from the outset to some aim—even if the aim
is only to gain knowledge of a subject—but this commitment has no necessary consequence for the way in which the inquiry will proceed. For example, a medical researcher’s agenda to cure cancer will make him more rather than less interested in understanding the causes and complicating factors involved in the disease. In the case of disability life writing, objections based on agenda have less force, since life writing does not often (and certainly does not necessarily) have as its aim the production of knowledge about anything other than a life, from the perspective of the one living it. Still, it is worth noting that any agenda, whether in storytelling, grocery shopping, or political campaigning, puts one in the position of paying more attention to some things than others and of interpreting things one way versus another.

Davis’s objection is more relevant to the case of Planet than to other instances of disability life writing, but as I will demonstrate throughout this chapter, it too is limited in its force. Kuusisto is obviously interested in representing his subjectivity throughout the memoir, and in order to do so produces remarkable and frequent passages of lyrical prose that provide a vivid sense of his experiences over the course of his life.

Against both of these arguments—that a focus on individuals’ stories tends to reduce social potency, and that political purpose risks marginalizing aesthetics—in this chapter I show that Planet of the Blind is an example of an aesthetically satisfying disability memoir that reflects a progressive disability politics. Planet avoids the rhetoric of overcoming that Davis questions, while still communicating that one’s interpretation of one’s body has a substantial effect on one’s experience of that body and of the world. Over the course of the narrative progression, Kuusisto moves from what Dorrit Cohn
would call dissonant self-narration to consonant self-narration. In other words, in the prologue, Kuusisto’s perspective as the narrator (the perspective Philippe Lejeune calls the narrating-I) is consonant with his perspective as a character (the experiencing-I) during events that occur chronologically later than the rest of the plot. For most of Part I, however, the narrator’s perspective is dissonant from Kuusisto’s as a character in his own story. By the end of Part II and in the epilogue, the narration approaches and eventually becomes consonant again precisely because Kuusisto has come to think positively and confidently of himself as an openly disabled man. Yet even as there is a clear trajectory to the memoir as a whole, the narrating-I’s perspective toward blindness is reflected in his lyrical treatment of blindness at moments when the experiencing-I takes a clearly negative view.

*Planet* is one of the clearest and best examples of an aesthetically sophisticated text that also does justice to the complexities of disability identity. It has been heralded as “a masterful coming-out story in which the author’s secret life involves not sexuality but blindness” (*Kirkus Reviews*). “Coming-out story” seems to me the right kind of description for this book’s structure: a story in which blindness goes from private and hidden, during which period Kuusisto is all but happy, to public and embraced, at which point his life and writing converge in ways I will describe in more detail as my discussion unfolds.

The memoir is divided into two sections: “The Village of St. Ovide,” which takes up over three quarters of the text and describes Kuusisto’s life from birth until he was approximately thirty-eight years old; and “Motion,” which occupies forty pages and is
concerned with the period shortly following Kuusisto’s decision to train to use and then be paired with a guide dog. The difference between the two sections is most accurately described as the difference between the years during which Kuusisto was ashamed of or ambivalent toward his blindness on the one hand, and during which he celebrated it, on the other. The narrative is structured chronologically, though it contains frequent and varied ellipses, analepses, and prolepses (gapped-out events, flashbacks, and flashforwards) throughout.

But in noting that Planet falls into two sections based on two ways of conceiving of disability, I do not mean to imply that only two ways of thinking about disability surface in the text. Granted, these two perspectives on disability inform Kuusisto’s account; however, those perspectives develop according to his experiences and knowledge as well as the different social arrangements of disability he encounters—arrangements that I characterize in terms drawn from research by JR Hanks and LM Hanks as well as Simi Linton. These arrangements are more and less prevalent at different moments and among different parties. Disability is by turns a primarily medical, legal, phenomenological, social, historical/cultural, and spiritual phenomenon in this memoir.

The dominant question on readers’ minds (the global tension) over the course of Planet is “How, if at all, will Kuusisto achieve contentment and stability as a blind man?” This question plays out in Kuusisto’s practical and professional circumstances and in his relationships with other people, whose knowledge of his blindness varies according to the nature of the relationship and when the relationship occurs in Kuusisto's life. Others'
attitudes toward Kuusisto's disability depend on both of these factors, and on the ways of conceptualizing disability available to them at a given time. In the end, Kuusisto’s development as an individual, his coming to terms with his blindness, and the progression of Planet as a memoir all center on how individuals, groups, and societies understand and relate to disability—but most importantly, how Kuusisto himself understands, relates to, and lives out his blindness.

The pivotal moment in Planet is Kuusisto's long-overdue acknowledgment of the need for and appropriateness of accommodations that will help him live openly as a blind man. Recently back from a year in Finland on a Fulbright scholarship—a moment when we might imagine Kuusisto to be at the height of self-assurance and forward-thinking confidence—he finds himself awash in aimlessness, without even “the vaguest idea about my true destination” (142). Having passed as sighted his whole life to this point, Kuusisto puzzles, “Why should it take so long for me to like the blind self? I resist it, admit it, then resist again, as if blindness were a fetish, a perverse weakness, a thing I could overcome with the force of will power” (142). Shortly after this, he calls the New York State Commission for the Blind to request orientation and mobility training as he confesses to himself and to readers, “I need help walking. I've needed help all my life. It's that simple” (143). In other words, finally reckoning with the facts of his blindness in such a way that he is prepared to embrace it, Kuusisto recognizes the foolishness of treating disability as a hurdle to be jumped or an inconvenience to be managed and minimized, and instead seeks to adjust his surroundings and the way he presents himself to others. At this point, he cautiously begins to explore disability as a potentially positive identity marker.
Lest I be misunderstood, I do not mean to suggest that it is only at this point that Kuusisto acknowledges he is blind. There has never been any question about that. His confusion is not about whether he is blind, but rather about what that blindness could be and mean. From his early life until he was in his thirties, it never occurred to Kuusisto “that blindness is a rich way of living.” Meanwhile, even as he describes an early life in which “[t]he very words blind and blindness were scarcely to be spoken...relegat[ed] to the province of cancer,” Kuusisto describes his residual sight as “a mad, holy vision...like living inside an immense abstract painting...like lying on your back in an ice cave and staring up at the cobalt sun” (7). Obviously, between those early years and the moment of writing Planet, something has changed about the way Kuusisto thinks about the experience of blindness and about blindness as part of his identity. The difference stems not from the knowledge that he is blind, but rather from his way of being blind and thinking about blindness. The narrating-I has claimed disability, while for most of the memoir the experiencing-I remains ashamed of it.

Whatever else it might involve, the transition from shame to embrace has something to do with language—“putting words side by side,” as Kuusisto puts it. In Planet, blindness—the experience of it, but also the words used to render that experience—is by turns attractive and terrifying. From beginning to end the memoir is a collection of evocative, lyrical, and densely allusive depictions of subjective experience. However, by the final portion of the book, disability's value has become distinctly positive as a result of Kuusisto's embracing his identity as a blind man. According to blind sociologist Rod Michalko,
Whatever we say and do, how we choose to live, always represents an answer to the question Who am I? We can say that whatever blind persons say and do, how they choose to live, represents an answer to the question What is blindness?...[W]e can say that how we relate to blindness, whether our own or the blindness of another, and how we think of blindness represent an answer to the same question. (*The Mystery of the Eye and the Shadow of Blindness* 33)

In other words, whatever Kuusisto or any other blind person does or says indicates and helps to create and signify what blindness means both to him and to those observing those actions and utterances.

Further, at the moment of claiming a disabled identity, Kuusisto’s conception of blindness in the world of the story—the events and experiences that constitute Kuusisto’s life—finally matches his conception in the world in which the discourse—the organization of those events as they appear in the book *Planet of the Blind*—was created. In other words, when the character Kuusisto claims disability, the self-narration is consonant, since the narrator Kuusisto narrates from a position of having claimed disability.

This distinction between story and discourse, though originating from work by the Russian formalists in the first part of the twentieth century, can be traced back to the earliest systematic thinking about artistic representation of real or imagined events. At least since Plato, scholars and teachers have debated the advantages and disadvantages—not to mention the potential moral implications—of different ways of representing events, as well as the purpose of doing so. One can, for instance, recreate an event vividly, as if in real time. Quite different, one might report events in the manner of a news report, with the primary concern being the transfer of certain information about events and with very
little attention to the subjective experiences of relevant agents in those events. In either case, however, the same story is being told—or so the scholarly thinking has typically gone. A story might begin, “The state legislature approved a bill today that will allot millions of public dollars for infrastructure improvement,” or else, “To the misplaced chagrin of fiscal conservatives, the state Senate today passed needed legislation that will allow thousands of central Ohioans to utilize public transit, which supporters of the bill rightly point out will ultimately if indirectly improve the state’s sagging economy.” In both versions, the speaker communicates that certain legislation with certain parameters was passed in a state government. The difference between the two lies in the nature of the presentation: for instance, the latter obviously comes from a perspective sympathetic to the legislation, whereas the former is basically neutral.\footnote{49} What I am claiming here is that at the time of writing \textit{Planet}, Kuusisto as narrating-I considered blindness a positive and productive way of being, whereas blindness throughout much of his life prior to the time of writing was a source of insecurity, shame, and self-protection. Thus there is dissonance between Kuusisto's earlier experience of blindness, before he embraced disability, and his experience of blindness at the moment of narration. Once blindness's meaning at the levels of narration and experience become consonant, however, the affect and tone of the book shift dramatically as Kuusisto turns toward his conclusion, at which point he has aggressively claimed blindness as part of his identity.

\footnote{49}{For three important treatments of story and discourse, see Viktor Shklovsky, “Art as Device” (1903); Gérard Genette, \textit{Narrative Discourse: An Essay in Method} (1972); and Seymour Chatman, \textit{Story and Discourse} (1978).}
In Kuusisto’s life, the journey toward a positive view of disability and an incorporation of disability into his sense of his own identity spanned decades and involved far more than thinking about himself as an isolated individual. Indeed, it meant thinking about everything from his family to history to politics to poetry and back again. In the text, however, it occurs at the single moment I mentioned above. Kuusisto’s discovery of blindness as an identity and a way of being signals the conclusion of his identity formation in this text (which is not to say it has not continued in his life or in other work). The movement toward and eventual arrival at that discovery serves as an organizing principle in the text, and the shift in Kuusisto’s attitude toward disability is revealed in his descriptions of the experience of blindness at different moments in his life and in the text.\textsuperscript{50} Ralph Savarese agrees that the development of a positive disability identity is at the heart of Planet, saying, “The memoir’s plot concerns the difficult project of embracing a blind identity” (198). Ultimately, blindness is indexed in Planet as a fundamentally positive characteristic and mode of experience, even as it retains at times qualities of uncertainty and fear—a way of living blindness that Michalko calls “living \textit{in}” as opposed to “living \textit{with}” blindness.\textsuperscript{51}

In order to trace the progression toward the convergence of the narrating-I and experiencing-I’s conceptions of blindness, I want to discuss Kuusisto’s conception of

\textsuperscript{50} In Phelan’s terms, the moment at which Kuusisto admits, “I need help walking” signals the conclusion of the “middle” portion of the text and the beginning of the “ending” (Experiencing Fiction 20-21).
\textsuperscript{51} According to Michalko, living \textit{in} blindness “allows for the possibility of many blindnesses. Blindness can be interpreted as a dynamic rather than a static phenomenon, and this interpretation flows directly from lived experience. At times, blindness is experienced as an unalterable negative condition. At other times, it is experienced as a tragedy, a stroke of unfairness, payment for wrong doings, or the bad luck of the draw. But it is also experienced as an occasion for thought. Thinking about blindness permits a blind person to live in the midst of many blindnesses and to claim blindness \textit{as his or her own}” (The Two-in-One 181-182).
blindness in four portions of *Planet*, including a brief discussion of the prologue, which, as I will explain, clues us into the narrating-I’s conception of blindness, against which we gauge the experiencing-I’s conceptions. The first long section is from Kuusisto's primary school years. There, blindness is a source of shame and embarrassment and a frustrating inhibitor. The second comes from his university years, in which blindness is still a source of anxiety and shame even as it is occasionally thrilling and Kuusisto more seriously entertains embracing it. The final section describes the period soon after Kuusisto was paired with his first guide dog, Corky. In this section blindness is finally indexed as a positively valued aspect of Kuusisto’s identity, a way of being he begins to experience as welcome and even pleasurable, even as he remains “blind for others, and this carries a thousand signifiers” (190).

After characterizing blindness in Part I of the book (which I divide into two subsections called “Early Years” and “University Years”), I discuss what Simi Linton calls the “social arrangement” of blindness that partially determines the status Kuusisto's disability has over the course of his account (*Claiming Disability*, chapter 3). I discuss these social arrangements’ appearance in *Planet* in order to demonstrate that, while Kuusisto as artist obviously created and structured this text and in doing so constructed meaning out of his experiences, the institutional, attitudinal, cultural, political, and relational environments that surrounded him in different periods of life at once enable and constrain Kuusisto's efforts to represent those experiences truthfully in the context of a memoir. The way Kuusisto experiences and represents blindness is made possible by the progression from shame about to the embrace of his disability over the course of his
life—the progression toward consonant story- and discourse-level conceptions of blindness. In turn, that progression unfolds within the broader sociocultural context by which Kuusisto's narrative is shaped, and which it has helped shape in turn.

Linton draws her four categories for social arrangements involving disability from a 1948 article by JR and LM Hanks—“The Physically Handicapped in Certain Non-Occidental Societies”—published in the Journal of Social Issues. Hanks and Hanks understood fifteen years before Erving Goffman (whose Stigma is often cited as a forerunner of what has come to be called the social model of disability) the social dimensions of disability. For instance, they point out at the beginning of their article the challenge of determining what “counts” as disability: “Here for us is a category of persons with social liabilities peculiar to the conditions of our society. It represents no logical or medical class of symptoms…Nor is the symptom itself the only criterion, for though the person with infantile paralysis may limp…yet the person with an ill-fitting shoe…will be excluded” (11). Further, Hanks and Hanks discerned the geographical and cultural contingency of disability, pointing out that a “disfiguring scar in Dallas becomes an honorific mark in Dahomey [Benin]…Nor is such a universal criterion as loss of physiological function satisfactory in this dilemma [of categorizing disability], if one recalls the binding of feet in China” (11).

Hanks and Hanks aim “to describe the social status accorded the physical [sic] handicapped in various foreign cultures.” They go on to delineate five social “positions” disabled people can occupy; these positions are determined partly by the social group’s sense of its obligation to “the afflicted” and partly by the social meaning assigned to a
given impairment by the community (11-12). Fifty years later, in *Claiming Disability* (1998), Simi Linton took up this taxonomy in the context of her examination of “social arrangements that have existed throughout history and around the world...[of] humans’ response to disability” (36). Though she expands and qualifies some of the original material and adds a sixth arrangement to the list that accounts for developments in the two generations since Hanks and Hanks' study, Linton’s decision to take this structure as a starting point is strategic. At first glance it does seem rather arbitrary to select a half-century old taxonomy when more current explanations of disability in context are available. As she points out and as I alluded to above, after Hanks and Hanks published their essay it would take another fifteen years for activists and scholars to articulate social models of disability self-consciously and for largely political reasons. But by the same token, Hanks and Hanks’ emphasis on how cultural, economic, and relational factors mold the experience and perception of physical difference shows that later explanations of disability in society are not simply the reflex of a shift toward social constructionism. Rather, Hanks and Hanks’ essay underscores how the experiences and opportunities all of us have, disabled or not, are to a substantial degree shaped by particular ways of being embodied and also by specific ways of receiving and responding to bodies in our specific cultural and material environments.\(^{52}\)

\(^{52}\) Anyone who has paid attention to literary and cultural studies in the past thirty years but has not spent much time thinking about disability might be surprised to see me taking up space with a defense of the social construction of disability. Didn’t we all agree a long time ago that just about *everything* is socially constructed? For more on the question of social construction, its particular (and peculiar) relationship to disability, and my own position on the question, see the Introduction.
In *Planet*, two different social arrangements can be mapped onto the progression from dissonant to consonant self-narration. I will describe these arrangements in more detail later, but they are called, respectively, Limited Participation and Active Participation and Accommodation. Obviously I am imposing the names of these arrangements on Kuusisto’s text and, *ipso facto*, Kuusisto’s life. However, just as Kuusisto’s different conceptions of blindness are evident in the text, so too are the varying attitudes of others—the different discourses and practices surrounding disability. Taken together, Kuusisto’s conceptions of blindness and the social contexts in which those conceptions exist reveal significant interrelations among form, content, and context in stories about disability.

**Prologue: Framing Disability**

The prologue to *Planet* functions as an important frame for the text as a whole. In it, the experience of being lost in Grand Central Station—one of the largest transit stations in the world—is no real cause for concern and thus establishes disability’s positive status for the narrating-I, before the narrative proper begins:

There is something about us, the perfect poise of the dog, the uprighteness of the man, I don’t know, a spirit maybe, fresh as the gibbous moon, the one we’ve waited for, the one with the new light…We [have]…no idea about how to find our train or the information kiosk. And just now it doesn’t matter. None of the turmoil or anxiety of being lost will reach us because moving is holy, the very motion is a breeze from Jerusalem. This blindness of mine still allows me to see colors and shapes that seem windblown; the great terminal is supremely lovely in its swaying hemlock darknesses and sudden pools of rose-colored electric light. We don’t know where we are, and, though the world is dangerous, it’s also haunting in its beauty. (1-2)
Though disability’s meaning and function shift over the course of the narrative progression, this opening expresses its overall positioning: “[T]hough the world is dangerous, it’s also haunting in its beauty” (2). As I pointed out above, we are from beginning to end of Planet established in a world full of pleasurable uncertainty. G. Thomas Couser rightly points out that the memoir’s lyricism, fully in evidence here, “foreground[s] the fact that, despite the danger and inconvenience entailed by his condition, Kuusisto experiences his blindness as a constant source of visual stimulation and aesthetic gratification” (Signifying Bodies 166). This sketch of Kuusisto standing with Corky in Grand Central Station anticipates and overrules the pity readers not accustomed to thinking positively about disability might indulge at the beginning of chapter 1. Further, as I indicated above, the prologue furnishes a kind of interpretive key for the book: here we find an orientation toward blindness that is conspicuously absent from the first part of the text and that only begins to take shape at the moment of seeking accommodation. From the beginning of chapter 1 to the end of chapter 12, then, we search for the moment or series of moments in which Kuusisto comes to inhabit a blind identity like the one we encounter in the prologue.

**Early Years: Shaming disability**

In the first three pages of Planet’s opening chapter Kuusisto continues largely in the spirit of the prologue, describing his blindness as “by turns magical and disturbing…lovely and terrible…glacial seeing” (7). These types of characterizations mark the prologue and, to an extent, the final section of the book—those portions of
Planet in which Kuusisto has taken up what Michalko calls a “mature relation to blindness” in his role as experiencing-I (The Mystery of the Eye and the Shadow of Blindness 156). On the same pages and increasingly as the early chapters develop, however, Kuusisto also explains his parents’ and the medical establishment’s discourse about and interpretations of his blindness. For example:

Raised to know I was blind but taught to disavow it, I grew bent over like the dry tinder grass. I couldn’t stand up proudly, nor could I retreat…I remained ashamed of my blind self, that blackened dolmen. The very words blind and blindness were scarcely to be spoken around me. I would see to this by my exemplary performance. My mother would avoid the word, relegating it to the province of cancer. (7)

As the first four chapters unfold, Kuusisto’s account of his life through adolescence is increasingly marked by the development of shame, embarrassment, and frustration with the tension between the fact of his blindness and the injunction to do anything and everything to avoid or minimize it. The social arrangement of blindness that surrounded him at the time prevents Kuusisto from valuing blindness positively as the experiencing-I as he recreates that period. While describing this period of his life, Kuusisto as narrating-I does describe moments of experiencing blindness as a pleasurable way of being in the world—a mode of being that he would only later experience. For instance, in his grandmother’s attic, Kuusisto finds “steamer trunks with rivets and leather straps, and inside them are smaller boxes…My hands are actually breathing. This is pleasure: to be blind in the museum dark, unwrapping and holding” (33). Predominantly, though, blindness is a troubling experience during this period. Kuusisto wonders,

What’s wrong with a life of color and light, inferences pouring through my skin like dream-water? How do you personalize darkness, make it yours, if you’re
living in denial? I have no affection for my life, must talk, impress my father, become a being of value. I thrived on suborning my blindness…I walk bent forward, shoveling words into life’s furnace. I am not lost. (41)

The imperative toward conformity in institutional settings further clarifies the extent to which Kuusisto’s blindness could hardly have been in this period anything other than a source of frustration and shame. An elementary school teacher not familiar with his blindness or how to interpret it directs negative attention to Kuusisto’s inability to see the blackboard and invites other students to note Kuusisto as deviant. In turn, his peers single him out for torment: “[L]eaving my reading lesson, a boy I think of as a friend steals my glasses and my panic brings me alive like a tree filled with birds…‘Hey, Blindo, over here!’ He laughs along with several others, then they run…On that particular afternoon I am instantly put on display. Now, in one stroke, I am a jellyfish, measureless and unwieldy” (21).

In reflecting on this moment of torment, Kuusisto articulates what I think is the key to understanding this portion of *Planet*: “More than thirty years have passed since that moment, but I’m still disconcerted by what it felt like to belong so thoroughly to other people, to be, in effect, their possession” (21). During this period, Kuusisto primarily experienced and therefore recalls blindness as the catalyst for ill treatment during his early life—a category others used to place and interpret his body, but nothing he ever learned or expected to take on as part of his sense of himself as a human being.
Consequently, Kuusisto characterizes these years as a period during which neither he nor his blindness was his own.\footnote{Compare Motherless Brooklyn, where the narrator-protagonist Lionel Essrog dislikes another character, Loomis, because of the way Loomis refuses Lionel the right to define his own (disabled) identity.}

In addition to the scenes I have just described, the following moments in the first four chapters of Planet reveal disabling attitudes and practices surrounding Kuusisto in his early years:

\textit{Chapter 1:}
- Kuusisto was “taught to disavow” blindness even though he knew he was blind (7)
- Kuusisto’s mother bought him a bicycle because of her “guilt” about his blindness (9)
- A Finnish woman chastises Kuusisto’s father because he, Kuusisto, was born blind, which reflects the belief that something was done to bring blindness down upon him (10)
- Buildings designed with the sighted in mind make motion difficult (11)
- No systemic provisions for disabled children or adults exist during Kuusisto’s childhood (12)
- People in Kuusisto’s community assume that blindness “is a profound misfortune, a calamity really, for ordinary life can’t accommodate it” (13)
- Blindness is stigmatized (13)
- In a public school Kuusisto will not learn orientation and mobility, while in a private school he will be isolated from his nondisabled peers (14-15)
- To Kuusisto’s mother, “the prospect of the white cane denotes the world of the invalid” (15)

\textit{Chapters 2-3:}
- There are no accommodations in Kuusisto’s public school (18)
- As a result, Kuusisto is labeled a “baby” and teased in front of the class when he asks another student to assist him reading something on the chalkboard (18)
- Peers single Kuusisto out for teasing because of his blindness (19-21)
- Popular representations of blindness like Mr. Magoo depict the blind as “blind fools, or conversely…suddenly cosmic”—nothing Kuusisto can relate to (23)
- More social exclusion and teasing at school because of his blindness (27-35)

\textit{Chapter 4:}
Because Kuusisto never talks about his blindness with his parents, his father is “content to view me as sighted. He is a man who believes in mind over matter” (39)

-The strain of passing in school leads to migraine headaches and back problems (43)

Faced with these disabling circumstances, Kuusisto’s blindness takes on an overwhelmingly negative value for him and those around him. This section is, however, dense with allusions to historical figures and is as lyrical as the rest of the book. These alternative interpretations and historically aware accounts of blindness belong to the narrating-I and serve as an omnipresent reminder of the framework provided by the prologue. The net effect of the negative experience of blindness joined with the lyrical narration is the dissonant self-narration in this portion of the book.

As many disability studies scholars (and others) have pointed out, disability resides as much or more in attitudinal, political, and other environmental conditions as in the body. That is, disability is social just as much as, and probably more than, it is biological, individual, or anything else. Kuusisto’s experience in his early life is no exception: the attitudes his family, teachers, and peers held toward disability, as well as the practices arising from those attitudes, were vastly more disabling than blindness itself. That Kuusisto’s social environment affects both his experiences and his later narrative presentation of them certainly validates the so-called “social model” of disability. The distinctive element I want to point out, though, is not that Kuusisto has arrived at any particularly novel insight about the way communities disable their members and others, but rather that this account of his personal life reveals the social character of disability—manifest that social character not just in the content of this account of his life, but also in
that account’s form. Blindness as an interesting and pleasurable way of experiencing the world belongs only to the narrating-I until the latter portion of the book—the portion describing the period of his life during which Kuusisto as experiencing-I finally claimed blindness.

Locating the presence of the narrating-I’s perspective toward blindness in the prologue and then in the discourse of the early portions of Planet shows even from an early point in the progression that this book is not an “overcoming” narrative. Kuusisto’s tightly controlled dissonant narration in the first section is framed by the consonance we find in the prologue. The difference between these qualitatively different types of narration produces the tension readers feel as we anticipate the experiencing-I becoming the narrating-I we encountered in the prologue; and the lyrical descriptions of even negatively interpreted blindness assure us that change will happen at some point in the narrative.

**University Years: Fleeing disability**

In some ways, Kuusisto’s arrival at university opened a new set of opportunities, as it does for many people. When he enrolled at Hobart and William Smith Colleges in 1973, Kuusisto gravitated toward literature courses. This was partly because the prevailing pedagogy [was] still centered on the New Criticism, a method of reading and analysis born in the years after World War II. This is a lucky break for me: the stress here is on the close reading of texts. One simply has to read a poem to death…I listen, hunched in my chair as the machinery of poets is dissected. We are eighteenth-century clock makers: nothing is too small for our rational little universe. (64)
The vicissitudes of intellectual trends were in this case fortunate. Still, Kuusisto did sit “hunched,” and carried in his pocket “a letter from the eye doctor addressed ‘To Whom It May Concern’”—it avows that too much reading is dangerous for me. ‘The scanning motions inherent in reading make retinal tearing more likely. Therefore Mr. Kuusisto should read in moderation’” (64).

For as much as the New Criticism and the power of choice university students have offer him the potential to live more freely as a blind person, Kuusisto continues to live largely in fear and shame about his blindness during this period. He calls the letter “frightening…in my pocket it feels like a letter bomb” because of his acute sense that disclosing his blindness can only be a negative disclosure both for himself and from the perspectives of those around him (64). Rather than using the letter to his advantage or exploring what it might mean to be a blind man in the world, he “move[d] in a solitude fueled by secrecy. O Lord, let me never be seen with the white cane. Let me roll through the heavy oceans like the beluga whale…Let no one find me out! This is my lacerating tune. Leaning over my private page, I shake with effort” (65).

At the same time, it is during these years that Kuusisto begins to realize the potential pleasures of life as a blind man given the appropriate adjustments and attitudes toward his disability. As he discovers poetry, he says, “[E]xploring what words can do when placed side by side, I’m starting to build the instrument that will turn my blindness into a manner of seeing” (66). If we can believe that Kuusisto actually had such thoughts as a university student—and we have no reason not to—then these are the first inklings at the story level that the experiencing-I is learning to embrace and potentially utilize
blindness as a way of being. The narrating-I's earlier remark that, at this point in his life, it had not occurred to him that “blindness is a rich way of being” is still largely in force, but this moment does hint at some future transformation.

Part of the reason words next to one another open the possibility that blindness is a way of seeing is that it is over words that Kuusisto builds his first meaningful friendships during this period of his life. He finds that Ramona, a woman who reads course material to him three days a week, is “a tremendous reader, the shadowy forms of things, ideas, gestalt, whatever, they move as she talks,” and with her, “[his] habitual shyness around women begins to fall away. Outside the library, I find myself conversing with my female classmates with ease. For the first time, I discover how conversations between men and women can be like warm soap dissolving in a bath” (69). He becomes friends with poets, loses his virginity, and goes on a study abroad trip to Greece with his girlfriend Bettina and other classmates. Eventually, he is accepted to the prestigious Writer’s Workshop at the University of Iowa. It seems during this portion of the book that Kuusisto has in large part discovered ways to live “in” his blindness, but two key passages reveal that without disclosing the nature of his blindness to those around him and embracing it publicly, he remains unsettled and unhappy.

Having found poetry, Kuusisto has also found some companions, and he convinces one of them, Jim Crenner, to take him bird watching one afternoon after developing an interest in birds. Jim takes him to a meadow. He knows Kuusisto “can’t see well,” but he does not know the extent of Kuusisto’s blindness. As they walk and Jim points out birds, Kuusisto becomes disappointed:
When I look through the binoculars, I see a coral blue/green bubble, perhaps my own eye, but nothing like a bird. I can’t quite bring myself to tell this to Jim…I have a major bird thirst, something untranslatable, I can’t share it, can’t cry aloud at my frustration. Instead, I pretend…I agree with everything Jim sees, adding my own intensifiers and adjectives. I don’t want to tell him I can’t see the damned things, fearing it will make him self-conscious, for then our outing will become an exercise in description…By pretending to see, I’m sparing us an ordeal. Sure I’m faking it with the binoculars, gloating over imaginary bluejays, but I’m alone with my own imagination, listening casually to an enthusiastic friend, my blindness locked away for the time. (74-75)

The problem here is that Kuusisto apparently cannot imagine a situation in which it might be enjoyable and profitable to see birds in a different way, or in which Jim might enjoy an excursion with someone who watches birds differently. Consequently, he keeps his blindness “locked away for the time,” and he sums up the experience by saying, “I think Jim imagines I’ve seen some birds, and maybe I have” (75). At this point he remains ashamed of his blindness, constrained to think of it as only a drawback and a burden to others.

While in Greece, Kuusisto finds himself more frustrated than ever with his blindness—not because he is blind, but rather because he has neither disclosed nor claimed his blindness. Not being fully aware of, let alone being up front about, the nature of his impairment and the adjustments that might make the trip more comfortable, enjoyable, and useful, he is frequently unable to participate in excursions and activities that are part of the trip. Describing the situation, he says, “I want to tell [Bettina], this girl who reads to me, how each shape and color is a restraint, that the issue isn’t merely the pages of books. But I don’t have words…I imagine the words come forth. That I can say them…I’m free to turn my face to the morning. Free to imagine the generous piece of
being blind…How simple this should be” (85-86). As in the bird watching excursion with Jim, Kuusisto is frustrated with his own inexplicable unwillingness to explain and claim his blindness before others—and to himself. But while in the former case he apparently could not imagine a mutually enjoyable experience of bird watching with Jim as an openly blind man, here Kuusisto envisions a better version of his experience in Greece. He imagines that after saying to Bettina, “I’m blind…give me your elbow, please. Guide me through the stones,” she would “offer me her arm with understanding, steer me with infinite concern and caring” and they would “go down to the harbor in search of morning coffee” (86).

Not only the physical, but also the relational environment would change amidst such a disclosure. Whereas Kuusisto could not imagine Jim enjoying describing birds to him, he pictures Bettina saying, “Those are sails like you might imagine the Phoenicians have…These are the lions of Delos…They appear to be leaping into the sky” (86-87). Here, he imagines Bettina taking pleasure in finding ways of describing the world that will simultaneously produce impressions in his mind and require her to take on an imaginative perspective toward the scenes and objects she sees. Were he able to claim it fully, Kuusisto might describe this fantasy as inviting Bettina to read and describe the world through the lens of blindness just as she had previously read written texts to him. This form of reading and describing is a mutually enriching experience, though at this point it is entirely imaginary. In reality, Kuusisto still attempts to think of himself as “lucky. Deep down I know it. I have colors. And although the visual eludes me, I have some of its shapes as keepsakes. In and out of the haze I go, feeling with my toes. O
Lord, let me look urgent, let me move with agility” (86). To confess and claim his blindness would be, he thinks, a defeat and an attempt to claim something he did not desire (disability) nor, he thought, deserve (accommodation). By the end of the trip, taking stock, Kuusisto retains only “uncompleted assignments…[and] the journal I should have kept about the reading I did not do while I stumbled through the ancient streets of the Peloponnese” (88).

The arrangement Hanks and Hanks (and Linton) call “Limited Participation” predominates in these two portions of Planet and the corresponding years of Kuusisto’s life. Under this arrangement, members of a given society are willing “to accept a disabled person among its ranks in any domain in which she or he can ‘keep up’ with the nondisabled” (Linton 53). In an educational setting, for instance, this arrangement might involve so-called “mainstreaming,” the practice of “incorporating students in general education for part or all of the day” on the condition that they can keep pace with the curriculum.

To be clear, a portion of Kuusisto’s early life—a few interactions with passers-by and some part of his mother’s view of blindness—did in some ways suggest the “Pariah” arrangement, in which disabled people are “denied all claims to succor by the protective group and deemed a threat to the group itself” (Hanks and Hanks 13). Kuusisto's mother’s fear of her son being associated with other disabled people and strangers’ assumptions that some family secrets produced his blindness are indicative of this arrangement. In fact, it is his mother’s fear of disability that leads her to advocate for Kuusisto attending public school, where he first encounters the institutional imperative,
characteristic of the Limited Participation arrangement, to learn and behave the way other children do and attain to the same learning outcomes. Kuusisto writes,

On the first day of school the teacher, Mrs. Edinger, posts a photograph above the blackboard; two chubby infants swaddled in diapers stare down on the class. Those who are caught whispering will have their names appended under the babies’ curled feet. “This is the Baby Board,” says Mrs. Edinger, “and anyone who talks out of turn will have their name put here. Only babies talk when they’re supposed to be quiet!” (17-18)

Questions of condescension aside, this rule seems on the surface harmless and even necessary. After all, order in the classroom is important, and having students talking makes it difficult to maintain order. On the other hand, a blind child will undoubtedly require some sort of description—whether from the teacher or another student—of, say, content written on a blackboard or any other visual cues incorporated into classroom instruction. During a lesson, Kuusisto says, “I must ask a question, some nearly useless thing like how many dogs are on the blackboard. I turn to Janet…and whisper, ‘How many dogs are there?’ ‘I see Stephen talking!’ cries the teacher, and there is the staccato of chalk in action. ‘Stephen’s name goes on the Baby Board!’” (18). Disallowed to seek accommodation that will enable his participation in the learning community, Kuusisto is “forced to listen. I listen like a person telephoning in the dark. I listen like the ornithologist who unwraps bird bones from tissue paper” (18).

Summing up his early educational experience Kuusisto says, “I count imaginary frogs, butterflies, spacemen, following the lessons without usable print or concrete numbers. The world is skewed according to the compensatory pictures flashing through my head. I follow the teacher’s words and make a kind of caged progress, trapped as I am
in my own neural nets” (19). Notice that he describes his progress as inhibited, “caged,” and that the source of limitations comes both from without—he lacks “usable print or concrete numbers”—and within—Kuusisto is trapped “in [his] own neural nets.” That is, the institutional environment and the attitude of his instructor are problematic for Kuusisto, and they also produce a certain sense of himself as limited by his blindness. This is not even to mention the physical problems like back pain and migraines that straining to “keep up” produce. Ultimately, being subject to the standard of performance—including the way in which tasks are performed—is an experience of “belong[ing] so thoroughly to other people [as] to be, in effect, their possession” (21).

Unable to keep up except at the expense of his own physical and emotional well-being, not to mention any positive sense of his blindness, Kuusisto developed a sense of shame and frustration about his blindness that led him to pass as sighted until well into his fourth decade. In representing these years, then, Kuusisto was faced with the task of presenting the experiencing-I’s negative experience of blindness at the level of story even as he continually indicates, in his capacity as narrating-I, that he will finally arrive at the moment in his life when he embraced disability identity.

**Best Years: Claiming disability**

In this section blindness becomes, for Kuusisto, a public fact, a way of being, and a source of new knowledge, joys and concerns. Meeting with an orientation and mobility specialist shortly after calling the New York State Commission for the Blind (a moment I discussed in the introduction to this chapter), Kuusisto reveals his “absolute terror of
curbs, hurtling bicycles, children’s toys, trash can lids, holes and more holes. Speaking with him, I discover how liberating it is to reveal my dread of the ordinary.” Finally taking hold of a white cane for the first time in his life, Kuusisto discovers that “[n]othing terrible happens. I can be disabled. On this ordinary street. I need to touch my hair. I want to feel my own face. Nothing is ever going to be precisely the same” (144-145). Having found freedom to move more confidently and yet newly aware of his markedness in public spaces, Kuusisto describes himself as feeling “at once lovely and flawed, like the Strangford Apollo [a famous statue of a Greek youth]” (146).

As in the previous section, I will point to two especially revealing passages that illuminate the way, at this stage of the narrative, the experiencing-I's conception of blindness has become consonant with the narrating-I's conception. In the first passage, reflecting on “the tender voice on PBS and the medium of television,” and more specifically on adaptive technology for the medium, Kuusisto begins to construct in his mind “a planet of the blind, where the video description from earth might be overheard” (147-148). He describes the planet in a kind of prose poem:

On the planet of the blind, no one needs to be cured. Blindness is another form of music, like the solo clarinet in the mind of Bartók.

On the planet of the blind, the citizens live in the susurrus of cricket wings twinkling in inner space…

The sighted are beloved visitors, their fears of blindness assuaged with fragrant reeds. On the planet of the blind, everyone is free to touch faces, paintings, gardens—even the priests who have come here to retire.

54 This revelation is similar to Simi Linton’s. In her memoir My Body Politic, the act of witnessing a disabled man and three nondisabled women flinging yogurt at one another on a Berkeley street corner one afternoon authorized Linton to live forcefully as a disabled woman. In her words, “Yes, I thought, if that's disability, I can do that. He made it look fun and sexy. Not woeful and sick-like” (My Body Politic 43).
There is no hunger in the belly or in the eyes.

And the furniture is always soft. Chairs and tables are never in the way…

God is edible.

On the planet of the blind self-contempt is a museum. (148)

Throughout Planet, Kuusisto crafts lyrical, arresting ways to recount the experience of being blind. Until this portion of the book, however, all those positive characterizations are in the present tense, in contrast to the past tense used in the narration of story events. For as much as Kuusisto beautifully describes, in the beginning of the book, his eventual recognition of “glacial seeing” as a joy, his early life and thus the narration of that life were characterized by a “sense of not-quite-belonging” (7, 67). This section signals the first time he has allowed himself to imagine a world in which blindness is not a source of shame and the world has adjusted and been adjusted to integrate blindness.

More radically, the passage just quoted shows Kuusisto thinking about a world in which blindness is the standard and the sighted are “visitors” rather than residents. In this prose poem he does not primarily correct misconceptions about blindness, though he does do that (for instance, by assuaging people’s fears of blindness and asserting that there is no deficit of experience or perception for the confidently blind). Rather, he sets blindness at the center of the world and considers what implications that re-centering would have for the blind as well as the sighted. He imagines that, among other things: blind people’s way of being in the world would be thought of as beautiful and unique; blindness would not be fearsome; touching would be the standard way of perceiving; and changes in the
built environment would follow from the centrality of blindness. Perhaps most important in terms of his developing conception of blindness over the course of the narrative, Kuusisto says that on the planet of the blind, “self-contempt is a museum.” In other words, his long-held shame and sense of “not-quite-belonging” are being replaced by a new way of conceiving of blindness and of being blind in the world.

This passage’s placement in the narrative progression is also important. Along with Kuusisto’s tentative claiming of blindness comes his initial appearances as “publicly blind.” His first amazement at being blind in public was that the world did not end and that nothing cataclysmic happened. In addition, he reports his initial experiences with sighted people who recognize him as blind. A child says Kuusisto must have been “bad” in order to become blind; people over-eagerly step out of his way on the street or remark at a distance about other blind people they’ve seen; and a woman politely helps him cross a street and then engages him in conversation as they walk the same direction once they’ve crossed. All of these responses will become common in time as Kuusisto continues to claim blindness. Some are negative, some positive, and some neutral. Importantly, then, it is not that a certain response or engagement from sighted people is required in order for Kuusisto to imagine the planet of the blind. Rather, claiming his blindness places him in a different kind of relation to others: his former shame and desire to hide blindness are replaced by willingness to be blind regardless of others’ responses. It is this same willingness to be a blind man that eventually leads Kuusisto to the decision to be paired with a guide dog—a decision that initiates him into a community of blind people and, eventually, his most profound sense of confidence in his blind identity.
The second passage that clearly demonstrates Kuusisto’s final, “mature” perspective on blindness occurs after he is paired with his guide dog, Corky. As he trains to receive the dog, he realizes what a difference having her will make. Touching a harness for the first time, he says, “I feel as if my hands have been waiting for this—as if I’ve touched something central in the life of an ancestor” (165). Reflecting on the difference between his long-standing experience of blindness and recent changes, he says, “For the first time I feel the sunken lanes under my feet. The street is more my own. I belong here. I’m walking without the fight-or-flee gunslinger crouch that has been the lifelong measure of blindness. I’m not frightened by the general onslaught of sensation. The harness is a transmitter, the dog is confident” (170). Relieved, he says, “At age thirty-nine I learn to walk upright. With the help of classmates and the trainers, I am choosing to be blind in a forceful way. I even begin to enjoy my mistakes” (171).

After finally receiving and going home with Corky, Kuusisto is living independently and happily in New York. One morning, evoking Walt Whitman, he says to the dog, “‘Let us go to Manhattan, Corky, and loose our barbaric yawps from the rooftops! … Let’s walk across the Brooklyn Bridge’” (182). Once there, Kuusisto describes the experience of crossing the bridge with Corky:

Out here, trembling like a compass needle, I tilt my face in the glorious light. I’m wearing the darkest glasses because my eyes ache where there is brilliance, but the light is perfection, the naked sun coming closer now as if Corky and I are prayerful gnostics who have silently identified the proper secret names for air and sunlight. My eyes fill with violet silhouettes, tricks of the air, shapes made by the cables of the bridge, a cluster of grapes hanging in the open air. No, it’s a turn of the century gaslight, still standing out here. I’m stock-still, filling myself—every microscopic and meandering raindrop inside a man must be replenished with
another. I picture myself holding the sieve of Theocritus above my head, the water falling in streams through my hair. (183)

In addition to the obviously euphoric and joyful experience this passage recreates, there are at least two salient features of the passage that signal the convergence of the narrating-I's and the experiencing-I's assessments of blindness: the evocation of an iconic American self-image, and a rehearsal of earlier themes and images that indicates the book is drawing toward its conclusion.

First, taking Kuusisto at his word that he did in fact mention Whitman when this event occurred, we can infer something about what the event signifies. The phrase “barbaric yawp” comes from Whitman’s *Song of Myself*—a poem known well for both its celebration of the individual (the opening line is, “I celebrate myself, and sing myself”) and of the collective, especially the American collective (the second and third lines are, “And what I assume you shall assume, / For every atom belonging to me as good belongs to you”). *Song of Myself* exults in contradictions and in a way of life that both asserts the worth of every individual and delights in the differences among people. Kuusisto as experiencer of this moment has finally arrived at a conception of himself—his blind self—that he is eager to celebrate, as well as a conception of himself in the world that allows him to be different than sighted people without shame or isolation.

Kuusisto and Corky’s walk across the Brooklyn Bridge, introduced by a Whitman phrase, also evokes Whitman’s “Crossing Brooklyn Ferry.” That poem opens with a juxtaposition of the immediacy of the physical environment over against the “curious” crowds on the ferry:
Flood-tide below me! I watch you face to face;
Clouds of the west! sun there half an hour high! I see you also face to face.
Crowds of men and women attired in the usual costumes! how curious you are to me!
On the ferry-boats, the hundreds and hundreds that cross, returning home, are more curious to me than you suppose.
And you that shall cross from shore to shore years hence, are more to me, and more in my meditations, than you might suppose.

As I discussed above, Kuusisto has a similarly exuberant encounter with his physical surroundings on the Brooklyn Bridge. Yet he also realizes that his ecstasy is quite abstract: “It occurs to me that my experience of the Brooklyn Bridge is so completely cerebral it is in fact a kind of metaphor, an imaginary headdress like those body-length hats worn by Tibetan women. In my version, the bridge falls over me in layers…These are the threads of being” (183). As he goes on to discuss several encounters with New Yorkers, Kuusisto will retain his confidence about himself, yet he will also be quite realistic about others’ continually negative interpretations of his blindness. In this way, Kuusisto’s East River journey is a repetition of Whitman’s, but with a difference.

Whitman concludes, as usual, on human solidarity and avows, “What is it, then, between us? / What is the count of the scores or hundreds of years between us? / Whatever it is, it avails not—distance avails not, and place avails not.” Kuusisto, on the other hand, ends the final chapter of Planet before the prologue this way:

To be alive is to be in adversity. Prudence, temperance, fortitude, and justice can only exist side by side with misfortune. But then I think this is too stoic, for I’ve discovered love from unforeseen sources. I try to hold on to the words from John, chapter one: “Beloved, now are we, the sons of God, and it does not yet appear what we shall be.” (189)
For Kuusisto, human solidarity includes adversity, and he has reconciled with the inevitability of people’s negative responses to him and his blindness. However, as Planet concludes, we find that Kuusisto has incorporated those responses into his still-Whitmanesque view of the world.

In addition to the celebration of himself signaled by the lyricism and the evocation of Whitman in this passage, the language and what we might call the “aesthetic of blindness” demonstrated in this passage matches that of the prologue. Blindness involves plays of light, odd shapes and colors that are simultaneously mysterious and delightful, and there is no hint of self-consciousness, let alone self-loathing, that prevents Kuusisto from taking in the experience of crossing Brooklyn Bridge. This is, of course, very similar to the experience in Grand Central Station, where “moving is holy, the very motion is a breeze from Jerusalem” (1). In this second, section called “Movement,” the freedom—and more importantly, the willingness and desire—to move in public as a blind man signals Kuusisto’s arrival (as experiencing-I) at a conception of blindness consonant with his conception as narrating-I. That both episodes take place in iconic locales of New York (and indeed American) transit only further confirms the significance of this moment in the memoir as a whole.

In this latter portion of the book, disability is positioned according to what Linton calls, adding a sixth category to Hanks and Hanks’s taxonomy, “Active Participation and Accommodation.” Under this arrangement, “there are…concerted efforts to accommodate all the members of the group and to adapt the procedures and standards typically imposed to reflect a range of abilities.” For Linton, this arrangement is
collaborative between disabled and nondisabled people for whom a “proactive stance is evident toward the equitable participation of all members of the society.” It involves “greater flexibility…and a broader range of objectives” than Limited Participation and other arrangements (54). Actual instances of such arrangements are rare (Linton’s examples are well-run independent living centers and, to a lesser degree, Martha’s Vineyard in the mid-nineteenth century), but Linton provides examples of architectural practices and educational approaches that move in the direction of integrating disability positively into social life. Clearly a social arrangement in which disability was a normative and valued part of the life of a community would provide a setting in which disability could function as, among other things, a generative aesthetic principle and a productive way of being in and engaging with the world.

Kuusisto’s life after he claims disability constitutes an example of Active Involvement and Accommodation. He receives orientation and mobility training—itself an example of accommodation that enables participation in social and civic life—and learns to move as a publicly blind man using a cane. It is during this period that he learns to “[walk] in safety at last” and acknowledge, “I can be disabled. On this ordinary street” (145). Eventually, however, he decides the cane “has done all that it can do. I’m thinking: dog” (150). At Guiding Eyes for the Blind, where he trains to work with a dog, Kuusisto develops relationships with other blind people. Just as important, he also develops a category for an environment in which disability is at the center. Guiding Eyes is built for blind people. Room numbers are raised and three-dimensional and very large. Braille is on everything…Walking around, I begin to understand that guesswork is overrated. The memorized phone number, the entire shopping list,
these were my specialties. I begin sensing that I can put some of this behind me. My damned brain can be freed from its inching memorization. (161)

In short, it is at Guiding Eyes that Kuusisto moves from his personal embrace of blindness toward a broader conception of a social arrangement according to which disability is integrated into the world as another way of being. As Couser puts it, Planet “is a story…not of triumph over impairment but rather of circulation in public made possible by an accessible environment, a cooperative community, and a kind of canine prosthesis” (167).

This evolving understanding of integrated disability is especially evident in Kuusisto’s interactions with nondisabled people after he leaves Guiding Eyes with Corky. Far from needing to appear sighted or “a being of value,” Kuusisto describes “an evangelical desire” to reassure people of the positive value of blindness (180). For example, after a little boy asks his mother about how Kuusisto functions in the world, he says he “want[s] to follow this mother and child through the tall laundry soap displays and tell them that the world doesn’t end. I imagine telling them that the blind are not hungry for objects. I want to take strangers by the hand and tell them there is no abyss” (180). As he learns to negotiate others’ inaccurate perceptions of his blindness (and disability in general) alongside his increasingly positive conception, Kuusisto develops a kind of imperviousness that allows him to “[l]et them disperse. I have to let them go” (191).

It is this simultaneous appreciation for blindness and his ability to free himself from the responsibility to explain himself or disability to others that allows Kuusisto to
recreate his experiences the way he does. In the epilogue we find Kuusisto and Corky again in Grand Central Station. This time, they encounter a “millennial soothsayer” who accosts them and says, “Did you know that the end is coming?” At an earlier time in his life, while he probably would not have assented to the man’s question as such, there was a part of him that shared the kind of apocalyptic fear this man conjures—fear that he would be found out and exposed, finally rejected by people around him and by the world at large. Now, though, having embraced disability in a way that allows him to “sound [his] barbaric yawps” both in story and in discourse, Kuusisto’s responds to the man’s question:

I clutch Corky’s leash and suddenly find that I’m laughing. “No, it’s not!” I begin dancing with the dog. “No, it’s not! No, it’s not!” I am chanting and dancing with a jumping dog. Some tourists snap our picture, blind man and dancing dog under the big clock in Grand Central. Rush hour going on all around us. The millennial soothsayer walks away without another word. (191)

Far from the world ending, Kuusisto recognizes in the period following his embrace of disability that the world has, for him, in many ways just begun. The journey toward that beginning and life on the planet to which we were welcomed in the prologue is the subject of Planet as a whole.

Kuusisto’s development of a positive disability identity and conception of blindness in the context of Active Participation and Accommodation required collaboration between Kuusisto and his environment. These ingredients are also discernible in the work of Rod Michalko and Georgina Kleege, two other blind academics and authors who have reflected on blindness as a valuable way of being in the world. Kuusisto is not alone in conceiving of blindness as he does in the prologue, late
chapters, and epilogue of *Planet*, even as the process of narrativizing his experiences of disability allows him to depict the evolution of that conception in a distinctive way, growing out of his own life history. Hence, though each experience of disability is uniquely situated, demonstrating shared themes and concerns among blind thinkers and writers reveals a broader pattern in literary representations of blindness.

Michalko, a sociologist at the University of Toronto, has written two books about blindness, both after he had been using a guide dog for at least nine years. Consequently, considering his reflections on blindness and the role using a guide dog can play in building positive conceptions of blindness can move us toward a better understanding of Kuusisto’s experience in the latter portion of *Planet*. Michalko explains that working with a guide dog “return[ed his] body” to him and restored “the grace of moving” by delivering the visual field to him through the dog’s physical contact with the environment. His analysis makes it clear that “choosing to be blind in a forceful way,” as both he and Kuusisto have done, involves both orienting oneself toward disability as a positive identity characteristic and making use of accommodations (in this case, a guide dog) that, in his words, make blindness “an occasion for me to act decisively and to think about what is important” (*The Two-in-One* 105).

Similarly, Georgina Kleege, a writer and professor at the University of California-Berkeley, has written about how blindness can serve to complicate and advance the way we think about things like reading. Kleege describes the experience of listening to readers on audio recordings of books:
For better or for worse, reading this way almost always feels like a shared experience. I feel myself not merely a passive audience but engaged in a kind of exchange...This is precisely what confounds the sighted reader who thinks of reading as a private and intensely personal act, a solo flight with no copilot to look over your shoulder, make snide comments, or gush about the view. (Sight Unseen 181)

Kleege also describes the way her students, whom she requires to read their work aloud both for her benefit and theirs, often feel compelled to address her in the recording after reading their work. One reader told her, “Reading something aloud makes him notice different things. But also, the responses he has feel raw, unembellished, connected somehow to the realm of spontaneous utterance rather than considered contemplation. It’s as if the act of reading aloud seems to open a more immediate line of communication. From his lips to my ear” (183). Here, Kleege’s blindness summons questions about reading practices that, in literate cultures, have gone largely unexplored since the advent of the printing press and silent reading—phenomenological questions about the experience of reading aloud and the way it “seems to open a more immediate line of communication.”

My point in bringing up these comparative, additional examples is to show that Kuusisto is not unique in reflecting on blindness’s generative potential when embraced as a positive identity marker. In each case, both accommodations and the inclination to conceive of blindness as a valuable way of being in and thinking about the world are part of developing and inhabiting a positive disability identity. What is distinctive about Planet is the way Kuusisto constructs the narrative about how he came to inhabit the identity that, by the end of his story, he claims as his own. Portraying the subjective
experience of blindness over time, Kuusisto reveals the external phenomena that inform, configure and constrain that experience and its representation.

**Conclusion: The value of disability life writing**

Couser warns that those who teach and write (or write about) disability memoir should “be aware of hostility to the genre…[for instance, from those] who are skeptical of narrative of any sort as a medium for challenging conventional discourse about disability…[because they] all represent disability as fundamentally an individual problem” rather than a social arrangement and way of organizing and valuing bodies (“Signifying Bodies” 110). As I mentioned at the beginning of this chapter, Lennard Davis has argued that “by narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story, as we have seen in so many films treating the subject of disability” (*Enforcing Normalcy* 4).

Criticisms about the potential individualism or even solipsism of disability memoir are valid, and I have frequently felt their force. For instance, whenever the word “overcoming” comes up in a class I’m teaching or a discussion I’m having about a disability memoir, I shudder. The term and its variants—referring to disability as an “obstacle” or a “hurdle,” for example—are veritable anathema among those who work in disability studies, for precisely the reasons Davis and Couser point out. Those who advocate for a progressive understanding of disability think of disability not as something to overcome, but rather something to embrace and integrate into our understanding of the
human experience—and further as something dwelling primarily in a society rather than individuals. For us, disability is something we move toward, not leave behind or “transcend.”

Faced with individualizing and often romanticizing interpretations of disability in general and disability memoir in particular, how should I proceed in teaching and conversation? Desiring to help enlarge and nuance people’s perceptions of disability without condescending or being dogmatic to students, colleagues, friends and family, what move should I make? Wanting people to see disability as a largely social rather than an essentially individual, medical phenomenon, what should I say? Further, does this common response to disability memoir mean the genre is by its nature incapable of representing disability as anything other than sentimental, an obstacle, and individualistic? Or are there disability memoirs that are both literary and sufficiently attentive to disability as a cultural issue?

*Planet of the Blind* is in fact both literary and attentive, and it is especially useful because Kuusisto structures the progression in a way that moves from consonant self-narration in the prologue to establish a frame for the memoir as a whole; to dissonant self-narration for the majority of the progression, which makes clear to readers the damage cultural attitudes toward disability can do; to consonant self-narration again by the end of the memoir at the moment when Kuusisto claims disability. Finally, in the epilogue, Kuusisto continues the consonant self-narration, but returns to some of the same types of negative treatment he encountered in his early life. In these final vignettes Kuusisto demonstrates the difference that a confident disabled selfhood makes in his
interactions with all types of people. He in no way condones or excuses people’s ill
treatment of him or their ignorance about disability, but he offers a realistic account of
what it is like to continue to live in a largely hostile environment under a new paradigm
of disability. Readers can compare Kuusisto’s experience under the new paradigm as the
experiencing-I with the earlier passages where the experiencing-I held a different attitude
toward disability.

Couser argues that disability memoir in general “warrants study…as potentially
powerful counterdiscourse to the prevailing discourse of disability”—quite the opposite
of reinforcing those discourses. Since it comes “from inside the experience of
disability…autobiography may represent disability in ways that challenge the usual
cultural scripts” (“Signifying Bodies” 110). In Couser’s account, the cultural location
from which disability memoir issues is valuable in itself; it is a “useful” genre that offsets
“most cultural representations of disability, which issue from nondisabled parties and
which may reinforce stigma and marginalization” (109-110).

While I agree that we need literary texts that challenge long-held but
underdeveloped understandings of disability, the call for such representations should take
into account the ongoing vigor of disability studies as a field. I think it is valuable to
highlight formally interesting disability memoirs like Planet of the Blind in a way that
supplements (but does not replace) disability studies’ commitment to supporting disabled
people’s rights in the world outside literary texts. A textually-driven appreciation for
disability issues and the particular formal and rhetorical strategies memoirists deploy in
order to raise them reveals the genre’s artistic value as well as their value to the field of
disability studies. Further, texts like *Planet* are examples of the ways that well-crafted
disability memoirs can yield interesting new visions of the disability experience. In cases
like *Planet of the Blind*, the formal and rhetorical strategies evident in the text provide
insight into the nature and meaning of disability in individuals and cultures. Thus, far
from being (at worst) self-indulgent or (at best) relevant only to a small niche readership,
well-executed disability life writing both capitalizes on the aesthetic potential of
disability and reflects on its social production.
Chapter 5—Growing Up, Graphically: Cultural Narratives and the Haunted Body in *It’s a Bird*…

**Introduction: Questioning Superman**

In Superman’s seventy-three years of life, he has become stronger, faster, and more resistant to any kind of harm, to the point of being basically invincible. He has also demonstrated the ability to deal with increasingly complex problems: Gone are the days of reforming wayward gamblers by giving them a stern talking to before they can commit suicide out of desperation and shame for having let their families down; here are the days of grappling with large-scale ideological questions and planet-sized problems with his god-like powers.\(^{55}\) As the scope of his adventures and powers expand and as he remains a pervasive presence in American culture, Superman’s universe offers a backdrop against which to investigate and reflect on that culture, as well as on his extraordinary origins and abilities in the world of his stories.\(^{56}\) What can we learn about cultural values from a figure and a mythology that has remained popular for over seven decades?

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\(^{55}\) Contrast the hapless criminals and quack doctors from the early issues of *Action Comics* with the 2004 comic miniseries *Superman: Red Son*, which features Stalin and JFK and deals with issues of individuality and ethics under an almost-global, totalitarian government with the Man of Steel at the helm.

\(^{56}\) In fact, for a period of time, there was not just a Superman universe, but a Superman multiverse. In order to allow for comics artists to create new stories and images without fear of contradicting one another, DC Comics engineered a story according to which different types of Supermen, enemies, allegiances and stories took place in different, parallel universes. In 1985 the multiverse was collapsed back into a single universe in the twelve-issue series *Crisis of Infinite Earths*.  

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In their 2004 graphic narrative *It’s a Bird…*, writer Steven T. Seagle and artist Teddy Kristiansen scrutinize Superman’s origins and powers as well as his status as an icon of truth and justice by contrasting Superman’s implausible invulnerability (among other things) with the reality of our own too-familiar flaws and contingencies. In this final chapter I engage the relationship between the Superman mythology and bodies. *It’s a Bird…* uses one of the most iconic bodies in American culture to explore our collective anxieties about our own bodies, others’ bodies, and bodies in general. I argue that disability and its specter of the “unwell” body—specifically, in this case, the chronically ill body—is a powerful framework for discovering what major cultural myths like Superman reveal about how we think (and what we fear) about bodies. Seagle and Kristiansen are making precisely that kind of investigation, using 1) narrative as a way of thinking about disability and 2) disability as a critical framework to show that Superman’s perfect body is a way for us simultaneously to flee from the reality of our imperfect bodies and to reassure ourselves that even with flawed bodies, we can be extraordinary.57

*It’s a Bird…* is not a Superman book in the sense of advancing the ever-expanding universe(s) and stories of the Man of Tomorrow. Rather, it is an autobiographical book about Seagle, a comics writer, sifting through his “issues” with Superman.58 Seagle first encountered Superman comics in a hospital waiting room as his grandmother died of

57 In fact, I will argue that *It’s a Bird…* even raises questions about what it means to say our bodies are flawed, since flaws presuppose an ideal that may not be as self-evident as it seems.
58 The author biography says that Seagle “acknowledges some similarities between himself and the character ‘Steve’ in this book, but only some, and in an interview on NPR’s *Fresh Air*, Seagle reported, “The facts [in the book] are all right; they’re just in the wrong order.” I will address the ambiguity of these remarks in this chapter’s conclusion.
Huntington’s disease, a degenerative and hereditary neurological disorder that Seagle may or may not also have. Near the beginning of the book, Seagle’s manager Jeremy calls him with an offer from DC Comics to write new installments of *Superman*, and the main story consists of Seagle’s process of deciding whether or not to accept the job. Shortly after receiving the offer, he says, “There’s no access point to the character [of Superman] for me…for anyone if they ever really thought about him. Too much about him makes no sense” (13). As *It’s a Bird…* unfolds, it becomes clear that for Seagle, things like Superman’s physical invulnerability and the always-positive valence of his distinction from other beings make him hard to relate to, especially but not entirely because of Seagle’s own family (medical) history.

When DC offers him the job of writing new Superman stories, Seagle (referred to throughout the book and henceforth in this chapter as Steve) is forced to face his family’s past, which he does by delving simultaneously into his own memories and into the mythology of Superman. The book consists of Steve’s process of deciding whether to take the job, interspersed with twenty short Superman-related stories that I will call “interpositions,” each presented in a different style of art and reflecting on a different aspect of Superman’s character and mythology. Steve uses these stories both as attempts to enter into the world of Superman and as a way to work through his own memories and anxieties about his family and his body.

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59 Ellipses are pervasive in the speech, thought, and dialogue bubbles / boxes in *It’s a Bird...* Where they are meant to indicate omitted material, I will bracket them. Non-bracketed ellipses are part of the original text.
The development of *It’s a Bird...*’s plot depends, then, on Steve’s evolving relationships with his own body, his family’s story, and Superman. The question of whether Steve will accept the job writing Superman comics drives the plot as such; but underneath that question lie Steve’s developing thoughts and anxieties about his body and his family, which equally important to the narrative progression. Steve’s anxieties play out in his thinking about the job offer and about Superman as a character. In this way, Superman functions as a backdrop for Steve’s development. Steve’s anxieties also produce conflict with other characters—most importantly, his father, who has been secretive about the disease’s influence on the family, and his long-time girlfriend Lisa. Steve immediately tells Lisa about the offer from DC, but mentions nothing to her about his family history with Huntington’s until almost the end of the book. Throughout the book, readers are interested in what Steve will do about the job offer, but our interests include wanting to know how his encounter with Superman will affect the way Steve conducts and conceptualizes his life and relationships.

Steve’s central question as an artist is, “Why is Superman so enduringly popular given his general implausibility and the relatively simplistic structure of his story?” I will trace his answer, but I will also attend to the important question, “How does the relationship between Superman and disability help us answer these questions about the character and his world?” I have separated the interpositions into four groups according to the types of “Superman issues” they engage. I will not follow their exact order as they appear in *It’s a Bird...*, and I will focus on those that are most clearly related to issues of disability, only briefly discussing others and leaving some out of my discussion entirely.
One interposition will appear in my discussion of the book’s introduction. Each of the remaining seventeen fits into one of five groups: Dubious Distinction, Double-Edged Swords, Outright Objections, The Hidden Self, and A New View. I have divided the interpositions by category in the table below. As I discuss these interpositions, I trace the unfolding relationships among Steve, Superman, and Lisa, as well as between *It’s a Bird*...’s implied author and authorial audience (concepts I discuss at length in previous chapters, especially Chapter 3).

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<th>Introduction</th>
<th>Dubious Distinction</th>
<th>Double-Edged Swords</th>
<th>Outright Objections</th>
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Table 1. Division of Interpositions in *It’s a Bird*...

Steve starts his investigation of Superman from an artistic or professional standpoint, questioning the Superman mythology as such. That investigation eventually collides with his personal relationship to the Man of Steel, and Steve reconciles the two by the end of *It’s a Bird*... However, both the implied author and authorial audience

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60 The interpositions I do not discuss in this chapter follow the patterns of their counterparts, but are less clearly connected to disability issues and are therefore left out of my discussion here.
recognize from the outset that the personal and artistic perspectives are intertwined from
the outset.

**Narrative Analogizing and Critical Disability Studies**

My focus is on elements of the Superman mythology that Seagle and Kristiansen
connect via the interpositions to Steve and his family’s story. Many aspects of
Superman’s character enter into the composition of *It’s a Bird...* (henceforth *Bird*); these
aspects are relevant both to Superman and to Steve’s family. At times Steve’s
experiences lead him to poke fun at the Superman mythology, while at other times the
Superman references work the other direction, from Superman to Steve’s family.
Ultimately, reconciling these two domains allows Steve to understand why the Superman
concept is powerful and enduring even as it has limitations. It also enables him to make
peace with his family and their history, as well as with his own body. I argue that Steve’s
eventual ability to make peace with the Superman myth depends on his employment of
two frameworks that he never names but nonetheless mobilizes throughout the book:
what I will call “narrative analogizing,” and critical disability studies.

Steve’s personal and family histories stimulate his resistance to and criticism of
the Superman story, and in turn, his reflections on Superman help him negotiate his own
feelings and thoughts about his and his family’s past. He thinks of Superman as an
implausible and in some ways sloppily-constructed character, but this is for personal as
well as creative reasons, arguably more the former than the latter. Yet by the end of *Bird*,
Superman’s resilience as an iconic figure has provided a framework for Steve to face
some of the painful and frightening aspects of his family and future with resilience of his own. This mutual relationship between Steve’s personal stories and the Superman story can be thought of as “analogical thinking” via the two narratives. Thus, the operation in which Steve is engaged throughout the text can be called “narrative analogizing”—that is, using aspects of one story to further one’s thinking about another, with the operation ultimately flowing in both directions, from one story to the other and back again.

Additionally, Steve’s skepticism toward Superman emerges from his unwillingness simply to accept the canonical story unquestioningly. To the contrary, in questioning the Superman myth, he responds to what psychologist Jerome Bruner might call the “narrative banalization” of the Superman story. In “The Narrative Construction of Reality,” Bruner claims, “[W]e can take a narrative as so socially conventional, so well known…that we can assign it to some well-rehearsed and virtually automatic interpretive routine.” However, “the moment a hearer is made suspicious of the ‘facts’ of a story or the ulterior motives of a narrator, he or she becomes hermeneutically alert” (9-10). Because of his and his family’s stories, Steve is suspicious of and thus hermeneutically alert to many aspects of the canonical Superman story, particularly the idea that a person with highly conspicuous traits suffers no ill will from the dominant majority.

By the end of the book, though, Steve basically grants that the Superman myth is not only an acceptable story, but also one that does important cultural work in giving people the sense that they can go on facing and fighting their problems. Fellow comics writer Joe Allen had tried to persuade Steve of this earlier in the book, reminding him:
At the time of Supes’s creation, you had immigrants leaving Europe in hopes of a better life in America…Siegel and Shuster were both kids of Jewish immigrants—sensitive about the expectations put on them to make it in America. So Superman, even though he’s from another world, is like the best citizen of his society. Anyone with the will can make it here. (49)

At this point Steve resists, objecting that what Allen has said is “the myth of America,” but that Superman’s otherworldly power in achieving the “American dream” disqualifies him from being a character people can relate to. As he wrestles through his “issues” with Superman over the course of the progression, Steve eventually grants legitimacy to the basic premise Allen has stated, though in a slightly revised form.

Thus, while Steve does challenge the Superman story and uncover some connections between it and his own life (and disability more generally), he ultimately remains complicit with the story. In this way, he relates to the Superman myth as Bruner suggests most people relate to canonical stories: we “form our own narratives of deviation while maintaining complicity with the canon” (20).

Bruner meant for his essay “to lay out the ground plan” of the role narratives play in helping people negotiate their worlds. However, he said that the “daunting task” remaining was “to show in detail how, in particular instances, narrative organizes the structure of human experience” (“Narrative Construction” 21). Building on work by Bruner and others, David Herman points out the usefulness of narrative as a problem-

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61 Allen’s explanation follows a line of reasoning that historical treatments of Superman have frequently identified, noting Siegel and Shuster’s status as cultural outsiders in the period of Superman’s invention. See, for example, Gerard Jones’s Men of Tomorrow: Geeks, Gangsters, and the Birth of the Comic Book.

62 Though his learning theories are highly disputed, subsequent research in psychology has borne out Bruner’s thesis that narrative functions to structure experience, especially with respect to human interactions. For example, see Daniel D. Hutto, “The Narrative Practice Hypothesis” and David Herman, “Stories as a Tool for Thinking.” Also see footnote 70 below.
solving resource in a broad range of contexts and situations because of its “extraordinary serviceability as a tool for thinking” (“Stories as a Tool” 171). Herman and others have demonstrated that organizing experiences in narrative form is a basic human cognitive strategy. For my purposes, I am interested in Steve’s use of an existing narrative as a template for organizing his own experience. Steve’s use of a pre-existing narrative is distinct from narratively organizing one’s own experiences. Consequently, my analysis of Bird is an application and a continuation of cognitive (narrative) theory’s understanding of how we use narrative—in this case, pre-existing narratives—as a resource for negotiating one’s dilemmas and experiences.63

Narrative analogizing as I conceive of it is similar to what Mark Turner and Gilles Fauconnier call “double-scope blending,” a process in which two input stories “are blended into a third story whose organizing frame includes parts of each of the input organizing frames. The blended story has emergent structure of its own” (Turner 128).

Turner uses the Christian story of redemption through Jesus’ crucifixion as an example:

In the story of Jesus, he is unsinning. His counterpart in the story of humanity is the human beings, who are sinful. This is an absolute clash. In the blend, we integrate features of Jesus with features of the human beings, producing emergent structure according to which the human beings no longer must bear the consequences of their sins. (129)

Two clashing stories are blended, and the result is a third story with emergent meaning of its own as a result of the blend.

63 I am indebted to James Phelan and to David Herman, respectively, for helping me label the phenomenon of narrative analogizing and for pointing me to Bruner’s and others’ work in this vein. Also, I do not mean to suggest that Bruner and others have not identified the tendency to draw on pre-existing narratives. Bruner points to this tendency in “The Narrative Construction of Reality” when he says, “Narrative genre…can be thought of not only as a way of constructing human plights but as providing a guide for using mind, insofar as the use of mind is guided by the use of an enabling language” (15).
In *Bird*, the two organizing frames are the Superman story and Steve’s life story, and the stories’ dissimilarities account for the majority of the tension in the book. Steve’s revised understanding of his life by the end of the book is a third story in which he has developed a new attitude toward his family history as well as his own life. I do, however, think there are differences between narrative analogizing and double-scope blending—or at least, that *Bird* may extend the taxonomy of types of double-scope blending. In *Bird*, Steve begins with two stories with which he is dissatisfied: his own, fraught with secrecy and fear about Huntington’s disease; and Superman’s, fraught with problematic elements to which Steve objects. Instead of a third story emerging, there seem to be two “new” stories: Superman’s, more palatable to Steve after he has considered it in light of his life experiences; and Steve’s, in which he now feels confident to face the uncertainties and challenges of life thanks to some reflection on the Superman story. Perhaps narrative analogizing could be thought of as a subset of double-scope blending in which two input stories mutually affect one another and result in two blended stories that are basically revised versions of the original input stories, each with new kinds of meaning as a result of the blending.

In *Bird*, Steve’s personal and family stories leave him confused and shameful. Circumstances lead him to hold those stories up against the Superman story, which clashes in substantial ways with his own. By a process of narrative analogizing and by using illness and disability as a way of questioning the Superman story, Steve integrates disability into his worldview and recognizes the cultural work Superman continues to do. While reading Superman comics is inefficacious in changing Steve’s circumstances—he
still either does or does not have Huntington’s, and he is still a comics writer—his experiences reading and reflecting on Superman comics and their themes do have a direct effect on how he interprets and acts on the world around him. That reading and those reflections also change the way Steve thinks about Superman. In other words, reading Superman helps Steve make sense of his past and present experiences and anticipate how he will respond to experiences in the future; and in turn, the changes in his own thinking affect how he thinks of the source material that helped him make those changes.

**A Body Story**

*Bird* indicates from its opening pages that it will engage the relationship between bodies and their changing features. In fact, the first panel in the book establishes a relationship between Superman and the body—specifically, his grandmother’s body. This connection between Superman and the body in the introductory section constructs an authorial audience that reads the rest of the book with particular attention to that connection.

The book opens with a blurred, incomplete image of a medical document. In the center of the document is a box labeled, “Diagnosis,” and underneath is an only partially visible word that ends in “TON’S,” the clearest letters on the form. The “s” is red and different from the rest of the letters, vaguely resembling the iconic insignia on the chest of Superman’s costume. The next several panels depict two young boys seated on a bench in a hallway. In the first panel Steve is the speaker, and the dialogue box superimposed on the medical document reads, “What I think about most is the big red
S…It didn’t look like the rest of the letters on the report. It looked out of place…like it was added later…an afterthought” (1-2). This “big red S” is the first invocation of Superman within the book’s pages.

Though the red “S” on Superman’s chest has changed slightly over the years, it is one of the few constants in his character and appearance since his introduction to *Action Comics* in 1938. Indeed, the stylized “S” inside its unusual pentagon has long been a metonym for the Man of Steel. That Steve remembers a large red “S” on the hospital form containing his grandmother’s diagnosis—the occluded word, we soon learn, is “Huntington’s”—shows clearly that Superman will be associated throughout the book.
with the disease and with this moment in Steve’s life. However, it is not only the appearance of the “S” that is significant to the book’s engagement with Superman, but also the letter’s function in the word of which it is a part.

As Steve puts it, the “S” seemed like “an afterthought” to the word on the hospital form. As we will find out in the ensuing pages, Steve thinks much of Superman’s character and story seems to have been an afterthought to Jerry Siegel and Joe Shuster’s original conception, even as changes to his character have been folded into his development over the past seven decades. It seems to Steve that much of Superman’s development consists of a network of highly unlikely contingencies and seemingly contrived constructions. There was, for example, the “multiverse,” which allowed writers to develop contradictory Superman storylines without having to keep track of others, followed by the “crisis of infinite earths,” which collapsed Superman’s world back to a single storyline. Yet Superman and his global appeal persist despite whatever credulity-stretching twists and turns he and his worlds have taken over the years.

Superman’s veritable antitheses, disease and vulnerability, can similarly be both afterthoughts and pervasive realities to the humans he so faithfully defends. On the one hand, our tendency is to assume that our bodies will function well. Illness or disability—whether at birth or later in life—almost always comes as a surprise. Yet at the same time, we are cognitively aware that our bodies or our loved ones’ bodies could at any point, from birth to the inescapable fact of death, change or fail us. In this way, the idea that our bodies’ may become anomalous rather than being perfect, like Superman’s, is both an afterthought and a notion of which we are constantly aware.
Steve later returns to the “S,” in the interposition called “S,” to reflect on the power of the letter itself as more than a symbol for Superman or for the ailing body. In this interposition, Steve describes the letter as “serpent swirl of the alphabet set” and points out, “More so than any other Roman letter…the ‘S’ wields surprising powers” (104). Its two most haunting powers are that it can “turn an isolated tragedy” (the word “Victim” appears in the panel for which this dialogue box appears) “into an epidemic” (and here a panel covered with multiple printings of the word “victims”), and that it can “possess. Take what it wants through association […] owning what it touches” (104). In the panels describing this power, “Brother” becomes “Brother’s” and in the interposition’s last panel, we see the word “Huntington’s,” where the “S” is the red letter from the opening of the book.
This late reflection on the “S,” which appears on page 104 of Bird’s 124 pages, comes immediately before Steve finally confronts Huntington’s when he visits his aunt Sarah, who also has the disease, in the hospital. After reading this interposition and Steve’s subsequent reflections on Huntington’s and its effect on people who have it, we are in a better position to understand what comes after the discussion of the “S” in the opening pages of the book. However, even on first reading we can clearly understand that Steve developed a fraught relationship with Superman as a young child.

After the initial discussion of the red “S,” Steve explains more about when and where he saw the medical document: “I was with my mom and dad and my brother,
David, in a hospital in North Carolina—or Colorado—or California—I don’t remember which exactly. I was only five years old” (2-3). In fact, at the end of the book’s prelude, consisting of these memories, Steve admits, “Maybe the big red S wasn’t even on the report…Maybe I’m confusing things…I was only five…but in my mind, that’s how I remember it” (6). Steve is saying that the exact details surrounding his introduction to the family’s complicated and secret history matter less than his subjective impressions from the environment of the hospital, his mother’s explanation that Steve’s nuclear family was ostracized by the rest of the family, and the impact of the possessive and possessing “S” on the hospital paperwork.64

Likewise, Steve’s later objections to Superman are not to particular details of the Superman plot or why certain things happened at certain specific moments in his biography. Rather, Steve’s concerns are with the general principles according to which Superman operates and the lessons those principles communicate, in turn, to the audiences who consume Superman’s stories.

When Steve’s manager Jeremy calls him to offer him the job, he assumes Steve will leap at the chance to write for Superman, as he believes any comics writer would. After all, as Steve tells us, “Know that there are two things your average comic writer waits his or her entire career to hear: ‘Can I have your autograph?’ –and— ‘We want you to work on Superman!’” (10). When Steve initially refuses the job, a surprised Jeremy fires back, “Superman is the top comic property in the world […] and don’t think about

64 It is also possible that the red “s” really was not on the form. Huntington’s is poorly understood and unknown enough that hospital personnel might literally have added the “s” as an afterthought, as Steve suggests.
sales—I’m talking big picture. Supes is the best-known iconic figure on earth” (11).

Steve comes around and says he will consider taking the job, and then he tells Jeremy the reason for his hesitation: “I have issues with Superman […] Back issues. As in…I’ll get back to you […] Let me think it through—see if I have anything to say” (12). The last panel during the telephone conversation is a close view of Steve’s sketchbook, on which he has drawn an “S” nearly identical to the red one on the medical form in the opening pages. This visual cue indicates that Steve is already thinking about the association between his grandmother (and thus disability) and Superman.

![Image 3. Page 11 of It’s a Bird... (Steven T. Seagle and Teddy Kristiansen; DC Comics)](image)

As he steps out to the street, Steve explains his objections to Superman’s inaccessibility as a character, initially based on his overall implausibility. However, having read the opening pages and seen the “S” in his sketchbook, readers are cued to look for connections between Steve’s problems with Superman and his reflections on his grandmother’s illness and its implications for his relationship to his own body. At this
point the book moves into the first interposition, one of three in the group I call Dubious
Distinction. I begin with this group not only because the “The Costume” is the first
interposition in the book, but also because it clearly raises the question of (bodily)
difference and how it is received and interpreted.

**Dubious Distinction**

The three interpositions in this group all relate to the fact that Superman’s
distinction as a superhero is always a positive one, marking him out for honors and
accolades. In the real world, meanwhile, distinctions are not always positive, often
marking people out for negative treatment by others and/or producing negative
experiences of their distinctions. Actual people’s distinctions are often dubious in the
sense of being suspicious to others. Meanwhile, for Steve, Superman’s distinction is
dubious in that it has been, historically, singularly positive to everyone but his obviously
despicable enemies. Superman’s is perhaps the only anomalous appearance and body
never to have been looked on with suspicion.

With respect to disability, Steve’s assumption is that having or being associated
with Huntington’s is a categorically negative distinction. The disease is a family secret,
freighted with shame and confusion about how it is transmitted, who might have it, and
when it will begin to manifest. More generally, news of disease is always bad news,
difficult both to deliver and to deal with—at least at first. In Steve’s family’s case, his
father’s siblings withheld the news that their mother had Huntington’s for what we
eventually learn was a period of years. Importantly, the period of Steve’s parents’
ignorance was also the period during which he and his brother David were born. This means that they had their two sons before they knew that each would have a fifty percent chance of developing the disease. In Steve’s mind, while the distinction of disease may eventually be manageable and incorporated into one’s sense of oneself, it is by no means typically or consistently positive. How, then, can anyone relate to a character whose absurd costume makes him visibly stand out in the world, but only in an admirable way?

In the first interposition in this group, “The Costume,” a seventh-grade boy named Jason Dobson is described as sitting “alone at lunch, painfully aware that even the geeks had someone to eat with,” overlooked and forgotten by teachers and peers alike. “But everything was different the day that Jason Dobson changed his identity…October 31st…Halloween […] He got a new suit, and for one grand morning, the girls thought he was cute and the guys joked with him like buddies. Jason Dobson was a star” (14-15). The panels—in this interposition, highly abstract people with no facial features—depict Jason donning a Superman costume at school on Halloween. When he is described as “a star,” Jason occupies almost the whole panel, arms raised to flex his biceps, with a female figure visible over each of his shoulders. “His spirit flew. For that one long afternoon, he was someone. Jason Dobson was Superman” (15). However, once his distinction is gone, the day after Halloween, Jason despairs at being himself again, which is to say unrecognized and unremarkable. So, a week later, Jason makes “a bold—if not desperate—decision. He wore the costume to school once more” in hopes of regaining his former, short-lived glory. “But it wasn’t Halloween. It was Thursday. And now Jason wasn’t cute, he was weird” (15). Jason is eventually suspended for the disturbance his
outfit causes after being chided by a teacher and bullied by fellow students. When he returns from his suspension, it is with the knowledge that he “would never be ‘super’ again” (16).

“The Costume” is introduced by Steve’s objection to Superman’s costume and its ridiculousness. But the interposition reveals that it is not the costume as such that bothers Steve. At one point Jason reflects, “A suit like that didn’t fit in with a world like this. But why? Wasn’t everyone’s clothing a costume of one kind or another? The jocks, the brains, the geeks?” (16). While everyone aligns himself with some group by outward indicators, some of those indicators single people out for negative attention, while others afford positive attention and still others provide anonymity. Why, Steve wonders, should Superman’s costume always make him the object of people’s admiration and never their puzzlement, if not their outright scorn? Superman’s experience in this regard is highly atypical; and for Steve at this point in Bird, it is also alienating. He also seems to think the experience of alienation when one is marked as different is common to others, as reflected by the art in “The Outsider,” which, as I mentioned, depicts people in a highly iconic fashion that invites reader identification with the figures in the panels (McCloud 36).

The second interposition, “The Outsider,” goes beyond the positive distinction of Superman’s costume to critique Clark Kent’s constant good standing in Superman’s life as the mild-mannered reporter. Drawn in simple, clear lines, “The Outsider” starts by

65 For a helpful treatment of the difference between realistic and iconic visual representation in comics, see Scott McCloud’s “The Vocabulary of Comics,” the second chapter in Understanding Comics.
pointing out that in his “Suit and Tie Hat and Glasses Clark Kent fits right in To the Walk-a-day Work-a-day Chit-chat Clickity-clack Paycheck and Collar-stay Water-cooler world of Metropolis” (21). As Superman he is loved by all, and as Clark Kent he blends perfectly into the majority population of the city, maintaining a well-paying job and enjoying a good reputation as a reporter. While the early Clark Kent in *Action Comics* endured some abuse from co-workers for his submissive nature, plenty of consolation came from the certainty that he acted that way as a cover-up. Clark Kent and readers always know that as Superman, Clark has more strength, physical prowess, and courage than anyone could imagine. By and large, though, from the beginning Clark Kent and Superman have been well liked and privileged and, in Superman’s case, revered nearly as a god. Why, this interposition asks, does Superman get to have it both ways, being both highly distinctive and universally revered?

“*The Outsider*” goes on to contrast Clark Kent with a hypothetical Daily Planet employee called Linda Goldberg, an accountant about whom people “Joke about how ‘Her People’ Are always ‘the ones handling Money.’ No Lunch Break long enough To allow her a Quick Change From her Heritage or its Critics” (21). Similarly, the black custodian DeRon Sanford “doesn’t Blend in So much as Vanish in Push and Sweep Plain Sight […] Until the Coffee Club Money Goes Missing from Someone’s Desk,” at which point “No one looks at Clark or even Linda[.] They don’t say a Word But don’t really have to And on his Lunch Break There’s no way DeRon can Push and Sweep away the Skin That makes him live Outside Himself” (22). The point here is that other “marked” bodies—here, ethnic and racial—do not enjoy an alternate life in which they shed the
stigmatized parts of themselves to be admired by all. Neither Linda nor DeRon, nor
“Greg Giddley Whose legs are Aluminum Spokes And Melissa Bandeau Whose
‘Boyfriend’ isn’t a Boy at all” enjoys the kind of respite from stigma in one part of her or
his life that Superman enjoys at all times (22). Only for Superman is distinction from the
dominant majority always positive, and as Clark Kent, he is a member of that majority.

As “The Outsider” ends, we find Steve in the waiting room at a doctor’s office.
Being there triggers his memory of being in the hospital where his grandmother died. The
next four panels return to the hospital scene from Bird’s opening. Steve’s mother tells
him, along with his brother David, that their grandmother has died of “Huntington’s
chorea”—the outdated term for the disease, based on the Latin word for “dance.” As he
reflects on that experience, Steve thinks both about Huntington’s and its genetic origins,
and about the influence of genetics on comics: “For a few years, I wrote some ‘mutant’
comics—trying to think of exciting new powers the heroes’ secret genetic structures
might give them.” The next panel shows Steve’s left eye, narrowed skeptically. He says,
“I quit when I realized that some genes don’t give powers…they take powers away.”

In the middle of the page is a shadowy image of a woman—presumably Steve’s
grandmother—lying on her back with a pained expression, her arms bent at a ninety
degree angle and her hands curled inward. The layout of the page highlights the way
Huntington’s has long been a shadowy yet pervasive part of Steve’s thinking: the image
of Steve’s grandmother is not enclosed in panel borders, and it flows into the bottom right
part of the page, becoming a final panel, also without borders—a ghostly image of a face
with sunken eyes and a gaping mouth.
Four caption boxes are superimposed along the left side of the central image, and they list some of the “powers” that genes can take away: “The power to walk. The power to sit up. The power to eat. The power to speak” (24). The next panel is another image of Steve’s face, wearing a guarded expression, and he says,

My parents never spoke much about what had killed my grandmother. They just said what they knew: that it damages nerves and runs in families. Unfortunately, what they knew wasn’t much because Huntington’s chorea isn’t a glamour
disease. Not enough casualties. No celebrities have died from it...just people like my grandmother. (24)

In these reflections, Steve makes two observations about disability. First, unlike superheroes’ genetic distinctions, which enhance their capacity for heroics, some disabilities inhibit people’s capacity for tasks like walking, sitting up, eating, and speaking. Second, some disabilities are recognized and understood to a degree by the general public, often because someone well known has or had that disability. More often, however, disability is not “glamorous,” but secret and shameful. This is the first instance in which Steve unconsciously applies a critical disability framework to his reflections on both comics and his family.

In his 2009 book Disability Theory, Tobin Siebers remarks that one key agenda for the field of disability studies is “to account for both the negative and positive valences of disability, to resist the negative by advocating the positive and to resist the positive by acknowledging the negative” (5). Siebers is calling for an understanding of disability that grants it both positive and negative value. Disability is positive, among other reasons, because it offers valuable ways of thinking about things like built environments, forms of cognition, and the effect of embodiment on knowledge, values, and relationships. At the same time, disability is negative in that disabled people encounter hostility and prejudice from individuals and institutions, and in that sometimes disability—especially chronic illness—produces pain and suffering. Disability studies is built on the foundational assumption that on the whole both disabled and nondisabled people have adopted,

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66 One of the most conspicuous examples is Christopher Reeve, who made spinal cord injury a topic of national interest and a massive recipient of financial donations.
disseminated, and internalized “largely harmful views about disability.” The field thinks of itself as seeking to mitigate and change those views as it “develop[s] its own understanding of disability as a positive contribution to society and both critiquing and comprehending” harmful views (Siebers 5). While Steve stops short of seeking to think of Huntington’s itself as “a positive contribution to society,” he does ultimately arrive at a more nuanced understanding of the disease, as I will discuss later in this chapter.

At the same time, the image of Steve’s grandmother in this scene sets a precedent for subsequent images of people with Huntington’s. The only images of Steve’s grandmother and his aunt Sarah—the only two people in the book we are certain have Huntington’s—depict them in hospital beds. The single image of Steve’s grandmother is reminiscent of a stereotypical image of a ghost or other-worldly presence, and the images of his aunt Sarah show her moaning incoherently and with eyes that suggest pain and disengagement from reality. Granted, people with advanced cases of Huntington’s can appear pained and disengaged; but the ghostly image of Steve’s grandmother and the absence of any depictions of either family member in a non-advanced stage suggest that for the majority of the plot, Steve can only think of Huntington’s as totalizing and devastating.

As he thinks about comics and about his family, Steve discovers tensions among comics, public discourse, and his own views of chronic illness. In comics, genetic difference in superheroes enhances their powers. In public discourse, some medical conditions are well known and at some level valued, while others are overlooked. Steve’s reflections are a site of conflict between these two views of bodily difference, as
alternately positive and negative. He recognizes that Superman’s positive distinction is attractive, yet at the same time he recognizes that not all bodily distinction is or can be viewed positively. It is at this early point in *Bird*, then, that we encounter the central question I mentioned earlier: Why is Superman so endurably popular given his general implausibility (part of which involves his always-positive bodily distinction from others)?

As *Bird* continues, Steve wrestles with that question by reflecting on other facets of Superman’s character and of his family history, most of which I will discuss below. First, though, I will address the final interposition in the Dubious Distinction group.

“The Alien” is the third to last interposition in *Bird*, coming at the climactic moment when Steve visits his aunt Sarah, who also has the disease. Sarah is unable to speak and lies contorted in a hospital bed. As Steve takes her hand and speaks to her, he thinks once again about the way Huntington’s “sets you apart[,] marks you as different…alien…” (107). Unlike Superman’s ability to hide his distinction—which, as we have seen, is positive anyway—behind the guise of Clark Kent, Huntington’s “is not a condition you could hide like a rash, or a tumor secreted on the inside” (107). On the contrary, when Huntington’s begins to manifest in, for example, loss of muscle control, it cannot be hidden—and in Steve’s mind, its revelation invariably brings with it a stigma for the person with the disease as well as that person’s family.67

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67 The notion of stigma is central to disability studies and originates in the work of sociologist Erving Goffman, who defined stigma as “the situation of the individual who is disqualified from full social acceptance” and theorized stigma as an experience originating outside the individual, specifically naming disabled people as a frequently stigmatized group. In 1963, when *Stigma: Notes on the Management of Spoiled Identity* was published, this proto-constructivism was an especially radical notion. Significantly, though dealing with a far more specific issue of construction, Goffman’s book predates Berger and Luckmann’s influential *The Social Construction of Knowledge*, which was published in 1966.
The watercolor interposition “The Alien” is a sort of dialect poem that indicts Superman for his separation from other “aliens.” Much like “The Outsider,” “The Alien” raises the problem of difference in the real world. Its confrontational speaker concludes,

I’d like to hit you. If you were just a little realer, a living breathing feeler with corporeal form that could connect with my left hook, you comic book crook—stole my faith in alien invasion as you complacently vacation and occasionally pop [Lex] Luthor in the jaw or let Mxyzptlk [another Superman villain] hem and haw and all so you can stay—take a page from me and get in touch with reality where folks with differences are treated egregiously, set apart from you and me, no make that just me—’cause you don’t really belong here, see? (109)

In this interposition, Superman is cast as the exceptional alien whose experience in no way relates to that of other people who come to the United States from other places.

Unlike the Man of Steel, these “aliens” are:

hopin’ to make it here, but hide in fear because what makes them different makes them targets too […] ’cause the land of the free ain’t as often brave and puts demands out to have them removed. Hunted by the I.N.S., hounded by racist duress, the unfeeling, uncaring, insensitive mess of mankind with nothing better to do, but they missed you? Kryptonian, please! (108)

Here as in the other interpositions in this group, Steve objects to the fact that Superman’s distinctions function so differently than distinctions in the real world—in this case, distinctions based on ethnicity. If Superman is an alien, and he is so by virtue of being from another planet, then why does he not encounter the struggles other “aliens” do?

If “The Alien” illustrates the forced shame ethnic “aliens” experience, the ensuing scene illustrates a shame that originates with the body. After the interposition, we see Steve’s father enter Sarah’s hospital room, not knowing he will find Steve there. When Steve confronts his father about why he kept his grandmother’s as well as his aunt’s sickness hidden, his father quickly becomes angry, physically attacking Steve when he
finds out Steve has been studying Huntington’s. As the altercation ends, Steve says, “In my father I suddenly realize what it is I’ve been fighting. I recognize his rage because it looks just like my own. I see it for what it is now…shame.” Specifically, Steve discerns that his father is ashamed that this negative distinction is an undeniable part of his family. “Most of all,” though, Steve’s father “doesn’t want to have to admit to himself that he might have doomed his own children…simply by having them” (116). Because he did not know about the disease when he had children, he unwittingly risked a fifty percent chance that each of his children would have it as well. And because he does not understand the disease or have any category for it being manageable or not shameful, he reacts with anger against any open discussion of it.

In these interpositions, Steve points out the difference between the way Superman experiences distinction and the way people in the real world do. All three take a cynical and resistant tone toward Superman, making him seem like a character to whom one might find it impossible to relate—which, we remember, was Steve’s original objection to Superman. The second group of interpositions, Double-Edged Swords, finds Steve taking a somewhat more balanced approach to Superman. These four interpositions identify and reflect on some of the more ambivalent elements of Superman’s character and story.

**Double-Edged Swords**

None of the interpositions in this group is directly summoned by Steve’s reflections on Huntington’s, but insofar as they address both the advantageous and
disadvantageous dimensions of different parts of the Superman mythology, they continue very much in the vein of critical disability studies (which seeks to discuss both the positive and negative valences of disability). Moreover, since the disease is on Steve’s mind throughout the book, it is not necessary to say that these interpositions are unrelated to Huntington’s just because he does not mention Huntington’s in direct connection with them. As I pointed out above, disability studies is committed to a thorough investigation of embodiment as always both a blessing and a curse. In these interpositions Steve considers important but also fraught parts of Superman’s identity: his incredible strength, his upbringing in a context emphasizing “family values,” his small town environment, his pursuit of justice, and his need for solitude in which to strategize about that pursuit. So while Steve’s personal and family histories of the body lead him to adopt a cynical attitude toward Superman, those same histories also demonstrate his ability to produce interesting new insights into the Superman mythology.

After trying to refuse the Superman offer, Steve leaves Jeremy’s office with a stack of Superman comics and a challenge from Jeremy to read them and then come back. Jeremy guarantees, “You won’t say no.” Steve sets himself the task of thinking more deliberately than ever about Superman’s potential points of weakness. These thoughts lead into the interposition “Invulnerable,” which centers on the question, “How could something ‘invulnerable’ also be flawed?” The paradox arises because, Steve says, “In Action Comics #1, Jerry Siegel and Joe Shuster declared their man ‘super!’ […] But did they mean that he couldn’t be harmed…or that he can’t be touched? Because the
former is extremely useful for a hero, while the latter is a fatal flaw for any man, super or otherwise” (33).

Steve reflects on other allegedly invulnerable people and structures. He explains that Achilles “became invulnerable” when his mother dipped him into the river Styx, “but while he was a leader of great armies and the hero of the Trojan Wars—it turned out he was just a heel, susceptible where he had been…dunked” (33). In this case, Achilles’ vulnerability came from the location on his body that marked the facilitator of his invulnerability: the heel by which his mother held him when she dipped him in the river. The Great Wall of China, meanwhile, seemed invulnerable to anyone standing next to it in “221 B.C.” “But the Great Wall turned out to be many separate structures with vast, indefensible gaps between them” (34). In this case vulnerability becomes visible if one has the proper perspective on the supposedly invulnerable object. Steve points out as well that Alexander the Great “died of a fever while plotting in Babylon,” and the “unsinkable Titanic […] proved no stronger than the ice floes of the North Atlantic” (34). Here vulnerability comes from unpredictable circumstances—unaccounted for, unavoidable, and ultimately overpowering. In all these cases, the principle is that nothing and no one is really, finally invulnerable. Obviously, for Steve, vulnerability has largely to do with Huntington’s.

When Steve arrives at Superman in this interposition, he says, “There is only one Clark Kent, and even he has his Achilles heel, his Titanic flaw…his invulnerability effective only in pulp paper fiction” (34). Just as there was a vulnerable point for each of the prior people and objects Steve considered, Superman’s great vulnerability is that he
literally “cannot be touched,” whereby his invulnerability proves inaccessible to real people. His invulnerability only exists in the fictional world to which he is unalterably confined. As compelling as his stories might be, and for however many people, Superman’s invulnerability is precisely what makes him both the quintessential superhero and necessarily fictional.

The fantasy of invulnerability in contrast to the reality of vulnerability is a key concept in disability studies. Tobin Siebers explains that we live with the following tension between contradictory ideas about our bodies:

The briefest look at history reveals that human beings are fragile...feeble and finite...And yet the vision of the future to which we often hold promises an existence that bears little or no resemblance to our history. The future obeys an entirely different imperative, one that commands our triumph over death and contradicts everything that history tells us about our lot in life. (7)

One of disability studies’ important insights is that in general, the emphasis in popular culture as well as science and other intellectual arenas is on progress: as we advance culturally and intellectually, we march toward a utopian ideal for ourselves, our societies, and our world. Meanwhile, we all continue to live with bodies that will not cooperate with the “imperative...that commands our triumph.” By turning its focus on bodies that do not conform to the injunction that bodies be perfect—which, scholars in the field will quickly point out, is pure fantasy and totally unattainable anyway—disability studies attends to extant, unruly bodies rather than hypothetical, “ideal” ones.

“Invulnerable” performs the same operation, but with a wider lens, pointing out the unalterably “woundable” nature of a series of larger-than-life people and structures. Steve scans history and finds the fantasy of invulnerability everywhere: the untouchable
hero, the unassailable structure, the unconquerable general, and the unsinkable ship. Yet in every case, he also finds vulnerability. In two cases, that vulnerability is located in human bodies. And while the Great Wall and the Titanic are not human bodies, the vulnerability that dooms them has to do with their limited “bodies”: the gaps in the wall and the natural bodies for which the ship’s “body” was no match. The implication of Steve’s reflections is that despite the tragedies that befell all these figures, they are ultimately far easier to relate to than Superman because their vulnerability makes them real. In other words, Superman’s invulnerability is “effective [that is, truly compelling] only in pulp paper fiction” (34).

Like many of his “invulnerable” counterparts, Superman has lofty ideas about what he can and should achieve. In particular, he has always fought for “justice.” And while fairness and equity are generally unobjectionable, they are also somewhat slippery concepts, especially when expanded to superheroic proportions. Steve reflects on this tension between high ideals like justice and the problem of defining those ideals in the interposition titled “Justice.”

At the end of a chance interaction on a New York subway, a man tells Steve that what he likes about comics is that “supa-heroes, dey know right from wrong” (75). This leads to the interposition, a hypothetical Superman plot in which a “madman” has “taken all the Earth’s lives” in his hands by creating “a hole in the heart of the world” (76). Superman has arrived in time to intervene in the apocalyptic scenario, but the question before him is, “At the end of the day[, a]t the end of the world[, w]hat is justice?” and consequently, what should Superman do with the madman (78)? By creating an extreme
situation like this, Steve is able to draw out some of the less straightforward aspects of Superman’s ostensible aims. When faced with a globally threatening madman, for example, what would constitute “justice” being served to the madman? “The superman could hurl the madman into the abyss he had opened[.] Is justice the fierce pain of flesh scalded from bone by sulfuric steam? Is justice the coarse collision of meat and bone with magma and base rock?” Alternatively, “The superman could force the madman to witness the final days of the planet he had crippled[.] Is justice the realization that one has brought doom to that which gave him life? Is justice living out the life sentence he has condemned others to serve?” (78). Finally Steve asks, “Or is justice nothing more than an ideal? Which, after a point, becomes purely [a]cademic” (78). In other words, Steve is asking whether Superman and the people who make him are qualified to answer—even if only implicitly, in the plot of a comic book—large-scale questions about what justice entails in a scenario like this one. Even if justice is desirable in principle, it is hard to determine what constitutes justice in practice, at least in certain scenarios and especially when the stakes are high.

Disability studies performs a similar operation by scrutinizing commonplaces about the body, especially those having to do with the fantasy of the ideal body I discussed in connection with the interposition “Invulnerable.” If “Invulnerable” connects to disability studies’ question of whether the ideal body is attainable, then “Justice” connects to the field’s question about how definable the ideal body is. Put differently, disability studies asks, “Just what is ideal?” when it comes to the body in the same way that “Justice” asks, “Just what is justice?” when it comes to avenging a madman bent on
world destruction. Is it possible, disability studies asks, that there is in fact no such thing as an ideal body—or at least, that there is no stable definition of what an ideal body would be?

In fact, the value and legitimacy of the concept “normal” have been more broadly discussed in disability studies than the notion of the ideal. For instance, Lennard Davis argues in *Enforcing Normalcy* that the category “normal,” not to mention the word itself, did not arise until the mid-nineteenth century, with the advent of statistics. Prior to the construction of normalcy, the basic paradigm under which people approached bodies was that there was an ideal that no individual met, and thus everyone’s body was flawed. Once normalcy was introduced, however, there were suddenly individuals who fell within “normal” range for a given trait. Those outside normal range are, by definition, deviant. The legacy of normalcy’s construction, Davis and others argue, is the contemporary world’s investment in standardizing and normalizing bodies. Yet because normalcy is a construction and not a fixed category, it can and should be questioned and unsettled. Once concepts like ideal and normal are destabilized with respect to bodies, we are free to reconsider what value we might assign to particular kinds of bodies. At least potentially, we are free to assign positive value to forms of embodiment that were formerly considered negative or disadvantageous.

For example, in Chapter 4 I discussed the positive value of blindness and an “aesthetic of blindness” as it develops in Stephen Kuusisto’s *Planet of the Blind*. In that chapter I also mentioned Simi Linton’s experience, described in *My Body Politic*, of

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68 See “Constructing Normalcy,” the second chapter in *Enforcing Normalcy*. 

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beginning to think of physical disability as “fun and sexy” rather than “woeful and sick-like” (43). In these and other disability studies-savvy texts, disabled people and their allies claim disability as a pleasurable and important way of being human. From a disability studies perspective, the practices of claiming, understanding, and discussing disability are advantageous because they provide the means for facing, enjoying, and talking about our bodies for what they are rather than what we might like them to be. The undesirable alternative is to long for a time in the future, likely after we are gone, when our bodies will comply with our wishes—which are themselves not intuitive but taught and internalized—for them never to fall or fail, break or leak. For disability studies, the way forward in dealing with our bodies is not to give up on cancer research or give in to hopelessness about our frailty. Rather, it is to explore ways to enjoy the bodies we have and be realistic about the difficulties they pose—especially insofar as those difficulties can be mitigated by changes to environments, institutions, and attitudes that affect our bodies. In this way, disability studies asks whether there might not be a different ideal than vigorous able-bodiedness for all of us to pursue.

Eventually, Steve comes to a conclusion about the Man of Steel that parallels the conclusion disability studies draws about bodies. That is to say, Steve ultimately embraces Superman not because of his perfection or his deeds, but because of the way Superman represents an important lesson about perseverance from which people can draw strength for themselves. It is not possession of a particular kind of body that allows one to function or thrive in the world. Instead, human flourishing depends on dealing with the bodies we have and learning to use them well. From a disability studies
perspective, Superman is both problematic and, at least for Steve, useful. He is problematic because he has an ideal body, yet he, like the rest of us, faces a ceaseless stream of danger and threats that must be negotiated from within his body. Steve’s narrative analogizing brings him to a place of contentment about his family at the same time that he recognizes the similar function Superman performs for people facing other circumstances in their lives.

Still, as I have already begun to indicate, there are elements of the Superman story that Steve objects to straightforwardly and unambiguously. These are the interpositions I call Outright Objections. Like those in Double-Edged Swords, the interpositions in this group are less explicitly connected to disability issues than those in Dubious Distinction or, as we will see, The Hidden Self. However, since Steve’s thinking about Superman and the body are constantly in dialogue with one another, we can suggest some connections between the two in at least one of the Outright Objections.

**Outright Objections**

“Kryptonite” in particular suggests connections to Steve’s struggles with the body. In this interposition, he objects to the idea that Superman’s only known weakness, though it does make him vulnerable, should be so obviously contrived as a device in the Superman story. Implicitly, this contrivance is objectionable at least in part because most people’s weaknesses are much more tightly interwoven with their experiences and thus closer to home. This tension between Superman’s weakness and others’ contains echoes
of disability issues that Steve faces at other points in *Bird* and that are prevalent in disability studies.

“Kryptonite” parodies advertising, billing the antidote to Superman’s superpowers like some kind of laughable diet pill or exercise product that cannot possibly deliver the results its marketers promise. Its hook is, “Feeling like there’s no way to defeat the ultimate man?! You’re right! So why not dig up a special little something that makes it super-simple?! KRYPTONITE!” (36). The interposition then points out the remarkably unlikely story of kryptonite, as told in Superman comics: “How does it work? What if—and stick with us on this one!—what if the planet Krypton sent off shards of itself when it exploded?! And what if those shards were like poison to anyone who used to live on Krypton as a baby?!” (36). Over a close-up image of Superman with an “X” in place of his one visible eye, indicating he is dead, a caption reads, “Too much you say? No way!” Adding to the incredible story of Kryptonite are the astronomic improbabilities: “Too much would be the idea of a tiny piece of rock hurtling randomly through infinite space—just happening to find its way to the exact same planet the baby in the rocket found his way to years before—and not burning up as it pierces earth’s atmosphere! That would be too much! That would be ridiculous! That would be…KRYPTONITE!!!” (37).

Finally, the parodic eye is turned toward kryptonite’s function in the Superman story as the captions ask, “Are you a villain trying to defeat the ultimate man? Are you a writer trying to unlock the corner you’ve written yourself into by creating a superman? A being so mighty that the only way to defeat him is to trump up a *deus ex machina* that can make a god un-godly?! KRYPTONITE! KRYPTONITE! Takes the ‘super’…out of the
‘man!’” (37). The idea that creating a weakness would require the plot contrivance of kryptonite sits uncomfortably next to the reality of both Steve’s world and the world in general. For Steve, as for most of us, there is no shortage of threats to health and wholeness in ourselves or in the world around us.

Near the end Bird, after the interposition “The Alien” discussed above, Steve reveals that he heard all of a conversation his parents had with his aunt and uncle at the time of his grandmother’s death. The conversation took place during the same hospital wait during which Steve first encountered Superman. As the adults in that hallway discussed the situation, Steve’s father said, “[I]f we’d known about the goddamn disease—we’d never have had David and Steve in the first place!” (112). Much earlier in the book we learned that at some point in the same conversation Steve’s father used the word “kryptonite” in connection with Huntington’s and its place in the family. When he heard his father’s comments about regretting having his sons, Steve began “reading the comic intensely so he wouldn’t know I’d heard him” (117). From this moment in his life on, Steve lived with the constant knowledge that something about his grandmother’s disease made his parents wish he and his brother had never been born. While Superman’s only known weakness is predicated on a cosmic coincidence, in Steve’s life the threat of bodily harm has loomed large from the beginning.

The assumption that the body is always vulnerable is foundational for disability studies. In fact, it has become a truism in the field to point out that anyone who lives long enough will at some point be disabled, or to make the related observation that even temporary illness or injury at some point in life forces one into an experience of
disability. Disability studies also observes that, as I pointed out early in this chapter, illness and disability almost always come as a surprise. In this way, disability is both an afterthought and a fundamental reality of human life. And because disability is not considered normative despite its pervasive presence in people’s lives, it remains both an afterthought and a fundamental reality.

As an artist, Steve objects to the artless introduction of Superman’s weakness. Yet that objection is informed by readers’ knowledge that Steve’s associations with Superman necessarily evoke the tenuousness of human life—both his grandmother’s because of Huntington’s and his own because of the contingency of his very existence based on his parents’ decision to have him, apparently against what would have been their better judgment. In Steve’s world, weakness is built into the body and the family, whereas for Superman weakness is a threat from outside the self. Ostensibly directed at the sloppiness of the Superman plot, Steve’s objection to kryptonite is in fact bound up with the nature and location of weakness in Steve’s and his family’s life.

Steve’s uncertainty about the role Huntington’s has played in the life of his family, combined with his uncertainty about whether he has the disease, produces anxiety—about whether the disease plays a larger role in his family and his life than he knew or can imagine, and also about letting other people in on his confusion and emotions about his history and, potentially, future. This latter anxiety leads him to a series of reflections on Superman’s hidden identity as a parallel to his own hidden history and possible future. These reflections on what self is the “real” self and the cost of sharing oneself with others form the group of interpositions I call Hidden Self. In these
interpositions, particularly “Hidden,” Steve finally begins to discover important and useful connections between Superman and himself. These discoveries ultimately turn him toward his conclusion, which entails his making peace both with his own past and with Superman.

**Hidden Self**

As Jeremy continues to press Steve about taking the Superman job, the manager eventually realizes that something more than Superman is on the writer’s mind. While they are working out together, Jeremy claims that Steve is “scared” to take the job for some reason and asks him what’s wrong. The next panel occupies a third of the page. Across it is the word “Huntington’s,” printed as it appears on the hospital form from the opening pages, including the red “s.” Steve is superimposed over the word in the center of the panel, and he says, “I…have a lot on my mind” (65). Though Jeremy tries to draw out Steve’s thoughts, Steve says he does not want to talk.

The two enter a steam room, and the first panel in the scene depicts them sitting next to one another. Over Steve’s midsection the word “twitch” appears, printed twice in lower-case letters. The next panel is a tightly framed illustration of Steve’s body. He holds his right hand in front of him and looks at it; underneath we read, “twitch twitch” (66). Steve has recently learned that “depression and involuntary movement” can be an early symptom of Huntington’s, and when Jeremy asks him if something is wrong with his hand, Steve initially deflects, saying he “must’ve strained it boxing” (66). He quickly deflects further, beginning to talk about how unlikely it seems that Superman, “for all
intents and purposes a *God,*” would “waste his time chasing bank robbers and helping old
ladies get cats out of trees” (66). Jeremy reminds Steve that Superman’s battles have
become much larger than fighting petty crime over the years, adding that “saving lives
isn’t a waste of time. If you had his powers wouldn’t you have rushed to the World Trade
Center to hold the buildings up? Move the wreckage? Look for survivors? Help people?
Why don’t you stop your intellectual *posturing* and really put yourself in his boots?”
(66). This imperative leads to the interposition “Hidden.”

Since readers know Steve is creating the interpositions, we can reasonably
interpret any uncharacterized narrating-“I” in an interposition as Steve himself. In
“Hidden” Steve describes two dreams, each involving him being “exposed.” In the first,
he wakes up and is, “for once, supremely confident. But as the door closes behind me, I
realize I’ve left my keys inside. I’m locked out. And worse…I’ve somehow forgotten to
dress. I am completely naked. For some reason I see no way to regain entry and feel I
have no choice but to try to make it through the day […] hoping no one will
notice…hoping to hide in plain sight” (67). In the other dream, “much the same thing
happens…the door…the keys…but this time it’s the world who is naked while I am,
thankfully, dressed. I’m relieved that I will not be the center of attention […] happy that
I’ll pass in the world unnoticed. But as it turns out…what I’m dressed in [a Superman
costume] leaves me no less exposed in this reverie than in the last” (68). Steve then says,
“I’ve come to believe the message of these dreams is this: There is nothing so terrifying
as having one’s hidden self…seen” (68).
One important feature of this interposition is that Steve both takes Jeremy’s advice about putting himself in Superman’s position and, as the ensuing scene reveals, begins to think about divulging his family secret to Jeremy. Visually, this means that though Steve is the “I,” the figure depicted in the interposition is Superman, recognizable in the first dream by the Clark Kent glasses that appear throughout the book, in the second dream by the coiffed hair of Superman, and in both by Superman’s build rather than Steve’s. By joining his thoughts to Superman’s body, Steve demonstrates that in taking Jeremy’s advice he has discovered a potential connection between himself and the Man of Steel—the first time anything of the sort has happened up to this point in Bird. Specifically, he wonders whether either Superman or Clark Kent ever feels self-conscious
about his identity, whether as himself or the hidden other. Clark Kent obviously worries about being found out as Superman, but does he ever feel insecure as Clark? And for as much as he is basically invulnerable, does Superman ever wish he could simply blend in with other vulnerable people instead of being the object of their adulation?

Apparently Steve takes some encouragement from this thought, because in the ensuing panels he begins to open up to Jeremy, saying, “[L]ook, you’re right. There is something going on. I—I’ve got some…family stuff that—[.]” Jeremy interrupts and says, “Let me guess. Lisa [Steve’s long-time girlfriend] wants to get married?” (69). The interruption stops Steve in his tracks, and a thought bubble in a panel showing only Steve reads, “This is the face I make when I’ve finally decided to come clean about something and the person I’m talking to interrupts me” (69). Jeremy responds to Steve as if the question of marriage is the one on his mind, and then he extends the deadline for Steve making a decision about writing Superman stories, giving him some time to sort out his “family stuff” (70). As he listens to Jeremy, Steve thinks to himself, “What you’re [Jeremy] trying to do to help me is only making things worse” (70). By “making things worse,” Steve does not mean that thinking about the Superman decision is difficult, but that the associations it triggers are painful, and he would prefer not to have to face them any longer. Moreover, now that he has identified a point of connection between himself and Superman that relates to the hidden self being revealed, his own story and Superman’s have begun to converge.

From the gym Steve goes to a bookstore where he runs into a friend named Marco, whom he finds out is producing a play called George’s Dance, which Marco says
is “about this weird, rare disease that runs in my family” (73). The disease, of course, is Huntington’s, and Marco gives Steve a copy of the play to read. At this point Steve’s thinking takes a noticeable turn as he admits to himself that it is not Superman but Huntington’s that has him in such inner turmoil. He reflects that he wants to read the play to learn “what someone else has been able to put down on a page about how it feels to be haunted by this disease. I really do want to, but—the fantasy that’s become my reality seems a whole lot easier at the moment,” he thinks as he puts the play in his bag and removes a Superman comic (75). Now that some connection between Superman and Steve has emerged, though, the connection between fantasy and reality will prevent Steve from using comics as a means of avoiding his past as well as from dismissing Superman outright.

Later that night Steve again decides to open up, this time with Lisa. But just like the last time, he does not ultimately share what he wants to. However, as he approaches Lisa with the intention of speaking frankly with her, Steve thinks, “I need to become superior. I need to find strength” (85). As he says this, one panel shows Steve looking as he usually does, and the second shows him in a Superman costume, with broader shoulders and coiffed hair. The next panel shows Steve in profile, still in the costume but larger now and looking even less like himself, his right hand touching the small of Lisa’s back as he says, “There’s something I want to tell you…” (85).

Though Steve does not actually tell Lisa what he intended to tell her, coming to the brink of telling her and then retreating leads into “Courage,” the first interposition that looks favorably on Superman and begins to move Steve toward his conclusion. I will
address “Courage” in the next section, but here I want to call attention to the way that Steve has begun to connect Superman with something other than sheer otherness. Seeking to share a difficult truth about himself, Steve wills himself to have courage and strength like Superman’s. This alignment with Superman stands in contrast to the interposition “Secret Identity,” also a part of the Hidden Self group. In “Secret Identity,” Steve implies that Superman’s secret identity is advantageous insofar as it is hermetically secret, never known to anyone. In “Secret Identity” Superman wears a mask in addition to his costume in order to ensure his two lives remain totally separate—so much so that when Lois Lane speaks with Clark Kent, it is as if Clark is not keeping any secret by withholding the truth about himself.

The problem with having his “real me” so hidden is that Steve is left uncertain about what else he has to offer the people around him. Eventually the part of him that comes from a particular family and has particular memories and fears will surface, and he will want to share that self with the people closest to him rather than “masking” it. By the time we arrive at “Hidden,” Steve has come to the point of desiring to share his “real” self, and he finds solidarity in Superman’s similar dilemma of identity. Both Steve and Superman are in the position of having a public self that obscures an exceptional body and a notable history. Both want to share about those bodies and histories, but the decision to do so is fraught in each case. The remaining four interpositions are those from which Steve draws favorable conclusions about the Superman story, empowering him to work through his past, reconcile with his family and with Lisa, and eventually make his decision about writing new Superman stories.
A New View

Throughout the book, Steve holds his family history and the unfolding of his own life up against the Superman story. Initially he finds Superman useful only as a foil to the way “real” life works. However, as the progression continues, Steve eventually finds that he, like many others over the decades, can use Superman’s story in order to help himself move forward. At the beginning of the chapter I called this operation “narrative analogizing” and connected it to Jerome Bruner’s ideas in “The Narrative Construction of Reality.” As I turn toward the interpositions in which Steve views Superman favorably and uses him as a source of inspiration and empowerment, I want to say more about Bruner’s account of the role of narrative in the development of the self.

Bruner argues that humans have an “‘innate’ and primitive disposition to narrative organization” to which our cultures add “new powers of narration through [their] tool kit[s] and through the traditions of telling and interpreting [narrative] in which we soon come to participate” (80). In a situation like Steve’s, one telling tradition into which he was introduced at a young age was the tradition of the Superman story, which he in turn uses in order to structure his understanding of himself and his history. At the beginning of Bird, Superman acts as an antagonistic shaping influence, and later as a helpful one. In the other groups of interpositions—especially Dubious Distinction—I focused on the relationship between the Superman story and disability, showing how Steve was unconsciously mobilizing a disability studies framework to critique the Superman story. In this final group I want to focus especially on the way narrative analogizing helps Steve
incorporate Huntington’s into his understanding of his life by drawing on the structure of
the Superman story.

In Acts of Meaning, Bruner argues that human beings construct themselves by
means of stories meant to help them negotiate their backgrounds, circumstances, and
goals. The self, Bruner argues, is constructed culturally as individuals and groups gather
and synthesize stories about themselves and important others. Ultimately, while there is
plenty of raw material from which to construct stories about ourselves, that material is
less important than what we do with it. Bruner quotes Roy Schafer, who says that in
using stories to make sense of the world, our aim is to “see how we can retell [our lives
and others’] in a way that allows [us] to understand the origins, meanings, and
significance of [our] present difficulties and to do so in a way that makes change
conceivable and attainable” (qtd. in Bruner 113). The interpositions that I have grouped
under the heading A New View constitute Steve’s arrival at this way of understanding his
own difficulties and possibilities for change via his engagement with the Superman myth.

As he tries unsuccessfully to summon the courage to tell Lisa about his family and
his fears, Steve reflects on Superman’s courage in the interposition “Courage.” As in
“The Costume,” Steve creates a character unlike Superman in order to illustrate
something about Superman. This time, the character is Nelson Corby, who has been
trying to “finally muster the nerve to ask [his assistant Nora] on a date after months of

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69 Along similar lines, in Story Logic: Problems and Possibilities (2004), David Herman argues that
narrative theory should be part of cognitive science, insofar as narratives function as “strateg[ies] for
creating mental representations of the world” (5). However, the centrality of narrative to consciousness and
identity formation is by no means a given in philosophy or psychology. For example, philosopher Galen
Strawson argues vigorously (particularly in “Against Narrativity”) that narrative is not an indispensable
part of understanding consciousness or selfhood.
practicing the proposition” in his apartment. However, a late meeting served as an excuse, and he did not ask. On his way home, Nelson sees that a girl has fallen in the street and is about to be struck by a bus. Nelson has “the chance […] to make a difference in someone else’s life. And all it requires is courage […] Someone must be willing to risk his own life to earn a chance at saving hers. Who will that be?” (86). The next panel shows a red and white streak arcing down in front of the bus and then up away from it. The girl is gone. The final panel of the interposition shows Superman ascending with the girl in his arms. Nelson stands below, looking down. The text reads, “Not you, Nelson. You’ve long suspected, but learned today—conclusively—that most hearts hold so much courage…but only so much, and then no more” (86). Nelson had finally summoned the courage to ask Nora on a date, but did not have any courage left to rush in front of the bus to save the girl. That was a job for Superman.

The lesson of “Courage” is, rather straightforwardly, that Superman has more courage than the average person, who only has “so much.” At this moment in his life, needing to tell Lisa his deepest secrets and let her into his private thoughts, Steve longs for Superman’s limitless courage, but does not have it. Instead, swinging to the opposite extreme, he tells Lisa he is going to leave their home in order to be better able to “think,” which, he quickly clarifies, means “work” (87). Lisa is understandably hurt, and she decides to leave before Steve does, telling him, “Get your work done, then you can call me…when you’re ready to be in a relationship with someone other than yourself. Maybe I’ll still be interested…maybe I won’t” (88). “Courage” does not take any jabs at Superman, but Steve also does not take any particular encouragement from his thoughts
in the interposition. Instead, dejected, he falls into a days- or weeks-long depression. Still, Steve’s recognition of Superman’s courage as an admirable asset marks a shift in his thinking.

Eventually Steve’s brother arrives at Steve’s apartment, and the two go to find their father, who left his home without word about where he was going. They find him at the facility where their aunt Sarah is staying. This is where the confrontation I described earlier between Steve and his father takes place. Before they leave Steve’s apartment, though, Steve reflects on his decision not to tell his brother about their father’s disappearance and on his brother’s willingness to seek Steve out after no one had heard from him for several days. This leads to the interposition, “Alternate Reality,” which deals with the question of what it really means to be “super.”

“Alternate Reality” opens with the observation that certain events and circumstances we witness in our lives invite the question, “Are you adding to the world or taking away from it?” Contrary to the unconscious assumption that “making it from morning to night is really all you can manage,” this interposition cites some of the important issues facing the global community and then makes the frank observation that “it is not people from another planet who are supermen” (99-100). Indeed, there are no such super-persons. Instead, the “super” person is “any individual able to see past their [sic] own little world…and reach out to the alternate ones beyond their limited scope of existence” (100). Importantly, though, the realization that to be super is to move toward others and come to their aid is not an indictment of Superman. Rather, Superman stands in this interposition as an example of a person who steps into another world and chooses
to “add to” it. At the end of the interposition, several people are depicted helping others, and all of them don either a full Superman costume or bear the iconic “S” somewhere on their bodies. Thus, at this point in the book Superman has become a symbol for the possibility and importance of stepping outside oneself to help others.

Image 6. Pages 99-100 of *It’s a Bird...* (Steven T. Seagle and Teddy Kristiansen; DC Comics)

Granted, *Bird* takes a sharp turn toward cliché with this interposition, and it will continue in that direction until its conclusion. With respect to disability, however, “Alternate Reality” marks an important shift toward understanding that vulnerability and need are normative, but also that vulnerability need not equal weakness. Distinguishing between the two removes the stigma people like Steve’s father experience when they think about the presence and threat of illness in their lives and bodies. Having begun to
separate sickness and shame in his own mind, Steve heads to the hospital where he will see his aunt Sarah, recognize himself in his father, and release his father from that shame by normalizing the frailty of the human body, his own included.

In an earlier exchange with a man on the subway about the current state of comics, Steve’s interlocutor asks, “So why you still reading ‘em?” Steve replies, “I keep hoping.” The man clarifies, asking, “For what?” As he leaves the subway car Steve says, “An answer to that question” (79). Steve’s two comments reveal a tension in his attitude toward comics: one the one hand, comics provide a sense of hope, while on the other, Steve is not sure what that hope is in or for. By the time he has confronted Huntington’s as well as his father’s shame, Steve has discovered some resolution to that tension. That resolution is the subject of the interposition “Escape.”

“Escape” occupies two pages and consists of only four panels. The first three depict Superman in near-silhouette—first, his chest, with the “S” emblem; next, his face in profile; and the third like the second, but closer up. In the fourth, a group of birds, again in silhouette, flies in the lower left corner, while an indistinct brown-gray blur—perhaps a cloud of smoke, perhaps an even closer-up image of Superman’s face—dominates the rest of the panel. The captions in the first two panels muse on Superman’s death and burial “in about 6 million household plots.”70 The third panel poses a potential objection to the resurrection: “Some felt there was no truth or justice to a story where a man could come back from the dead. There’d only been one other bestseller in history to

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70 In the early 1990s Superman died, later to be resurrected during a period of rapid and complicated change in the Superman universe. The details of those changes are not important for my purposes here, only the fact that Superman died and then reemerged.
use that plot successfully” (115). This is the type of objection Steve would have supported wholeheartedly earlier in *Bird*. At this point, however, forced to face his family’s and his own vulnerabilities, he defends the Superman story, connecting it to an important broader function of comics in general. The caption in the fourth panel reads, “But the willful use of the impossible is exactly what comic book stories are for…to remind us that when the real world is too much to take, there’s always a place we can go…where man, or Superman, can escape anything set against him” (115).

Confronting illness and death and recognizing his father’s sense of helplessness about them, Steve employs the first person pronoun “we” in connection with Superman for the first time as he identifies the power of comics in general and of Superman in particular. Following “Escape” is the passage about Steve’s father’s inability to talk about Huntington’s, discussed above in my section on "Dubious Distinction." While a different way of thinking about bodies would also authorize him to process and come to terms with the disease and its influence on his family, in this case Steve’s thinking about the power of the Superman story moves him to embrace his father and say, “Dad? You didn’t do anything wrong by having Dave and me” (120). Before that, however, comes the final interposition, “Hero,” which further emphasizes the usefulness of the Superman story, *including* some of the very implausibility Steve so stridently opposed earlier in *Bird*.

As he recognizes his father’s turmoil, Steve recounts that after he heard his father say he would not have wanted children if he had known about his mother’s Huntington’s, he “started reading the [Superman] comic intensely so [his father] wouldn’t know [Steve had] heard him” (117). “Hero” is his recollection of the substance of the comic. In brief, a
villain called The Hunter releases evil beasts in public. Superman engages in a lengthy battle with the beasts in Metropolis. Steve notes that as a boy he “didn’t question the plot holes”—for example, why Superman pursues the beasts instead of the villain who controls them, and why he does not simply do away with The Hunter when he first encounters him. Instead, Steve says, “I let the story take me into it…as the pages rolled by, I bought into the crisis…believed in the danger…and at the end, though I never would have admitted it…I was emotionally invested” (119). More than just being emotionally involved, though, Steve was learning an important lesson about stories as he eagerly sought what would happen next in the book: “There’s always a ‘next.’ Always. That’s what Superman is all about. To remind us that we have hurdles…but as long as we keep jumping them…we’re in the race” (119).
In “Alternate Reality” and “Hero” there are visual cues indicating that Superman’s value has increased in Steve’s mind. In the former, numerous individuals display the “S” insignia that held only an ominous, negative value at the beginning of the book, and all of those individuals are depicted as potential heroes. In the latter, Steve returns to the initial hospital scene from his childhood, this time citing the event as where he first encountered the idea that people can continue facing whatever hurdles they might encounter. Though Steve never goes so far as to think of Huntington’s as positive, he does extract positive value from the Superman story in a way he explicitly refused to do in Bird’s early pages—a fact powerfully attested by the book’s visual field.

As I mentioned above, earlier in the progression Steve would certainly have objected to the plot holes in this Superman story. Here, though, he takes the lesson to heart and tells his father, “Something gets all of us. In the end, something gets us all. Maybe it’s cancer, or a bus, or a bullet, or maybe it’s some crappy, indiscriminate disease…but I’d rather have known my family and fallen in love with Lisa, and written my stories, and then come down with Huntington’s, if that turns out to be my fate…than not to have lived, and missed all that” (120). In the next panel Steve, Dave, and their father embrace in silence.

As with “Alternate Reality,” we have entered the realm of sentimentality to a degree here. What is important, though, is the way that Steve’s personal narrative and the Superman narrative have converged to bring Bird to its concluding resolution of tensions and instabilities. Like so many other people, Steve needs Superman in order to stay “in the race,” and the Superman story needs to be informed by the reality of the human
condition in order to remain relevant and vital as a cultural product. Over the course of
the narrative progression, Steve has realized that he must process the experiences of his
youth, if only because he is now aware that he may have the disease that killed his
grandmother. But since his family does not openly discuss Huntington’s—his “parents
never spoke much about” it, and when he asks his mother she protests, “Stop making me
think about that!”—Steve has no context in which he can openly discuss it. Moreover,
when Steve does want to reach out to someone in conversation, he finds he lacks the
language in which to do so. After his thwarted attempt to open up to Jeremy he remarks,
“Language was failing me” (70). And as he tries to build up the courage to open up to
Lisa, he says he needs “the right words. But I’m without words…at odds with
words…angry with words…every word” (85). And this is where Superman comes in: to
provide a narrative framework on which Steve can map his complex past, his troubled
present, and his uncertain future. Just as Superman always faces the villain, Steve can
face the uncertainty and pain illness has caused in his family, come what may.

In the end, Steve does tell Lisa about Huntington’s in his family: in the
penultimate scene Steve and Lisa attend the premiere of Marco’s play George’s Dance.
After the show, Steve and Marco talk about using stories to come to terms with one’s life.
Marco says he is by no means unfazed by Huntington’s, but “ignoring something doesn’t
make it less real […] something isn’t fiction just because you choose not to acknowledge
it.” To which Steve replies, “That’s…true. That’s totally true. I hope I find a way to use it
in my work half as well as you did” (122). Lisa is present for this dialogue, and the
scene’s final panel shows the couple walking away from Marco, each with an arm around the other.

As I mentioned above, *Bird* becomes somewhat cliché in its final pages, centering as it does on the unhelpfully general claim, “[W]e all have hurdles…but as long as we keep jumping them…we’re in the race” (119). The happy ending—the final sequence takes place in a sunny room where Steve mentions the idea of having children, and on the final page Steve tells two boys an object in the sky is Superman—certainly increases the extent to which this otherwise dark book takes a saccharine turn in its final panels. However, for as tidy as its ending might be, both visually and verbally, *Bird* does not finally reinscribe able-bodiedness as a state to be sought at all costs. The very fact that Steve is considering having children demonstrates this resistance to normative ideals about the body, since he knows that the nature of Huntington’s is such that his children could acquire the disease even if he does not manifest it. I do not object to *Bird’s* ending, but I do want to raise one important objection to the book as a way of turning toward my conclusion.

**Conclusion: The Stories We Tell Ourselves**

Since I am interested in the relationship between contemporary disability narratives and the culture in which they are produced and consumed, I should mention that *Bird* is notable for its near-total neglect of disability as a social issue—at least in contrast to books like *Motherless Brooklyn* (Chapter 2) and especially *Planet of the Blind* (Chapter 4). At a few points Seagle does approach disability sociologically (e.g., when
Steve mentions that it is not a “glamorous” illness, or in “The Outsider,” where the discussion of social “Others” includes mention of a wheelchair user alongside particular ethnic and sexual identities). But for the most part, disability is a private issue for Steve and his family, and apart from his sarcastic description of Huntington’s as relatively unknown because “no celebrities have died from it,” Steve never addresses the way this disease and other disabilities are framed in the culture at large (24). A more disability studies-savvy book might have taken up issues like independent living, the health care system, or the phenomenology of illness and pain.

However, this objection is hardly fair, since I have been arguing throughout the chapter that Steve only unconsciously adopts a disability studies framework as he thinks about Huntington’s. Moreover, Steve does consider the way Lisa might react to his disclosure about the disease. This reticence is similar to that of his family members, who do not even discuss the disease with one another. In the former case, with Lisa, one could reason that Steve is fearful of losing the relationship, knowing that Lisa wants children and that for him to have children would entail a fifty percent risk that those children would have Huntington’s. Focusing on such fear would not really be a treatment of the social dimensions of Huntington’s. However, Steve’s family members’ unwillingness to talk about Huntington’s suggests that they think of the disease as shameful, as well as revealing their likely sense of confusion and fear about their own relationship to their loved ones given the possibility that they also have the disease. So, while on the whole, *Bird* does not seem overly concerned with the social aspects of disability, the book does
imply some of the cultural attitudes that underlie people’s reservations about discussing disability.

Instead of faulting *Bird* for not doing something it is not trying to do, though, I want to conclude by considering the rhetorical effects of its ambiguity with respect to the experiences of its flesh and blood author Steven Seagle, who really did (and does) have to come to terms with the reality of his family and his body.

Seagle has been careful to steer clear enough of saying *Bird* is straightforwardly autobiographical to keep readers from thinking of the book in those terms. As previously mentioned in a footnote, Seagle commented in an interview on NPR’s *Fresh Air* that all the events in the book’s diegesis are autobiographical, but they do not appear in the order in which they actually occurred. Seagle is similarly careful in the book’s author biography, which says he “acknowledges some similarities between himself and the character ‘Steve’ in this book, but only some.” By leaving the referential status of Steve’s thoughts and emotions ambiguous even as he confirms the referential status of the events of the plot, Seagle creates a specific rhetorical space for his authorial audience—one in which we are free to use Steve’s story as a vehicle for reflecting on our own body stories, but in which we must also recall the reality of Steve’s and his family’s stories.

In this space between fiction and nonfiction, readers occupy a position somewhat like Steve’s, but with an additional dimension. Each of us has our own body stories, and each of us comes into contact with cultural artifacts like literary narratives. In fact, many of us have probably encountered Superman in some way, even if only indirectly. Having accompanied Steve through the process of narrative analogizing, we are better positioned...
to be critical readers of more or less pervasive narratives in the culture—readers who also mine those stories for useful lessons we can use as we negotiate our worlds.

Phelan argues that the development of a narrative “involves the interaction of two kinds of change: that experienced by the characters and that experienced by the audience in its developing responses to the characters’ changes” (Experiencing Fiction 7). Narratives are engaging in proportion with the kind and degree of changes characters experience and responses those changes elicit in audiences. In Bird, Steve begins as a curmudgeonly comics writer with a long-nursed personal grudge against Superman. After discovering that he might have the same disease that killed his grandmother around the time he first encountered Superman and that causes so much shame and secrecy in his family, Steve begins to take a new perspective on Superman. His new perspective allows him to understand in a new way the value many people find in the Superman story, especially the lesson that facing one’s problems and helping others move through theirs is possible and worthwhile. Readers leave Bird appreciating Steve’s development over the course of the progression, knowing that Steve is newly equipped to process his emotions and build close relationships with the people in his life. Moreover, Superman has changed for readers, who have now spent time considering some of the potential limitations of the Man of Steel’s character and story, even as he is ultimately vindicated. In short, both Steve and Superman are more well rounded and likeable at the end of Bird than they were at the beginning.

In Bird, these changes and the responses they engender depend, as I have been saying, on two vehicles: a critical disability studies framework and narrative analogizing.
Steve mobilizes key disability studies insights like the unavoidable vulnerability of the human body and the importance of facing and acknowledging our bodies in all their gritty reality. His questioning of the Superman mythology depends on his own and his family’s experiences, and this is one side of the narrative analogizing at work throughout *Bird*. The other side is the way Superman’s resilience and other favorable characteristics provide a framework for Steve to speak about Huntington’s, its influence on his family, and the possibility that he has the disease. Readers of *Bird* finish the book with a template for our own narrative analogizing vis-à-vis our cultural stories and our bodies.

*Bird*’s ambiguous generic status—somewhere between fiction and non-fiction—solidifies its usefulness for readers’ own narrative analogizing. Because it is nonfiction, it is a real-world example of someone using stories to process his experiences and make sense of his world. Because it is fiction, readers have more license to draw on it for their own benefit. Moreover, resisting the book’s categorization as a work of nonfiction also decreases its investment in faithfully representing Steve’s real-world experiences (what Phelan would call its mimetic function). Instead, the thematic aspects of Steve’s story take precedence: How does one go about using a fictional story as a rhetorical, cognitive, and emotional resource? What types of issues does the Superman story allow Steve to consider? Taking themes from a fictional story for one’s own purposes is precisely what Steve does in his dealings with Superman; and thus *Bird* provides a template for readers to perform similar operations by using the thematic elements of Steve’s story (and Superman’s) for our own purposes.
Of the texts I have discussed in this project, *Bird* is the clearest example of the mutually beneficial exchange between disability studies and narrative theory, precisely because that exchange plays out in a single narrative text and because its lessons are easily transferable to real world experience. As this book demonstrates both on its own terms and, potentially, in readers’ lives beyond their reading, well-crafted narratives remain one of our most important rhetorical, cognitive, and communicative resources for understanding issues of embodiment in general, and illness and disability in particular.
Conclusion: The Role of Stories in the Future of Disability

In the preceding readings of contemporary disability narratives, I have argued that the texts in question represent disability as a generative and often pleasurable part of human identity. With only one exception, I have claimed that all of the texts I explore offer an at least partially progressive account of disability, and that locating that account does not depend primarily on a priori interpretive commitments. Rather, attention to these texts’ narrative progressions—the unfolding and resolution (or lack of resolution) of tensions and instabilities from beginning to end, including the judgments audiences make about that unfolding and (lack of) resolution—and their rhetorical properties as communicative acts reveals a posteriori that their implied authors hold attitudes toward disability that significantly reflect some of the attitudinal changes sought by the Americans with Disabilities Act and the broader disability rights movement. For example, Stephen Kuusisto’s movement toward consonance in claiming blindness as part of his identity as narrator and character in Planet of the Blind reveals an unfolding understanding of blindness as “a rich way of living, rich as an oak tree or strong grapes” (59). And in Curious Incident, Christopher Boone’s thoughts and actions suggests a vision of autism that goes beyond the kind of limiting characterization I called
“symptomatic”—a richer perspective on autism that surfaces when one attends to distinctions among audience positions and a careful reconstruction of the implied author.

By way of conclusion, I want to trouble this claim about the positive effects of contemporary representations of disability. The goal of this troubling move is to gesture toward the wider culture in which these narratives were produced and in which they continue to circulate. Specifically, I will highlight the ambivalent position toward disability the texts as a group take, and then consider them in light of disability’s ambivalent status in the contemporary world. My goal, as the title of this conclusion suggests, is to comment on the role of stories in the future of disability’s status in the contemporary United States.

**Contemporary narrative, contemporary disability**

I want it to be very clear that I am not suggesting—and I do not think anyone in disability studies would want to suggest—that a certain kind of narrative or style is the best means to engage contemporary disability issues. While a given approach to or attitude toward disability might lead to certain formal choices or generate a new kind of aesthetic, there is no necessary connection between form and ethics or ideology. This is not to say that there is no relationship between form and ethics/ideology, or that certain formal devices cannot be or are not used to make certain kinds of ideological claims. Rather, it is to say that there is no sense in which a particular formal device or narrative
structure is inextricably tied to a certain kind of ideological or ethical position.\textsuperscript{71} Distinguishing aesthetic preferences from value judgments is also crucial to this study. To use Phelan’s terms, I do not believe there is a correct “ethics of the telling” for disability narrative.\textsuperscript{72} A given audience member might come to any number of conclusions about how much he likes any of the primary texts I discuss on the grounds of his aesthetic preferences. That judgment of preference will depend on many contributing factors, and it is in the end a basically inviolable judgment. However, it is easy to imagine that an audience member might reach an unfavorable aesthetic judgment about a text even as he acknowledges that it affirms an ethical value he also affirms.

For example, students in my literature classes have made unfavorable aesthetic judgments about \textit{Motherless Brooklyn} because of the lack of salient plot events in the middle portion of the novel compared to its beginning. At the same time, they are able to identify just as clearly as students who make favorable aesthetic judgments that Lionel’s story of Tourette’s constitutes a portrayal of the syndrome as a livable and sometimes pleasurable way of being. My sense is that these students’ aesthetic preferences have been conditioned by their reading, viewing, and playing habits over time and in a particular socio-cultural environment. Those habits differ enough that some students enjoy the character-driven nature of \textit{Motherless Brooklyn} while others imagine a preferable version that relies more on events for its development. Yet regardless of their

\textsuperscript{71} For examples of relationships between narrative form and ideology, see Brian Richardson, “I et cetera: On the Poetics and Ideology of Multipersoned Narratives.” For a helpful treatment of the relationship between formal and contextual narrative theory, see Dan Shen, “Why Contextual and Formal Narratologies Need Each Other.”

\textsuperscript{72} For more on the question of a “poetics of disability,” see the conclusion of Chapter 2, pp. 76-79. For an example of disability aesthetics suggested by disability narratives, see pp. 55-56.
judgments of taste, these students, like most audiences, are capable interpreters of the ethical status of disability in *Motherless* and other texts I explore in this project.

These variable judgments of preference alongside the consistent assessments of ethical values demonstrate that contemporary disability narratives appear in a range of styles that will appeal to an array of aesthetic tastes, yet many of them place disability similarly and reflect the status of disability in the contemporary United States that I posited in the Introduction. In other words, contemporary disability narratives engage a range of tastes even as they convey similar, identifiable messages about disability. Thus, an understanding of disability as an identity is expressible in various forms and available to audiences with widely varying tastes. Patrick Colm Hogan has persuasively demonstrated there are universal prototype narratives, yet we know that those narratives are expressed in nearly innumerable idiosyncratic ways depending on who does the representing, for whom, on what occasion, and for what purpose. There may be narrative universals, but those universals do not have determinate meanings or functions in their various contexts.

In this project I hope to have provided a template for reading disability narrative that allows both for a shared experience of narrative among readers and for differing judgments among those same readers. However, I do not mean to suggest that the disability rights movement has achieved its goals, and thus that these narratives’ value is now purely (or even primarily) aesthetic. While disability’s status in contemporary culture has changed, disabled people have by no means attained the kind of access and

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autonomy the pioneers of the ADA seem to have had in mind. Those who produce narratives, legal documents, and other discourse seeking those rights are still working to draw American culture at large into, as it were, the “authorial audience” of disability rights discourse. This is a slow process that involves bridging contexts between those who by experience or education agree with disability rights agenda and those who, up to the time of encountering a given text, do not. Moreover, both disabled and nondisabled people still wrestle at times with our own complicated relationships with our own and others’ bodies. We may find ourselves fluctuating in various ways between thinking of disability as, for example, dwelling primarily in the body versus dwelling primarily in our built, institutional, and attitudinal environments. This intermediate position between limiting and liberating understandings of disability is reflected in my primary texts, not to mention many others I did not discuss in this project. For this reason, the continuing production and careful reading of these and other disability narratives—individually and as a corpus—is an important part of the developing stories of both disability studies and the disability rights movement.

For example, both *Motherless Brooklyn* and *Curious Incident* feature disabled narrator-protagonists who cast themselves as detectives. Lionel self-identifies as a disabled detective, while Christopher identifies himself as a detective but not as disabled; instead, the implied Haddon cues the authorial audience in to Christopher’s autism in the ways I described in Chapter 3. In both *Motherless* and *Incident*, the detectives succeed in cracking the cases they set out to solve: Lionel finds Frank Minna’s killer and ensures
justice will be done, and Christopher discovers who killed Wellington and reunites with his mother.

Additionally, both novels suggest connections between mystery and disability. Both Lionel and Christopher are mysterious to other people, frequently questioned about why they do what they do and say what they say. As I argued in Chapter 3, reading in Haddon’s authorial audience requires that we identify Christopher as autistic and track his “symptoms” without Christopher’s involvement in that identification and tracking. And in *Motherless*, much of Lionel’s work on the case of Frank Minna’s murder has to do with his own puzzling over what kind of Tourettic person he will be in the absence of his mentor. But whereas readers make judgments about Christopher unbeknownst to him, readers *accompany* Lionel as he develops an independent Tourettic identity. Part of this difference might be attributable to age. After all, Christopher is only fifteen, and Lionel is twenty-eight. Yet as I pointed out, the implied Haddon is of two minds about autism, and one of those minds seems to believe that, because of his symptoms, Christopher would not be capable of mature self-awareness regardless of his age. Thus, while both Lionel and Christopher are to some extent “puzzles,” only Lionel is allowed to define his own identity, which throughout the novel very much involves disability.

The difference between Lionel’s participation in his self-definition and Christopher’s subordinated account of himself reflects the tension surrounding disability in the contemporary world. In principle, disabled people have the right to direct their own lives and define themselves. But in practice, the legal statutes meant to protect those rights are often under-enforced, and the momentum of the disability rights and
independent living movements are often stifled by the misperceptions and consequent actions of nondisabled people.

I want to move now to discuss a real-world example of a set of operative assumptions about bodies that stifles the possibility of disabled people publicly and proudly claiming disability. This example mirrors the tension between *Motherless Brooklyn* and *Curious Incident* in that the conflict in question hinges on who has the right to make bodies matter—specifically, who determines what bodies mean in public settings, in private settings, and in public discourse.

The foundational goal of the Rolling Quads was to make independent living normative for disabled people, as opposed to institutional care or forced dependence on family and friends. It was this vision of independent living that spawned the broader disability rights movement. More than forty years after Roberts arrived at Berkeley, the independent living movement still faces significant barriers. The as-yet unpassed Community Choice Act, last introduced in the Senate’s 2009-2010 session, aims to restructure the distribution of federal money allotted for long-term care for disabled people. The Findings in the Act’s introduction point out, “[A]bout 60 percent of Medicaid long-term care dollars are still spent on institutional services, with about 40 percent going to home and community-based services. In 2007 only 11 States spent 50 percent or more of their Medicaid long-term care funds on home and community-based care.” The Act also notes that in 2007, 69 percent of Medicaid long-term care spending for older people and adults with physical disabilities paid for institutional services. Only 6 states spent 50 percent or more of their Medicaid long-term dollars on home and community-based
services…while ½ of the States spent less than 25 percent. This disparity continues even though, on average, it is estimated that Medicaid dollars can support nearly 3 older people and adults with physical disabilities in home and community-based services for every person in a nursing home.

Why would the federal government act against economic logic in order to fund institutional care rather than community-based services? Among the possible reasons is that many people still view disability as unseemly, unfortunate, and undesirable. Consequently, those people are motivated, consciously or not, to enforce institutional and observable distinctions between disabled people and nondisabled people even in the face of disabled people vigorously claiming their rights.

On April 21, 2011, the Akron Beacon Journal reported on controversy surrounding a house in an upscale neighborhood in Copley, Ohio, an Akron suburb. The house’s new owners have plans to convert it into a residence for six elderly people who require twenty-four hour care. The residents of the house would have a caretaker regulating medication, but no other medical services would be provided there. Neighbors are protesting the plan on the basis of the potential decline in property value, even though the exterior of the home would not change, and again, the only medical services offered in the home would be the dispensing of medicine.

The argument against the plan for the house is not solely economic. An orthopedic surgeon who lives in the neighborhood explained an additional objection: “I feel sorry for the homeowners who have houses next to this place if they have small kids, when people are coming and going and ambulances are occasionally taking people to the hospital.” This is a succinct statement of a still-prevalent attitude toward disability: the
body that requires medical support, or that draws attention to itself through its way of being or of doing certain things, is objectionable. Such a body lowers the value of real estate and frightens children.

Obviously there are plenty of issues to consider in this particular story about the legality and ethics of the decision to convert a private residence in residential area into an assisted living facility. But for two reasons, the situation serves as a useful example of disability’s contested status in contemporary culture: First, a mother who bought the house to live in with her six children would certainly not meet the same objection, since that arrangement would preserve a particular cultural vision of domesticity. The second important consideration is the fact that a supported living arrangement carries with it institutional associations such that neighbors think of it as a categorically different type of living arrangement than a “typical” home. The neighbors’ strong reaction points out the incomprehensibility to the cultural majority of a living arrangement that disabled people think of as desirable and much more “natural” than an actual institution.

What role might stories play in the ongoing transition from stigmatizing to integrating disability in contemporary culture? Could the production or consumption of narratives in any way mitigate the tension in this wealthy Ohio neighborhood?

**Narrative analogizing revisited**

The potential residents of the house in Copley stand in approximately the same relation to the protesting neighbors that Christopher stands in relation the authorial audience in *Curious Incident*. According to the neighbors, even before any actual elderly
people move into the neighborhood, these hypothetical people’s unruly bodies foreclose any stories they might tell about themselves or their bodies. The symptoms of their bodies’ status as elderly and declining in functionality define them in the same way that the symptoms of Christopher’s autism define him for the (conflicted) authorial audience. However, just as Christopher’s actions and discourse reveal ways in which he exceeds symptomatic autism, the story of a resident of the house could well lead to revised judgments about the meaning and value of elderly bodies. Such an opportunity for self-definition would also resemble Lionel’s or Kuusisto’s in articulating their own sense of themselves even as others still had the opportunity to respond according to their own perspectives. And a story that described ways of coping even with an uncooperative body alongside supportive others could lead to an experience, like Steve’s with his family and with Superman, of enlarging one’s concept of what constitutes a life worth living.

Disabled people’s right to independence entails the importance of their stories, and further that many of those stories will be, as Lennard Davis suggests they ought to be, stories of interdependence. Both fictional and nonfiction stories about disability do important cultural work in representing the varied experiences and desires of disabled people, educating their audiences and making them more alive to disabled people’s perspectives and priorities in a world that often proves hostile to both. And encouraging careful attention to such stories does important cultural work in putting all of us who encounter them in the position to incorporate others’ narrative sense making into our own, blending their stories with ours in order to generate new cultural stories in which bodies matter in new ways.
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