

Disability in Spanish- speaking and U.S. Chicano Contexts

Disability in Spanish-speaking and U.S. Chicano Contexts:

Critical and Artistic Perspectives

Edited by

Dawn Slack and Karen L. Rauch

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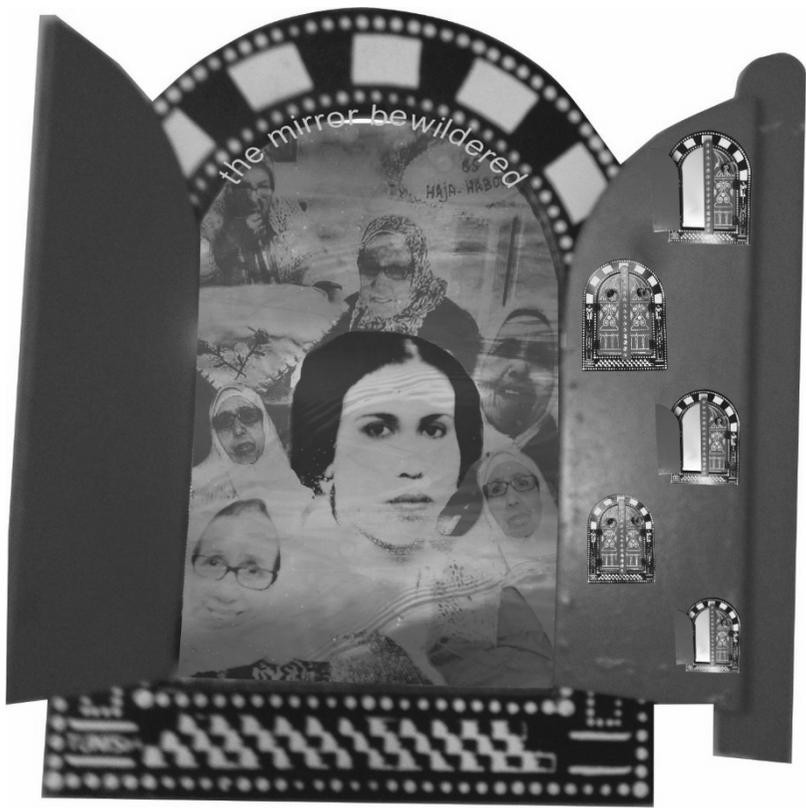
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TABLE OF CONTENTS

Habiba 2 Khédija Gadhoun	
in a sense	1
Khédija Gadhoun	
Introduction	3
Dawn Slack and Karen L. Rauch	
Chapter One.....	12
Plotting Trauma: Reading, Writing, and Resisting Blindness in Two Works by Lina Meruane Beth E. Jörgensen	
Chapter Two	28
The Redefinition of the Disabled Chicana in Ana Castillo’s <i>Peel My Love Like an Onion</i> María Esther Quintana Millamoto	
Natalia 2 Khédija Gadhoun	
oxymora as a pledge	45
Khédija Gadhoun	
Chapter Three	46
Alternative Ways of Being in <i>La mujer loca</i> by Juan José Millás: How Language Seeks to Normalize “Living at the Limits” Jennifer Brady	
Chapter Four.....	68
Identity, Community, and Communication: Three Perspectives on Disability Dawn Slack	

Bilel 1 Khédija Gadhoun	
footprints uncoiled.....	91
Khédija Gadhoun	
Chapter Five	92
Alternative Body Owners and Their Machines: The Acquisition of Dominant Subjectivities by Sick/Disabled Individuals in Mario Bellatin's <i>Perros héroes</i> Jennifer Thorndike	
Chapter Six	110
Body-Shaming in the Seventeenth Century: The Accidental Making of a Playwright Gloria Jeanne Bodtorf Clark	
Bilel 2 Khédija Gadhoun	
yet Bilel	143
Khédija Gadhoun	
Chapter Seven.....	145
Disability, Intertextuality, and Xenophobic <i>Mestizaje</i> in the Literary Construction of the Modern Barbarian in <i>El jorobado</i> and <i>Astucia de una negra</i> by Eduardo Gutiérrez Carlos Rodríguez McGill	
Chapter Eight.....	169
Narrative Prosthesis in the Short Stories of Marcio Veloz Maggiolo Karen L. Rauch	
Chapter Nine.....	183
Representing (Dis)ability and Inability in Contemporary Spanish Cinema: <i>Yo, también</i> (2009) and <i>El truco del manco</i> (2008) Meredith L. Jeffers	

Habiba 1 Khédija Gadhoun	
one thousand and one	213
Khédija Gadhoun	
By Way of Conclusion	215
Dawn Slack and Karen L. Rauch	
Natalia 1 Khédija Gadhoun	
bodies in exile.....	219
Khédija Gadhoun	
Contributors' Biographies	221



IN A SENSE¹

*Menue, fragile, gardienne des traditions,
elle est saisie dans des gestes ancestraux.*

Driss Chraïbi

the young girl's first love was a sanctuary
of another world that now she recalls
as the anesthetic dispersal of being.

in boundless yellow june she dreamed
of baking bread and *couscous* for hungry cradles
in the shadow of the room she could hardly
encounter her way back to the past.

down in the deep valley of inquiry she
stumbled upon the misty white jasmines
under the iron fist of amnesia. and she forgot
they were called jasmines ...

half-open into the fleeting past
she is still fighting against memory

(not because you are insane, ma')

in delicate silence the mirror
is bewildered by who she is
and what she forgot to fight for.

...

with orange flavor your vanilla cake
silently awaits on the dining room table
almost falling asleep waiting to be recognized
neither burnt
nor a promise.

finally you go within without your veil
from your overdue self to heal and shield
what has always been you before time.
you mutate your silence through silence
through pain
through anger
and you grow into you.

to Habiba

Note

¹ The poetic and mixed-media creations throughout this volume, and on the cover, are by Khédija Gadhoun. She dedicates them to the following Gaia survivors, whose heroic fight has been nurturing dawns of hope as well as seasons of love, resilience, and faith. To all of them, she surrenders her very humble verse: Habiba Gadhoun-Lassoued, Natalia Gómez-Mulligan, and Bilel Briki-Gadhoun. She also expresses her gratitude to the following friends, family members, and colleagues for their help in the production of her mixed-media designs: Afifa Briki-Gadhoun, Bilel Briki-Gadhoun, Eia Briki-Gadhoun, Habiba Gadhoun-Lassoued, Natalia Gómez-Mulligan, and Anupama Mande.

INTRODUCTION

DAWN SLACK AND KAREN L. RAUCH

Our purpose in this volume is not to provide an over-arching view of Disability Studies, nor of Disability Studies in the Spanish-speaking world; rather, we conceive of our study as a collection of nine unique essays reflecting a variety of applications of Disability Studies theory to Spanish-speaking and U.S. Chicano artistic creations. The chapters herein span hundreds of years and thousands of miles; yet, we are cognizant of the fact that some contemporary Disability Studies critics, such as Lennard J. Davis, trace the beginnings of the concept of disability to the Industrial Revolution. But, as Encarnación Juárez-Almendros clarifies in her introduction to a special issue of the *Arizona Journal of Hispanic Cultural Studies* dedicated to Disability Studies:

It is . . . of great importance that any analysis that pre-industrial texts ground itself in their geographical, historical, and cultural contexts. Nevertheless, there are significant theoretical concepts of disability that can be usefully applied to study pre-industrial disability. (2013, 155)

Given that aim, in this introduction we outline some of the key theoretical foci that imbricate with our authors' contributions before we summarize each of the chapters.

Rosemarie Garland Thomson has published prolifically in the field of Disability Studies, and many of the critics whose work is included in our anthology borrow particularly from Garland Thomson's early work in the area of the cultural representations of disability. Her *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* helped to inaugurate the shift from a medical view of disability to a social/cultural perspective. In her study, Garland Thomson coins the term "the normate," a highly influential neologism that has informed Disability Studies, transforming the discipline. According to Garland Thomson:

[The normate] names the veiled subject position of cultural self, the figure outlined by the array of deviant others whose marked

bodies shore up the normate's boundaries Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them. (1997, 8)

Of further pertinence for many of the studies included in our anthology is Garland Thomson's assertion that "the non-normate status accorded disability feminizes all disabled figures" (1997, 9).

Feminized, marginalized, and outside the "normate," the disabled may at times endeavor to conform to the "ideology of able-bodiedness" (Siebers 2004, 13) by means of the process of "passing." More often than not, when one hears about passing, the context is assumed to be racial or ethnic. A example exploded across the headlines in 2014 when *The New York Times* writer Christina Saenz-Alcántara wrote about white Hispanics. She commented: "[It] is not a discussion of Afro-Latinos against white Latinos or the white Spanish against the indigenous. It is more about how Latinos are making sense of the confusing label[s]" (2014, n.p.). Thus, the existence of labels (with their frequently negative connotations) and the pressures of hegemonic society can, then, understandably lead to the phenomenon of passing among those with disabilities. As Siebers concludes: "Passing is possible not only because people have sufficient genius to disguise their identity but also because society has a general tendency to repress the embodiment of difference" (2004, 3).

The degree of ability to pass for non-disabled depends upon the type of disability and the social context, as illustrated by the life story of Johna Write, a young blind woman who also suffers from chronic pain. While she could not mask her blindness, she strove to do so with her other health issues, in an effort to fit in and not be labeled inferior or to be defined further by her disabilities: "I've always been treated as lesser than my classmates, despite the fact that I was placed into the gifted education program in kindergarten" (Write 2018, n.p.). Since her blindness was overtly recognizable, she took control of her "invisible disability" by masking it. The Invisible Disabilities Association highlights the conundrum: "Unfortunately, the very fact that these symptoms are invisible can lead to misunderstandings, false perceptions, and judgments" (n.d., n.p.).

Indeed, invisible disabilities may give rise to a variation of passing theorized by Tobin Siebers, who extends the idea of traditional passing, by introducing the concept of disability as *masquerade*, which he defines as "structurally akin to passing but not identical to it, in which they disguise one kind of disability with another or display their disability by exaggerating it" (2004, 4). Grounding his theory in queer and feminist

studies, such as Eve Kosofsky Sedgwick's *Epistemology of the Closet* and Joan Riviere's "Womanliness as a Masquerade," Siebers asserts that "The concept of the masquerade . . . offers an opportunity to rethink passing from the point of view of disability studies because it claims disability as a version of itself rather than simply concealing it from view" (2004, 5).

Siebers underscores the ambivalent role of prostheses in the process of masquerade. Whereas a prosthetic device may come to define or emblemize the disabled person for those in the normate, a prosthesis may also serve as "a resource for changing the meaning of disability" (2004, 12). In effect, in her study of the body image of amputees, titled "Body Image, Prostheses, Phantom Limbs," Cassandra S. Crawford concurs:

Despite their initial desire for or even preoccupation with passing, many amputees come to reject the impulse toward or imperative of the real, exposing the artificiality of their limbs to others with purpose, engaging in a lived politics of distinction. (2015, 232)

Crawford traces the change from wanting to pass via prosthetization (to appear "normal") to "becoming public" by virtue of the prosthesis; in other words, it is "a means through which dismembered bodies are transformed into voyeuristic objects for the purpose of revealing rather than hiding" (2015, 234). In this way, the prosthesis messages and underscores the exceptional nature of the body rather than disguising impairment. The allure of passing for non-disabled can be as powerful as proudly proclaiming, if not flaunting, one's disability, as is evident throughout our volume.

Crucial to this process of becoming public is the use of language. To return to Garland Thomson, in her essay "The Story of My Work: How I Became Disabled," the critic recounts how the legacy of the Civil Rights and Women's Movements allowed her to change her answer to the question: "What is wrong with you?" Whereas she used to respond, "I was born this way," identity politics eventually allowed her to reply, "I am disabled." This linguistic shift marks a profound establishment of disability identity. Indeed, Wilson and Lewiecki-Wilson aver that there is no definitive answer to "what language can or cannot do or its role in the sociopolitical meaning of disability The work of 'reassigning' meaning to disability begins with analyzing the ways the disabled have and are inscribed in language and culture (2001, "Disability . . .," 3-4). The articles within their volume conceive of the intersection among language, rhetoric, and disability in various manners, including the concepts of "speaking for the other" and communicative literacy or "speaking well" (Brueggemann 2001, 116 and 119-121); language as "a social practice," "an instrument of agency," and

“social performance (Wilson and Lewiecki-Wilson, 2001 “Disability . . .,” 2-4); and the language of metaphor in referencing disabilities (Nye 2001, 230-232).

David T. Mitchell and Sharon L. Snyder have also changed the map of Disability Studies through their numerous books and other scholarly work. Of particular import for our volume is the concept of narrative prosthesis as elucidated in their *Narrative Prosthesis: Disability and the Dependencies of Discourse*. For Mitchell and Snyder, this term refers to the “perpetual discursive dependency on disability” (2000, 47). In other words, narrative is set into motion by the “problem” of disability, a deviation from the norm that needs to be cured or, in some cases, erased. Disability, in its myriad forms, becomes the motor of the plot. Yet, Mitchell and Snyder go beyond looking at the pervasiveness of disabled characters in literary works to studying their metaphorical function.

The use of metaphor at the juncture between Disability Studies and Post-colonialism is as relevant as it is thorny in the context of many of the chapters in our volume given the postcolonial legacy in the Spanish-speaking Americas. Barker and Murray observe that:

While disability is frequently used, problematically, as a metaphor for the “damaged” or abject postcolonial body politic, there are many semantic permutations to disability representation. Disability metaphors may be meaningful not just as “crutch[es]” (Mitchell and Snyder 2000: 49) in the telling of some “other” tale of postcolonial experience, but as part of foundational cultural and historical *disability* narrative. (2013, 71; emphasis in the original)

In her book *Carnal Inscriptions: Spanish American Narratives of Corporeal Difference and Disability*, Susan Antebi, for example, develops two key manners of interpreting disability. The first, grounded in a literary and cultural studies, focuses on the concepts of monstrosity and its “figurative site for the proliferation of meaning” (2009, 4), while the second, reflective of a humanities-based methodology, delves into the representation of “material bodies and their individual histories” (2009, 4). With this approach, as in-depth as it is broad, Antebi’s work has become fundamental to Disability Studies, particularly where said field intersects with Spanish American literatures. Furthermore, and in accordance with Antebi’s study, a clear parallel exists between the historical treatment of the disabled individual and the conquered/colonized body: born of violence, then moving through a mix of banishment, exile, isolation, devaluation, and finally acknowledgement, if not understanding and full acceptance. With its

historical trajectory, such a hybrid methodology is particularly applicable to our current volume given the range of time periods and genres, as well as the myriad theoretical bases included therein because, as Antebi points out: “[D]isability and corporeal difference in the text suggest more complex entanglements of ethics, aesthetics, and unpredictable signification, and therefore require more detailed attention” (2009, 200).

Julie Avril Minich does indeed pay attention and, in *Accessible Citizenships: Disability, Nation, and the Cultural Politics of Greater Mexico*, she details how the individual body, be it disabled or not, serves as a metaphor for nation (and we would add nations) and thus, can be a site for both individual and political identity. In so doing, Minich also raises the vital issues of delineating disability and disability’s role in society:

I do not define disability as a bodily construction or essence. I emphasize this because, although scholarly inquiry in the humanities now accepts race, gender, and sexuality as social constructs, it is still common to think of disability as a medical condition located in the body and not in the society that refuses to accommodate it. (2014, 7)

Throughout our volume, while the various analyses of disability do highlight corporeal aspects, they also form a strong critique of society, challenging the tendency to associate nationalism with a “singular, hegemonic bodily ideal” (Minich 2014, 195). These essays relocate individuals with disability from the margins to the center, thus fulfilling what Minich would deem a way to “transform our very conceptualization of the nation itself” (2014, 195-196).

In the current anthology, we eschew regional and chronological organization in favor of thematic clusters. Thus, we begin this volume with Beth Jörgensen’s essay “Plotting Trauma: Reading, Writing, and Resisting Blindness in Two Works by Lina Meruane.” In her essay on Meruane’s work, Jörgensen strives to deconstruct the false separation between the “able” and the “disabled,” even going so far as to suggest that all of us have limitations and it is those limitations that breed creativity. Jörgensen examines blindness as a literary trope and explores cultural and medical perceptions of blindness. She grounds her study in a range of critical analyses including approaches that are specific to blindness (Georgina Kleege and Julia Miele Rodas), as well as others that speak to the broader scope of Disability Studies.

Similarly, in “The Redefinition of the Disabled Chicana in Ana Castillo’s *Peel My Love Like an Onion*,” María Esther Quintana Millamoto relates how the female protagonist moves from a place of marginalization

as a woman, a Mexican-American, and a unique body in an ableist society into a world in which she re-creates her self-image by embracing her right to her own sexuality and to artistic creation. Quintana Millamoto's use of feminist and postcolonial theory brings to the fore the key concepts of "female genius" and "social melancholy," as adumbrated by Kelly Oliver in *The Colonization of Psychic Space: A Psychoanalytic Social Theory of Oppression* and Quintana Millamoto herself in her book, *Madres e hijas melancólicas: Novelas étnicas de crecimiento de autoras latinas*.

Jennifer Brady's chapter, "Alternate Ways of Being in *La mujer loca* by Juan José Millás: How Language Seeks to Normalize 'Living at the Limits,'" develops the fundamental themes of language, identity formation, and empowerment, as the disabled female characters control their own destiny on their own terms. Of particular note, and in dialogue with Susan Wendall's essay "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," are the central female characters who are depicted with mental impairments (exemplified by the the title character) and chronic illness.

Various characters with disabilities are also examined in "Identity, Community, and Communication: Three Perspectives on Disability," in which Dawn Slack develops the link among the three key concepts iterated in her title as she examines three short stories by Latin American authors, aiming to underscore the alienation and silencing experienced by individuals with disabilities. She notes the sharp critique of societies that exclude, institutionalize, and even abuse those with impairments. These foci are developed in concert with theorists at the forefront of Disability Studies in Latin American contexts, such as Antebi and Minich.

Jennifer Thorndike's chapter, "Alternative Body Owners and Their Machines: The Acquisition of Dominant Subjectivities by Sick/Disabled Individuals in Mario Bellatin's *Perros héroes*," centers on the Mexican-Peruvian author's work, analyzing the dominant subjectivity in his novel *Perros héroes* from the perspective of neoliberalism's alienation of the disabled as "non-productive" members of capitalist societies. The concept of biotechnology, particularly prosthesis, is highlighted in Thorndike's analysis of the novel, as she expands the definition of prosthetic devices to include other beings, human and animal alike.

"Body-Shaming in the Seventeenth Century: The Accidental Making of a Playwright," by Gloria Jeanne Bodtorf Clark, uses Juan Ruiz de Alarcón's personal experience of what we would call "body-shaming" as a springboard for her analysis of his play *Los favores del mundo*, in which the playwright makes the case for a moral code based on individual merits and not on class or a normalized embodiment. Clark underscores the Early Modern theme of dissimulation as it relates to the contemporary notion of

“passing.” Her chapter thus forms a bridge between twenty-first century Disability Studies and some seventeenth-century realities.

Carlos Rodríguez McGill focuses on late nineteenth-century nation-building in the works of Argentine author, Eduardo Gutiérrez, in whose novels the bodies of foreign immigrants and ethnic minorities are marked as disabled, thus allowing their bodies to be read as undesirable elements in the forging of the Argentine state. “Disability, Intertextuality, and Xenophobic *Mestizaje* in the Literary Construction of the Modern Barbarian in *El Jorobado* and *Astucia de una negra* by Eduardo Gutiérrez” draws a clear parallel between the infirm nation and the infirm body, echoing the work postcolonialist theorists, such as Homi K. Bhabha. In the context of his chapter and the literature studied therein, Rodríguez McGill views *mestizaje* as a push toward modernity via a eugenic experiment aimed to civilize and whiten the population.

Disability is likewise a metaphor in “Narrative Prosthesis in the Short Stories of Marcio Veloz Maggiolo,” by Karen L. Rauch, who proposes to broaden the field of Disability Studies by weaving both Postcolonial Studies and Trauma Studies into her approach. Taking as her springboard the concept of prosthesis in the formulation of the plot in two of Veloz’s short stories, she goes on to analyze—and to recuperate for Disability Studies—the impaired body as a metaphor of the nation, the lack of political agency concomitant with postcolonialism, and the themes of loss and tragedy.

Meredith L. Jeffers offers evidence that perhaps the tide is turning, at least in recent Spanish cinema, as she studies the role of disabled protagonists portrayed by actors who share the same disability as their character. One impetus for Jeffers’s analysis is Benjamin Fraser’s reference to the United Nations’ Convention on the Rights of People with Disabilities (2006) and its focus on every individual’s right to make his/her own decisions. Thus, in her chapter, “Representing (Dis)ability and Inability in Contemporary Spanish Cinema: *Yo, también* (2009) and *El truco del manco* (2008),” she delineates the role of autonomy and self-determination among the disabled characters.

Throughout the volume, original poems and mixed media photo-images by Khédija Gadhoom expand the critical discussions on disability. Her artistic creations explore three main disabilities that the artist has been witnessing among family and friends: Alzheimer’s, autism, and cancer. Aesthetically, Gadhoom’s works exhibit a collage of the fragmented body. The artist’s creative inspiration is informed by theoretical approaches espoused by philosophers and critics such as Aristotle (*Poetics*), Michel

Foucault (*Folie et déraison. Histoire de la folie à l' âge classique*), Henri Bergson (*Matter and Memory*), and Susan Sontag (*On Photography*).

While this literary, cinematic, and photographic whirlwind in no way presents itself as being either a comprehensive or an exhaustive examination of artifacts by Spanish-speaking or U.S. Chicana authors whose works touch on disability, it does provide a sampling of topics including the use of disabilities as a means of transgressing societal norms and creating/empowering subjectivity; the interplay between normative and non-normative bodies and the effects of such constructs on esteem; the metaphoric function of disability particularly as it pertains to creating a narrative prosthesis; the relationship between disabilities and socio-cultural, political, and religious critique; the use of disabilities to expose and question the predominance of normative foundations; and, the manner in which disability can be portrayed through poetic and visual means.

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CHAPTER ONE

PLOTTING TRAUMA: READING, WRITING, AND RESISTING BLINDNESS IN TWO WORKS BY LINA MERUANE

BETH E. JÖRGENSEN

Illness and Disability at the Center

The New York City-based Chilean writer and literary scholar Lina Meruane (1970-) is known for her unconventional and decidedly unsentimental representations of illness and disability in works of prize-winning fiction and literary analysis. Her interrogation and creative refusal of the social and cultural meanings of illness are at play in three very different pieces of writing that she has called an “involuntary trilogy” of illness (2016a, 35). The 2007 novel *Fruta podrida* features a young woman with diabetes who refuses to follow her prescribed treatment regimen, and travels from Chile to the United States to carry out acts of medical sabotage against terminally ill patients in a hospital located in a big city, often understood to be New York. Three distinct narrators including, in two chapters, the protagonist herself, tell the story of the character’s rebellion and eventual death, facilitating the novel’s examination and critique of the relationship of the body to modern social and medical regimes of control, and the relationship of the dominant global North to the economically subordinate but potentially subversive global South. Meruane’s groundbreaking scholarly monograph *Viajes virales: La crisis del contagio global en la escritura del sida* (2012), translated as *Viral Voyages: Tracing AIDS in Latin America* (2014), studies the representation of AIDS and its attendant stigmatization in Latin American literature as a cultural and political construct with complex origins, manifestations, and consequences in the neoliberal era. Finally, the novel *Sangre en el ojo*, winner of the

Premio Sor Juana Inés de la Cruz in 2012, and translated into English in 2016 under the title *Seeing Red*, narrates a period of temporary blindness based on a similar episode experienced by the author, and can be read as an example of creative disability life writing. In this chapter, I will treat two works by Meruane, an essay titled “Blind Spot: (Notes on Reading Blindness),” published in 2016, and the aforementioned *Seeing Red*.¹ The first reflects on blindness as a literary trope, and the second narrates it as a personal experience.

“Blind Spot:” Limitation, Loss, and Creativity

I have chosen to discuss the essay first, although its writing and publication date follow that of the novel, because the readings that inform the essay largely predated and certainly shaped the writing of the work of biographically-inspired fiction.² In addition, my reading of the novel plays off of the essay’s meditation on blindness in the Western literary imagination and Meruane’s reflections on how and why she wrote the novel. In analyzing both texts, I will show that each one makes a distinct contribution to Disability Studies. The essay critically examines and connects a wide range of representations of blindness while it opens up questions about the positive role of limitations in the creative process, including that of disability conceived of as a radical limitation on “ability.” *Seeing Red* unflinchingly and imaginatively narrates a challenging experience of sensory impairment and effectively deploys blindness as a narrative strategy,³ but the novel also draws on many of the negative meanings that Western society associates with blindness, as attested to in any number of studies of literary representations of blindness.

Disability Studies scholars were quick to observe the complex role played by the blind in literature since ancient times, and to suggest that these representations have an impact on the real lives of real people. Georgina Kleege is one of the preeminent scholars dedicated to deconstructing the cultural meanings of blindness in the West, and in her 1999 book *Sight Unseen*, she unpacks the cultural meanings that have been attached to blindness over many centuries and into the present. Chapters on the English language, American film, and landmark works of Western literature combine linguistic and textual analysis with personal experience to provide evidence of the stigmatized nature of blindness and the pervasive misunderstanding of what it means to be “blind” or to have low vision. Kleege attests to the commonly accepted notion that sight is central to human life, and she judges the consequences of such a belief in this passage from the chapter “Call It Blindness:”

The belief that human experience, both physical and mental, is essentially visual, that any other type of experience is necessarily second rate, leads to the conclusion that not to see is not to experience, not to live, not to be. (1999, 30)

In “Introduction: Blindness and Literature,” written for a special issue of the *Journal of Literary and Cultural Disability Studies*, Kleege reiterates the point:

It is safe to say that blindness has held a particular fascination in every culture since the beginning of time. Since sight is understood to be the predominant sense in humans, the loss of sight is assumed to be tantamount to a loss of life, or a loss of a fundamental quality that makes someone human. (2009, 113)

Julia Miele Rodas, in her essay “On Blindness,” similarly emphasizes the linguistic and cultural construction of blindness, and she affirms: “[T]hat blindness is ultimately about language and, for this reason, it exists as a reflection of the culture that describes it, rather than as a representation of the condition and identity it ostensibly names” (2009, 116). Her article brings to our attention the ways in which the stigma around blindness is embedded in the English language in a long list of expressions starting with “blind alley” and ending with the phrase used for comic effect in the movie *A Christmas Story*, “You’ll put an eye out” (Rodas 2009, 116). Similar findings can be made for Spanish. Both “Blind Spot” and *Seeing Red* have much to say and to ask about these same ideas and observations.

In Spanish American literature, it is easy to identify characters who embody the negative meanings assigned to blindness. For example, in *Santa*, the canonical Mexican novel by Federico Gamboa from 1903, the blind piano player Hipólito represents the impotence or sexual disability that is often attributed to the blind, while at the same time he possesses the superability of “seeing into” and understanding the souls of others, a kind of magical (in)sight also frequently attributed to the blind. Tiresias, the blind seer, models this association for Western culture. In the section from *Sobre héroes y tumbas* (1961) titled “Informe sobre ciegos,” Ernesto Sábato embodies evil in a secret sect of the blind who conspire to control the world, and he utilizes once and again the ancient and persistent linking of blindness with shadow, darkness, and evil. Jorge Luis Borges, for his part, manifests an ambivalent attitude toward his own blindness, at times conceiving of it as a misfortune, and yet also as a gift or at least an instrument of creativity.⁴ Although Borges describes his own low vision not as total blackness but as shades of blue, green, grey, and yellow, Kevin Goldstein observes that in Borges’s poetry, he frequently relies on traditional metaphors that equate

blindness to darkness and night (2016, 49). The metaphorical use of blindness, with its connotations of ignorance, death, danger, mystery, tragedy, evil, and the monstrous, is born out of a long history of the ways in which the sighted think about blindness and project the alterity of the blind, while privileging sight and stigmatizing its lack, as Kleege convincingly shows throughout the chapter “Call It Blindness” in her book *Sight Unseen*. One way to undo this privilege is to read texts written from within the experience of blindness, although as I will show in Meruane’s works, a perspective from within does not necessarily guarantee a rethinking and overturning of old attitudes and meanings.

“Blind Spot” was written in response to an invitation extended to Meruane to reflect on the pervasive presence in her fiction of characters who are ill or disabled. The resulting piece, published in the edited volume *Libre Acceso: Latin American Literature and Film through Disability Studies* (2016), focuses on three interconnected themes: the process of writing the novel *Seeing Red*; Meruane’s reading of the trope of blindness, and disabling conditions more generally, in works by Jorge Luis Borges, José Saramago, Clemente Palma, James Joyce, and others; and on her own persistent creation of literary characters who live with a chronic illness or a disability. As she traces her reading, listening, and writing journey through the landscape of blindness, she touches on topics that have been treated by Disability Studies theorists such as those cited above.⁵ Meruane’s unique manner of meditating on blindness in the literary imagination affirms the validity of in-valid bodies, the legitimacy of works produced under the sign of disability, and a critique of the medical model with its “unscrupulous desire for health” (2016a, 36), as well as the aim of “adding pathology to the imaginary of the normal” (2016a, 37), all of which situates her thought within the broad scope of Disability Studies. These topics have not yet been adequately explored from a Disability Studies perspective in the context of Latin American literature, nor have they been adequately represented in works belonging to the literary canon, where the tendency toward stigmatization and the metaphorical use of disability continues to figure prominently, with some exceptions, of course.⁶

Employing a lyrical and polysemic language, “Blind Spot” begins as a poetics of loss, but ultimately resolves into a poetics and an ethics of resistance, resistance, that is, to the privilege granted to health and what is typically called “ability.” “Blind Spot” does not treat a lived experience of vision loss as its central concern, which the novel will do, but rather it examines the reading and writing of blindness by means of a serious and sustained intellectual engagement with literary works. From a certain emotional remove, the author considers deliberately and critically the

cultural construction of blindness and its consequences for both blind and sighted bodies. In the essay, Meruane carries out a re-view and a re-vision of her own blind characters, blind characters in the works of other authors, and the status of blind writers, in an attempt to reframe the values and meanings that have been imposed on sight and blindness over the course of centuries. Among other innovative ideas that result from Meruane's "reading blindness," are her notes on bodily ethics and aesthetics in a society ruled by the preference for ability and by the demands of capitalism.

The first section of the essay, titled "brief retelling of a loss," reflects on the writing of *Seeing Red*, as given in this passage:

Loss appears like a sticking point around which all conduct changes and at times collapses. Because blindness, I think or thought, while I was writing this novel, threatens all of our assumptions, all the habits that anchor each of us safely in our work. (2016a, 30)

The loss of the sense of security that is grounded in familiar, habitual behaviors, and the need to adapt to new circumstances, motivate new ways of conceiving of ability and disability on the part of the writer, who employs an active and questioning reading practice to find solutions to the dilemma that she confronts. Little by little, Meruane begins to discern a new ethics of the body in her novels *Fruta podrida* and *Seeing Red*, and also in the writings of other authors. This new ethics is founded upon personal and political resistance to "the diverse experiences of loss of validity, of invalidity, brought about by bodily decay" (2016a, 35) and a rejection of the "capitalist system of incessant production," which demands standard, "normal" bodies to sustain it (2016a, 36).

At the same time, Meruane refuses to make a virtue or a form of heroism out of illness; that is, she does not succumb to a simple reversal of traditional values by privileging the anomalous body, ill and/or disabled, over the healthy one. Rather, she attributes a positive quality to imperfection itself, and abandons sterile hierarchies based on putatively opposite values. This revelation is triggered by a moment of impasse in writing the essay, when she becomes aware of "going off track" from her initial theme (her own creation of disabled characters). Feeling that the essay has become "a text that cannot complete its task" (2016a, 37), Meruane pauses to reconsider what she is writing, and a sudden memory about Oulipo, a French literary group of the 1960s, releases her back into creativity. The Oulipians promoted the value of making literature under the strictures of techniques designed to limit the supposed artistic freedom of the author, such as writing

a novel without using the vowel “e.” Meruane cites their “inspiring logic” of limitations:

[T]he imposition of limitations as an indispensable requirement of the creative process. Limits as resource, obstacles as a way of carrying language and literary form to a higher imaginative level. Thinking about the Oulipian technique, I return to the limited body. To the physical restrictions that could lead to the formulation of a poetics and an ethics of the possible. (2016a, 38)

Meruane’s *Seeing Red* is narrated under the sign of disability as radical limitation, and it deploys blindness as a narrative strategy to yield valuable, albeit ideologically mixed, results with regard to its narrator-protagonist’s retelling and reinventing of the lived experience and the cultural meanings of blindness.

Meruane further cites the work of the Romanian writer Emil Cioran, who asserts that perfect health makes us inattentive to reality, asleep to our body’s functioning and needs, while the consciousness that is necessary to live a full life is born out of the imperfect body with its aches and pains. Health is “an insignificant state of perfection” according to Cioran (qtd. by Meruane 2016a, 39). Meruane then states, paraphrasing Cioran, that illness or disability “is a superior form of consciousness” because “in its beginning stages, consciousness is consciousness of the organs” (2016a, 39). Therefore, as Meruane processes her “notes on reading blindness” in literature, she starts with loss but ultimately arrives at a recognition of the power of limitations, and the value of the attentiveness to our bodies and to the world around us that disability and illness can facilitate, perhaps making possible creative work that the apparent ease of limitless ability would forestall.

Near the beginning of “Blind Spot,” Meruane explains one of her purposes in writing *Seeing Red* in the context of all that she has read and heard about literary depictions of illness:

[I]nstead of marginalizing the sick from the scene, place her in the center, disseminate that bodily experience, impose it on others. Cut the distance between the healthy and the sick, between the sighted and the blind, between the valid and the invalid. Do this in the new novel, certainly, but also in a wider sense, add pathology to the social imaginary of the normal: destabilize the certainty that a border exists, depose health as the norm. (2016a, 36-37)

This passage is a significant point of departure for my reading of *Seeing Red*. As her words suggest, in the novel and in other writing that is less obviously autobiographical, Meruane's narrators and characters refuse the marginalization of the "sick," while also calling into doubt the safe space of normalcy in which the healthy believe they live. Her protagonists and their traumatic plots complicate in literary form the fluid and uncertain relationship between body and subjectivity, well-being and disability, and self and other; concepts that are central to Disability Studies theories and the challenges they pose to long-established norms.

Seeing Red: Resisting the Lived Experience

Having already called *Seeing Red* an autobiographical novel and a work of creative disability life writing, I will situate the book within the phenomenon of disability life writing, as well as considering its textual representation and deployment of blindness. The many conventional forms of life writing—autobiography, collaborative autobiography, memoir, biography, diary, letters—when produced or co-produced by a disabled person, occupy a place of privilege for some Disability Studies scholars, who view them as an alternative to traditional literary representations and the limiting, exclusive meanings about disability that they codify. Life writing also emphasizes the protagonism and agency of the person with a disability, placing him or her at the center of the narrative rather than in a secondary or supportive role; thus, the author has the potential of portraying the lived experience of disability in an ableist society with greater nuance and complexity than is typically achieved in fiction. This is not to say that such texts are transparent, "true-to-life" accounts, but rather like all life writing, no matter the subject, they tell us a great deal about society precisely because they are highly mediated narratives in which cultural norms and stereotypes and the ideological pressures exerted by language figure alongside resistance to those norms. G. Thomas Couser and Susannah B. Mintz are two prominent theorists of disability life writing, whose critical works have contributed to the recognition and study of these texts. The following statement by Couser applies well to *Seeing Red*:

The relation between bodily dysfunction and personal narrative is a complex one; the former may both impel and impede the latter. Bodily dysfunction may stimulate what I call *autopathography*—autobiographical narratives of illness or disability—by heightening one's awareness of one's mortality, threatening one's sense of identity, and disrupting the apparent plot of one's life. Whatever form it takes, bodily dysfunction

tends to heighten consciousness of self and of contingency.
(1997, 5)

For her part, Susannah Mintz treats disability and illness narratives by eight American women in her monograph *Unruly Bodies: Life Writing by Women with Disabilities*. She points out that the women autobiographers under study “write their bodies—their gendered, disabled bodies—as textually produced but also phenomenologically alive” (2007, 4). Her analyses highlight the treatment of “family dynamics, medical intrusions, media representations, and structural barriers” experienced by women living with a variety of disabling conditions (2007, 4).

Seeing Red can legitimately be read as autobiographical fiction or creative disability life writing, in light of Meruane’s numerous statements about the book’s genesis in her own experience of temporary blindness. For example, in “Blind Spot,” she states: “A few more words so as not to lose sight of a decisive fact: the writing of *Sangre en el ojo* was triggered by my own experience of temporary blindness” (2016a, 30). With the claim to a biographical basis established, it is also easy to perceive how the book aligns with the characteristics summarized by Couser and Mintz. Having lived since childhood with diabetes, Meruane initially resisted writing about her blindness. Illness seems to have impeded, for a time, any impulse to engage in personal narrative. “Writing about illness was something that I had spent years mulling over. Years putting off” (Meruane 2016a, 34). However, she says that at a certain moment, with William Styron’s book *Darkness Visible: A Memoir of Madness* and Sylvia Plath’s *The Bell Jar* in mind, she resolved to write her own memoir, not of depression, but of blindness. Illness changed from an obstacle to a motivation to write. That memoir soon transformed into a novel when Meruane realized that: “I never found the right register. I couldn’t stick to the facts. The act of imagining what is not seen took precedence, getting the better of me” (2016a, 34). *Seeing Red* tells the story of Lina’s confrontation with the threat to her identity and the disruption of her life’s plot caused by the loss of sight, which are central themes of disability life writing.⁷ Comparing both the essay and the novel, “Blind Spot” attests to a move toward blind creativity that *Seeing Red* does not record.

As Meruane, in the passage quoted above from “Blind Spot,” proposes to achieve with her writing, *Seeing Red* unquestionably places the blind narrator-protagonist at the center of the story, and the fictional narrator resists any impulse to represent herself as a victim. Lina does not serve to enhance or further the moral development of another character, as is common in much literature (think of Dickens’s Tiny Tim), nor does she symbolize a social ill or communicate a lesson to the supposedly healthy,

able-bodied characters. In this sense, the novel is thematically innovative within Spanish American letters. Nevertheless, many details of the story and the language it employs reiterate conventional ideas and stereotypes of blindness. As I will show, Lina cannot conceive of blindness beyond the taken-for-granted connotations of suffering, loss, and invalidism or invalidity, for all that she resists playing the part of the victim, never mind the virtuous victim. My analysis will focus on the representation of blindness and its deployment as a literary device, and on the text as an example of disability life writing with a strongly fictional dimension.

In the novel's opening chapter, the protagonist loses sight in one eye while attending a party with friends, and soon the other eye goes blind as well. It is a "blindness foretold," because the delicate veins that finally rupture and spill blood into the vitreous humor, are a side effect of the character's life-long diabetes. Lina has experienced less drastic leakages in the past and has lived in anticipation of precisely this feared and transformative event. Stubbornly opposed to the possibility that her blindness might be permanent, Lina pursues both real and imagined medical treatments to restore her sight, while at the same time coping with daily life without the crutch of clear physical vision. The novel's story unfolds over the course of three months. The trauma undergone by Lina and her new boyfriend Ignacio, the new rhythm of Lina's life as she confronts changes in her everyday routines and her relationships, her visits to the ophthalmologist accompanied by Ignacio, their trip to Chile to see her family, and their return to New York for a long-awaited surgery are narrated retrospectively in chronological order with relatively few flashbacks to a time prior to the incident of the burst veins in her eye. Although she has the surgery and her recovery seems to go fairly well, the hoped-for happy ending is thwarted when the procedure is not completely successful, and at the end of the novel, Lina is obsessed with a rather disturbing desire for a transplant of "ojos frescos," fresh, living eyes that she menacingly swears to obtain one way or another. As both the Spanish and English-language titles express, anger, even rage, is the narrator-protagonist's predominant emotion, and it spares no one—not her boyfriend, her parents, nor Lina herself—from outbursts of resentment and a furious refusal to be a victim or a "patient."⁸ Neither patient, nor resigned, nor heroic, Lina only desires to regain her sight, without caring too much for what her loved ones might have to sacrifice in the process.

The sudden onset of an illness or a disability creates an interruption in the life course and threatens one's identity and sense of wholeness, as Couser has stated in *Recovering Bodies*, cited above. Within Meruane's novel, blindness is an apparently insurmountable obstacle to the protagonist's

vocation as a writer, although her friends push her to continue her writing projects, saying that she lives in words. In a phone conversation with her poet-friend Raquel, she responds defiantly to Raquel's insistence that she return to writing an unfinished novel: "You can't give up, she insisted, and I: it's not giving up, it's an interruption, a temporary impossibility" (2016b, 69). Lina's refusal to reengage with writing contrasts with the move toward creativity through accepting limitation that the essay explores, while her use of the word "interruption" connects her to others who experience the onset of a disability once their sense of self and their life course has already been formed. Lina's response to this interruption and this threat is refusal and rage, recalling such cultural icons as Sampson, and Homer's Polyphemus, who rage against their vision loss and fulfill the stereotype of angry blind people that is concisely captured by the expression "blind rage" (Rodas 2009, 115).

Meruane takes exquisite care with narrative form and language in all of her writing, and as a consequence, one of the strongest aspects of *Seeing Red* is the skillful deployment of a rich variety of literary techniques and tropes within a narrative that is remarkable for its concision. In accordance with the narrator-protagonist's state of mind and her incomplete adjustment to the loss of sight, the structure of the text is often confusing and even syntactically violent. Blindness is therefore deployed as a narrative technique along the lines of what Michael Bérubé (2017) suggests for intellectual disability in his recent monograph *The Secret Life of Stories*. Brief chapters narrate episodes of Lina's life during the three months that transpire between the first burst of blood in her eye and her surgery. Within the chapters, lengthy paragraphs are built out of short segments of diverse narrative discourses without providing clear markers for sudden transitions. Fragments of narration, description, dialogue, interior monologue, and self-reflection are thus juxtaposed. This disorienting style creates the impression of a nervous groping in the dark, like a newly blind person, for an elusive glimpse of order and coherence. At the level of the sentence, painful or anxious thoughts are sometimes left incomplete, syntactically reproducing anger, anxiety, and disorientation. The reader must be alert to constant changes in discourse, which occur unannounced by conventional punctuation, as if to represent as directly as possible the narrator-protagonist's agitated state of mind and to throw the reader off balance, suddenly also vision impaired.

The "I" of the narrator-protagonist is prominent throughout the novel and can be interpreted as a sign of self-absorption. It is the case that Lina, facing a serious threat to her identity, is largely focused on her personal crisis and dilemma.⁹ The first-person narrative voice is also

utilized in such a way as to reflect the impact on relationships that a disability can have. Lina's "I" constructs her relationship with Ignacio, for example, as one of both intimacy and distance, in that she addresses him directly as "you" and refers to him as "he," in alternating passages throughout the novel. The second-person form, "you, Ignacio," appears alongside verbs in the first-person plural "we" in entire chapters that are enclosed in parentheses. These chapters, in which Lina speaks to Ignacio only in her mind and not in reality, often silently apprise him of Lina's perspective on shared experiences or give information about her family, creating a sense of wished-for intimacy and solidarity between them. In contrast, when the narrator speaks about Ignacio in the third person, the tone is frequently combative or disappointed because of some perceived miscommunication.

An economical use of personification, dehumanization, and metaphor conveys an experience of loss and denial and the attendant emotions of anguish and rage. These tropes often have an aggressive character that contributes to the sense of a world turned suddenly hostile and dangerous. The following passage from the chapter "house of hard knocks" treats Lina's first traumatic days adapting to a new apartment, and illustrates these features of the prose style:

The house was alive, it wielded its doorknobs and sharpened its fixtures while I still clung to corners that were no longer where they belonged With one eye blind with blood and the other clouded over at my every movement, I was lost, a blind-folded chicken, dizzy and witless The windows must be somewhere and I bumped into Ignacio. You're dangerous, he told me, angry, trying not to yell at me; stop wandering around, we'll end up breaking all of our bones. I know he stood there looking at me because I felt his eyes on mine, like snails coating me with their slime. (2016b, 19-20)

The personification of the house as a hostile, living organism, the dehumanization of the protagonist turned "blindfolded chicken," the physical clash against Ignacio's body, his presence as a speaking subject and also as an object of Lina's observations, and the image of Ignacio's eyes "like snails coating me with their slime," evoke the anxiety of feeling oneself lost in a threatening space and held in an unexpectedly challenged, uncertain relationship. The snail is a soft-bodied organism housed in a hard shell from which it emerges, as vulnerable as an unprotected eye, to move through space not on legs or feet but propelled by its "stomach" and leaving behind a viscous path traced by its mucus. With regard to the human life