

# Introduction

## *A Latin American Context for Disability Studies*

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“Let’s achieve a miracle” (Logremos un milagro) was the slogan of the first Telethon in Chile, a charity fund-raiser for the rehabilitation of children with disabilities. “La Teletón,” founded by Mario Kreutzberger<sup>1</sup> in 1978, was so successful that its name and structure have been replicated through an umbrella organization operating in twelve different Latin American countries.<sup>2</sup> Images of children equipped with state-of-the-art rehabilitation devices for learning how to walk thus came to appear regularly on television screens throughout the region, accompanied by slogans of hope for the future, love, and solidarity, along with pleas for donations by media celebrities. As in the case of similar televised fund-raisers in the United States and elsewhere, Teletón’s use of children with disabilities to evoke the public’s compassion—and to open its wallets—exploits the children in question, legitimates the activity of staring at them, and equates disability with a tragedy to be erased or overcome.<sup>3</sup> Latin American disability rights activists and scholars have similarly criticized the Teletón model, advocating for human rights and social justice rather than voyeurism and charity, particularly in the wake of the 2006 United Nations’ Convention on the Rights of Persons with Disabilities, which has been signed by most Latin American countries.

Yet the specificity of the Latin American Teletón’s beginnings and its slogan of miracle making also suggest something further about the role of disability representation in contemporary Latin American societies. The

1978 reference to the “miracle” of fund-raising and rehabilitation echoes Milton Friedman’s description of Chile’s “economic miracle,” in the era of Pinochet. In the years following the 1973 military coup, a period during which the Pinochet regime murdered thousands of political dissidents, the privatization of state-run industries and the massive reduction of public spending would come to define Chile’s economy in a global context, through increased opportunities for foreign investors and a widening gap between the wealthiest and the poorest population sectors. For proponents of neoliberal economics the metaphor of a miracle defined Chile as a potentially exportable model of economic success in the region. Similarly, Chile’s Teletón miracle became the basis for the disability charity enterprise throughout Latin America. Most criticism of Teletón in Mexico, Chile, and other Latin American countries has tended to focus on the issue of economic exploitation, as privately run television stations are said to benefit from the tax write-offs made possible by public charitable giving, while transnational corporations reap the rewards of Teletón advertising spots, creating a positive association between their products and compassion for disabled children. In Mexico, the very substantial channeling of public funds by the federal and state governments into the private Teletón enterprise has also been the target of criticism.<sup>4</sup> In a contemporary global and Latin American cultural scene increasingly defined by visual media and the rapid circulation of literal and symbolic capital, the miracle metaphor falls flat for many consumers, and yet for large sectors continues to generate interest, affect, and economic participation.

Disability and its representations in Latin America are thus increasingly marked by public critique of socioeconomic inequality, uneasy boundaries between public and private sectors, and by profoundly contradictory messages. Market-driven initiatives such as Teletón have increased the visibility of disabled people<sup>5</sup>—albeit in troubling ways—while growing national and international engagement with disability as a human rights issue has contributed to public awareness regarding disability rights in a more positive sense. Yet it is nonetheless true that stigma and exclusion continue to define the status of many disabled people in the region, in contrast to both Teletón’s promise of a miracle, and recent legislation that purports to eliminate discrimination on the basis of disability.

We begin *Libre Acceso: Latin American Literature and Film through Disability Studies* with the miracle metaphor of the Chilean economy and of Teletón as a means to underscore the complex conditions impacting the politics and representation of disability in Latin American contexts. Teletón’s use of disability tends to reinforce the familiar stigma of physical disability as a personal tragedy to be overcome. Yet the overarching metaphoric role

of the miracle also reveals disability and its extended web of meanings as central to the broader notions of neoliberal economics, national transformation, and the politics of inequality. Although this particular cultural scene is just one of many possible, varied examples with which one might choose to illustrate disability representation in the region, it effectively points to a tension we wish to highlight in this volume, between disability defined through individual experience, and through a more biopolitically oriented emphasis on populations or collectives.

In this book, we focus on selected Latin American literary and filmic representations of disability, grounding our approaches at meeting points between the fields of disability studies and Latin American literary and cultural studies. The broader context for the volume includes the social, legal, and cultural changes around disability that have been occurring in Latin America over the course of the past fifteen to twenty years, as documented in disability studies scholarship by Latin American academics. The changing constructions and roles of disability make a regionally informed disability studies not only relevant but urgently needed in order for research in the humanities to keep pace with a shifting ideological landscape. Disabled people in Latin America have traditionally been drastically marginalized, remaining isolated and hidden from view in the family home or less often relegated to institutions,<sup>6</sup> or publicly visible only in the activity of begging on the streets.<sup>7</sup> In the context of late twentieth and early twenty-first century disability activism and reevaluation of the meanings of disability, acquiescence to these long-standing discriminatory practices is being vigorously challenged.

Evidence of a growing paradigm shift can be seen in Mexico's initiative in proposing the drafting of the United Nations Convention on the Rights of Persons with Disabilities in 2007, and the impressive number of Latin American nations who are now signatories of the Convention.<sup>8</sup> Disability rights activism assumes different forms in different national contexts, but it is on the rise throughout the region. According to the prominent Mexican activist Federico Fleischmann, in 2011 Mexico had more than one hundred and sixty organizations that were active in the movement, and many of them were created by and for people with disabilities. The disability rights activist and author James Charlton points to the specific case of Nicaragua, where the Organization of Disabled Revolutionaries was formed in the early 1980s as a result of the imperative to respond to the needs of those who were disabled by war injuries during Nicaragua's lengthy civil conflict (142–143).<sup>9</sup> In Chile, which ratified the U.N. Convention in 2008, the February 27, 2010, earthquake and tsunami cast a harsh light on the inadequacy of stipulated preparations to assist those with physical

disabilities during natural disasters and it prompted criticism of the government's response by such groups as Rehabilitation International and the U.N. Committee on the Rights of Persons with Disabilities.<sup>10</sup>

### Disability Studies in the Latin American Context

As an academic discipline, disability studies in Latin America can trace its origins to sources including local activism, legislation and policy analysis, and international dialogue in the fields of education and psychology among others. In addition, disability studies scholarship in the region has developed in relation to academic and activist models from the United Kingdom, the United States and Canada, as well as Spain.<sup>11</sup> Such models, which together have produced the interdisciplinary field of disability studies now increasingly present in universities in the Global North, may in turn be traced to the rise of disability rights movements in several locales in the 1970s and 1980s, with developments in the United Kingdom often leading the way.<sup>12</sup> As disabled people saw civil rights activism for racial equality in the United States and women's movements in many nations gain strength, they soon perceived the transformative potential of speaking and acting on their own behalf against stigmatization and discrimination, and for equal rights, access and full inclusion in society. In a manner parallel to the emergence of African American or Africana studies and women's and gender studies, disability studies in the academy developed from an activist base, and it retains an important ethical and social justice dimension as well as a commitment to interdisciplinarity. Apropos of this book, the study of literature and film was transformed for many scholars, particularly in the United States and the United Kingdom, by the questions that the new disability studies theories raised for understanding our cultural representations of disability, illness, and debility, and new ways of reading both canonical and emerging texts soon made their appearance.

In our research experience in Latin America to date, disability studies and related scholarship tends to appear in the social sciences, more than in the demonstrably rich field of literary discourse. The recent work of such Latin American scholars as Patricia Brogna, Miguel Ángel Vite Pérez, Manuel Aramayo Zamora, Carolina Ferrante, and many others working in a variety of disciplines and in countries throughout the region demonstrates growing interest in disability studies and related issues, particularly in the context of debates on human rights, social justice and economic inequality. Aramayo Zamora's 2010 edited volume *Hablemos de la discapacidad en la diversidad* (Let's talk about disability in diversity), highlights the Venezuelan

context, addresses inclusion in education, and proposes a uniquely Venezuelan adaptation of the social model aimed toward the challenge of social transformation in a framework of social diversity (85). Recent work by Miguel Ángel Vite Pérez and Carolina Ferrante, on Mexico and Argentina, respectively, emphasizes the socioeconomic vulnerability of disabled people in relation to the neoliberal marketplace, as well as the roles of the state and of the informal sector in this dynamic.<sup>13</sup>

Patricia Brogna's 2009 edited volume, *Visiones y revisiones de la discapacidad*, offers a range of scholarly approaches to disability and disability studies from Latin American, Spanish, U.S.-based and British authors, and encompassing disciplines such as history, psychoanalysis, anthropology, legal theory, literature, law, sociology, and political science, as well as areas typically viewed as part of the "medical model" of disability studies, such as rehabilitation, psychiatry, and medicine. In bringing together this geographical diversity of scholars from widely varied disciplines, Brogna creates an important dialogue between distinct approaches to the field, and implicitly proposes a disability studies that is at once Latin American and global. The volume makes evident some of the trajectories of disability studies scholarship and activism in Latin America that may not have been previously familiar to humanities-based Latin Americanists (including scholars of literature). As Brogna notes, while disability studies in the Anglo-American context has historically focused more on the question of individual rights, in Latin America, emphasis has tended toward analysis of the macrosocial ("Introducción," 16). This observation suggests, as we have also noted here, that those who seek evidence of disability studies, or what they consider to be disability studies, in the Global South may have to adjust their expectations, critical tools, and avenues of research. In addition, Brogna's comment reflects the overall framework we propose for the present book, in which we explicitly juxtapose individual and collective models of disability studies, though here, unlike Brogna, we are especially interested in reading disability through literary and filmic discourse.<sup>14</sup>

The framework for this volume, though oriented toward the study of literature and film, nonetheless must incorporate possibilities for dialogue with those in fields whose disability lexicon and foundational concepts may be different from the prevailing theories in humanistic research. In this sense, the interdisciplinary model we propose for a Latin Americanist disability studies means the foreclosure of a finalized definition of "the field" and an opening to expanded contexts for analysis. We note, too, that there is an immediate risk inherent in disciplinary "encounters" across geopolitical spaces, especially in the context of Latin American studies, in which the South too often serves as raw material for imported theoretical processing

and export, and in which “encounter” often works as a thinly coded term for violent conquest. Yet disability and disability studies, as we have shown here, are already present and active features of Latin American academics, activism and cultural production, in some cases in dialogue with Anglo-American intellectual traditions, and at times in ways more attuned to the specificity of local circumstance and disciplinarity. Our initial task is to better understand the terms and risks of this interdisciplinary, international engagement. In this regard, we offer as examples one publication and a recent international colloquium that further demonstrate how disability and disability studies have achieved relevance in Latin Americanist and transnational approaches to cultural production and social theory.

In the introduction to his book, *Nothing About Us Without Us*, James Charlton describes that he first came across his title phrase in 1993, as used by leaders of the group “Disabled People South Africa” (3). Yet he didn’t begin to use the phrase as his working title until two years later, when he saw a picture in the Mexican newspaper, *La Jornada*, of peasants marching with the banner, “Nunca Más Sin Nosotros” [Never Again Without Us] (16). This anecdote effectively captures the way in which disability oppression and resistance acquire a particular inflection in regions that Charlton—writing nearly two decades ago—called “underdeveloped,” and that we term the Global South. Disability cannot be defined exclusively by global, racialized structures of inequality or lack of access to resources. Yet such patterns parallel disability oppression, compound it, and frequently create it. In other words, Charlton’s work highlights an inextricable link between disability and what Aníbal Quijano has defined as the coloniality of power.<sup>15</sup>

In January of 2013, the editors were invited by Benjamín Mayer Foulkes and Beatriz Miranda to speak at a colloquium at the 17 Instituto de Estudios Críticos in Mexico City, with the title “De cómo la Discapacidad entrecomilla a la normalidad” [On How Disability Puts Normality in Quotation Marks]. The event brought together more than twenty scholars of disability studies and related fields, as well as artists, writers and activists, with a high level of public attendance. That such an event took place, and included Mexican, Latin American, and a few Anglo-American disability studies scholars, attests to the internationalization of the field, and to a growing interest in disability studies in Mexico.<sup>16</sup> Though the public included a large percentage of graduate students from the 17 Instituto, focused in areas such as psychoanalysis and critical theory, many in attendance were not academics, or in some cases expressed interest in the question of disability as divorced from discipline-specific academic pursuits. The space of the colloquium allowed for a questioning of the parameters of what constitutes “disability” and “disability studies” and required participants to continually

shift disciplinary languages in order to engage in effective dialogue with one another. This event thus demonstrated how focus on disability means working both within and beyond the confines of the academic sphere, in ways specific to day-to-day embodied experience and physical space.

### Disability Studies and Latin American Studies: A Transdisciplinary Approach

This volume stages an encounter between two complex and vigorously debated disciplines: Latin American literary, film, and cultural studies, and disability studies. In a variety of important ways, scholars of Latin American literary and cultural production have been “doing” disability studies for some time—that is, they have been articulating debates in which some of the concerns of disability studies implicitly emerge. However, disability studies per se is not yet highly visible in Latin American studies as practiced in the U.S. academy or as demonstrated, for example, in the research presented by international scholars at the annual congress of the Latin American Studies Association.<sup>17</sup> Latin American studies worldwide has not engaged extensively with disability studies in the humanities. To cite evidence from one essential source for research on literature and film, the bibliography of the Modern Language Association (MLA) in mid-2013 listed 579 entries under the rubric of “disability studies,” of which roughly a dozen were immediately identifiable as pertaining to Latin American topics. While factors such as the determination of search terms perhaps figure into the underrepresentation in the bibliography, it is nevertheless clear that disability studies has not taken hold in our field to the same extent as in Anglo-American theory and criticism.<sup>18</sup> In the experience of the editors and the contributors to this volume, there are relatively few venues for presenting our research, and our work in disability studies is often received with expressions of surprise, which can be either welcoming or dismissive. Considering that Latin American studies frequently engages with issues relevant to contemporary disability studies, such as political oppression and resistance, the delimitation and exploration of minority identities, the affective politics of the multitude, and theorizations of the subject, the body and the collective, the lack of engagement with disability itself seems worthy of critical attention.

The high stakes of lived, embodied, and unpredictable corporeality and its representations, as well as the practices and consequences of discrimination based on bodily and cognitive difference make a well-grounded engagement with disability studies a crucial project for scholarship on Latin American literature and film for a variety of reasons: the pervasive presence

of cultural representations of disability in the region; the changing social, political and human rights status of disabled people; the increase in the production of art by disabled people, some of which represents disability from an “inside” perspective; and the ethical imperative to interrogate and overturn histories of stigmatization and oppression—histories that often overlap with those of other marginalized communities—and to recover instances of resistance to that oppression, among many others. In such circumstances, we read disability and disability identity as more than just another “other” to be added to the list of minority identities.<sup>19</sup>

In response to these pressing demands on our attention, *Libre Acceso: Latin American Literature and Film through Disability Studies* brings together essays on multiple genres of literature and film from seven countries of Latin America, produced in the twentieth and twenty-first centuries. Works from Argentina, Brazil, Chile, Colombia, Cuba, Mexico, and Peru are examined, thereby spanning highly diverse societies of North America, the Caribbean and South America. The diversity of genres is equally wide: narrative fiction (novels and short stories), poetry, autobiography, essay, children’s literature, the colonial codex and colonial medical reports as intertexts, and narrative and documentary film. Our incorporation of both literature and film in the volume is based on a notion of cultural production that is inclusive of diverse media and genres, and attentive to the ways in which a variety of works—in this case, films and written texts—may speak to one another. We do not attempt to offer a fully representative spectrum of works from each medium, but rather to consider the presence and complexity of disability in Latin American cultural production, and hence the relevance of disability studies-informed approaches to these works. Readers will undoubtedly also find many of these approaches useful to works not considered here. In the essays, corporeal, sensory, and psychosocial conditions come into play in analyses that question their status as commonly perceived deficiencies. Disability also intersects with factors of class, race, and gender to prompt critical reflection on the complexities of the social and cultural construction of disability as well as the human being’s inescapably embodied experience of the world.<sup>20</sup>

In what follows of the introduction, we first review several foundational concepts and debates for the history of contemporary disability studies in order to contextualize the recourse to Anglo-American theory in many of our analyses of Latin American literature and film. Readers who are not already well-versed in the field will find ample references to prior studies to prompt further exploration. Then we discuss the specificity of conducting humanities-based disability studies research in Latin American contexts, and we conclude with an overview of the organization of the volume and the thirteen individual chapters.

## Concepts in Disability Studies

The development of the social model of disability and the interrogation of the concept of normalcy are two highly significant achievements of the 1980s and 1990s, which led to a series of ever more radical challenges to the status quo around issues of disability. The articulation of disability as socially constructed and not inherent in certain bodies marks a foundational moment, one that is repeatedly invoked in Anglo-American disability studies scholarship. As Tom Shakespeare has described, the “social model” of disability arose in the 1970s in Great Britain through the activities and ideology of UPIAS or Union of Physically Impaired Against Segregation (“Social Model” 214–215). It represented a radical alternative to the prevailing medical model, which posited that disability inheres in the individual body or mind, and that anomalous human conditions (“impairments”) should be subjected to treatment and rehabilitation to cure the individual (216). UPIAS defined disability as: “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (quoted in Shakespeare 215). Impairment was defined as “lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body” (Oliver 11). This definition of disability has achieved slogan-like status in many disability studies programs, and in some cases effectively removes disability from the individual body, relocating it almost exclusively in social structures and physical environments. The distinction between disability and impairment has historical significance in the evolution of disability studies, because it has allowed for emphasis on topics such as accessible education, work, and living environments for disabled people, and social and cultural representations of disability, rather than on disability as a problem belonging to individual sufferers in need of a medical solution. Strict adherence to the social model has subsequently been questioned by many contemporary disability studies scholars. Shakespeare (cited earlier) notes limitations to the model, including the fact that it de-emphasizes the material, bodily effects of impairment, such as the sensation of pain, it ignores the social aspects of impairment, and it presupposes the possibility of removing all barriers to access in the world (218–220). It has also been noted that it was developed by men with spinal cord injuries and responded primarily to their conditions and needs, and has much less to say about neurodiversity, cognitive disability, or those who have more complex physical impairments. The emphasis in Oliver’s definition on missing or defective limbs illustrates this observation.

In another significant move, disability studies scholars challenged the nearly universal privileging of normative ability and “health,” an ideology captured by the term “ableism.” Lennard J. Davis’s book *Enforcing Normalcy* (1995) made an early and enduring contribution to disability studies by tracing the history of “normalcy” to its origins in the Industrial Revolution and the requirements of industrial labor, and demonstrating its deleterious impact on people with anomalous bodies and minds.<sup>21</sup> The rise of nationalism, as David Mitchell and Sharon Snyder show more recently in their article, “The Eugenic Atlantic,” also contributed to the privileging of the normal, as the strength of the nation was seen to depend on the fitness of its citizens.

Disabled people have been termed the world’s largest minority group, and as some disability studies scholars have noted, disability is the only minority identity that crosses the lines traced by other identity markers, such as gender, age, race, ethnicity, nationality, and sexual orientation. It is estimated that 10 percent to 15 percent of the population worldwide lives with a disability, and it is the one significant identity category that any one of us can enter at any time, and that most of us, as we age, eventually will.<sup>22</sup> Nevertheless, the great diversity of physical, cognitive, and psychosocial conditions that are categorized as disabilities and the inherent instability of any person’s status as “able” have prompted a rich debate over the meaning of disability as a minority identity and the coherence of the category itself. The work of Lennard Davis and Tobin Siebers represents important yet divergent positions in this debate. Davis, in his book *Bending Over Backwards* (2002), advocates for conceiving of disability as an inherently unstable identity category and for extending its application broadly across society against the background of the exhaustion of identity politics and contemporary science’s dismantling of the biological bases for many long-standing identity categories. (23–26).<sup>23</sup> Siebers in *Disability Theory* (2008) leaves the category of disability more or less in place, but argues for claiming disability as a valid and valuable form of human diversity, rather than a personal defect or misfortune (3). He posits that one of the strengths of persons with minority status, including the disabled, is that they are able to critique aspects of hegemonic ideologies from their position outside or marginal to the privileges that these ideologies grant (26).

Although the debate illustrated by Davis’s and Siebers’s positions is crucial to the evolution of disability studies, and relevant to Latin American contexts, it is complicated by scholarship on disability as a global phenomenon. As Robert McRuer’s discussion of global bodies underscores, the idea that “everyone will be disabled if they live long enough” shifts its function in the face of a display of coffins nailed to a wall near the Tijuana airport,

representing the number of Mexicans who die each year in attempts to cross the border, those who “didn’t live long enough” (200–201). And as Michael Davidson notes, “While it is true that many individuals will become disabled, it is just as certain that those who become disabled earlier in life (. . .) are poor and live in an underdeveloped country” (172). In his reading of globalized disability, Davidson further emphasizes that attention to community contexts necessarily undermines the model of disability based on individual rights (173). Reading disability in Latin American cultural production thus requires becoming attuned to diverse and sometimes conflicting models of disability identity, community, and the politics of inequality.

### Literary and Cultural Disability Studies, Latin Americanist Readings

Tanya Titchkosky and Rod Michalko’s statement that “studying disability” is not the same as disability studies has relevance for the project that this volume takes up (*Rethinking* 5). Their observation clarifies the critical split between a health sciences or medical model of disability and disability studies as a critical mode of inquiry in the humanities. That is, a disability studies approach to cultural production does not seek to diagnose disabled characters in literature and film, or to project desires for the characters’ greater adherence to normalcy, but rather to examine the narrative function and the cultural valence of the representation of disability. For this reason, narratives in which disabled characters “overcome limitations,” provide inspiration to readers and viewers, or serve to further the redemption of morally flawed but otherwise “normal” characters are frequently critiqued as problematic from a disability studies perspective. Such literary representation sustains the view that disability is a problem in need of a solution or is primarily valuable as an instrument of another’s salvation.<sup>24</sup> Instead, disability studies reads disability either as socially and politically constructed, or somewhere at the juncture or melding of the social and the corporeal as proposed by Siebers’s concept of “complex embodiment” (*Disability Theory* 23–25). Disability studies approaches to the humanities concur in viewing disability as a significant and valuable aspect of human experience, interaction and diversity as we have outlined.

Influential contributions to the study of literature from a disability studies perspective include David Mitchell and Sharon Snyder’s groundbreaking work, *Narrative Prosthesis* (2000) and Ato Quayson’s *Aesthetic Nervousness* (2007). Mitchell and Snyder advance the theory that literary fiction often depends on the representation of disability, like a crutch or

prosthetic limb, in order to tell its story, and to offer the illusion of tangible materiality to the text. A frequently cited term from this work is “metaphorical opportunism,” by which the literary work takes advantage of the seemingly evocative and meaning-laden qualities of the disabled body, in order to advance its own symbolic agenda. In reference to Mitchell and Snyder’s model, one might note that the recognized canon of Latin American literature is replete with characters who “suffer” from disability or disabling illness, and whose discursive presence and literary destiny primarily serve to jumpstart the narrative and further the development of the “able-bodied” protagonists of the texts. María, of Jorge Isaac’s eponymous novel, is both epileptic and “biologically Jewish” (although professing the Christian faith), and her death from tuberculosis conveniently removes her as an obstacle to her criollo lover’s assumption of his destiny in Colombia’s “national romance.”<sup>25</sup> Robustiana, Don Zoilo’s “consumptive” daughter in Florencio Sánchez’s play *Barranca abajo*, acts as a foil to her morally inferior kinswomen, and her death contributes to her honest, but ineffectual father’s decision to commit suicide rather than continue to live in a state of humiliation and powerlessness. In *Santa*, Federico Gamboa’s bestselling 1903 novel about a beautiful Mexican prostitute, the blindness of the piano player who falls in love with her is a convenient pretext for the detailed narration of her physical attributes, visible only to the musician’s young assistant. Thanks, too, to the man’s blindness, he remains a faithful lover despite the effects of age and the venereal disease that eventually kill Santa.<sup>26</sup> Similar instances of the prosthetic function of literary disability are legion, but have gone largely unexamined from a disability studies perspective.

Ato Quayson effectively adapts elements of Mitchell and Snyder’s theory to his analysis of disability in postcolonial literature. For Quayson, however, “this prostheticizing function is bound to fail” (210), meaning that the representation of disability ultimately unsettles its ostensibly categorical function. In many of the most familiar works of twentieth-century Latin American literature, too, the unstable function of the narrative prosthesis is apparent. This is strikingly so in major works of the Boom, such as Gabriel García Márquez’s *One Hundred Years of Solitude*, or José Donoso’s *The Obscene Bird of the Night*, novels in which the anomalous features of characters’ bodies seem to bring the stories to life, even as the narratives themselves center on the dizzying, otherwise ungraspable circularity of a repeating and frustrated project. In García Márquez’s text, national history becomes a seemingly endless procession of names, battles, and family generations that point not to a productive future but rather to a vortex of pre-determined self-destruction. The novel’s conclusion illustrates national and familial history as this fulfilled prophesy of destruction, through the figure

of a human infant with a pig's tail, the last of his lineage, who is ultimately devoured by ants. Here Quayson's notion of aesthetic nervousness, or the unmoored prosthesis, is useful in pointing to the ways in which disability underscores the continuous, self-reflexive unraveling of the narrative project.

The study of literature and film has an undeniable importance for disability studies, just as disability studies brings necessary new insights to our reading of literary and filmic texts. As individuals and as communities, we create our sense of self and other and our collective identities in large part through our absorption and processing of the stories that come to us through time and those that are continually produced in the present. Paul Ricoeur speaks of our "narrative identity" to capture the sense that human action and subjectivity are "entangled in the stories" and informed by the "intrigues we received from our culture" ("Life" 131). A historically and culturally situated disability studies is a critical tool for interpreting the stories that shape our lives and for enlarging the "narrative identity that constitutes us" ("Life" 131) in ways that are more inclusive and just.

The essays collected in *Libre Acceso*, with their focus on the roles and representations of disability in Latin American cultural contexts, necessarily highlight phenomena of stigmatized identity and radical social inequality that are inextricably bound to specific economic and politico-historical processes. These include racialized colonialist violence, instances of entrenched authoritarianism, and the material effects of contemporary global capitalism. Such conditions, it is worth noting, translate into higher percentages of disabled people in Latin America and in the Global South overall.<sup>27</sup> Indeed, recent scholarship on disability as a global phenomenon, whether from a social sciences perspective, or read through the lens of postcolonial discourse, often notes the socioeconomic disparities that produce unequal distributions of disability, and points to the need for disability studies approaches that would account for such global inequalities, while transcending dominant Anglo-American frameworks.

Shaun Grech has emphasized the need for a decolonization of disability analysis in the contexts of the Global South, pointing out the danger of what he calls "academic neo-colonialism" (Alatas, 601; quoted in Grech, "Disability and the Majority World" 59). He also notes the pervasive intertwining of neocolonial globalization and the oppression of disabled people, borrowing here from the work of key Latin Americanist thinkers such as Fernando Coronil and Aníbal Quijano. Along similar lines, Stuart Murray and Clare Barker address disability studies in the context of postcolonialism, contending that, "the history of colonialism . . . is indeed a history of mass disablement" (230). They contend that the common disability studies practice of criticizing associations between disability and trauma or loss

becomes problematic in contexts where, “the *acquisition* of disability may be tied into wider patterns of dispossession—the loss of family, home, land, community, employment” (230). The challenge for a global disability studies and for this volume is to maintain awareness of the situated contexts in which disability or disablement take place, as well as strategic responses to these contexts, while at once allowing for openness to more unpredictable meanings and valuations of disability, not necessarily limited by a logic of prescribed causality.

Reading disability and the construction of otherness in Latin American literary contexts also requires attention to traditions in which cannibalism, monstrosity, and racial difference frequently operate as mutually referencing figures and in which resistance to oppression may often stem from this dynamic. The ways in which disability sometimes emerges as a metaphor in Latin American literature is thus partially determined by elements derived from a colonialist tropology of otherness.<sup>28</sup> Although this discursive tradition is inseparable from the political and economic histories of the region, it is important to note that the literary discourses participating in the configuration of otherness and national or individual selfhood do not map directly onto an overarching reading of global capitalism and geopolitics, but instead add greater complexity to the representations and experiences of disability that this book examines.

### Libre Acceso

In the present volume our aim is to open an interdisciplinary and transregional dialogue on disability studies, so as to expand our analysis toward what disability might mean and might allow in its future Latin Americanist configurations, as well as in the interdisciplinary humanities more generally. To this end we employ a critical framework and chapter organization that highlight the tension between a Latin American lettered tradition that tends to emphasize what we call the cultural production of the self, and a focus on communities and populations through which the body becomes a feature of collective experience, practice, and representation. Paying attention to overlaps and points of contact between these seemingly divergent modes of reading Latin American cultural production allows us to consider the shifting characteristics of the field, and to locate disability as central to a dynamic through which collectives and selves might encounter, contest, or engage one another.

We have organized the thirteen chapters into four sections according to shared thematics and discourses. The sections themselves trace an over-

arching movement from a consideration of disability in the construction of individual identity and consciousness as expressed in autobiographical discourse; to an emphasis on collective phenomena and human rights in literary and filmic works of fiction and nonfiction; to an examination of the intersection of race and social marginality with disability; and concluding with two texts that create alternative worlds through the exercise of the imagination and authorial experimentation as modes of questioning typical categories of normative and anomalous embodiment and neurological function and of literary form. The question of disability in the analyses that comprise the book continues to define a tightrope walk between self and community and between localized, embodied, or represented experience, and the more globalized biopolitical readings that inevitably inform contemporary approaches to both Latin American cultural studies and theories of the body.

The three chapters that comprise Part I, “Disability Life Writing and Constructions of the Self,” represent divergent literary genres and writing styles around the common project of a writer’s exploring and inscribing his or her own identity as a person with a disability. The specific conditions of blindness and the physical limitations due to cerebral palsy inform the poetry, interviews, essays, short stories, and autobiography that are treated here. The opening chapter by the acclaimed Chilean novelist Lina Meruane stands apart from the other chapters of the book, as it is a literary essay with a significant autobiographical dimension and not a research study per se, and yet it also provides a disability-centered reflection on practices of reading and writing. In “Blind Spot: (Notes on Reading Blindness)” Meruane enacts a reading journey through the literature of blindness and traces the process of writing her most recent novel *Sangre en el ojo* (Seeing red), winner of the 2012 Sor Juana Inés de la Cruz Prize. To a greater degree than her other works, *Sangre en el ojo* represents a literary transformation of the writer’s own experience, that of temporary vision loss.

Meruane weaves several thematic threads drawn from texts by Jorge Luis Borges into her essay, and these are picked up and reworked in the following chapter on the famed Argentinian writer. The idea of disability as an advantage or a gift for the writer, the need for the blind person to “see” through the prosthesis of others’ eyes, and the “secret power” attributed to the blind in Western culture are concepts that reappear in Kevin Goldstein’s study of Borges’s poetry. In “La cara que me mira: Demythologizing Blindness in Borges’s Disability Life Writing,” Goldstein examines the resistance in Borges’s late work toward positioning the figure of the blind seer in isolation, and an expressed interest in the banality of the blind body. This demythologizing tendency coincides with a growing shift in Borges’s work

toward life writing: personal essays and lectures and, at times, nearly confessional lyric poems.

The final chapter of Part I “Negotiating the Geographies of Exclusion and Access: Life Writing by Gabriela Brimmer and Ekiwah Adler-Beléndez,” serves as a bridge from the autobiographical reflections highlighted thus far to the concern with collective identities and human rights in Part II of the volume. Beth Jörgensen’s chapter examines life writing by two Mexican poets and activists with cerebral palsy. This reading of *Gaby Brimmer* by Elena Poniatowska and Gabriela Brimmer and of poetry by Ekiwah Adler-Beléndez draws on theories of disability life writing, and incorporates Tobin Siebers’s theory of complex embodiment in an analysis that attends in part to sexuality and access to the spaces of pleasure as a particularly stubborn taboo for people with disabilities

Part II, “Global Bodies and the Coloniality of Disability” includes four chapters focused on dilemmas specific to the geopolitical locations of disability in Latin American cultural contexts. In the films and novel under consideration, disability representation appears as intrinsic to tensions between local and global economies, and to the individual and collective bodies through which such economies operate. The notion of collective bodies is crucial here, and illustrates a partial contrast with the mode of disability representation centered on the characteristics, experiences, and rights of the individual body as subject, as emphasized in the chapters of Part I. Emphasis on biopolitics and collective corporeality also contextualizes these essays in relation to contemporary debates in Latin American literary and cultural studies on the multitude and on theories of affect.<sup>29</sup>

Ryan Prout’s essay “Otras competencias: Ethnobotany, the *Badianus codex*, and Metaphors of Mexican Memory Loss and Disability in *Las buenas hierbas* (2010)” offers a reading of María Novaro’s film focused on the interplay between the pre-Columbian pharmacopeia as depicted in the *Badianus codex* and the global phenomenon of dementia diagnosed as Alzheimer’s disease. As Prout suggests, the film centers on a female ethnobotanist with Alzheimer’s, and incorporates visual material from a sixteenth-century indigenous herbal almanac, so as to move between the global and the local, and to offer an implicit critique of contemporary globalized biomedicine.

Following Prout’s essay and also treating film, “Crippling the Camera: Disability and Filmic Interval in Carlos Reygadas’s *Japón*” by Susan Antebi examines the role of cinematographic technique in contributing to an intercorporeal mode of disability as both representation and embodied identification. The technique is manifested when the viewer follows the uneven “limping” perspective of the camera and then sees in a subsequent frame that the protagonist limps and uses a cane. The essay argues that Reygadas’s

film creates a unique landscape through which diverse bodies and objects may become interchangeable, questioning the boundaries of individual bodies, and creating an unpredictable, at times collective mode of disability.

Victoria Dickman-Burnett takes up a related theme in her chapter, “Bodily Integrity, Abjection, and the Politics of Gender and Place in Roberto Bolaño’s *2666*,” by juxtaposing the role of the visual artist, Edwin Johns, who cuts off his own hand in order to increase the value of his paintings, with that of the violated and murdered bodies of the hundreds of young women of Santa Teresa, a fictionalized version of Ciudad Juárez. As this chapter shows, *2666* interrogates the dilemma of differently valued, exchanged, or commodified bodies in the borderlands between global North and South, space of a violent global marketplace through which bodies circulate and may become mutilated or disappear.

Part II concludes with Victoria L. Garrett’s essay, “Violence, Injury, and Disability in Recent Latin American Film,” focusing on Francisco Vargas’s *The Violin* (2005) and Claudio Llosa’s *The Milk of Sorrow* (2009). Garrett argues that the disabilities of the protagonists of both films intersect with their racial, social, aged, gendered, and/or political alterity to indict social injustice in their respective societies. In considering how recent Latin American cinema treats the injury that results from structural violence and violent states, the chapter takes up one of the key challenges of engaging disability in postcolonial contexts. Specifically, Garrett negotiates both the potential and the pitfalls of disability representation as an ethical intervention in the globalization of inequality.

The four essays of Part III, “Embodied Frameworks: Disability, Race, Marginality” continue the thematics of Part II by paying attention to disability in the representation of communities and populations, and as inseparable from the impact of global capitalism. More specifically, these essays highlight the complex roles of disability, race, and social marginality as metaphorical or at times literal cross-references of one another. The connected themes of fixed versus porous identity categories and intersectionality have become central to debates in disability studies, and link the field to gender and queer studies and critical race theory. As Patricia Hill Collins describes: “[a]s opposed to examining gender, race, class, and nation as separate systems of oppression, intersectionality explores how these systems mutually construct one another . . .” (63; quoted in Erevelles and Minear, “Unspeakable Offenses” 130).<sup>30</sup> As identities open toward the referencing or construction of one another, their boundaries may be called into question, returning us to the debate surrounding disability as a stable versus unstable category.

In “Sô Candelário’s Inheritance: Leprosy as a Marker of Racial Identity in João Guimarães Rosa’s *Grande Sertão: Veredas* (1956)” Valéria Souza

focuses on the portrayal of leprosy in this sprawling novel, set in the nineteenth century but in dialogue with ancient, medieval, and modern notions of disease and race, including frequent convergences between these categories. In Souza's analysis of the encounter between two leprous characters, one figured as white and the other as Afro-Brazilian, leprosy threatens to emerge as lighter marks on darker skin, confounding the division between the hereditary and the contagious, and intertwining anxieties of racial difference and illness. Melissa E. Schindler's chapter "*A solidão da escuridão: On Visual Impairment and the Visibility of Race*" also treats the intersecting categories of race and disability, but through emphasis on (primarily) Brazilian literary encounters between blindness and blackness, and on the related dilemma of "seeing" race.

Following these chapters on disability and race, are two essays that treat representations of mental illness. Nicola Gavioli's "Mythicizing Disability: The Life and Opinions of (what is left of) *Estamira*," similarly focuses on a Brazilian cultural context, but in this case emphasizing the construction and representation of psychosocial disability in documentary film. Gavioli examines the ethics of disability representation through an analysis that combines perspectives from disability studies with theories of testimonial literature, documentary filmmaking and trauma, in order to consider the intertwined dilemmas of authenticity, aesthetics and the representation and construction of marginality.

"'En ninguna parte': Narrative Performances of Mental Illness in *El portero* by Reinaldo Arenas and *Corazón de skitalietz* by Antonio José Ponte," closes Part III of the volume. Laura Kanost reads the two Cuban narratives in the context of national mental health policies of the 1980s and 1990s, under which many formerly institutionalized patients came to occupy a transitional placelessness, at times inextricable from the liminality of the socially marginalized. In Kanost's chapter, as in Schindler's, Souza's and Gavioli's, the characters' experiences of corporeal or cognitive differences complicate the historically and discursively determined categories they appear to occupy.

Part IV, "Imagining Other Worlds" concludes the volume with two chapters that examine the production of a disability aesthetic in works of experimental fiction that privilege the imagination as a way of resisting conventional categories of disability. Here we circle back to a focus on individual writers, and on the representation of individual disabled people, as in Part I, but without returning to the autobiographical mode. The chapter by Emily Hind, "The Disability Twist in Stranger Novels by Mario Bellatin and Carmen Boullosa" considers the dilemma of inclusivity and its limits in narrative fiction, through her analysis of experimental works by the two

Mexican writers. Hind suggests that alternatives to the traditional narrative arc that tends to diagnose and cure its characters allow us to reflect on the relationship between disability and novelistic fiction, even if such literary experiments do not ultimately transcend what Lennard Davis has referred to as the realist average that is central to the novel as genre.

Juan Manuel Espinosa reads Gabriel García Márquez's iconic *One Hundred Years of Solitude* alongside recent popular culture uses of characters with Asperger's syndrome in the book's final chapter. In "The Blur of Imagination: Asperger's Syndrome and *Cien años de soledad*," an understanding of the faculty of imagination based on Kant's definition provides an unexpected connection between the experience of reading the novel and that of misreading Asperger's. Ultimately, Espinosa's chapter argues against the ways in which a condition of apparent "otherness" like Asperger's has been medicalized, suggesting that the reading of *One Hundred Years of Solitude* can have a role in promoting an expanded, ethically sound response to the diversity of experiences and thought processes that constitute human life.

The research and writing of this volume has taken place at a time in which the field of disability studies, as well as that of Latin American literary, film, and cultural studies, have continued to undergo processes of self-questioning and critical redefinition. In disability studies, an increasing diversity of approaches, as well as attention to interdisciplinary models and to the paradigm of globalization have led some to express concerns that the field may be co-opted and diluted in its political efficacy. Latin American cultural studies, in the meantime, can no longer be primarily defined in terms of its alliances with the subaltern or with other political subjects, but instead represents multiple angles on the question of what might constitute a politically and culturally relevant Latin Americanist project, including approaches in which no identifiable subject of alliance is posited.<sup>31</sup> In both cases, the dilemma of the discipline's future hinges not simply on who or what is the specific subject with whom one communicates, identifies, or expresses solidarity. In tracing the movement between disability as articulation of the self, and as that of the collective, or more amorphous multitude, we have sought to underscore this critically productive tension as a focus through which to bring disability studies and Latin American literary, film, and cultural studies into dialogue. In addition, if disability in the contexts of Latin American cultural production demands long-overdue critical attention, it is equally true that Latin Americanism as academic discipline might benefit from turning to disability, not only as a key element of human subjective experience, but also as a social process that itself demands ongoing redefinition.

## Notes

1. Kreuzberger, or “don Francisco” is also the host of the popular television show, *Sábado Gigante*.

2. Brazil, Chile, Colombia, Costa Rica, El Salvador, Guatemala, Honduras, Mexico, Panama, Paraguay, Peru, and Uruguay. Teletón was modeled on the work of Jerry Lewis in the United States.

3. See Paul Longmore for a critical analysis of the use of disability in telethons in the United States.

4. Rafael Cabrera’s 2012 article in the journal *emeequis* offers ample evidence that in Mexico one of every three pesos donated to Teletón is from public funds, which go to supporting the organization’s privately built and run rehabilitation centers. He quotes Clara Judisman, a former secretary of Desarrollo Social in Mexico City as saying that Teletón has become a monopoly, to the detriment of other organizations and governmental services to disabled children.

5. Some disability studies scholars prefer the “people-first language” term of “people with disabilities.” Others favor the term “disabled people” as a way to emphasize that disability can be a central and celebratory element of human identity, rather than an incidental, secondary characteristic, or a motive for shame. As Tanya Titchkosky suggests, people-first language posits that disability is a problem to which this same language offers the solution; its goal is to “dismember disability from the self” (“A Rose By Any Other Name” 134). However, we note the frequent usage of “personas con discapacidad” (literally, “persons with disability”) in Spanish-speaking disability studies contexts, and we recognize that the appropriacy of terminology depends on a variety of contextual factors. For this reason, both terms appear at different points in the book.

6. Disability Rights International has conducted research on the abusive conditions in institutions for disabled people, particularly in psychiatric facilities, in Mexico, Argentina, Peru and Paraguay. See [www.disabilityrightsintl.org](http://www.disabilityrightsintl.org).

7. See Carolina Ferrante on this topic.

8. Latin American nations that are signatories to the Convention are Argentina, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Guatemala, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, and Uruguay.

9. James Charlton’s book *Nothing About Us Without Us* showcases the work of disability activists in Latin America and other world regions, primarily through interviews, in combination with a Marxist analysis informed by the British social model of disability. As scholars of Latin American studies will recognize, this title and the dynamic it invokes suggests close ties to the genre of *testimonio*, and to the highly politicized debates surrounding its role as literary and political discourse and as tool of education and resistance.

10. The U.N. report was covered in an April 15, 2010 article posted in the online version of the *Santiago Times*.