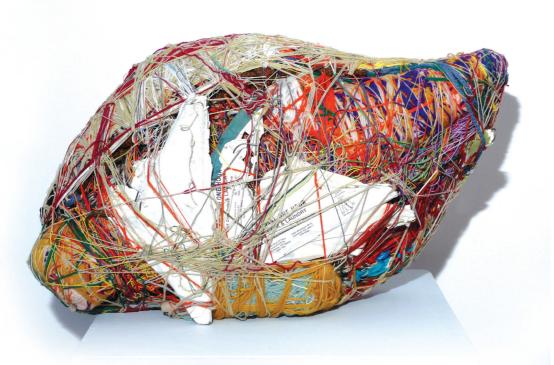
Disability Studies and Spanish Culture

Films, Novels, the Comic and the Public Exhibition

Benjamin Fraser



Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition

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Disability Studies and Spanish Culture

Films, Novels, the Comic and the Public Exhibition

Benjamin Fraser

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Introduction

In the introduction that launches his landmark 1997 reader on the Isubject, Lennard J. Davis notably frames Disability Studies as a political project, embracing an approach that envisions the field as at once 'an academic field of inquiry and an area of political inquiry' ('Introduction' 1). In my view, this is yet another way of embracing the critical aim of cultural studies as described by one of the eclectic (and still forming) discipline's founders, Raymond Williams. In 1986, Williams retrospectively summed up the premise of cultural studies as 'the refusal to give priority to either the project or the formation—or, in older terms, the art or the society' (152). In other words, the critic needs to grapple at once with the discourse of art (formal aspects, content, style, tone...) and also with the context in which a given work of art is produced (social, cultural, economic, political...) while attempting to give equal weight to each. In this study, this means attending not merely to issues regarding the cultural representations of disability—which are, of course, already political—but also to research foregrounding the real-world circumstances in which disabled people find themselves as they strive to find love and engage in meaningful work.

Rather than attempting an exhaustive treatment of the representation of disability in Spanish cultural products, this book is an attempt to bring a Disability Studies perspective to bear on selected Spanish materials as diverse as fiction films, documentaries, novels, and even the sequential art of the graphic novel/comic. While this book is undoubtedly a piece of humanities scholarship, it nonetheless establishes a selective dialogue with existing research on disability from a wide spectrum of approaches (philosophical, historical, social). Its

central focus, however, is the analysis of representations of disability in recent Spanish cultural products. In every case save one (the 1981 novel Angelicomio, in chapter 3), those cultural texts selected fall in the date range of 2004-11. It is important to point out that there is undeniably a social bias—both inside of Spain and elsewhere—that ends in the funding and mass-marketing of literary and filmic projects developed by physically and cognitively abled artists, to the detriment of disabled artists and producers. I do not defend this situation. I do believe, however, that if we want to understand, appreciate—and in some cases, perhaps even change—the kinds of images of disability that are routinely consumed by the able-bodied majority of contemporary societies, these projects must be discussed in depth and analyzed critically. This is intended not as a substitute for social science approaches to disability, but rather as a complement to such perspectives. While the cultural products analyzed throughout this book are of interest for their representations of people with disabilities, in the concise epilogue that concludes the book I turn to a 2011 exhibition of paintings, as well as comics, short stories, and poems, all produced by people with disabilities themselves.

Disability Studies at a Glance

This book has been conceived and written as a way of introducing general readers interested in the analysis of film, novels, comics, and other cultural products to a field with which they may not be very familiar. This being the case—and at the risk of repeating information with which specialists in Disability Studies are undoubtedly well versed—it is important to sketch out the general dimensions of this interdisciplinary field. Perhaps like many still-evolving and necessarily interdisciplinary academic fields, Disability Studies is the meeting place for number of scholarly concerns. These include 1) practical emphases on the education and social integration of people with disabilities; 2) more theoretical, philosophical, and aesthetic engagements with disability itself; and 3) of course, cultural issues implicated in the representation and ultimately even self-representation of people with disabilities—all of which will be discussed in this book. The general English-language reader will be, perhaps, more familiar with the first of these concerns given the high international visibility of such badly needed social reforms as the Americans with Disabilities Act of 1990 (ADA) and the disability rights movements that engendered it (see Carlson, Faces; also Carey, chapters 7–9). Even so, she or he may not

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be familiar with the nature of various disabilities themselves, nor with the reality that the struggle to secure full social rights for people with disabilities continues (Pardeck). At the risk of stating the obvious, it is important to point out that—contrary to what some may unfortunately believe—contemporary disability legislation has not, in one single blow, solved the social problems faced by people with disabilities nor has it even managed to effect lasting and satisfactory change.

It is also important to recognize the heterogeneity of the group commonly referred to as 'people with disabilities.' In reality, this label groups together people with greatly different needs and circumstances. For this reason it can be difficult to generalize regarding both the problems faced by the various populations with disabilities and also their potential solutions. Making such generalized discussions more difficult is the heterogeneity that characterizes even more specifically defined populations of people with disabilities (e.g. people with Down syndrome, people with autism). Just as the nature and severity of a disability can vary greatly, so too can individual circumstances and needs, which may in turn be informed by individual, familial, and regional variables, as well as degrees of access to existing institutions.

Whether in Spain or elsewhere, there is one trend in the approach to disability that speaks at once to the diversity of the existing academic subfields and also to the cultural geographies and life circumstances particular to a wide range of populations with disabilities. That trend involves the replacement of a medical paradigm of disability with a social one. A great deal of recent scholarship in Disability Studies speaks to a paradigm shift in the way we think of disabilities, which are no longer to be viewed as a purely medical issue (see Brosco). It is perhaps true that some degree or another of medical treatment may be necessary in certain cases in order to ensure that a given person with a disability can lead a relatively autonomous life—to give one example, the discussion of the autobiographical novel Quieto in chapter 3, about a father's shared life with his severely and multiply disabled son, advances a much more ambivalent perspective on medicine than other cultural products treated in this book. Nevertheless, the social paradigm of disability in many ways constitutes the foundation of the field of Disability Studies. This paradigm represents a staunch refusal to view people with disabilities through medicalizing discourses that frame disability as deviation or abnormality. In addition, the prevalent view that the able-bodied majority do not themselves pass through periods of dependency is mistaken, as will be discussed further in chapter 4.

Taking the first step toward understanding the social dynamics surrounding disability means recognizing that interdependency is the rule of human societies. We are all dependent on others: for food, clothing, and medical care; for support networks, social opportunities, and more. The issue is that, historically, people with disabilities have had to grapple with an able-bodied majority whose institutions, attitudes, and beliefs concertedly frame disability as a problem. The consequences of this entrenched viewpoint have been legion, leading to marginalization, neglect, medicalization, and even direct violence against populations with disabilities. As feminist/Disability Studies philosopher Licia Carlson succinctly reports in her book *The Faces of Intellectual Disability: Philosophical Reflections* (2010):

Historically, disability has been defined according to the medical model—viewed as a particular trait in the individual departing from what might be called *normal species functioning*. As many disability theorists point out, this model has been responsible for numerous beliefs and practices surrounding disability and the disabled. The view that disability is objectively abnormal and thus undesirable gives rise to a related constellation of assumptions that have been termed the 'personal tragedy model': that disability is objectively bad, and thus something to be pitied, a personal tragedy for both the individual and her family, something to be prevented and, if possible, cured. That notion that disability constitutes a blemish on the rosy face of medical science and societal well-being explains many of the practices associated with it, ranging from involuntary sterilization, institutionalization, and forced rehabilitation to social marginalization, euthanasia, and 'mercy killing.' (*Faces* 5, original emphasis; see also Carlson and Kittay)

In a similar fashion, scholar Harlan Lane points to what he calls the 'mask of benevolence' as a metaphor for what the medical paradigm of disability has routinely accomplished—the institutionalized oppression of people with disabilities under the guise of a helping hand, purporting merely reaching out to those in need. The preference for a 'social model' thus privileges the notion that 'disability' is a relational term (Carlson, *Faces* 5). That is, disability is not an objectively existing difference, but one that is constructed in relation to a given cultural environment and necessarily negotiated socially. By and large, Disability Studies scholars employ the social model in order to unmask the ways in which disability has been constructed within the popular imagination as necessarily standing in opposition to such equally created (and socially negotiated) notions as 'normalcy' and

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'able-bodiedness'—notions that are routinely taken for granted and that, moreover, are perniciously unmarked categories (see Carlson, 'Cognitive Ableism'; Davis, *Enforcing Normalcy*).

Even outside of Spain there have been relatively few academic treatments linking disability and cultural production, specifically—even if their number has been steadily increasing over the last decade or so. Although this book dialogues throughout—explicitly and implicitly with this wider tradition of socio-cultural studies of disability, here I will give just a small handful of examples. Disability Studies pioneers David T. Mitchell and Sharon L. Snyder begin their essential co-authored book Narrative Prosthesis: Disability and the Dependencies of Discourse (2000) with a preface that speaks to the way academic scholarship on disability grew out of work on other marginalized subjectivities (esp. ix-xiv) and an introduction that contextualizes their book as an attempt to 'locate disability's place on the map of multicultural studies' (2) by focusing on narrative art. Similarly, Tobin Siebers—as the author of The Subject and Other Subjects and also the editor of The Body Aesthetic: From Fine Art to Bodily Modification—has produced a corpus of work focused on issues of subjectivity and the body that he has recently brought to bear on disability (Disability Theory, published in 2008) and on disability and art explicitly (in his Disability Aesthetics, published in 2010). The central premise of this most recent work is that 'disability has a rich but hidden role in the history of art' (Siebers, Disability Aesthetics 4), and its author appropriately asks how treating this history more deliberately might change the way we view artistic production in general.

Apart from such pertinent and pointedly social and cultural analyses, many more titles in Disability Studies grapple with philosophical or otherwise theoretical questions relevant to the growing discipline. This is the case with Carlson's book, which maintains that 'philosophical questions that emerge in connection with intellectual disability are matters that not only are worthy of scholarly interest but speak to the deepest problems of exclusion, oppression and dehumanization' (Faces 3). Carlson has also published a volume, co-edited with Eva Feder Kittay, titled Cognitive Disability and its Challenge to Moral Philosophy (2010) in which 22 essays are organized around the examination of such themes as 'The Medical Model,' 'Justice,' 'Care,' 'Agency,' 'Speaking about Cognitive Disability,' and 'Personhood.'3 Similarly, as the author of such works as Enforcing Normalcy and Bending Over Backwards, the aforementioned scholar Lennard J. Davis has attempted to frame disability as 'the missing term in the race, class, gender triad' (Enforcing Normalcy, 1), mobilizing work on corporeality and forcing a confrontation with the framework of disability.

In fact, many Disability Studies scholars in the Anglophone world, while they may deal with disability specifically, see it as an important part of their work to draw connections between the interests of their primary field and the struggles of other marginalized subjectivities. Relatively new book series such as those from the University of Michigan Press ('Corporealities: Discourses of Disability,' edited by Mitchell and Snyder), Manchester University Press ('Disability History,' edited by Julie Anderson and Walter Shalick) and Liverpool University Press ('Representations: Health, Disability, Culture and Society,' edited by Stuart Murray) have been created specifically to address this lacuna in academic (cultural) treatments of disability—although to date none of the above has published a book devoted to Spanish issues or cultural production in Spain. Significantly, the aforementioned contributions have yet even to broach the subject of the wider Spanish-speaking world in any semblance of depth.

To my knowledge—although there have been a number of isolated essays published within the small subfield of Hispanic Disability Studies (e.g. those written by Madeline Conway, Encarnación Juárez-Almendros, Matthew Marr, Julie Minich, Ryan Prout, and Victoria Rivera-Cordero, as well as my own essays)—there has not yet appeared a book in English on disability in Spanish cultural production. To my mind, the only books devoted to disability in Hispanic cultural production at all are Susan Antebi's monographic work Carnal Inscriptions (2009), which focuses exclusively on Latin America, and my own edited/translated collection Deaf History and Culture in Spain (2009)—the latter inspired by Susan Plann's even more compelling (but historically focused) work A Silent Minority: Deaf Education in Spain 1550–1835. To put it simply: the book you are reading is the first of its kind. It bears repeating that this is not an exhaustive or encyclopedic work—there are thus many Spanish cultural products that focus on disabilities that have not been taken into account here. I have avoided certain films and books that have either already received some degree of scholarly attention or whose treatment of disability simply did not meet the needs of this volume. In the former category there are widely screened films such as Mar adentro (2004, dir. Alejandro Amenábar), Carne trémula (1997, dir. Pedro Almodóvar), Acción Mutante (1993, dir. Álex de la Iglesia) and Jardín de las delicias (1970, dir. Carlos Saura); while such nonetheless interesting works as 1% esquizofrenia (2007, dirs. Ione Hernández and Julio Medem), Piedras (2002, dir. Ramón Salazar), Desde mis ruedas (2002) by Asun Balzola, Soy Julia (2001) by Antonio Martínez, Mary Ann (1985) by Fernando Márquez and Los renglones torcidos de Dios (1979) by Torcuato Luca de Tena fall under the

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latter classification. I strongly encourage scholars seeking to interrogate representions of disability in Spanish literature and film to turn to these works as well as new works that are being published each year. Disability in Spanish cultural production—just as in Latin American cultural production—continues to be an almost completely unexplored area of academic research. Even works published in Spain on disability and culture tend to avoid a serious and sustained discussion of Spanish cultural products.⁴

Moreover, as the reader will note, this work is envisioned as a corrective to the path taken by what few sources on disability and Spanish culture exist. While it seems to be more common—both within and outside of Hispanic Studies—for scholars to discuss physical disability alone, this work is an attempt to give more attention to disabilities that are intellectual (developmental, cognitive, neurological) in particular. While research into the cultural representation of physical disability is no less important, this book's chapters focus overwhelmingly on Down syndrome, autism, agnosia/alexia, and cerebral palsy (although physical disabilities are also discussed briefly, for example in chapter 3's look at the novel Angelicomio). Such intellectual disabilities have not always been a part of the public discourse on disability, generally (internationally) speaking, and they have been overshadowed by physical disabilities in Spanish culture, specifically. It is not a requirement that this book's reader should have extensive knowledge of Spain or of Spanish culture. In order to give the reader a basis for understanding the state of representations of disability in Spain, the next section provides a concise overview of Spain's recent history with an emphasis on the flowering of disability organizations within the country's post-dictatorial context. This section begins by noting the recent global turn within the wider field of Disability Studies and ends by discussing a few high-profile, visual points of reference for understanding the current state of awareness of intellectual disabilities among the Spanish people.

Spain and the Global Turn within Disability Studies

Disability Studies is now entering a new, international phase. In 2010, the premier journal in the discipline—the *Journal of Literary and Cultural Disability Studies*—featured two special issues expressing an explicit commitment to the goal of pursuing a global or transnational vision for the field. In special issue 4.3, titled 'Disabling Postcolonialism,' editors Stuart Murray and Clare Barker provided an

important forum for discussions of disability and power in a range of contexts (Indian-American, Pacific Nuclearism, Canadian-Kenyan, Luso-African, Ghanaian, and Nigerian). In addition, in special issue 4.2 of that journal, editors David Mitchell and Sharon Snyder included five essays and an introduction grouped around the theme of 'The Geo-Politics of Disability.' Therein, the editors stress the concept of 'ablenationalism' as a way of potentially mapping the social dynamics of (dis)ability to concrete cultural realities in diverse national contexts. They write that:

One result of this effort is the ability to begin undertaking necessary comparisons and contrasts between people with disabilities around the globe. This is not in order to draw up universalizing conclusions about duplicative states of social rejection (the forms of social rejection experienced by people with disabilities are often quite unique), but rather to gain an understanding of the nuances of ablenationalism's tactics on a global scale. (114)

These are important and timely contributions to the recent global turn in Disability Studies. There is clearly a great need for studies that look at what is 'unique'—to use Mitchell and Snyder's term—about the cultural practices surrounding disability in Spain. For reasons having to do with the field of Hispanic Studies—my home discipline and the area from which I have recently moved into Disability Studies—I am not interested here, however, in arguing for the uniqueness or exceptionality of Spanish discourses on disability.

Instead, in the chapters that follow, I show how current Anglophone models of humanities disability scholarship are applicable to the Spanish context. I intend this to be part of a first wave of Hispanic Disability Studies. There may certainly be disadvantages to this approach. It is likely that these disadvantages may be more easily perceived by existing Disability Studies scholars working in social science fields or departments of English rather than in departments of Hispanic Studies, a field that has been somewhat slow to take an interest in disability. Nonetheless, I hope that this book will interest two divergent groups of researchers—those in Hispanic Studies already working on issues of corporeality, the body, and identity formation as well as Disability Studies scholars who routinely engage in close readings of cultural texts (films, novels, comic) in contexts outside of Spain.

Here, there is reason to assert the reality that Spanish films and literature are, of course, composed, produced, and marketed in an international context. My book is most attentive to this fact in Introduction xvii

chapter 4, which looks at a documentary film with Spanish directors and producers that was filmed in the United States (in English), focusing on an internationally known American fiber artist named Judith Scott. This international perspective, of course, is relevant to other chapters as well. Chapter 1's discussion of the representation of disability in two recent Spanish films follows logically from the fact that—internationally speaking—there have been far too few films in which characters with disabilities have actually been played on screen by actors with disabilities. Moreover, in chapter 2 the published autobiographical reflections (in English) of prominent writer and US university professor Temple Grandin, who has autism, are quite relevant to a Spanish graphic artist's portrayal of the life he shares with his daughter, who like Grandin also has autism. My hope is that my incorporation of Grandin's own work and story serve as a reference for readers familiar with Anglophone work in Disability Studies. Similarly, the medium of the comic/graphic novel is certainly one in which American culture, specifically, has had an enormous influence on graphic traditions in other countries, Spain in particular (see García). In addition, while chapter 3 looks at two books devoted to the topic of children with disabilities written and published in the Spanish context, it is short-sighted not to acknowledge that there is a growing, international selection of autobiographical books on that topic that are increasingly marketed to parents of children with disabilities—a publishing market for memoirs that is not without its own problems (see Piepmeier).

As a way of contextualizing the cultural analyses that follow, of course, it is nonetheless appropriate to reflect briefly on the Spanish context. Throughout much of the twentieth century, the Spanish people lived under the dictatorship of Francisco Franco (1939-75), which followed the Spanish Civil War of 1936-39. With Spain's post-1975 transition to democracy—and the Spanish Constitution of 1978—the country entered a period of 'staggering' changes: the fundamental change from dictatorship to parliamentary democracy, the adoption of a new constitution and reforms of statutes and administrative codes, the influx of younger generations into politics and trade unions, and many economic and social changes (Montero 315). Culturally speaking, democracy proved—unsurprisingly, of course—to be a much more tolerant environment for populations that had suffered marginalization and exclusion (if not worse) under the officially Catholic and undoubtedly machista Spanish society of Francoism. In the decade following the transition (the 1980s), identities of gender and sexuality that were excluded by Franco's

normativizing and patriarchal state—women, gays, and lesbians, for example—were celebrated, perhaps most famously in the films of internationally known director Pedro Almodóvar. With censorship officially done away with, the production of cinematic as well as literary and musical works increased notably. Spain's legacy of the cine social (social cinema) developed in the 1990s, in particular, favors the representation of 'present-day social problems (crime, drugs, domestic violence against women and children)' and brings 'Spanish cinema closer to European (and thus exportable) cinema,' as scholar Núria Triana-Toribio explains in her book Spanish National Cinema (156-57). Linguistically, those languages that had been officially outlawed by the Franco dictatorship—such as Catalan, Basque, and Gallician—experienced a resurgence, as publishing industries in those languages started up again. Politically, the socialist and communist strains of Spanish society that had flourished during Spain's Second Republic (1931–36) were reintroduced into a democratic state that officially embraced pluralism, even if old antipathies continued to linger for many years after Franco's death on 20 November 1975.

Although this book is not a historical treatment of disability in Spain, it is worth noting in passing that the dramatic social, political, and cultural shifts toward pluralism mentioned above have necessarily influenced the lives of disabled populations to some degree. By far the most powerful contemporary disability organization in Spain is one that is dedicated to a physical disability and that formed during the Franco dictatorship. The Organización Nacional de Ciegos Españoles (the Spanish National Organization of the Blind), or ONCE as it is popularly known—discussed at greater length in chapter 3—was formed shortly after the Spanish Civil War as a way of supporting the country's wounded. Nevertheless, over the years it has come to function as a sort of umbrella-organization for the needs and rights of other physically disabled populations. Even more important still, the transition to democracy has seen a notable increase in a range of other advocacy organizations tailored to the needs of specific groups of people with disabilities. As Spain's capital, Madrid is understandably home to the headquarters of many such organizations, which include, for example: ADISLI (the Asociación para la Atención de Personas con Discapacidad Intelectual Ligera e Inteligencia Limitada [Association for the Attention of People with Mild Intellectual Disabilities]), FEAPS (Federación de Organizaciones en favor de Personas con Discapacidad Intelectual [Federation of Organizations Supporting People with Intellectual Disabilities]), the Asociación para el Empleo y la Formación de Personas con Disacapacidad [Association

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for the Employment and Education of People with Disability], CERMI (Comité Español de Representantes de Personas con Discapacidad [Spanish Committee Representing People with Disabilities]), COCEMFE (Confederación Coordinadora Estatal de Minusválidos Físicos de España [State Confederation Coordinating the Physically Handicapped in Spain]), CNSE (Confederación Nacional de Sordos de España [Spanish National Confederation of the Deaf]), and many more. Moreover, the fact that the Spanish state comprises 17 autonomous communities and two autonomous cities and that several regions in particular boast their own state-recognized linguistic minority groups (speakers of Catalan, Basque, and Gallician in particular) assures the existence of a largely de-centralized approach to disability advocacy, with each region having created its own associations and organizations. The recent video Discapacidades humanas [Human Disabilities (2010), produced by the Fundación ONCE in collaboration with Productora FARO, estimates that 9 million Spanish people have some form of disability (DVD 1: "Presentación" 4:59), and—given its extensive interviews with a variety of people with disabilities and its pedagogical aims—it is a great place for some readers to start learning about the numerous Spanish organizations dedicated to people with varying disabilities.

A brief look at the recent highly publicized documentary titled Capacitados [Capacitated People] (2010)—promoted by Spain's ONCE organization on both Spanish television and on the web-provides an informative look at how far Spanish society has come since Franco's death, but it also points to the limitations of the current public discourse on disability in Spain. The strength of this video by a high-profile disability advocacy group is that it shows how even nonacademic, contemporary treatments of disability intended for large Spanish audiences are highly conscious of the opposition between the notions of 'able-bodied' and 'disabled' and more specifically of the central tenet of Disability Studies that disability resides not in the body of the individual but instead in the (social) environment. On the other hand, it must be stated from the outset that, perhaps because the documentary has clearly been made with the intention of reaching the widest possible viewing public, Capacitados thus risks a rather un-nuanced presentation of disability—one that necessarily fails to capture the full heterogeneity of Spain's disabled populations, those with intellectual disability, specifically.² Notwithstanding, even if it might ultimately fall short in this (important) category, the documentary is in a sense a welcome contribution to the public advocacy for populations with disabilities in Spain.

The 28-minute Capacitados seeks to give three prominent and successful able-bodied working professionals the experience of working a full day with a disability—chef Ferran Adrià must work in the kitchen of his restaurant El Bulli (located in Roses, Girona; now closed) 'con unos auriculares inhibidores de sonido, que le impiden oír por completo' [wearing sound-inhibiting headphones that prevent him from hearing completely]; Marcos de Quinto, the president of Coca Cola Iberia, spends the day 'con unas gafas opacas que no le permiten ver en absoluto' [wearing dark glasses that prevent him from seeing anything whatsoever]; and María Garaña, the president of Microsoft Ibérica, goes to work in her office in a wheelchair (see the booklet accompanying Capacitados, 7). Although Capacitados may not be as nuanced a treatment of disability as some of the cultural products discussed in greater depth in the following chapters, it nonetheless testifies to and dramatizes to great effect the general public's lack of understanding of the day-to-day realities experienced by certain populations with disabilities. After completing her own work experience, Microsoft Ibérica's president Garaña makes a poignant comment that recalls Carlson's characteristic Disability Studies notion of disability itself as a relation: she states that 'Esta experiencia me ha enseñado que la discapacidad no reside en las personas, sino en el entorno' [This experience has taught me that disability does not reside in people, but rather in the environment] (Capacitados booklet 9).

Capacitados is, of course, a welcome but not necessarily a unique attempt to educate the Spanish public on matters of disability. One recent 4-minute Spanish television news spot, for example (available also on the internet at YouTube.com as '2010 CERMI Madrid Tour Disacapacidad'), notes the inadequacy of city infrastructure for disabled populations in the northern Chamartín district of Madrid; ramps are non-existent or else inadequate, and auditory crosswalk signals are faint or else turned off during certain hours. Similarly—with great relevance for chapter 1 of this book—an extensive campaign has been launched collaboratively by two advocacy groups (both the Obra Social Caja Madrid and Down España) to promote 'Derechos para las personas con discapacidad intelectual' [Rights for People with Intellectual Disabilities], resulting in a series of notable television spots. One such 30-second spot (also available on the internet at YouTube.com, see 'Campaña') opens with the high-angle general shot from inside an apartment's second-story window depicting two blurry figures loading a moving truck on the street. As a female voiceover intones the words 'Nunca piensas que va a llegar este momento' [You never imagine that this moment will come], the viewer sees, in

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sequence, a mid-shot of a proud, smiling Spanish mother; next, a closeup of her hand brushing the empty coat hangers in her son's closet; and, finally, a another close-up shot of her picking up a photo of her son clad in ski-gear, his face obscured by ski-goggles. After clutching the photo close to her chest, she spies her son's mobile phone on the dresser and runs down to hand it to him as the voice-over says: 'Pero ahora sé que tiene que volar solo' [But now I know that he has to fly solo]. As she steps up to hand the phone to her son and give him a hug, a slow zoom accentuates the effect of the emotional musical sequence and we see that he is a young man with Down syndrome: the voiceover one again comes in to say 'Y yo voy a estar allí, aportándole' [And I will be there, supporting him]. A male voice—that of her son—then reads the words subsequently projected on the screen for the reader's benefit, which summarize an article of the recent UN Convention on the rights of people with disabilities: 'Artículo 19: Derecho a vivir de forma independiente y a ser incluido en la comunidad' [Article 19: The right to live independently and to be included in the community]. Similar TV spots dramatize other articles of the UN Convention for the Spanish viewing public, such as Article 27, the right to employment (see 'Campaña [2]'), and Article 5, the right to equality without discrimination (see 'Campaña [3]').

Such televised spots implicitly point to a growing international awareness of the need to secure rights for people with intellectual disabilities such as Down syndrome and autism, among others. Alison C. Carey's recent work On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America (2009), for example, makes it clear that intellectual disability is 'a contested social construction, not an objective biological condition. Activists draw on and construct various understandings of disability in their struggles to establish or restrict rights' (13; see also Carlson, Faces 86-91; Siebers, Disability Theory, chapter 3). As the recent Spanish video project Capacitados shows, however, there is much work to be done in Spain, just as there is elsewhere. Through its choice to foreground three physical disabilities in particular—relating to hearing, vision, and physical mobility—the project fails to discuss intellectual disabilities and in the end marginalizes them further. Spanish journalist Amparo Mendo is perhaps the contributor to the booklet accompanying the Capacitados project who best signals the limitations of this effort by pointing out a single, but incredibly revealing, flaw of the documentary project:

Ahora, sólo un 'pero': la discapacidad intelectual está tratada al final, con la aparición del ayudante de dirección, el chico que maneja

la claqueta. A mí me hubiera gustado un poco más un esfuerzo de imaginación para integrarla con algún personaje que hubiese vivido la experiencia de la discapacidad intelectual. Por todo lo demás, un diez. (43)

[I have only one complaint: intellectual disability is depicted only at the end, with the appearance of the director's assistant, the young man who works the clapperboard. I would have liked to see a greater effort to integrate it (intellectual disability) by way of the inclusion of someone who had to live the experience of intellectual disability. Everything else deserves a '10'].

Although she praises *Capacitados* overall, this drawback is for the commenting journalist a major one since 'Desafortunadamente, la discapacidad intelectual es la que menos llega a la sociedad' [Unfortunately, intellectual disability is the least socially visible of all] (43). If this video is any indication, it would seem that Spain—just as do other countries—has much more work to do if people with intellectual disabilities are to be more fully understood and integrated into contemporary society.

The large target audience of both the recent Spanish documentary Capacitados and the televised spots associated with the 'Rights for People with Intellectual Disabilities' campaign, to name just two recent and prominent examples, indicates that public awareness of disability in Spain may be reaching a new level. Even so, research that foregrounds the representation of disabled characters in Spanish cultural products—as opposed to social studies focused more directly on rights and educational or social institutions, or even medically oriented studies of disability (which may be largely peripheral if not anathema to scholars embracing the 'social model')—is a less-recognized if still growing subfield of Disability Studies taken as a whole. Although it is of great significance that intellectual disabilities such as Down syndrome, autism, and alexia/agnosia are now attaining widespread recognition through recent cultural products in Spain, it is important to underscore that this book is not content to discuss the mere fact of representation. While work that documents the representation of disability as the prioritized content of literary and filmic works is itself a greatly needed aspect of the political project of Disability Studies, this book—throughout—goes beyond mere content alone to analyze the formal aspects of the works looked at from the perspective of the literary/cultural critic. Ultimately it is not merely that disability is represented, but also how it is represented that matters. To once again

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invoke Raymond Williams's definition of cultural studies—although each chapter's discussion of a given work may tend to lean toward one or the other, *Disability Studies and Spanish Culture* seeks to put both the 'project [art] and the formation [society]' on equal footing. Each of the book's chapters thus seeks to blend artistic discourse with the discourse of disability.

Chapter Summaries

The goal of this project as a whole is to give the reader an understanding of the diverse ways in which various disabilities have been represented in specific Spanish cultural products and to explore how these representations themselves either resonate with an explicitly political project of Disability Studies or promote simplistic understandings of disabilities that have been extensively critiqued by a growing body of critical and theoretical work. In this sense, the book constitutes a uniquely Spanish contribution to the extensive debate surrounding the growing field of Disability Studies.

Chapter 1, 'Filming Down Syndrome,' blends Disability Studies as a political project with formal analyses of two recent Spanish films that have as their protagonists (multiple) people with developmental disabilities, specifically Down syndrome. Through a detailed analysis of both films and a simultaneous exploration of recent legislation on disabilities in Spain (and throughout Europe: the 2006 UN Convention on Disability, the organization Down España), the case is made for granting more autonomy to people with disabilities. At the same time, certain details of the presentation of the disabled characters in the films are of great theoretical interest, in that they differ in their presentation of the idea held by the more 'cognitively abled' member of society that disabled people are 'childlike' (Carlson 'Cognitive Ableism'). It is important to note that the representation of disability that occurs in the first film considered—titled Yo, también (2009)—is particularly path-breaking. Daniel is played by Pablo Pineda who is, in extra-filmic reality, the first European university graduate with Down syndrome.

The second half of the chapter briefly looks back to the film *León y Olvido* (from 2004) as a point of comparison. The goal is to read both the earlier film's successes and its failures from a Disability Studies perspective against the (in my estimation, somewhat more progressive) model offered by *Yo, también*. While *León y Olvido* functions as a well-intentioned corrective to the lack of depictions of disabled characters (and also to the lack of disabled actors) in Spanish films

more generally, the titular (bordering on incestuous) relationship between siblings León (who has Down syndrome) and Olvido (who must suddenly become León's guardian) is rendered in sensationalistic and over-dramatized terms that ultimately mitigate its significance. Nevertheless, the discussion also foregrounds the film's strong supporting cast of actors/characters with Down syndrome and its treatment of the theme of autonomy, which is subsequently addressed more fully by *Yo, también*.

'Envisioning Autism,' chapter 2, looks at the presentation of a single story across two different cultural products and types of visual media. The first half of the chapter thoroughly engages the graphic novel/comic book *María y yo* (2007) drawn by well-known Spanish graphic artist Miguel Gallardo. Gallardo—who made a name for himself within the context of the post-dictatorial cultural scene known as the Movida Madrileña during the 1980s—gives the reader a wonderfully complex, entertaining, and even educational, autobiographical look into the life he shares with his autistic daughter, María. The analysis of his comic blends discussion of the heightened notion of visuality for populations with autism (as per the writings of Temple Grandin) with an appreciation of the formal (comic-art) and pedagogical strategies employed by Gallardo in *María y yo*.

The latter half of this second chapter reads first-time director Félix Fernández de Castro's eponymous cinematic 'adaptation' of the comic book (*María y yo*, 2010) implicitly against Gallardo's original creation as both an extension of the latter and as a complex cultural product in its own right, focusing on each work's representation of disability. Ultimately, I see the film as a less nuanced cultural product that tends toward a medicalized view of autism where the comic book had largely avoided this problematic. In each case—whether in the original comic or in the film's use of comic-book sequences—the hypothesis advanced by Sarah Birge in her essay published in *Disability Studies Quarterly* rings true: 'Comics, a relatively understudied medium for representations of disability, have enormous potential for providing important critical perspectives in disability studies [through] depicting cognitive disabilities in the nuanced context of embodied life' (no pag.; see also Hacking and McGeer).

The third chapter, 'Narrating Childhood Disability,' looks at the presentation of children with disabilities in two underappreciated novels from contemporary Spanish literature. The first half of this chapter approaches an almost unknown novel by the Murcian writer Salvador García Jiménez by way of the theoretical paradigm of Disability Studies. Taking into account the definition of the 'social

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model' of disability signaled by various critics (both in the United States and in Spain), the novel Angelicomio launches a critique of the insufficient institutional and state support available for populations of adolescents with disabilities. Published in 1981—and notwithstanding the fact that its narrative action may be fictional—the novel marks a turning point in the developing awareness of this educational and formative issue, given that 1982 saw the passage of a 'Law on the Social Integration of the Disabled' (LISMI, Ley de Integración Social de los Minusválidos). Angelicomio captures in detail the internment and harsh treatment of a group of disabled children at a fictional institution in a rural area of Murcia, from the perspective of the education of children with a range of disabilities. The analysis of this novel synthesizes discussions of novelistic form and content with an eye toward indirectly critiquing educational policies that evolved under the Spanish dictatorship and that lasted through the transition to democracy (1975) to the 1982 implementation of LISMI.

The second half of chapter 3 launches ahead to the 2008 publication of the autobiographical novel Quieto by Màrius Serra, which narrates seven years in the life of his disabled son, Lluís (nicknamed Llullu). From Angelicomio's treatment of multiple children with disabilities, we pass to discussion of a single child with multiple disabilities. Whereas García Jiménez's novel embraced a strongly social model for disability, the novelistic treatment of the severe nature of Llullu's disabilities serves as a limit point of sorts for that model, reminding the reader that medical treatment is sometimes an integral part of living with disability. Nevertheless, even in this limit-case, Quieto proves to be remarkably similar to Angelicomio in that it denounces the false promise of a miraculous religious 'cure' for disability and actively mitigates the need for a medical model of disability even as it accepts medical treatment as a fact of Llullu's life. Moreover, the ingenious folioscope (flip-book) included in the final pages of Serra's novel (pp. 157–219) alone makes this novel worthy of critical attention, as it foregrounds matters of mobility and expresses artistically and compellingly the author-father's frustrated dream that his son one day run.

Chapter 4, 'Documenting Cognitive Disability,' turns to two documentary films produced by noted Spanish director Julio Medem on the topic of disability. While Medem is well known for his complex and visually stunning fiction films (e.g. *Amantes del círculo polar, Tierra, Vacas*; on the latter see Fraser, 'Hacia una teoría'), he has in recent years become even more prominent as a producer through his production company, 'Alicia Produce.' This company, which is named after his daughter who has Down syndrome, has produced a number

of films pertinent to the topic of disability. Here, Medem himself adopts a supporting role as comparatively lesser-known directors take the lead in constructing intriguing cinematic portraits of disabled protagonists. The first half of this chapter looks at the 2006 documentary, ¿Qué tienes debajo del sombrero? (dirs. Lola Barrera and Iñaki Peñafiel), which focuses on the life and art of American fiber artist Judith Scott (1943–2005), who had Down syndrome and was also deaf (see also Siebers, Disability Aesthetics 15–19; Sedgwick). On the way to suggesting innovative social and even economic models of inclusion for people with disabilities, close readings of specific scenes from the film dismantle the medical understanding of disability and examine the unusual opportunities offered by the Creative Growth Art Center, where Scott worked for many years as an artist.

The second half of chapter 4 moves on to consider the representation of disability that obtains in another (understudied) documentary film produced by Medem's company: Más allá del espejo (2007, dir. Joaquím Jordà). As with ¿Qué tienes...?, celebrated documentary filmmaker Jordà's Más allá portrays the social significance of disability instead of a medicalized view—here focusing on Esther Chumillas, and even on the director himself, as a way of drawing attention to visual agnosia and alexia. The film is not merely informative about the social consequences of living with these neuro-visual disturbances, it also develops an artistic chess-game metaphor to invite further meditation on larger scale issues associated with the general frailty of the human condition. As with previous discussions, it is not merely the content of the film that is of interest, but also the documentary's formal properties.

Finally—following on the heels of the discussion of the representation of American artist Judith Scott by Spanish directors in chapter 4—the epilogue of this book, 'Exhibiting Art,' glances at paintings, comics, short stories, and poems produced by Spanish artists with developmental disabilities themselves. Rather than analyzing these works at length, instead a concise argument is made for the importance of analyzing such self-representation and self-advocacy by disabled artists in future scholarship.

Notes

1 On the matter of the CNSE and deafness in Spain, see my *Deaf History and Culture in Spain* (Gallaudet University Press, 2009) as well as my essays 'Deaf Cultural Production in Twentieth-Century Madrid,' *Sign Language Studies*

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(2007), and 'Spain, 1795: A Reconsideration of Lorenzo Hervás y Panduro (1735–1809) and the Visual Language of the Deaf,' *Dieciocho* (2010). It is important to note the distinction between deaf with a lower-case 'd' and capital-D Deaf—the first being a disabled group, and the second being a linguistic minority with a shared culture. As my work with the Deaf in the past has focused on the Deaf as a cultural and linguistic minority, I have chosen not to address deafness in a book on disability such as this one—apart from chapter 4's Judith Scott, who had Down syndrome and who was also deaf.

- 2 Capacitados has been distributed along with a 64-page book that greatly adds to the documentary's treatment of disability by including introductory texts as well as 26 two-page spreads featuring comments by prominent journalists, intellectuals, and performers.
- 3 In my estimation this book is additionally important as in some respects it compensates for the fact that 'Affect' studies has been unable to substantially grapple with Disability Studies, as is evidenced from the lack of discussion of disability in the otherwise impressive collections *The Affect Theory Reader* (Gregg and Seigworth, eds., 2010) and *The Affective Turn* (Clough and Halley, eds., 2007).
- 4 I was thrilled, for example, to get my hands on a copy of Olga María Alegre de la Rosa's book titled *La discapacidad en el cine* (Tenerife: Octaedro, 2003)—only to find that the vast majority of its contents related to disability in film outside of the Spanish context. The work is heavily slanted to focus on Hollywood films. The only Spanish titles I could find were *La torre de los siete jorobados* (1944) by Edgar Neville and Jacques Tourneur (starring Antonio Casal and Isabel de Pomés), *El bosque del lobo* (1970) by Pedro Olea (starring José Luis López Vázquez and Amparo Soler Real), *La noche sagrada* (1992) by Nikolas Klotz (starring Miguel Bosé), *Mater Amatisima* (1980) by José Antonio Salgot (starring Victoria Abril and Julio de la Cruz), and *Habla mudita* (1974) by Gutiérrez Aragón. Also mentioned were *Los olvidados* (1950) and *Tristana* (1969) by Luis Buñuel, and Almodóvar's *Carne trémula* (1997).

CHAPTER 1

Filming Down Syndrome

Yo, también (2009) and the Political Project of Disability Studies

Aquellas sociedades que dividen y apartan a las minorías son sociedades mutiladas.

[Those societies that separate and cordon off minorities are mutilated societies.]

Daniel, protagonist of Yo también

t the heart of Álvaro Pastor and Antonio Naharro's film, Yo, también [Me, Too] (2009), there is the seed of a wonderfully understated political project, pushing for the full social and economic inclusion of people with disabilities, developmental disabilities in particular. Screened at festivals in both San Sebastian and Cannes (2010), the film documents a crucial and transitional period in the life of Daniel, a 34-year-old Sevillano who has become Europe's first person with Down syndrome to have obtained a university degree (to this extent, the character reflects in broad strokes the life of university graduate and lead actor Pablo Pineda, who, like the character he portrays, also has Down syndrome). Daniel, whose portrayal won Pineda San Sebastian's Concha de Plata [Silver Shell Award] for Best Actor, takes a job in public administration advocating for people with disabilities, where he meets Laura (Lola Dueñas, winner of the Goya award for Best Lead Female Actor). Widely disseminated publicity images for the movie present Daniel and Laura laughing together on a beautiful day by the water, intimating the possibility of an amorous relationship between the two that might complement their working relationship. Similarly, the official synopsis of the movie emphasizes this theme of love, recounting that 'Ambos inician una relación de amistad que pronto llama la atención de su entorno laboral y familiar. Esta relación se convierte en un problema para Laura cuando Daniel se enamora de ella' [The pair initiates a friendship that soon attracts the attention of their co-workers and families. This relationship becomes a problem for Laura when Daniel falls in love with her]. Nevertheless, *Yo también* is more than just a love story. The dual thrust of the film is to strongly advocate for equality for disabled people in the realms of both love and work; in the process, it provides filmic anchors for specific articles of the 2006 Convention on the Rights of People with Disabilities.

There is, in fact, a wide range of critical literature that can aid viewers in understanding the complexity of the film's advocacy for disabled populations. The following contextualization thus emphasizes the film's resonance with arguments by scholars who frame Disability Studies as a specifically political project, one that requires unmasking the power structures associated with terms such as 'normalcy' and 'dependency' (Carlson, 'Cognitive Ableism' 141; Davis, Enforcing Normalcy xii; Kittay, Jennings, and Wasunna 443; Sedgwick 23). It is also important to underscore the film's careful presentation of disability in general terms by pointing to criticism that has highlighted the often-skewed representations of disabled people that appear in popular media forms (Rapley, Riley). The analyses that follow thus turn, first, to the sphere of love, and second, to that of work, as a way of giving equal weight to both the film's love story and to the non-amorous aspects of its political project. In reality neither of these can be separated from the other, a case that is made compellingly by the film. Each of the subsequent sections once again makes a point of engaging with the growing body of critical literature on disability. In the end, Yo, también is a compelling point of entry into the long-unfolding struggle to secure for persons with developmental disabilities the right to make their own decisions and life choices—to enjoy the autonomy that the cognitively abled routinely take for granted.

The Politics of Disability Studies

Disability Studies is not merely an academic subject but is, in fact, a political movement that attempts to correct for a long history of academic neglect and social inequality. As Lennard J. Davis has written:

The case must be made clear that studies about disability have not had historically the visibility of studies about race, class, or gender for complex as well as simple reasons. The simple reason is the general pervasiveness of discrimination and prejudice against people with disabilities leading to their marginalization as well as the marginalization of the study of disability. Progressives in and out of academia may pride themselves on being sensitive to race or gender, but they have been 'ableist' in dealing with the issue of disability. While race, for example, has become in the past twenty years a more than acceptable modality from which to theorize in the classroom and in print, a discourse, a critique, and a political struggle, disability has continued to be relegated to hospital hallways, physical therapy tables, and remedial classrooms. The civil rights movement, a long history of discussion of the issues around slavery, the attention demanded by the 'problem' of inner cities, and governmental discrimination have created a consciousness among progressives that legitimizes ethnicity as a topic for cultural study [...] but it has been virtually impossible to have a person teaching about disability within the humanities. ('Introduction' 1)

From this perspective, the move to discuss disability in the classroom or publish books and articles on disability as it has been represented in cultural products—while still somewhat novel in the humanities and virtually non-existent in Hispanic Studies, specifically—is an important part of raising social awareness and political consciousness of the rights and struggles of populations with disabilities.

Another component of the present approach is to understand how simplistic are perspectives that frame disability as a deviation from the self-sufficiency and independence that presumably define a state of 'normalcy.' As noted feminist philosopher Licia Carlson has written, turning her attention to (in this case intellectual) disability, we must first dispense with the perspective of cognitive ableism, 'a prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the potential for them) against those who are believed not to actually or potentially possess them' ('Cognitive Ableism' 140; original emphasis). Her inversion of the terminology through which people with intellectual disabilities have been historically framed in terms of lack represents a challenge to the colonizing ideology embedded in the prevalent use of terms such as 'feebleminded.' Theorists such as Carlson and others have worked to establish broad-based critiques of marginality, forming connections between and across various marginalized groups in order to displace the hegemonic power upheld by processes of social, cultural, and economic exclusion.¹

As critical scholarship on disability has underscored (Kittay, 'When Caring, 'Love's Labor; Kittay, Jennings, and Wasunna; Sedgwick; Carlson, 'Cognitive Ableism'), there is a fundamental conceptual problem that needs to be addressed, whether in Spain or elsewhere—that of viewing disabled populations merely as a foil for an able-bodied majority. This majority tends to (and has the social power to) support a peculiar image of themselves as 'normal,' a view that is bolstered by what Kittay, Jennings, and Wasunna call 'the myth of the independent, unembodied subject' (445). Contrary to this view, they make clear—drawing on Marx's declaration that we are a 'species being'—that dependency is in fact the basis for the human experience (see also the essays in Carlson and Kittay's co-edited 2010 volume titled Cognitive Disability and its Challenge to Moral Philosophy). We are all born as dependent beings, and we are also confronted throughout life with longer or shorter periods where we are 'inevitably dependent' (443). Speaking more generally, she asks the rhetorical question: 'Who in any complex society is not dependent on others, for the production of our food, for our mobility, for a multitude of tasks that make it possible for each of us to function in our work and daily living?' ('When Caring' 2001 570).

Importantly, Yo, también begins with a strong statement shunning marginalization and pushing for inclusivity. Intercalated amid the film's initial establishing shots are close-ups of Daniel delivering a formal lecture before an attentive audience, wherein he argues powerfully for the necessary inclusion of all minority groups in Spain's democratic society.

Es como el cuerpo humano. ¿Qué sería del cuerpo sin sus miembros? Sí, son frágiles. Porque aquellas sociedades que dividen y apartan a las minorías son sociedades mutiladas. No están unidas. Parece como si cada uno fueran islas desiertas. Eso es lo que no se pretende. Lo que quiere es todo lo contrario, es unir. Aquí no hay ni mujeres, ni negros ni homosexuales ni nada. Aquí todos somos personas. Por eso el trabajo nos ayuda a sentirnos parte de esta sociedad, porque lo somos, siempre lo hemos sido, y queremos tener voz en esta sociedad, que para eso se llama democrática. Muchas gracias.

[It is like the human body. What would happen to the body without its limbs? Yes, we are fragile. Because those societies that separate and cordon off minorities are mutilated societies. They are not united. It is as if each person were a desert island. This is not what we need. What we need, on the contrary, is to come together. Here there are neither women, nor blacks, nor homosexuals, nor anything else. Here we are

all people. It is for this reason that work helps us to feel a part of this society, because we are, we have always been, and we want to have a voice in this society, which is after all a democratic one. Thank you.]

The intercalated shots of Daniel are gradually repositioned as if to constitute a pan of approximately 90 degrees, starting from his left side, settling in front of his podium, and alternating throughout with shots of audience members listening intently. Tying the initial shots together, the upbeat song 'I Don't Believe in Love,' by the band The School, works together with the images to encourage the film's viewers to see the speech as moving and even inspirational. Daniel's closing words are received with applause, and a final punctuating close-up allows viewers to share momentarily in his satisfaction with his successful delivery. The topic of disability, here, is not explicit but instead implicit in the speech—it is embodied in Daniel's performance. Tellingly the word 'disabled' is not even uttered (at least in the section of his lecture presented on screen).2 This detail, which may seem to constitute a curious omission for many viewers, in fact reflects the wider arc of the film. Throughout, directors Pastor and Naharro have avoided, on the whole, the superficial presentations of disabled populations that routinely obtain in media products. In his book Disability & the Media (2005), Charles Riley, for example, has critiqued such superficial representations, pointing to the ubiquitous media formulas that emphasize either the 'sadcrip' or the 'supercrip' (see also Enns and Smit). In short, either a person is deemed sufficiently disabled so as to have earned the viewer's pity or, on the flipside, the person seems to have transcended his or her disability so as to have earned the viewer's respect. The clinical perspective of disability as a problem to be solved, as scholar Mark Rapley notes in his book The Social Construction of Intellectual Disability (2004), frequently appears in films and television programs. In Yo, también, however, this trend is wonderfully displaced by a social perspective: Daniel, his brother Santi, and the latter's wife Reyes all work in some position related to the public administration of disability programs and decidedly not in a medical or clinical context.

Although the film deals in part with the trope of normalcy (its tagline reads '¿Para qué quieres ser una persona normal?' [Why do you want to be a normal person]), its emphasis is not on the proper assimilation of disabled people into a 'normal' society, but rather on the rights of this population to lead as rich and full a life as they desire, however that might play out. In this, the film holds true to the Convention on the Rights of Persons with Disabilities promulgated by the United Nations as recently as 2006 (opened for signature in 2007, entered into

force in 2008). In the prologue to a lengthy publication dedicated to the Convention, the president of the organization Down España writes:

De todos los derechos que la Convención Internacional de los Derechos de las Personas con Discapacidad—del año 2006—reconoce a las personas con discapacidad intelectual, quizá el más importante y al mismo tiempo el más inesperado (respecto de las que tienen discapacidad física, nadie lo pondría en duda) es el que hace mención de su 'libertad de tomar las propias decisiones.' Con autonomía personal, o sea, con independencia, con su escala de valores, con su propio criterio; acertado o equivocado, pero el suyo. Es el primero de los ocho principios en los que la Convención pretende fundamentar toda su labor y lo incardina nada menos que en la 'la dignidad inherente' a las personas. (9)

[Of all the rights secured for people with intellectual disability by the International Convention on the Rights of People with Disabilities—from the year 2006—perhaps the most important and at the same time the most unexpected (no one would doubt its relevance for people with physical disabilities) is that which specifies their 'freedom to make their own decisions.' Via personal autonomy, or rather, independence, their own prioritization of values, their own criteria; either right or wrong, but in any case their own. This is the first of the eight principles upon which the Convention seeks to ground all of its work and it is firmly rooted in (recognizing) 'the inherent dignity' of people.]

In Spain, as in other countries, this UN Convention represents a paradigm shift in the approach to disability in that it underscores the right for persons with disabilities to lead autonomous lives. As we saw in the Introduction to this book, specific articles of this UN Convention have been translated into a massive televised campaign to raise public awareness of the rights of disabled people (see also 'Campaña', 'Campaña [2]' and 'Campaña [3]').

A few words are perhaps in order regarding the history of disability legislation in Spain. Gloria Soto and Orit Hetzroni's article 'Special Education/Integration in Spain' (1993) provides the following abbreviated outline: although there was no institutionalized education for children with developmental disabilities prior to 1900, the first half of the twentieth century saw the establishment of segregated schools for the disabled, and by the 1960s there arose demands for educational rights on the part of parent associations and social services departments, demands that were unfortunately left unaddressed by

the Spanish government under the Franco dictatorship. The General Education Law of 1970 'formulated the special education concept' (182), and the creation in 1975 of the Instituto Nacional para la Educación Especial (under the Ministerio de Educación y Ciencia) established educational curricula, coordinated educational services, and designated economic resources to that effect. The Spanish Constitution of 1978 made education a universal right regardless of a disabling condition, and the 1980s saw the creation of new public policies and laws, among them the important Ley de Integración de los Minusválidos (LISMI) of 1982, which was followed by subsequent positive steps forward.³

The film Yo, también does well in highlighting some of the most notable successes that have ultimately come out of this legislative and social struggle for equality, giving us frequent visual access to an innovative, if fictional in this case, day program for adults with disabilities. The center known as Danza Móbile, run by Santi and Reyes together, boasts a fully equipped dance studio and provides opportunities for both choreographed group dances and individual dance therapy. Still, we become aware of the relative lack of support for such programs when Daniel goes behind his agency's back to get Pedro a 'visiting spot' in a program that is otherwise at full capacity. This not only provides the young man with disabilities a place to go during the day, but also saves his mother from the costly burden of having to look after him herself while holding down employment. While the film's twenty-first-century representation of the opportunities available to people with developmental disabilities necessarily goes beyond what would have been feasible in the 1960s, and though Daniel (who is a university graduate) certainly is an exception to previous norms, 4 Yo, también is far from presenting a self-congratulatory view of the state of Spanish integration. Integration, after all, may not be enough if it is accompanied by a perspective that denies true autonomy and independence to people who become systematically identified by their disability alone. Pastor and Naharro's film, as discussed below, clearly points out that there is more work to be done, particularly with regard to love and work.

Love in the Wake of a Clinical Perspective on Disability

As developed throughout *Yo, también*, the theme of love constitutes an attempt to go beyond a clinical view of disability, to bring Daniel and Laura together by emphasizing their shared, universal human desires,

and ultimately to advocate for the rights of its other disabled characters to lead the same fully realized if necessarily interdependent lives—lives that cognitively abled people are routinely permitted to lead with much greater autonomy. While the formal aspects of the film are perhaps purposely understated (and as a result somewhat conventional),⁵ they nevertheless serve to underscore this theme throughout. The recurring trope of a heart, for example, functions as a visual touchstone reminding us of the importance of love, in the process providing consistency across the film's various storylines: Daniel gives Laura heart-shaped earrings and, during their outing to the beach, applies sunscreen on her back in two arcs that likewise form a heart. Further, in the storyline concerning the budding relationship between Pedro and Luisa (two adults with developmental disabilities who meet at the film's highlighted day program at Danza Móbile), a key prop discovered by Luisa's mother shows a heart drawn around Pedro's name on a piece of paper, and Pedro later shows Daniel a heart he has had tattooed on his arm as a gesture of love for Luisa. Nonetheless, the very success of the film lies in its ability to use the theme of love to draw attention to the way in which the needs, desires, and the very autonomy of people with disabilities are habitually subjugated to a clinical view of disability. The consequences of this subjugation are such that the person with disabilities is either forced to break established rules to experience the togetherness they see all around them or to necessarily resign him- or herself to a life of loneliness.

This pair of limited options routinely presented to adults with disabilities is very clearly embodied in the increasing attention devoted by the film to the emerging relationship between Pedro and Luisa. This relationship develops in parallel to the one between Daniel and Laura—perhaps as a way of preventing the film's viewer from adopting a convenient stereotype that disabled populations approach love in a given way, and thus encouraging a richer and more personalized understanding of such experiences. When Pedro is given a spot in the Danza Móbile day program (through the efforts of Daniel and Santi's ability to operate outside institutional procedures to the benefit of people with disabilities and their families), his dancing ability quickly catches Luisa's attention. One day, Reyes returns to the studio room to clean up and finds the two of them making out on the floor. She explains to them that they cannot do such intimate things in a public place, pointing out that they do not see her and Santi doing such things in public. The lack of autonomy afforded the pair influences their access to space and thus their ability to secure time alone. When Luisa's mother, having found her

daughter's drawing of a heart around Pedro's name, complains to Santi and Reyes (in an infantilizing tone) that the problem is Luisa's inability to distinguish between a 'dancing partner' and a partner 'in reality' ('distinguir entre pareja de baile con pareja en la realidad'), she feels forced to withdraw Luisa from the day program for as long as Pedro is attending. Pedro ultimately manages to find the bakery where Luisa works with her mother, and, reunited, the pair waste no time, stealing away with cash and a wedding cake for what becomes one of the most rollicking sequences of the film. Since they have no access to a space of their own, Luisa and Pedro pay for a carriage ride, eat cake, dance in a plaza with a homeless man who joins in the fun, and ultimately decide to check into a pensión (an inexpensive boarding house) with the hope of a more intimate encounter. The pair's escape predictably prompts desperation on the part of Luisa's mother, delight on the part of Luisa's dance class partners, general frustration for the administration of Danza Móbile-and it ultimately makes for a key piece of dialogue between Santi and Daniel reflecting on the lack of autonomy generally experienced by people with disabilities as regards feelings, love, and desire:

- —Vamos a ver. Esto no es el fin del mundo. Sólo quieren estar juntos.
- —Daniel. No han ido a la universidad, Daniel.
- —Pero no hace falta estudiar para tener necesidad.
- —Necesidad, ¿Tú sabes el morrón que tengo? Si tienen necesidad que se masturben.
- —Pero eso no es todo. Es tener compañía, es tener afecto, es tener algo.
- [—Let's see. This is not the end of the world. They only want to be together.
- —Daniel. They haven't attended college, Daniel.
- —But one doesn't have to have studied to have needs.
- —Needs... do you know the trouble I'm in? If they have needs, let them masturbate.
- —But that isn't everything. There is (the need to have) a companion, affection, something.]

Underlying Daniel's words is the fact that even in the twenty-first century, even after the UN Convention, the physical and emotional rights of people with disabilities to love and to express affection and desire are far from secured.

The film notably goes to great lengths to showcase the reality of such needs throughout,⁷ perhaps most dramatically when Daniel

becomes flustered by Laura's ongoing rejection of his advances during a work outing. Seemingly in response to her questioning if he has ever tried prostitution (a question which he initially answers by humorously asking her if she thinks women would pay him for his services—'¿Tú crees que las mujeres me pagarían?'), Daniel takes a cab to a brothel where he is referred to as a child by the bouncer and turned away at the door despite his protests that he is 34 years old and holds two credit cards. While perhaps this may not be what is meant by Article 30 of the UN Convention securing 'Participación en la vida cultural, las actividades recreativas, el esparcimiento y el deporte' [Participation in cultural life, recreational activities, amusements and sport], it nevertheless points to the gap between the access to society afforded cognitively abled people and the limitations placed on the needs and desires of persons with disabilities.8 In treating Daniel as a child, the bouncer models a reaction to adults with disabilities that is all-too-common—and yet the film's directors have focused equally on Daniel's ability to make such misconceptions work for him, as seen in the way he initially seeks out Laura's affection. When they first meet, Laura tellingly mistakes Daniel for a client and not a co-worker, even though his arrival has been clearly announced and anticipated by all. He soon takes advantage of this to play the victim around her, hoping to receive more attention: and for this he is well rewarded. When Daniel asks Laura to direct him to a photocopier that is not broken, he allows her to think he has not understood her exaggeratedly deliberate instructions, forcing her to accompany him and allowing them to spend time together. Similarly, he often allows her to tie his shoes for him, even though he later finds himself trapped in this helpless role such that he is forced to scold her, saying that he has known how to tie his shoes since he was ten ('Yo tengo treinta y cuatro años, y sé atarme los cordones desde los diez' [I am thirty-four years old, and I have known how to tie my shoelaces since I was ten]).

Dueñas's Laura is well developed and functions as a welcome counterpoint to Pineda's Daniel. If Daniel exaggerates his dependence as a strategy toward securing affection from Laura, she does quite the opposite in her relations with men, keeping her guard up and avoiding meaningful connections (as she says near the end of the film, despite having 'slept with' many men, she has never 'made love'). Rather than provide a 'normal' foil for the characters with disabilities who are marginalized in varying ways throughout the film, Laura importantly and even movingly demonstrates the challenges faced also by people without disabilities, the way that both

communities may be victimized and dependent on others, as well as their identical needs for love, affection, desire, and community. In Laura's case, this demonstration unfolds along two paths that are perhaps interconnected. On a day-to-day level, and as a concerted counterpoint to the self-sufficiency modeled by Daniel, Laura demonstrates that possessing her own autonomy may also entail being unable to hang a picture or being unable to cook anything other than a premade packet of food. At one point, she and Daniel collaborate in making a breakfast of real eggs in a pan, to humorous effect. On a deeper level, she is unable to confront her past head-on. With this in mind, the most moving parallel established between Daniel's and Laura's storylines entails their relationships with their respective parents. Daniel's mother tearfully explains to him her early struggle to accept his having Down syndrome, asking for his forgiveness which he lovingly grants with a hug. Laura's estranged father, just before dying, mistakes Laura's sister-in-law, Nuria, for his daughter and asks for forgiveness for an implied childhood molestation—information that is relayed to Laura via her sister-in-law and that both allows her some degree of closure and the promise of a new beginning. These and other parallels signal a shift away from the clinical approach to disability toward a paradigm in which access to meaningful human relationships is paramount for both disabled and nondisabled populations alike. Likewise, Laura's father's prolonged hospital stay provides an illustration of the point made by Kittay, Jennings, and Wasunna regarding the inevitable periods of dependency through which we all must pass ('Dependency').

The most poignant disruption of the clinical paradigm of disability occurs in Daniel's own explanation of his disability to Laura while at the beach. Laura's initial remark regarding the shape of Daniel's hands prompts a response clearly directed not only toward her character alone but also toward those in the film's general audience who remain relatively unfamiliar with Down syndrome.⁹

⁻Son gorditas [las manos], ¿no?

[—]Sí, bueno, ese es un rasgo del síndrome de Down, una característica. Luego también tenemos más características, ¿sabes? Por ejemplo, el paladar, es más estrecho. Eso también afecta al habla, porque se nos puede, se nos traba la lengua, y nos cuesta mucho hablar.

^{[—}They (your hands) are a little fat, aren't they?

[—]Yes, well, that is a trait of Down syndrome, a (typical) characteristic. We also have other characteristics, you know? For example, the palate

is more narrow. And that also affects our speech, because it can get our, it can leave us tongue-tied, and it takes a great effort to speak.]

Daniel's empowering opportunity to control his own self-representation in this case¹⁰ mirrors the film's emphasis on self-determination and autonomy. A key scene occurring later in the film illustrates how this sort of autonomy might be granted: Pedro and Luisa are sharing a table in the family bakery and even being served food by Luisa's mother, showing that the latter has taken steps toward affording her daughter greater autonomy in making decisions in the realm of love, even if the precise dimensions of the couple's relationship are left unclear. 11 If people with developmental disabilities are to enjoy the autonomous life emphasized by both the organization Down España and the UN Convention, 12 this must also apply to the realm of love. As the film makes clear through the voice of Daniel, another limitation placed on people with developmental disabilities, regardless of circumstances, is the need for couples to receive approval from their parents or guardians before they can be married, as is the case with Luisa and Pedro. Shortly after being hired, Daniel also remarks that the only thing left for him is to get married ('Ya sólo falta casarme' [I only need to get married]). Yet love, as the following section will address, is only one of the areas in which people with disabilities must be afforded equality. The film's significance lies also in the fact that it advocates for the full inclusion of disabled populations in the realm of work.

The Importance of Meaningful Work Opportunities

In order to understand the contribution of *Yo, también* to the struggle for equal employment rights, it is imperative to point to trends governing much recent work on employment and disability in general (Morris; McGuire and Chicoine; Moxley; Contardi; Parmenter, 'Living', 'Quality of Life'; Pardeck; Chima; Wehman, 'Supported Employment,' 'Integrated Employment'; Kiernan; Vilà et al.; Migliori et al.; Citron et al.), as well as studies on employment for people with developmental disabilities in particular (Abbott and McConkey; Hartnett et al.; Lack; Morris; Ping-Ying Li et al.). Such recent research has acknowledged the importance of meaningful work for people with disabilities, and with Down syndrome in particular, asserting that this population 'can be adversely affected by the limited number of jobs available to them and by the lack of independence and control they have over their own lives' (McGuire and Chicoine 227). The extent of the problem becomes

clear when one reads that people with developmental disabilities struggle with unemployment figures that are 'horrific ... (hovering at a steady 80 percent even before the last recession)' (Riley 10). In Spain, an announcement by El Comité Español de Representantes de Personas con Discapacidad (CERMI) dated June 23, 2010 has proposed various reforms aiming to correct the 'designaldad que tienen las personas con discapacidad en el mercado de trabajo en relación a la población en general, con una menor tasa de empleo y una mayor tasa de desempleo' [inequality faced by people with disabilities in the job market with regards to the general population, a lower rate of employment and a higher rate of unemployment].¹³ These reforms become even more important in light of one study's findings suggesting that 'having employment enables people with intellectual disabilities to develop more positive self-concepts' (Ping-Ying Li et al. 30). Abbott and McConkey argue that previously applied purely social models of integration for people with developmental disabilities have been insufficient at best. 14 Simply put, achieving full social integration requires allowing persons with disabilities the opportunity to engage in meaningful work.

For these reasons, the UN Convention speaks in Article 27 of 'el derecho de las personas con discapacidad a trabajar, en igualdad de condiciones con las demás' [the right of people with disabilities to work, subject to the same conditions as others]. Putting Daniel's employment and working relationships at the center of this film is a clear call advocating for the inclusion of people with disabilities in the workforce—this much should be clear. He is welcomed by his co-workers as part of the team, invited to participate in work-related functions and parties both in and outside of the workday. Although not a documentary, part of the success of Yo, también lies in its heavy reliance on the handheld camera to simulate real-world and naturally occurring social interactions on the way to achieving a certain degree of social realism. The intent is clearly to give the audience a sense that people with disabilities should not be forcefully excluded from public work environments nor mandatorily segregated in separate work facilities. This is an important visual legacy of the film, given Spain's response to Article 27 of the UN Convention:

En 2009, el Gobierno de España aprobó por vez primera una cuota específica para personas con discapacidad intelectual en el acceso al empleo público proporcionado por la Administración General del Estado. Hasta ese momento, existía una cuota del 5% a favor de personas con discapacidad, sin distinción de tipo. Una vez aprobado el

cambio normativo, la cuota se elevó al 7%, dedicándose el 2% de incremento a personas con discapacidad intelectual, dada su peor situación en cuanto a empleabilidad e inclusión laboral, y la inferioridad de condiciones de igualdad si tienen que competir en los procesos selectivos con otras personas con discapacidad. ('Derechos')

[In 2009, the Spanish government approved for the first time a specific quota for people with intellectual disabilities in the access to public employment afforded by the General State Administration. Up until now, there was a 5% quota for people with disability, with no regard for type. Once the normative change was approved, the quota rose to 7%, dedicating an additional 2% for people with intellectual disabilities, given their disadvantaged situation regarding employability and inclusion in the workforce, and the unlikelihood of equal conditions if they must compete in selective processes with other people with disabilities.]

In light of this statistic, the film perhaps points to the Spanish hesitancy with regard to the implementation of this reform. Indeed, we are informed by Laura that Daniel's position is a temporary replacement for someone who has post-partum depression, and not a permanent position. Moreover, it is a bit difficult to avoid seeing Daniel as an exception of sorts. Along these lines, the film makes it clear in scene after scene that Daniel has had many advantages that have played no small role in his success: first and foremost loving and caring parents, a background of middle-class means (assuring the resources to push him on to high levels of education), a brother and father with whom he can easily stay active and engaged (going to basketball games and exercising in the pool), and so on. On a personal level, he is blessed with an enviable sense of humor (and timing), empathy, and patience. He also possesses a gift for language (he is working on English with his mother, and throws a few words into his conversations with Laura to impress her: 'Your hair is beautiful,' for example). All the same, these details may ultimately only suggest how much more work there is to be done in the area of work reform. The bottom line is that Daniel's work with the agency importantly provides him with the opportunity to form a positive self-concept just as it does for the cognitively abled employees there. In a sense, the film is content to show Daniel as meaningfully employed—and perhaps it should be. Meaningful work is one of the best ways to achieve a sense of autonomy by being involved in situations with decision-making potential and participating in a shared social world.

In privileging Daniel's situation, however, the film perhaps leaves a more incisive criticism to be made and implemented more broadly. Before her ephemeral escape with Pedro, we see Luisa at work in her mother's bakery, minding the counter while her mother is in the back, presumably having been given the autonomy to use the register if necessary. Nonetheless, the film leaves unanswered more than one question related to her remuneration: What, if anything, is she paid? Does she control her own finances? Does she have access to her own accounts? Can she make her own purchases? We can, perhaps, attribute some of the imprecision of the film regarding this volley of questions relating to employment and work to the prominence of the melodramatic theme of love. So much of the action centers on Daniel's love for Laura and thus to the question, 'What more-or-less normal girl would fall for Daniel?' (formulated by his mother in these words, '¿Qué chica medianamente normal se interesaría por un chico como Daniel?'). While this manner of pitching the movie to a general audience is perhaps necessarily part and parcel of the need to package the film as a conventional love story, playing upon the predictable desire of some viewers to find out definitively whether Laura and Daniel will get together at the end or not (the movie resolves this issue leaving no room for doubt), it is Yo también's more fundamental preoccupation with the political project of equality for people with disabilities that holds all its disparate elements together.

That the film emphasizes the political project of providing work opportunities for people with developmental disabilities is far from surprising once one sees that one of the producers of Yo, también is none other than Julio Medem. Here, just as in the Medem-produced documentary ¿Qué tienes debajo del sombrero? (2006, dirs. Lola Barrera and Iñaki Peñafiel), the production company is listed as 'Alicia Produce'—bearing the name of Barrera and Medem's daughter who is a person with Down syndrome. As chapter 4 of this book will discuss in detail, ¿Qué tienes debajo del sombrero? notably introduces us to American Judith Scott, who was both deaf and a person with Down syndrome, precisely through her identity as a working fiber artist. In both cases, the accomplishment is the creation of a multilayered film that, although touching on both disability and wider issues (in Yo, también, the universality of love; in ¿Qué tienes debajo del sombrero?, the enigmatic nature of artistic production), puts the working identity of individuals with developmental disability first and foremost.

It is clear that disability studies seen as a political project necessarily requires the exploration of a number of strategies for improving the lives and socio-economic conditions of people with developmental

disability. Whether in love or work, this means granting independence and autonomy to a population that has, for too long, been constrained by the yoke of what scholar Harlan Lane has termed, albeit in different yet nonetheless relevant circumstances, 'The Mask of Benevolence.' To truly gain an appreciation of the challenges faced by people with disabilities in our society, we have to push not only for integration and equality in love and work, but also to unmask the myth of cognitive ableism and recognize the universal dependence of humanity.

In this sense, the film's title conveys everything one might need to know about the film's position and content—the words 'Yo, también' function simultaneously as a call for inclusion and as a declaration of self-determination. The figure of Daniel allows the viewer with little or no experience of (developmental) disability to see the numerous ways in which limitations are placed on disabled populations both in love and at work. The film's implicit resonance with aspects of the UN Convention serves as a reminder of how much more we must do if we are to realize Daniel's articulation of a society that no longer divides and separates minorities.

Deciphering the Mixed Messages of *León y Olvido* (2004)

Teón y Olvido is in many ways the precursor of Yo, también. The film is about a pair of 21-year-old twins who have 'sentimientos intensos y contradictorios' [intense and contradictory feelings] toward one another (Hernáez Rioja and Martínez Ollé 67): Olvido is played by Marta Larralde (also from the 2004 film Mar adentro), and her brother León is played by Guillem Jiménez. As with Pineda's role in the 2009 film, Jiménez's 2004 role is also a first of sorts—Jiménez was the first person with Down syndrome to have graduated from secondary education in Spain, and he likewise enjoys the title of being the first to star as the protagonist of a Spanish film. Like Pastor and Naharro's later film, León y Olvido succeeds in numerous respects—like Yo, también it is a similarly substantial, nuanced and largely positive portrayal of a character with Down syndrome, it includes a number of secondary characters with Down syndrome who complement Jiménez's title role, and it is savvy enough to point beyond the character-driven narrative toward broader social issues associated with disability, aspects that are addressed in turn below. These successful aspects of the film

are of course—given the paucity of films highlighting the theme of disability at all in Spain¹⁵—merely icing on the cake, which is not to say that the way disability is portrayed in itself in the film is not important. As Carmen Pereira Domínguez makes clear in her essay from 2007, the cinema serves as a sort of public forum that allows for subsequent pedagogical intervention (she lists the film along with 13 others on the theme of disability)—the mere novelty of foregrounding a protagonist with Down syndrome allows for discussions regarding disability to take place among the wider viewing public and in the media, discussions that would be less likely to take place if the disabled character had a less prominent role. Nevertheless, its numerous positive aspects notwithstanding, Léon y Olvido ultimately stakes out a somewhat contradictory position, there being many problems with the film that stem from its somewhat heavy-handed plot. In the end the sensationalistic aspects of Olvido's story eclipse the film's portrayal of disability.

As the interested reader may consult the extensive discussions of the complex storyline of *León y Olvido* found in essays by Martín Ruano et al. and Hernáez Rioja and Martínez Ollé, here I will strive only for the most concise of synopses. After their parents die in a car accident—and after León is kicked out of a number of educational centers/ group homes—Olvido reluctantly finds herself in the position of having to be his legal guardian. At the time, Olvido is in a relationship with a doctor named Iván that eventually ends when he decides to go to Africa with a non-governmental organization, and she similarly faces disappointment in work when she is asked to leave her unstable job at a factory. For the duration of the movie, the two siblings seem to be trapped in a relationship riddled with incestuous tones. Juan Fragueiro writes of 'algunos innecesarios momentos de tensión sexual' [several unnecessary moments of sexual tension] (18) between the twins that become most overt in sensual bedtime rituals (in the ritual. he 'boards' her shouting 'al abordaje' [all aboard] as if she were a ship and he the captain) and the act of bathing together and sleeping in the same bed. 16 It may be true that siblings of people with disabilities often have a conflicted relationship with their brother or sister—experiencing a range of contradictory emotions that include love, jealousy, and guilt, as well as frustration at the dependence and greater needs of the sibling with developmental disability. My view, however, is that the film balks at a realistic treatment of such a complex emotional bond, ultimately tending to reproduce the serialized over-dramaticism of a thriller with a central femme fatale.

The twins' 'love-hate' relationship (Hernáez Rioja and Martínez

Ollé 68) is punctuated by Olvido's numerous attempts throughout the film to either abandon León or even kill him:

Se inicia la película proponiéndole a León que coja una flor cerca de un precipicio y a lo largo del film va incrementándose la agresividad. En una ocasión le deja abandonado en el campo, y la guardia civil le recoge. La asistenta social le recrimina su acción y ella se muestra impotente. En otra oportunidad intenta huir de casa con una maleta para dejarlo solo pero León la descubre a tiempo. Otro día intenta envenenarle y León tiene que ser ingresado de urgencias en un hospital. También incita a un perro que encuentran por la calle a que le muerda. Finalmente le dispara con una pistola que resulta ser de fogueo. (Hernáez Rioja and Martínez Ollé 68)

[The film begins with Olvido asking León to pick a flower close to the edge of a cliff and throughout the film her aggression steadily increases. On one occasion she abandons him in the countryside, and the Civil Guard picks him up. When she is reproached for this by a social worker, she seems unconcerned. At another point she packs a suitcase and tries to leave home in order to get away from León, but he discovers her plan in time. On another occasion she tries to poison him and León has to be admitted into emergency hospital care. She also incites a dog they find in the street to bite him. Finally, she shoots at him with a pistol that turns out to be loaded with blanks].

Quite frankly—and even leaving out a subplot that toys with Olvido becoming a prostitute after having been fired from a wedding shop job by her employer's wife—one half of León y Olvido's storyline is overtly sensationalist. Perhaps this is a response by the director to the apparently widespread opinion—one I do not hasten to embrace—that films focused on disability have tended to yield less intriguing plots (such an opinion is suggested by Martín Ruano et al. as a possible motivation for the film's complicated story). Many more subtle aspects of the plot are similarly somewhat incredible. For example, although Hernáez Rioja and Martínez Ollé make much of Olvido's struggle to have León be independent—'en los desplazamientos, en vestirse, en el orden de la casa, en la cocina' [in getting around, in getting dressed, in cleaning the house, in the kitchen] (68)—some viewers more familiar with the full range of behavioral problems that sometimes characterize disabled populations may find it unconvincing that León's character, who is in many other ways seemingly a fully autonomous and even mature 21-year-old man, is presumed to be unable or even unwilling to help

his sister. The problem in this instance is not in Jiménez's acting, but rather in the script itself. Although it may aim to portray León as initially incapable of independence, in reality his worst problem regarding autonomy seems to be that on one occasion he is wearing a red sock on one foot and a yellow one on the other (12:30, 'y siempre vas a ir como tú te vistas' [and you're always going to wear whatever you put on]).¹⁷

It should not be ignored that the film's director, Xavier Bermúdez, grew up around people with Down syndrome—'El director ha tenido desde niño relación cercana con personas que padecen el síndrome Down' [Since his childhood, the director has had close relationships with people who have Down syndrome] (Hernáez Rioja and Martínez Ollé 67)—a fact that may explain its otherwise nuanced and largely positive treatment of disabled characters. Given the large audiences that may potentially be reached by cinematic texts over other cultural products, the pedagogical/educational effect of the film should not be undervalued. As actor Jiménez explains: 'Así la gente puede conocer mejor cómo somos las personas con síndrome de Down, porque no somos enfermos ni mongólicos. Yo soy catalán no de Mongolia' [In this way people can better understand what people with Down syndrome are like, because we are neither sick nor Mongolian. I am Catalan, I'm not from Mongolia] (qtd. in Fragueiro 18; note that the original Spanish plays implicitly with 'mongoloide' [Spanish]/'mongoloid' [English], an objectionable term historically used to refer to people with Down syndrome). Since films are potentially not merely representations of people with disabilities but also themselves employment opportunities for disabled populations, León y Olvido was a chance to combat widespread misunderstanding of Down syndrome on both sides of the camera. As noted by critic Juan Fragueiro, also the father of a child with Down syndrome:

La popular creencia—por otro lado bastante desacertada—acerca de la conducta de las personas con síndrome de Down (que son bravos, que son inconstantes, que hablan mal, que tienen un aprendizaje lento, etc.) no los beneficia a la hora de los malditos castings televisivos, cinematográficos, para spots de breves minutos o cualesquier escena pixelada. (17)

[Popular beliefs—which are also quite erroneous—about the behavior of people with Down syndrome (that they are uncivilized, that they are fickle, that they talk poorly, that they learn slowly, etc.) do them no favors when it concerns those confounded casting calls for television

and film roles, for spots lasting only a few minutes or any recorded appearance whatsoever].

Disregarding, for a moment, the aforementioned excesses of its storyline, *León y Olvido* is remarkably successful as a film that portrays its numerous characters with disabilities in a largely positive light. The following sections address, in turn, both the positive portrayal of disability in the film and also the way that Olvido's story ultimately, for this viewer, trumps many of its potential successes through an emphasis on Olvido's (over-)dramatic and eccentric behaviors.

The Successful Presentation of Down Syndrome

León y Olvido's first success is, of course, the fact that Guillem Jiménez occupies center stage—even though the film's long list of prizes were awarded instead for Bermúdez's direction and for Marta Larralde's acting (see Hernáez Rioja and Martínez Ollé 67-68). But its treatment of other secondary disabled characters, and its inclusion of numerous secondary roles played by actors with disabilities, also deserves special mention. The film opens with a shot of León in his room as a male and female voice call his name from outside in the hallway, asking him to open the door. He is alone in an unlit room, bathed in shadows and, facing the window, backlit to further emphasize that he is cloaked in feelings of loneliness. He does not answer for over a full minute (0:54– 1:51); he continues to be shrouded in shadow later when at home with his sister (e.g. 21:46-22:00). He moves only to pick up a photograph of his sister that has been torn in half. As he arranges the two halves together, a semi-subjective shot bordering on a point-of-view (where we see his hands obliquely—but not from his own perspective) allows the form and content to collaborate on delivering a snapshot of a fundamental duality that vertebrates the movie. There is a play of presence/absence at work here—León is, throughout, simultaneously both with his twin sister and also alone. The implication is that even in the company of others he is marginalized. The presentation of the character of León is thus nuanced in that he conveys both the pain of being alone that may be experienced by people with disabilities who have yet to find supportive social structures and also their potential for achieving self-sufficiency and independent living (even if this is not achieved in the film's plot). As opposed to a one-dimensional image of people with disabilities as either being incapable of anything or on the other hand as champions who seem to not let anything get

them down, here we have a humanized portrayal of León as a multidimensional person in his own right who faces, as we all do, both successes and failures.

But the film also succeeds in its presentation of other characters with disabilities. For example, a substantial, almost two-minute long (14:45–16:40), scene depicts León in his new classroom of peer-students, all of whom are adults with Down syndrome. It should be stated that the importance of Disability Studies approaches for education continues to be articulated as the shift from a medical to a social model of disability continues to unfold. Even in their 2011 book, *Rethinking Disability*, authors Jan W. Valle and David J. Connor note that:

Disability Studies (DS) provides a counterbalance to the deficit-based understanding of disability that permeates education [...] how we educate students with disabilities has everything to do with how we *understand* disability. Without wishing to oversimplify, we might think of the medical model as primarily concerned with identifying and changing the student who does not fit the school context (i.e., based upon a perception that a child is intrinsically disabled), whereas the social model focuses on adapting the school context to fit the student (i.e., based upon the perception that the environment can disable a child). (xi, original emphasis)

As if living up to this ideal of an education driven by the social model of disability, in this first classroom scene¹⁸ the students' teacher, Raquel, does not engage in drawing attention to the students' inadequacies nor in correcting their errors, but rather in an activity that allows each student to speak for themselves and outline individualized goals for his or her future. Raquel asks the students what they want to accomplish in their lives. León is the second-to-last to speak before the end of the classroom scene, saying that he would like to take care of his sister: 'Tengo que cuidar a mi hermana [...] Somos iguales. Le prometí a mi madre que iba a cuidarla cuando ella muriese, y ella ya se murió' [I have to take care of my sister (...) We are the same age. I promised my mother I would take care of her when she died, and she is already dead]. When Raquel presses, him, noting that his answer is a good one but asking if there is anything he wants to accomplish for himself, he responds that he doesn't know (16:32). Perhaps due to a historical lack of social expectations for people with disabilities, León has not yet learned to 'dream big.' But the real value of this scene is the variety of answers given by the other students in the class: Estrella says, 'me gustaría tener un novio, que está trabajando, y me gustaría tener hijos' [I'd like to have a boyfriend, who has a job, and I'd like to have children]; José answers, 'Tener una novia, tener unos hijos, casarme y... ir a fútbol, y tener vacaciones' [To have a girlfriend, to have some children, to get married and... play soccer and go on vacation]; and Mónica responds, 'Pues me gustaría tener novio, casarme, irme de vacaciones y tener mucho dinero' [Well, I'd like to have a boyfriend, get married, go on vacations and earn a lot of money].

In a way this sequence goes far beyond the mere portrayal of a disabled character to match even Yo, también's presentation of a disabled population. The implicit message here is one expressed by Andrea Lack in her essay in the edited collection Down Syndrome: Visions for the 21st Century, which is that people with Down syndrome are now in a position to chart out their own paths: 'After decades of few to no expectations of the abilities of people with Down syndrome and systematic repression of any vision they or their parents may have had for them, they deserve opportunities to develop, grow, and achieve in all aspects of their lives' (441). The section of that pathbreaking edited collection titled 'Part II: Self Advocacy'-featuring essays on 'Having a Life' (Illarramendi et al.), 'Follow your Dreams' (Burke) and 'Life After High School' (O'Neill)—similarly renders the visual success of this cinematic scene intercalated in León y Olvido in words. Therein, Jeffrey Mattson expresses a similar desire to get married (110), Mia Peterson is proud to be 'the first self-advocate who has Down syndrome to be working for the Down Syndrome Association of Greater Cincinnati' (110), and Chris Burke—formerly 'Corky,' the star of the US television show 'Life Goes On'-advises readers, 'So, don't let anyone stand in your way and who knows, you might wind up doing what you set your mind to' (113). Likewise, Josh O'Neill writes of the value of learning to live independently (115), something that the disabled characters in Bermúdez's film seem to already value. Most importantly, as this scene of León y Olvido shows, these adult students have the ability and the confidence to speak for themselves. As Paul Williams and Bonnie Shoultz write in We Can Speak For Ourselves, a book on the origins and development of selfadvocacy by people with intellectual disability (from 1960s Sweden to the US and Britain), this is an important step in securing greater social rights.

There may be a gap, in this case, between speaking for oneself and learning to live independently—as *León y Olvido* is aware. This struggle is dramatized best in the subplot involving Jonathan, a classmate of León's whose respect for all things organized sets him apart from the other students. For instance, in the aforementioned classroom scene

some of the students begin to argue about whose turn it is to talk (Mónica is humorously persistent in drawing attention back to herself throughout the sequence), and Jonathan stands up to recite what he has presumably learned from Raquel: 'Hay que respetar los turnos y si no podemos hablar al mismo tiempo, elegimos representantes' [We must respectfully take turns and if we cannot speak at the same time, we will elect representatives (15:07–15:15). The privileging of Jonathan's storyline is an important aspect of the film—and not merely because it succeeds in giving a broader picture of multiple life-experiences of disability, refusing to implicitly support the stereotypes that can often develop from having knowledge of only one person with disability. Jonathan, who is portrayed as a model student and the paragon of successful living, is seen acting as a kind of mentor to León, as when in a long-shot-we see him from afar conversing with León after school, and giving him a friendly slap on the neck before going home. Later on, Jonathan invites León to room with him and a few others his age as a step on the path toward a higher degree of independent living ('y esta puede ser tu habitación' [and this can be your room] 50:11), and even encourages him to go on for further study ('pues tienes que esforzarte y estudiar más' [well then, you need to apply yourself and study more]). The directorial decision to allow Jonathan to take center stage is an effective way of showing the potential for León—and by extension many more adults with developmental disabilities—to live independently and to realize a self-autonomy that disabled populations have historically seldom been encouraged to achieve. This makes the way in which his subplot ends all the more disappointing. At 1:19:30, after being informed while in class with Raquel that Jonathan has been hit by a car, León visits him in the hospital. Jonathan says he felt worse the day before, to which León replies 'Me parece que vas a morir' [It seems like you are going to die] (1:20:20). After Jonathan says he is only feeling a little bad, León becomes more forceful and intentional with his words: 'Creo que vas a morir' [I believe you are going to die]. Jonathan then insists that the doctor has told him he will recover soon, to which León objects that doctors will say that sort of thing to patients, but this doesn't explain why his mother is so sad. Strangely enough, León turns out to be right, and a subsequent scene captures his classmates attending Jonathan's funeral (1:27:00-1:27:33). It is not clear whether this is intended to be a cautionary tale about disabled populations being careful crossing the street (in their hospital conversation, León reprimands Jonathan for not being careful enough), or whether the point was to illustrate León's social intelligence (having noted that people's behavior and the circumstances of Jonathan's hospitalization didn't match the information given by the doctors). Either way, it is a bit over-dramatic.

Whatever Jonathan's fate, part of the success of the film is that we are witness to the steps León takes toward independent living. For example, as in Yo también, here, too, we have a cooking scene. León is shot in profile at the stove wearing an apron as he breaks eggs into a saucepan in a single long take (35:32-36:23). Although he has resisted cooking for his sister or himself (preferring that others do the work for him), all indications seem to be that he has cooked before, and successfully at that (although in another scene he uncharacteristically drops a fish on the floor, 1:15:45). After initially complaining that he needs to be accompanied to and from school by his sister, he quickly adapts one day (perhaps too quickly to be believable) when she doesn't show up. After being shown on screen taking a deep breath, accepting his fate (with a mature, responsible demeanor that the film contradictorily indicates he does not yet possess), he decides to walk home from school by himself (28:30). Demonstrating his maturity and selfsufficiency, he even spends the remaining (unspecified) daylight hours wandering around town and gazing into a wedding shop. Many hours go by unnoticed—and, moreover, uneventfully—and it seems not to have been a problem at all (30:30). Eventually (after an abrupt cut that shifts us from daylight to the dark skies of night) León returns home happy and energetically seeking dinner. Later in the film we see him with the rest of his class gaining practical work experience in carpentry, as if to prepare them all for a type of workshop employment previously considered to be one of the only options for disabled populations (1:18:30–1:19:00).

Ultimately, however, even despite its many disabled sub-characters, there is something a little bit off in *León y Olvido*'s presentation of disability. We may be dealing with people with Down syndrome who have Exceptional Language Development (Rondal)—as is the case with Daniel in *Yo, también*—but there is no basis for comparison given that it lacks a presentation of less verbal characters (in contrast to *Yo, también*). Prior to what was previously believed, Jean A. Rondal suggested in 1995 that 'phonology and grammar may be acquired and function relatively independently from other processes' (1), and thus that many more people with Down syndrome might be able to improve their verbal abilities. Yet what *León y Olvido* fails to explain—and what *Yo, también* shows so well through Daniel's self-descriptions—is how it is that we have come to see a group of adults with Down syndrome who seem to be able to communicate with so little difficulty. Whether intentional or not, Bermúdez has created a film in which disabled

characters either act out in group homes (as does León prior to the film's narrative action, having been kicked out of four institutions in two years, 48:00) or function as relatively autonomous adults who experience no frustration, with little or no attention paid to the gap between these two extremes. It is not that this is in itself a bad thing, rather it is merely one more indication that the storyline of Olvido might have received more of the director's attention.

León vs. Olvido: Competing Storylines

Returning to the opening scene of the film helps us to understand that León y Olvido is caught by the desire to tell two stories that are poorly integrated with one another. The first is the compelling story of León, his struggles with group living and his learning to cope with the lack of a family or even any support structure. The second story is an overdramatized if not sensationalized story about Olvido, which at times takes on the tenor of a hackneyed 'femme fatale' Hollywood-esque tale. Although the first shots of the film—of León in a dark room, alone—undoubtedly strive to frame León as the co-protagonist of greater interest, the abrupt shift from the torn photographic image of Olvido to the graphic match of her passionless face driving a car (1:51) also belies a shift in the film's emphasis. This is also a film, as we are instructed visually in these early scenes, about a young woman struggling to integrate and fully realize herself and her own personality. Just as with the photograph of her in León's possession, she seems to be a woman split in two. As she continues to drive, shadows ominously fall across her face (1:56) just before a cut to an exterior pan of the car's movement (1:57-2:00), pointing somewhat predictably to a darker side that we will see play itself out on screen. It is of course intentional that León is to be the victim of her dark side, perhaps as an instruction from the director that populations with Down syndrome must be trusted only to willing and capable caretakers. Although ultimately the question of whether *León y Olvido* is successful at integrating these two stories may be up to the viewer, I suggest that the fact that Marta Larralde won awards for her performance¹⁹—and that Guillem Jiménez did not—may be a clue as to which storyline has been emphasized by the director perhaps even despite his own intentions.

The use of the set of the wedding shop—at which León stops on his way home from school one day—illustrates how Olvido's narrative comes to eclipse that of León in the film. When he first passes the shop (28:50), this initially reminds us of the discussion by his peers

saying they want to get married, thus advancing the social narrative of disability. The wedding dresses at first seem to symbolize the possible futures of his classmates, if not León—pointing in this way to generalized notions of self-advocacy and autonomy and perhaps even the notion of matrimonial rights (as voiced by *Yo, también*'s Daniel). When León watches as an attractive shop assistant squats down to fix the bridal mannequin's dress, the established theme of weddings blends with that of desire and the question of sexual relationships for disabled populations (a topic addressed, perhaps, more directly in *Yo, también*). But this same wedding shop is soon folded into Olvido's competing and sensationalistic storyline, as she takes a job there and is eventually asked to become a prostitute by the owner's wife.

Another way in which Olvido's story eclipses that of León lies in the film's overarching theme of danger and death. Critic Antía María López Gómez perhaps rightly sees the film as being concerned not necessarily with disability, but rather with death: 'El referente del relato no es, sin embargo, su discapacidad, sino la imparable, inacotable e inagotable pulsión de muerte que atraviesa todo el filme, y que instala todas las relaciones humanas, todos los actos, todos los propósitos, en el sinsentido abocándolos al fracaso' [The referent of the story is not, however, his disability, but rather the unstoppable, unbounded and unavoidable pull of death that runs through the entire film, and that imbues all of its human relationships, all of its acts, all of its aims with a sense of chaos, leading them all to ruin] (López Gómez 22). This idea is introduced early on in the film. After Olvido picks León up from the group home, the pair stop to sit on a grassy cliff overlooking the sea (6:20) and the games with death begin. She asks him to pick her a flower far down on the rocky part of the cliff, and as the point-of-view shots establish—he looks at the flower, she sees him look at the flower, we see an idea occur to her—she sees the possibility of being rid of León for ever. As he slips and falls on the cliff—crying out to her for help—she seems to regret her trick and helps him up. But she continues to flirt with danger, death, and destruction throughout the film—through trying to have a dog bite León, poisoning him, and even firing a pistol at him that she believes is loaded (although it is loaded only with blanks). Her emotional distance throughout the film is displayed through her routinely cold, silent, and impassive stare; an affect that she perfects not merely when interacting with León but also with the other adults around her (the Civil Guard, the staff at León's group home, and even her boyfriend Iván) and even when she is alone (driving in the car, curled up in a fetal position on the couch, and so on). Whereas some of the games she plays with León—such as hesitating before picking

him up after school (for a full minute on screen from 19:58–21:00)—perhaps demonstrate that she is merely reluctant to fully commit to being his guardian or even that she may be considering forcing León to mature (and thus to walk himself home), these other more drastic events by their nature and their frequency portray her as herself in need of psycho-social help. As I argued above in the case of *Yo, también*, the contrast between Daniel's autonomy and Laura's dependence made for an interesting counterpoint, linking both disabled and cognitively abled populations in a shared social world in which we all need some kind of help. Here, however, Olvido seems to be in need of medication for depression, if not an antipsychotic, to control her dangerous impulses. It is unclear whether this specific aspect of the contrast is intentional on Bermúdez's part—and thus the problem.

The theme of death comes up once more, obtrusively, in a drawn-out joke told by Olvido in a candle-lit room of the rental for which they can no longer afford to pay the bills. The fact that in the previous scene she has tried to pack her bags and escape from León for good (though he spotted her and thereby 'foiled' her plan) makes this joke all the more pertinent—it is an attempt to communicate obliquely with León regarding her (perhaps) unconscious desire to kill him. When the scene opens, Olvido is explaining to León that he has not understood the joke that she will now retell for the camera ('No lo has entendido, es imposible que lo entiendas' [You haven't understood it, it is impossible for you to understand it], 104:58). The joke is as follows:

Unos bandidos tienen preso a un hombre. El hombre está encerrado en la habitación de al lado. El no los puede oír. Y deciden que lo van a matar. Echan las sueltas para ver quién lo mata y le toca a uno. Este coge la pistola, la guarda en la ropa y va a buscar al preso. 'Vamos a dar una vuelta por el campo... que hace mucho que no sales.' Salen. Es de noche. El preso está asustado. '¿Adónde vamos?,' dice. 'A dar una vuelta.' Caminan entre los árboles. Todo está muy oscuro. Y vuelve a decir el preso '¿Adónde vamos?' 'Tranquilo, no te preocupes, sólo a dar una vuelta.' Los lobos se aullan. Y se eschuchan ruidos raros. Los dos hombres asustan y se abrazan. '¡Tengo mucho miedo! ¡Tengo mucho miedo!,' dice el preso. Y le dice el bandido, 'Pues anda que yo que después tengo que volver sólo.' (1:05:30–1:06:53)

[Some bandits have taken a man prisoner. The man is locked up in the next room. He cannot hear them. And they decide that they are going to kill him. They draw lots to see who will kill the man and one of them loses. He grabs the pistol, lodges it in his clothing and goes to get

the prisoner. 'Let's go take a walk outside... it's been a while since you went out.' They leave. It is night. The prisoner is scared. 'Where are we going?,' he asks. 'For a walk.' They walk through the trees. Everything is dark. And again the prisoner asks, 'Where are we going?' 'Relax, don't worry about it, we're only taking a walk.' The wolves howl. And they hear strange noises. The two men become afraid and they huddle together. 'I'm really scared! I'm really scared!' says the prisoner. And the bandit says to him, 'You think you're scared?! I have to make the trip back alone!']

Clearly the intercalated joke is meant to function as a commentary on the narrative action of the film. León is the prisoner sentenced to death, and Olvido is the one who must kill him, even though he may be unaware of his fate. This connection between the joke and the storyline of the twins' relationship is made concrete when, after Olvido has told the joke, León pretends to understand it by repeating—tellingly—the words spoken by the prisoner and not the punchline delivered by the bandit ('iTengo mucho miedo! iTengo mucho miedo!' [I'm really scared! I'm really scared!]).

Olvido has been trying to rid herself of León, and it is only after telling this joke that her attempts become more drastic. Immediately afterward she gives him a glass of poisoned juice, tempting him with promises of a bedtime pirate-ship boarding game if he drinks it all. The next scene is of an ambulance arriving at the hospital—and ultimately León recovers from this murder attempt quite quickly, as he is soon back home in bed with Olvido (1:11:08-1:12:17). From this point on, the narrative action centered on Olvido becomes less and less believable. She gets a job at the same wedding shop first spotted by León—with no explanation given. At the very moment she sets foot in the shop for the first time, a man implausibly walks in brandishing a knife and attempts to rob the store (the storekeeper gets a gun and sends the attempted robber packing, 1:13:45).20 Olvido later puts a gun in her own mouth and thinks about pulling the trigger (1:31:20) before finally—in the penultimate scene of the movie—shooting at her brother (with blanks) while on a 'last-supper' style picnic (beginning at 1:37:38). Even in this scene, León jokingly exclaims once more 'iTengo mucho miedo! iTengo mucho miedo!' [I'm really scared! I'm really scared!], recalling the earlier joke told by Olvido and reaffirming his role as victim. The last shots of the movie capture the pair at home in the shadows, with León making light of their pistol encounter and Olvido lying down, morose, on the couch. Ultimately the acting of the film—and particularly the acting by those actors with Down

syndrome—is successful, unique, and compelling. But here it is the storyline itself that does them no favors.

This chapter has focused on the fictional and filmic representation of two protagonists with Down syndrome. Upon first glance, both films deserve praise for being strong exceptions to the international trend of giving only minor roles to disabled actors. As the scholarship on disability in film shows, many times an able-boded actor is given the role of a disabled protagonist—a practice that warrants our disapproval. Yet to label both Yo también and León y Olvido a success merely for having people with disabilities acting as their protagonists is not enough. We must go further and consider the film on its own terms, as a work of art understood in the context of social expectations. Here, the central issue of each film is the same. Both suggest the importance of sustaining a social dialogue on the topic of the autonomy of people with disabilities. Nevertheless, while Yo también's presentation of its protagonist Daniel is a nuanced look at what are clearly universal human needs-most of all the need to love and be loved and the need for meaningful work—León y Olvido falls into many traps that have traditionally plagued the filmic representation of disabled people. The latter film's emphasis on a femme-fatale storyline ultimately allows Olvido's character to overshadow our closer consideration of León's social circumstances. All things considered, the film's message seems to be that León deserves a better family, but not necessarily that people with Down syndrome can and should be allowed the same level of autonomy routinely taken for granted by populations without disabilities. The casting of a number of minor characters who also have Down syndrome adds a certain richness to the film, but even then, the death of Jonathan's character (together with Olvido's flirtation with killing her brother León) distracts from the issue of allowing people with Down syndrome to dictate their own lives.

Notes

- 1 See, for example, Davis's Enforcing Normalcy (1995), McRuer's Crip Theory (2006), Sedgwick's Touching Feeling (2002), and Carlson's article in Hypatia (2001).
- 2 This speech is complemented by a moment further on in the film in which

- Daniel's mother watches a black-and-white video of his graduation, including a speech presumably delivered on that occasion. As Daniel is noticeably younger in these images, it is tempting to conclude that these are the actual images of actor Pineda's own graduation.
- 3 Among these further steps, Soto and Hetzroni cite the 1986 creation of the Centro Nacional de Recursos para la Educación Especial and the 1990 passage of the Ley Orgánica de Ordenación General del Sistema Educativo (LOGSE). In the 1980s, integration was approached more openly than ever before, with Ministerio de Educación y Ciencia Álvaro Marchesi's statement that 'The major goal of the integration principle is to facilitate the maximum social, intellectual, and psychological development of children with disabilities through social contact and interaction with their peers' (paraphrased in Soto and Hetzroni 185). Marchesi is mentioned in passing also in a slightly different context still pertinent to disability legislation in my *Deaf History and Culture in Spain* (206–07, 208, 260 n.11).
- 4 In the film, Laura asks Daniel to explain his success:
 - -¿Por qué eres así? ¿Por qué eres más listo?
 - —En mi caso es porque mi madre me hablaba mucho desde pequeño. Nos poníamos a hablar, de historia, de política, me preguntaba muchas cosas y yo, pues, le respondía y como mi madre veía que yo entendía lo que estaban diciendo, pues decidió que fuera a colegio, no veas, la que armó para que fuera a colegio, madre mía.
 - —Yo pensaba que era mosaico o leve.
 - —No, no, para nada, yo soy síndrome de Down de los pies a la cabeza, no... entero, entero.
 - [—Why are you like this? Why are you more capable?
 - —In my case it is because my mother talked to me a lot since I was little. We would chat about history, politics, she would ask me many things and I, well, I would respond to her, and as my mother saw that I could understand what was being said, well she decided that I would go to high school, don't you see? The one who pushed me to go to school was my mom.
 - —I thought that you were mosaic or mild.
 - —No, no, not at all, I am Down Syndrome from head to toe, no... all of me, 100%.]
- 5 For example, as Laura prepares to drive Daniel to the beach, her image is split between two mirrors, highlighting her fragmented self-image as well as pointing toward her two possible futures, one in which she pursues some kind of relationship with Daniel and one in which she does not.
- 6 Reyes cautions the couple in this way: 'A ver chicos, a mí me parece muy bien que tengáis vida privada. Que os beséis, que os toquéis y que hagáis lo que queráis. Incluso que tengáis secretos para vuestros padres. Pero para hacer eso hay que buscar intimidad... Hay que buscar un sitio privado, y la escuela no es un sitio privado. Aquí se viene a bailar... Por la mañana os podéis dar un besito pero la lengua en su sitio, ¿Eh? ¿Vosotros me veis con Santi revolcada por el suelo dándome besos?' [Listen up, kids, I think it's great that you have a private life. That you kiss each other, that you touch each other, and that you do what you like to. Even that you keep secrets from your parents. But to do all that you must seek out privacy... You have to find a private place, and school is not a private place. We come here to dance... In the morning

- you can give each other a kiss, but keep your tongues in check, okay? Do you see me with Santi rolling on the floor exchanging kisses?]
- 7 A brief scene near the beginning of the film shows Daniel accessing explicit video he has stored on his computer, and he later has a sexual dream regarding his female co-workers, Rocío, Estrella, and Macarena, that causes him to break into laughter at work. During office sequences, POV shots emphasize Daniel's developing desire for Laura. Later, in a conversation that Luisa milks for its humorous potential, Daniel attempts to instruct Luisa and Pedro in the proper use of a condom. The hit song performed by the group La Casa Azul (finalists in the Spanish Eurovision Song Contest), 'La revolución sexual,' also figures prominently in the film, highlighting this theme.
- 8 As discussed in 'Derechos humanos y discapacidad,' violations of Article 30 occur when 'Las personas con discapacidad se sienten discriminadas cuando intentan acceder a discotecas y salas de fiesta' [People with disabilities feel discriminated against when they attempt to gain access to discotecs and party venues] (43).
- 9 The name for Down syndrome comes from papers written by John Langdon Down during the 1860s.
- 10 This sort of self-representation is increasingly a way to wrest discursive control on disability from the colonizing tendency of 'official' perspectives, as seen in the decision to encourage the participation of persons with disabilities as part of the publication 'Convention Internacional de Naciones Unidas sobre los Derechos de las Personas con Discapacidad vista por sus protagonistas' [The International United Nations Convention on the Rights of People with Disabilities as Seen by its Protagonists] (see Otón Hernández).
- 11 First Luisa and then Pedro boisterously shout 'Esa es mi madre' [That's my mom], intimating that there has at least been some reconciliation and acknowledgment that Luisa is not 'confusing a dancing partner with a partner in real life.' Through a conversation between Reyes and Luisa's mother, the film implies that Luisa is particularly unable to make many of her own decisions given that she is only 24. As regards disability and reproduction more generally speaking, the 2009 Spanish report on 'Derechos humanos y discapacidad' [Human Rights and Disability] points out discriminatory language in 'La Ley [Law] Orgánica 2/1010 (3 de marzo)' on reproductive health and voluntary termination of pregnancy that grants an extended time period for decision making when the fetus may have a disability (19). Similarly, 'Los progenitores con discapacidad son juzgados públicamente, no solo por la administración de justicia, también por los servicios sociales e incluso por la sociedad en general, como personas que no tienen el mismo derecho a ser padres o madres porque se las prejuzga como no válidos (o menos válidos) para hacerlo. Es preciso combatir estos prejuicios y prevenir las vulneraciones de este derecho, evidenciando y respetando que las personas con discapacidad, si cuentan con los apoyos necesarios, pueden, pero sobre todo deben, ejercer su derecho a ser padres en igualdad de condiciones que cualquier hombre o mujer sin discapacidad' [Parents with disability are publicly judged, not only by the judicial process, but also by social services and even society in general, as people who do not have the same right to be fathers or mothers since they have been previously judged to be unfit (or less fit) to do so. It is necessary to combat these prejudices

- and prevent infringements of this right, making clear and respecting that people with disabilities, if provided with the necessary support, can, but above all should, exercise their right to be parents in conditions equal to any other man or woman without disability] (30).
- 12 The organization Down España, whose website boasts the slogan 'Autonomía para la vida' [Autonomy for life], has the following to say: 'En DOWN España consideramos que la promoción de la vida autónoma debe ser uno de los pilares fundamentales en los que se asiente cualquier programa o legislación referida a las personas con Síndrome de Down' [At DOWN España we believe that the promotion of an autonomous life should be one of the fundamental pillars upon which to base any program or legislation relating to people with Down syndrome] (www.sindromedown.net/index.php). Article 19 of the UN Covention underscores the 'Derecho a vivir de forma independiente y a ser incluido en la comunidad' [Right to Live Independently and To Be Included in the Community] (www.sindromedown.net/adjuntos/cPublicaciones/ 57L_guia.pdf).
- 13 One study from 2009 reported that the unemployment rate for people with intellectual disabilities in Spain was at 60% (Hirtz).
- 14 'Social models of disability tend to emphasize the contribution of specialist services to this exclusion [of people with disabilities], which was particularly evident during the era of the long-stay hospitals. Even so, it has become apparent that physical presence within a community does not guarantee greater social inclusion. Taking part in activities, and using local facilities, does not necessarily lead to meaningful social contact with others, particularly the non-disabled population' (276).
- 15 The Spanish films *Vida y color* (2005, by Santiago Tabernero) and *Te quiero, Eugenio* (2002, by Francisco José Fernández) feature characters with Down syndrome as well (Fragueiro 19). As my disappointing experience with the 2003 volume *La discapacidad en el cine* (by Olga María Alegre de la Rosa, discussed briefly in a note to the Introduction) conveys, there has yet to appear an effective encyclopedic work detailing the representation of disability in Spanish film.
- 16 In yet another scene (approx. 39:40), Olvido goes upstairs, taking her bathrobe off halfway up, and León returns to the stairway again and again, hoping, perhaps, to see her naked. She then comes downstairs wearing only her underwear to put on a dress in front of him. After asking if she looks pretty in it, she takes it off and puts on another dress, asking if he likes her more in the second one. Also, when she picks him up at the Civil Guard station after having abandoned him, the female guard tells her that her brother 'tiene una gran virilidad' [has a large male-organ].
- 17 It is similarly unconvincing that at one point he mistakenly uses the word 'meses' [months] instead of 'días' [days] when stating that he is still new to the school (21:18).
- 18 The classroom scenes vertebrate the film. In another such scene, León (26:43) stands at the board explaining a logical sequence ('Todos los hombres son mortales. Sócrates es un hombre. Luego Sócrates es mortal' [All men are mortal. Socrates is a man. It follows that Socrates is mortal]). Another episode features Raquel, the teacher, instructing the class on dancing (53:35–54:27, yet another commonality with *Yo, también*). A later shot of the same

- class shifts from fast music to a slow dance (56:00–56:44), and we see Raquel dancing with her arms around Jonathan, her head on his shoulder.
- 19 The opening credits of the film point out that Larralde has won the Globo de Cristal a la mejor actriz (Karlovy Vary International Film Festival), the Premio a la mejor actriz (Festival de Cine Independiente de Ourense [España]) and the Premio a la mejor actriz (Black Nights Film Festival [Tallinn / Estonia]). The director, Xavier Bermúdez, has also been the recipient of a few awards, but Jiménez notably has not.
- 20 The reason she gives the shopkeeper for needing the job so badly is that 'Tengo un hermano mongólico a mi cargo' [I have a mongoloid brother in my charge].

CHAPTER 2

Envisioning Autism

Miguel Gallardo's Comic María y yo (2007)

iven that cultural products foregrounding disabled protagonists Jointinue to be a relative rarity in Spain—just as elsewhere—it is particularly (and appropriately)1 intriguing that one of Spain's most notable graphic artists, Miguel Ángel Gallardo, has written (and drawn) a wonderful comic centered on the theme of autism. Gallardo's name might ring a bell as he is a well-known figure associated with the Movida Madrileña of the 1980s, an explosion of cultural activity in the wake of the death of the Spanish dictator Francisco Franco that gave rise to a range of liberated artistic expressions in music, film, performance art, and more.2 While director Pedro Almodóvar is perhaps the best-known figure to have come out of the Movida—continuing to make films even in the twenty-first century (Volver 2007; Abrazos rotos 2009), but famous for his films of the early and late 1980s, including Mujeres al borde de un ataque de nervios of 1988 (see also Triana-Toribio 2000 and Graham and Labanyi 1995)—other graphic artists associated with the period have not garnered as much fame in international circles. As noted in a three-page entry in the two-volume Atlas español de la cultura popular: de la Historieta y su uso, 1873–2000, edited by Jesús Cuadrado, Gallardo is a designer, publicist, illustrator, and animator who was born in Lleida, Catalunya in 1955. He began as a practitioner of historietas (comics) in 1977 and directed the first era of a popular graphic series titled Makoki. Regarding the latter, Cuadrado notes that 'su coautoría del popular personaje Makoki [...] oscureció su compleja personalidad de autor gráfico multidisciplinar' [his co-authorship of the popular character Makoki (...) overshadowed his complex identity

as a multi-faceted graphic artist]. The encyclopedia entry goes on at length listing Gallardo's extensive production of series, publications, monographs, catalogues, illustrations, animation, television work, and more (510-12). One of Gallardo's other notable roles was as collaborator and co-creator of the pioneering graphic magazine El Víbora (see Alary 56, 60; Beaty 116, 119; Dopico 318-34; García 165; Vilarós 211–13), and the recent republication of his works of that time period (e.g. 1981's Makoki: Fuga en la Modelo, by the Barcelonan publisher La Cúpula in 2009) only reaffirms the value of his contributions to the comic world in Spain. In addition, he is a prize-winning comics artist (doubly praised by the Salón del Cómic de Barcelona, and the winner of a Serra D'Or prize for his guide to disability for children, ¿Qué le pasa a este niño?) who has worked regularly as an illustrator for La Vanguardia and other Spanish and international publications (including the Herald Tribune and the New Yorker). Problematically, however, until now there has been no sustained, nor even thorough, critical examination of Gallardo's visual texts by Hispanist critics.

With this in mind, this chapter does not seek to provide an exhaustive analysis of Gallardo's cultural production as a whole, but instead to focus on his more recent autobiographical comic work María y yo (2007) and, below, on the adaptation of that work to a complex documentary feature by director Félix Fernández de Castro (2010). The present analysis of Gallardo's work is significant because he has not yet sufficiently attracted the attention of academic scholars in general—a landmark 'cultural studies' approach to the Spanish transition (1973–93) by Teresa Vilarós mentions him on only two pages. Even though his name is frequently invoked as a way of pointing to the cultural production of the Spanish transition, if not the Movida culture of Madrid specifically, these invocations serve as mere indexes, with scholars seemingly reticent to devote more time to understanding his style and contribution in-depth. That being so, his recent incorporation of the theme of disability is doubly marginalized—first, because the comic is still, generally speaking, a neglected medium in academic circles (this is particularly true with regards to Hispanic Studies), and second, because there are no more than a handful of researchers within Hispanic Studies who incorporate Disability Studies approaches into their work, and even fewer, perhaps, who do so in the realm of Spanish (Peninsular) cultural production as opposed to that of Latin America.3

Even outside of Spanish cultural studies, the study of comics is just beginning. As recently as 2007 it was possible for critic Craig Hight to write that: 'Although comics are a medium as rich and complex as any other, the study of comic forms is a comparatively neglected field within media studies, with attempts to identify the defining characteristics of comic narratives and aesthetics still in their infancy' (181). In 2009, Thierry Groensteen similarly noted the 'considerable lack of legitimacy' enjoyed by comics, writing that 'Comic art suffers from an extraordinarily narrow image, given the richness and diversity of its manifestations' (Groensteen, 'Why' 3). On the other hand, many have started to view comics as a 'legitimate' subcategory of literature (e.g. Versaci's *This Book Contains Graphic Language: Comics as Literature* from 2007).

Although fans and scholars of comics know better, those unfamiliar with the breadth and depth of comics artistry may tend to think that many if not all comics are reducible to a 'finite set of visual attributes, which are either inherent to the medium or historically stable' (Cohen 13). Instead, comics enjoy a wealth of visual, formal qualities just as they possess a dynamic history. While published scholarship on the development of comics generally tends to point to a modern prehistory rooted in the 1800s (e.g. García 28), the publication of Spanish comics directed toward adults only took off in the 1960s–1970s (Alary 35; cf. García 163), and a significant appreciation of the artistic nature of comics emerged even more recently. According to Viviane Alary's essay 'La historieta en España: entre el futuro y el pasado':

Nuestro fin de siglo legimita la historieta de diversas maneras. Se la ve como un lenguaje en parte dependiente de su condición de producto de consumo ligado al desarrollo de una cultura de masas; pero, a la par, se reivindica su condición de arte, el noveno, capaz de desarrollar un lenguaje artístico peculiar. (Alary 35)

[Our turn of the century legitimized comics in many ways. It was seen as a language in part dependent on its condition as a marketable product, linked to the development of a mass culture; but at the same time, it was revindicated as an artistic creation of the ninth art, capable of developing an individual artistic language.]

Spanish comics are an important if undervalued and under-researched European comics industry—they are barely mentioned, for example in Bart Beaty's book *Unpopular Culture: Transforming the European Comic Book in the 1990s.* Spanish graphic artists have struggled to achieve the same critical acclaim afforded to English-language, Japanese, and even French comics, among others. If one peruses, for example, the chapters of recent edited volumes on the art of comics—such as those

collected by Robin Varnum and Christina T. Gibbons in *The Language of Comics* (2001); by Ian Gordon, Mark Jancovich, and Matthew P. McAllister in *Film and Comic Books* (2007); or by Jeet Heer and Kent Worchester in *A Comics Studies Reader* (2009)—one will find virtually no mention of Spain nor of Spanish artists. Even Spanish comics artist/scholar Santiago García's recent and encyclopedic work *La novela gráfica* (2010) is more of a general introduction to the history of all comics than a work focusing on the Spanish context (it is notably full of examples taken from English-language comics, among those from other non-Spanish traditions).

Spanish scholar Pablo Dopico's illuminating study of Spanish comics (El cómic underground español, 2005) is a giant step forward in this sense, but although its topic matter is strictly Peninsular, it nonetheless ostensibly confines itself to the period of time between 1970 and 1980. Despite the impressive, wide-angle lens through which it treats this formative period in Spanish comics, it does, however, touch upon Miguel Gallardo's artistic activity during the mid-1970s immediately after the death of Franco, including his work with Juan Mediavilla and their collaborative urban representation of 'la gran ciudad y los extraños personajes marginales que allí habitaban' [the big city and the strange marginal characters that were living there] (209). As Dopico reports, Makoki was created in 1977 by Gallardo, Mediavilla, and Barrallo and soon became one of the most 'emblematic characters of the Spanish counterculture' (296; see also 298–300). A brief section on Gallardo, specifically, here functions as a general introduction to his earlier work (355-69). Nonetheless, little of this information is of interest to the present chapter, which focuses on a much more recent—and, thematically and stylistically speaking, very distinct—period in his artistic production, one which should prove to be quite intriguing for Disability Studies scholars.

Just as the topic of disability remains an undervalued area of scholarship at large, that subfield devoted to the representation of disability in comics is virtually unexplored. The existing edited collections on comics available in English—some of which are mentioned above, and many of which are published by the University Press of Mississippi—feature not a single chapter focused on disability. The notable exception is the lone essay by Margaret Fink Berman in *The Comics of Chris Ware: Drawing is a Way of Thinking* (2010). Still, even this essay focuses on Ware's depiction of a woman with physical disability, leaving issues relevant to developmental disabilities, such as autism, unaddressed. This lack may be attributed to the fact that the notion of Disability Studies has only recently begun to command attention from

academics working in more culturally oriented fields of scholarship. But there may also be another complementary reason.

The paucity of comics scholarship focused on disability may be the problematic legacy of mid-twentieth-century comics as explicitly formulated (in the influential American context) by the Comics Code of 1954. As Scott McCloud notes, in that year,

comics publishers agreed to a strict code of ethics that would dominate the industry for decades to come and created an authority with the power to enforce it. The Comics Code imposed the severest restrictions of any narrative medium of its day. Gone were any depictions of gore, sex or sadistic behavior, but gone too were any challenges to established authority, the unique details of any crime, any hints of 'illicit relations' or the condoning of divorce, any references to physical afflictions or physical deformities, and any allusions to 'sexual perversions' of any kind. (*Reinventing* 87)

This 'cleansing' of all manner of social, cultural, political, sexual, and corporeal difference from the comics of that period greatly affected the subsequent development of those themes not merely in the United States but arguably also necessarily in other countries where comics artists looked upon the American industry as a thriving model. Even in a contemporary context where comics art has been seen through the various lenses of critical theory—the volume edited by McAllister, Sewell, and Gordon boasts sections devoted to gay/lesbian/queer comics, gender politics, nationalist myth and nostalgia, and the urban poor, for example—disability doesn't seem to make the list. While I am not sure whether there is a lack of comic books/graphic novels with disabled protagonists or a lack of scholars interested in the theme of disability and comics, both explanations are likely true to a certain degree. Whatever the reason, more and more cultural critics are recognizing that 'the portrayals of life found in comic art are not neutral or random images. In practice, not just in theory, often comics' portrayals of social issues and representations of particular groups have significant ideological implications' (McAllister, Sewell, and Gordon 5). In this context it is more important than ever that critical Disability Studies be systematically mobilized to shed light on the portrayal/lack of portrayal of representations of disability in the wider comics world.

Part of the strength of Gallardo's comic *María y yo*—which focuses on his relationship with his daughter, who has autism—stems from its autobiographical approach; and in this sense, it implicitly pays homage to a distinctly American mode of autobiographical comics art.

Such an autobiographical mode is widely associated with the emergence of work by Harvey Pekar. Pekar, dramatized in the film American Splendor where he is played by actor Paul Giamatti, initiated a period of comics production steeped in 'a radical appreciation for the mundane' (Hatfield 111; see also Hight), thus departing from the approach that over-valued superheroes. This shift from the superheroic theme and the mythic (read national) frame to the quotidian and the personal allowed for alternative stories to be told, stories that have historically had less mainstream marketability. As Charles Hatfield discusses, comics as reimagined by Pekar spoke to a different audience, embracing a more delicate psychology and permitting self-reflection, both by the artist and the reader alike: 'For Pekar autobiography is a means of autodidacticism, as his comics represent a struggle for an understanding both emotional and intellectual' (110); he concludes that 'The cartoon self-image, then, seems to offer a unique way for the artist to recognize and externalize his or her subjectivity. In this light, comics autobiography may not be alienating so much as radically enabling' (115).

Gallardo's self-representation and his depiction of the life he shares with his daughter in María y yo is, in this sense, radically enabling: he externalizes both his own frustrations with the social situations that surround disability and his love for his daughter, and in the process he also gives voice (or better, shape) to María's own struggles, joys, and ways of thinking in ways that only a parent might be able to do. This autobiographical approach capitalizes on a characteristic intimacy associated with comics that has been noted by a number of scholars. David A. Beronä, for example, notes that 'Comics have always forged a personal—almost singular—relationship between the artist and reader' (39; see also McCloud, Reinventing Comics xii). All in all, following Hatfield's assertion that 'autobiographical comics that strive after authenticity have the potential for radical cultural argument' (128), Gallardo's comic is thus a powerful document of the life-experience of disability at the same time that it is a unique cultural expression in an underappreciated medium.

María y yo is just as informative regarding the quotidian aspects of living with disability as it is an intimate expression of a father's relationship with his daughter. The back cover of the 2007 comic states Gallardo's goal quite clearly: 'En este libro, Miguel Gallardo, acostumbrado a comunicarse visualmente con su hija María, quiere compartirlo con sus lectores como si nosotros fuéramos ella y a través de sus dibujos entendamos su mensaje simple y breve de una manera inequívoca' [Through this book, Miguel Gallardo, accustomed

to communicating visually with his daughter María, wants to share this with his readers putting us in her shoes and, through his drawings, allowing us to understand his simple and concise message in no uncertain terms]. While Gallardo may happen to be an established graphic designer with over twenty years of experience, it is more than appropriate that his autobiographical rendering of his relationship with his (then) 12-year-old daughter—and, moreover, of her relationship with her own social environment—should take shape in such a visual medium. The comic thus succeeds on two levels at once. First, it succeeds as a document and a recasting of the life-experience of a girl with autism (and of that of her father). To that effect, as is noted once again on the comic's back cover (copied from the book's epilogue by Amaia Hervás):

Un gran atractivo de este libro es que corrige muchos tópicos sobre los niños con autismo, un síndrome que se diagnostica cada vez con más frecuencia. María no es distante ni fría, sino emocional, afectuosa, más allá de las peculiaridades del trastorno que padece. Nosotros también podemos hacer más feliz a María y a todos los niños como ella, sencillamente aceptándola tal cual es: única, como todos los demás.

[A great strength of this book is that it corrects many common misundersandings of children with autism, a syndrome that is diagnosed with increasing frequency. María is neither distant nor cold, but rather emotional and affectionate, undetermined by the specifics of the disorder from which she suffers. We, too, can make María, and all the children like her, more happy simply by accepting her as she is: unique, just like everyone else.]

The latter slogan, 'I'm unique just like everyone else,' figures in English prominently on María's shirt as seen on the drawn cover of the comic, on its dedication page and even on a page near the middle of the book in a section labeled 'Única' [Unique] (18). In every appearance of this slogan, the book foregrounds that its contribution is to visually elaborate on the realities of living with someone with autism (through the form of the comic) while succumbing neither to the problematic trope of exceptionality nor to a mainstream idea of a homogeneous normalcy.

Secondly, in addition to being a comment on and contextualization of the reality of living with a disability such as autism in a society unprepared and at times even unsympathetic to what that means, the comic *María y yo* is also a rich visual text in its own right, mobilizing

the full range of formal qualities of sequential and comic art to achieve its artistic and educational goal. While this chapter seeks to address both of these concerns—*María y yo* as document of disability and *María y yo* as cultural text—even relating them where appropriate, it proceeds from a discussion of the first to that of the second, preceded by a section concisely presenting the link between autism and visuality. It is to this preliminary (and necessary) discussion that we now turn by briefly exploring the written works of Temple Grandin.

The Visual Paradigm of Autism Seen Through the Writings of Temple Grandin

Temple Grandin (PhD, University of Illinois) stands out as one of the most well-known persons with a form of autism (Asperger's syndrome)—one writer even goes so far as to say that she is 'possibly the world's best-known autistic' (Halpern 38). Her own published autobiographical reflections on her skills, strengths, and vulnerabilities provide a valuable point of entry into how *María y yo* might be approached by both casual readers and scholars alike. Although she is also noteworthy for having written more recent books (e.g. *Animals Make Us Human*, co-authored with Catherine Johnson) and having been the subject of a biopic in which she is played by actor Claire Danes (*Temple Grandin*, HBO films, 2010), the works *Emergence: Labeled Autistic* (co-authored with Margaret M. Scariano, first published in 1986) and *Thinking in Pictures* (first published in 1996) provide the most relevant understanding of her life-experience as a person with autism.

Emergence documents everything from Grandin's childhood memories and early school years to her graduate school experiences and beyond.⁴ As it is quite simply a path-breaking book, written by an autistic person about the topic of autism, she makes an effort to provide initial explanations for those who may be unfamiliar with the condition (for a concise scientific perspective, the reader might consult Frith and Hill, 'Understanding Autism: Insights from Mind and Brain'). These descriptions are, of course, also important to understanding the contribution of *María y yo* in this chapter. Grandin explains:

Autism is a developmental disorder. A defect in the systems which process incoming sensory information causes the child to over-react to some stimuli and underreact to others. The autistic child often withdraws from her environment and the people in it to block out an onslaught of incoming stimulation. Autism is a childhood anomaly

that separates the child from interpersonal relationships. She does not reach out and explore the world around her, but instead stays in her own inner world. (13)

Using the first person and drawing on her own experiences, Grandin describes behaviors and characteristics that are in many ways typical of people with autism. She writes of her characteristic sensitivity to noises (23), noting that she was often threatened by noises 'violating my ears and very soul' (23) and was also unable to grasp the concept of rhythm easily (30–31). She tended to avoid tactile stimulation (32), even though this is just as important for autistic children as for others (33). To meet this frustrated need, she eventually designed a 'squeeze machine'-modeled on a device she saw on a cattle ranch-that provided her with the warmth and comfort that she was uncomfortable receiving from other people (86–99; see also Thinking 62–81). After all, as she explains, autistic children 'prefer (proximal) sensory stimulation such as touching, tasting and smelling as opposed to distant (distal) sensory stimulation of hearing or seeing' (33)—but it is likewise important for the autistic child to be able to control the terms of that proximal stimulation, as Emergence and Thinking both emphasize. If Grandin's early autobiographical narrative is any indication, people are typically seen as unpredictable and overstimulating by people with autism—'as a child, the "people world" was often too stimulating to my senses. Ordinary days with a change in schedule or unexpected events threw me into a frenzy' (25). On a social level, she was very often isolated, 'Communicating with someone—anyone continued to be a problem' (85). On a personal level, she was prone to 'Obsessive questioning and perseveration' (35), just as to 'uncontrollable laughter' (36) or an 'obsession with a particular topic' (36). Some of her behaviors were perhaps less typical of autism (and more idiosyncratically psycho-social), being 'so impulsive and bizarre' they surprised even Temple herself (28).

Yet while these descriptions of behavior associated with autism are instructive and perhaps even, to a large degree, accurate, we should nevertheless be wary of reading too much into them or prioritizing them in our treatment of people with autism. In his foreword to Grandin's subsequent *Thinking in Pictures* (pp. 11–18), Oliver Sacks points to an incomplete and superficial image of autism that is nonetheless deeply rooted in the popular consciousness. 'The word "autism" still conveys a fixed and dreadful meaning to most people—they visualize a child mute, rocking, screaming, inaccessible, cut off from human contact' (11). In *Emergence*, Grandin works to correct this

misperception, stating early on, for example, that 'autistic children have more socially related behaviors than many people realize [...] To say that an autistic child has absolutely no response to people is a misconception' (15). *Thinking in Pictures* returns to and extends the autobiographical approach that Grandin began in *Emergence*, but it also delivers the picture of a better-adapted and more successful Grandin, in the process meditating more explicitly on the significance of the visual field for both herself and, perhaps, others with autism.

Perhaps the most interesting thing about *Thinking in Pictures*—signaled in the title itself—is its primary focus on the topic of visuality. This was, of course, a dimension of the earlier *Emergence*, to which Grandin turned briefly in chapter 11, which begins, 'My mind is completely visual, and spatial work such as drawing is easy' (135). She writes there of 'seeing' and 'reading' book pages in her mind, of the fact that pictures can be used effectively to communicate with autistic children, and of the opposition between visual and sequential thinking (135–36), but the effort is not sustained. In *Thinking*, however, we have a much more thorough, sustained, and conscious evaluation of the role of visuality in Grandin's autism, now clearly seen as a source of strength and confidence. The book begins with a strong affirmation in the first chapter, titled 'Thinking In Pictures: Autism and Visual Thought':

I think in pictures. Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head. When somebody speaks to me, his words are instantly translated into pictures [...] One of the most profound mysteries of autism has been the remarkable ability of most autistic people to excel at visual spatial skills while performing so poorly at verbal skills. When I was a child and a teenager, I thought everybody thought in pictures [...] my visualization skills far exceeded those of most other people. (19–20)

Grandin undertakes a concerted and detailed explanation of her own visual way of thinking. 'Unlike those of most people, my thoughts move from video-like, specific images to generalization and concepts. For example, my concept of dogs is inextricably linked to every dog I've ever known. It's as if I have a card catalogue of dogs I have seen, complete with pictures, which continually grows as I add more examples to my video library' (27–28).⁵ She suggests that autistic children may tend to learn nouns more easily than other words 'because they directly relate to pictures' (29), and that the process of working from

specifics to generalized concepts occurs 'in an associational and nonsequential way' (32). Conversely, reading may sometimes prove difficult as she is sometimes unable to 'convert text to pictures' (31). Interesting in this respect is that making sense of concepts 'such as learning the give-and-take of a relationship' only made sense to Grandin after having been visualized through the relevant 'visual symbols of doors and windows' (34). Likewise, she reveals that a visual image helped her to understand the notion and necessity of 'getting along with people' (36). Her visual skills have also been extremely valuable in her famed redesigning of numerous cattle-handling and slaughter facilities, as she is able to visualize the ideal functioning of machinery in her mind (40–41). In fact, the reader unfamiliar with Grandin's story may be surprised to learn that 'One third of the cattle and hogs in the United States are handled in the facilities I have designed' (142).

Yet visuality is important to her not merely as a tool in her mental engineering work, but as a form of acquired empathy. Chapter 8 of *Thinking*, 'A Cow's Eye View: Connecting with Animals,' goes further in highlighting the importance of visuality for many people with autism, as Grandin describes the many insights she has experienced from putting herself in a cow's place.

When I put myself in a cow's place, I really have to be that cow and not a person in a cow costume. I use my visual thinking skills to simulate what an animal would see and hear in a given situation. I place myself inside its body and imagine what it experiences. It is the ultimate virtual reality system, but I also draw on the empathetic feelings of gentleness and kindness I have developed so that my simulation is more than a robotic computer model. [...] Cattle have a very wide, panoramic visual field, because they are a prey species, ever wary and watchful for signs of danger. Similarly, some people with autism are like fearful animals in a world full of dangerous predators. They live in a constant state of fear, worrying about a change in routine or becoming upset if objects in their environment are moved. (143–44)

Grandin splendidly milks the idea of a connection between the visual perception of both cows and autistic children over a number of pages, highlighting the disturbance caused by novel objects in their visual fields (e.g. 146). But just as important as the way in which this chapter points to the power of visuality for some people with autism is the way it undermines a poorly situated belief that they are absolutely incapable of empathy. Although Grandin is unlike many other people whose diagnoses locate them on a different area of the autism spectrum and

who may neither have had the same access to education nor received as much family support, her motivation and success illustrate that there may be other non-traditional routes to empathetic thought for people with autism. If Grandin's autobiographical narratives are any indication, visuality may be taken as one of the dominant tropes associated with autism—as the basis for an 'autistic mode of thought' (see also Hacking and McGeer) and even as a pathway leading toward empathy. My hope is that as the reader ventures further into the subsequent analysis of the text *María y yo*, Grandin's explanatory discussions of autism will provide a touchstone for the behaviors and social environment of María and also for the unique visual style advanced by Miguel Gallardo.

Autobiography, Disability and Comics Form in María y yo

The best way to approach *María y yo* is as a visual autobiography drawn by one person but experienced by two—a father and daughter pair. In this respect, it should not be taken lightly that Miguel Gallardo is listed as the second author of the comic, with his name listed behind that of his daughter, María. María, although she has not contributed any drawings to the book, is a part of every page and in a sense has inspired (at the very least) if not actively shaped the narrative, events, and the very content of the volume. *María y yo* is, importantly, a rendering solely of the time spent together by father and daughter—notably there is no set-up centered primarily on Miguel, nor is there any attempt to detail María's life apart from her father (one intimates, correctly or not, that she more regularly lives with her mother). The basic premise is made explicit as text by Gallardo on page 3.7

María vive con su madre en Canarias, a 3 horas en avión de Barcelona, donde vivo yo. A veces nos vamos de vacaciones los dos juntos a pasar una semana en algún resort del sur de Gran Canaria frecuentado por alemanes y otros guiris. Esta es la historia de uno de esos viajes, volviendo de Barcelona y aprovechando los últimos días del verano en uno de esos hoteles. En esos viajes María y yo hablamos, reímos, hacemos listas de gente y comemos hasta hartarnos.

María tiene 12 años, una sonrisa contagiosa, un sentido del humor especial y tiene autismo. $(3)^8$

[María lives with her mother in Canarias, three hours by plane from

Barcelona, where I live. Sometimes the two of us take a vacation, spending one week in a resort in the south of Gran Canaria frequented by Germans and other foreigners. This is the story of one of those trips, returning from Barcelona and taking advantage of the last days of summer in one of those hotels. On those trips María and I talk, laugh, make lists of people and eat until we are stuffed.

María is 12 years old and has a contagious smile, an endearing sense of humor, and autism.]

Gallardo's creative talents are, throughout, consciously mobilized first and foremost to deliver a sympathetic and humanizing portrayal of his relationship with his daughter, and perhaps only secondarily (or, after all, perhaps not) an informed presentation of disability, specifically autism, to those who may be unfamiliar with it. Whether or not he intended the comic to have a pedagogical component, one that in the end deserves to be approached from a Disability Studies framework, it definitively succeeds in this respect. *María y yo* notably goes beyond commonly held stereotypes of people with autism to deliver a thorough portrait of the textures of the daily life that Miguel and María share together—it is entertaining and even educational while showcasing a high degree of artistic creativity.

A detailed look at the initial section, 'De Barcelona a Canarias' [From Barcelona to Canarias] (4–5), serves as a concise introduction to Gallardo's presentation of disability, his depiction of María's perseverative behaviors, and to his characteristic sense of humor. It is one of the most traditional sections of the comic from the perspective of formal features, first and foremost because it foregrounds a linear plot through what are—more or less—four rows of sequential art on each page. It is significant that the first pages after the grounding image of María (2) and the concise textual explanation of the book's contents (3) comprise an attempt to ground the work in a traditional format that would be easily appreciated by both advanced and casual readers of comics alike. This is particularly so given that, as will be discussed below, the book evolves by progressively abandoning this approach in favor of one that presents numerous connections with what might be seen as an 'autistic visual sensibility.'

In terms of plot, 'De Barcelona a Canarias' begins with María and Miguel's arrival at the airport in the first panel of page 4 and ends with their boarding of a plane at the end of page 5. The section seems conscious of its role as narrative, and Gallardo begins the first panel by introducing the reader to a problem of sorts that will be eventually resolved at the end of page 5. Through a point-of-view mid-shot

we see the outline of an airline employee standing behind a desk informing María and Miguel that, since they have arrived late, they may have to travel separately. Just as in more traditional non-comic narrative Gallardo here begins also in medias res, thrusting the reader into a situation that would certainly be a nightmare for any parent and child traveling together. There is a human quality to the pages (which perhaps contrasts with his co-authored work such as Makoki: Fuga en la Modelo) in that Gallardo, at least in this instance, has chosen to hand-draw the panel-frames of the sequence without a straight-edge and seemingly rather quickly at that. The resulting lines are unequally shaded, irregular, and at times purposely imprecise, rendering visible the traces of the human hand that has drawn them.

As the pair hustle through the airport to the gate in the subsequent three framed drawings (page 4 consists of 11 sequential drawings-only seven of which are framed as separate panels-and an explanatory footnote), Gallardo cycles through a number of the wordimage combinations that may obtain in comics as described by Scott McCloud in his foundational text Understanding Comics (1994). Panel 2 presents the 'additive' combination, as Miguel spies a clock in the hallway and exclaims 'iMierda! Faltan 20 min. para embarcar!' [Shit! Only 20 min. until boarding!], panel 3 the 'word-specific' combination as the picture merely illustrates Miguel's own perseverative thought pattern ('iCorrer! iCorrer!' [Run! Run!]), and panel 4 the 'duo-specific' combination as María in close-up screams louder than before (terms from McCloud, Understanding 153-55). This chaotic and rapid cycling through various word-image combinations assists in imbuing the sequence with a sense of visual complexity and narrative chaos. María y yo's characteristic two-tone appearance (only black and red inks are used) aids in creating an effect of two-channel overstimulation. Here, through the black ink, we directly see that it is Miguel who is overstimulated by the pressure to arrive on time at the gate and to deal also with María's constant perseverative yelling. And yet María herself is also likely characteristically overstimulated by the hustle and bustle of the airport, not to mention her father's own hurried sense of time running out. While it is not the case that the color red is always used throughout the book as an extension of María's experience (it is used quite extensively to provide depth of narration in a variety of ways), here it is used to great effect as a way of pairing María's red hat with her wailing repetition of 'Ceiba es fea' [Ceiba is ugly]—as we are informed by page 4's sole footnote, Ceiba is the name of one of María's favorite cousins in Canarias. There is a practical element to this pairing—just as there is elsewhere in the comic—in that using the same color for

hat and wail allows the reader to see that it is María herself who is the origin of the scream, but the color also adds intensity to the crescendo effect through which her words progressively occupy more and more of the panel. In panel 3 the word 'Ceiba' appears in red very close to María, panel 4 is equally split between María's head in the lower half and gigantic red letters in the upper half, and what would be panels 5 and 6 consist of one stretched and unframed image as Miguel drags María through the airport while her red-ink scream virtually eclipses the torso and face of a passer-by. As McCloud notes, comics artists will erase the frames of an image as a way of manipulating the reader's received sense of time (Understanding 95-103), and here María's scream has a greater emotional impact and temporal weight that is insufficiently mediated by Miguel's small-lettered/black-inked meek protest ('iiMaría... por favoooooor!!' [María... Pleeeaaase!!]). Her scream (still in red) in fact echoes through three more panels on pages 4-5. After a passer-by judges Miguel for having a badly behaved child (panel 7) and the appearance of another non-framed image of a (red) clock with the title 'El tiempo pasa' [Time Passes] (panel 9)—thus emphasizing the temporal duration experienced by the two in the airport—Miguel and María sit down on a bench where she continues to scream, to the disapproval of many others in the airport. The entirety of page 7 is a large panel of a small plane in mid-air with the red-ink words 'Ceiba es feeeeeaaaaa' emanating from the plane and dominating the otherwise rather stark image.

On page 5, after Miguel tells María to stop screaming (and is unsuccessful), Gallardo includes a sprawling scene of a line of people who are all waiting to pass through gate 28 (a line which, unframed, threatens to take up half of the page). Faced with the long line (and with the [im]possibility of being separated on two different flights), Miguel moves to the front of the line saying 'Perdone amable señorita, voy a pasar por delante de toda esta cola, porque María bla blu bli bla...' [Pardon me young lady, I'm going to jump ahead of this line because María blah, blah, blah, blah...]. A red line connects María's face to the young lady's eye, and the latter responds 'Oh... sí claro, caballero' [Oh, of course, good sir]. Boarding the aircraft, Miguel speaks to the flight attendant about being late and about the problem of overbooking, explaining that he and María cannot be separated, and the last image on the page shows us a red-inked abstract figure abruptly being hurled out of the parked plane with the humorous caption 'Rápidamente encuentran una solución' [A solution is quickly found]. The fact that the word 'solución' [solution] appears in red heightens the humorous effect. On these two pages we have a triple

introduction; to the plot of María y yo, to Gallardo's characteristic style, and, not insignificantly, to his treatment of disability. Already we have an understanding that the comics artist wants to portray the day-to-day realities of interacting with his daughter. This will clearly include activities that are enjoyable or, as here, frustrating. True to the title relationship, it will highlight both María's reactions to her social environment as well as Miguel's perceptions of the often skewed reactions of strangers who lack a way of making sense of María's autism. Part of relating the day-to-day realities of their experiences together means revealing the coping strategies Miguel has developed to deal with this ignorant public-even if that means taking advantage of public perceptions as occurs in the above-related episode of cutting to the front of the line. The style of María y yo, and as we will see later, its formal qualities and development of what might be considered an 'autistic visual aesthetic,' accentuate this attempt to visually represent an autobiographical experience of autism. The hand-drawn panel borders, the seemingly unrestrained personal honesty of the narrative, and the mundane nature of the subject-matter all contribute to the sympathetic presentation of disability in the comic.

Part of the strength of María y yo—at the level of content—comes from its nuanced but (apparently) unvarnished presentation of the characteristics traditionally associated with autism. As with the larger population (to a great degree), some of these behaviors are, perhaps, frustrating, while others are endearing and others, well, just are. Keeping in mind Temple Grandin's descriptions in Emergence and Thinking, we see María engage in perseverative behaviors and acting out (screaming, for example) in public. We see her (on the inside front cover no less) characteristically completely absorbed in the repetitive act of letting beach sand fall through her fingers (also 18-19, 36; a behavior depicted also in Fernández de Castro's film, to great effect). The drawing of her chewing her resort buffet food (a favorite shared activity of the father-daughter pair) is labeled with the red-inked word 'superconcentración' [superconcentration] (13). These behaviors are not always problematic. María perseveratively asks questions, but Miguel's pictures of people provide an outlet for that behavior, as on page 10 where the two share the same space by the pool amid a warm, red-inked background of plants-María engaging with her pictures and Miguel sipping a drink. '[Miguel:] Amigos, esto es vida, tomando el sol, con mi pulserita rodeado de alemanes que hacen lo mismo que yo... iMe siento integrado!' [This is the life, my friends, out in the sun, with my red bracelet surrounded by Germans doing the same thing as me... I feel at ease!']; '[María:] ¿Quién es,

papi?' [Who is this, daddy?].10 At times, the narrative reflects that María's behaviors may not be as frustrating as the social response to them by strangers. On one compelling full-page panel, for example, we see shaded-in outlines of María and Miguel walking on a blank page beneath 13 disembodied eyes as the text emphasizes what it feels like from Miguel's perspective to be the center of public attention if not scrutiny and judgment ('Y otra vez las miradas, siempre las miradas' [And once again the stares, always the stares]; 26, italics indicate red ink). Gallardo emphasizes the importance of routines while at the resort (24) and María's understandable reactions to deviations from those routines (25). But he also presents her 'Estereotipias, movimientos sincopados que obedecen a algún ritmo interno y que son difíciles de parar si no le ofreces un plan concreto' [Stereotyped movements, syncopated movements that follow an internal rhythm and that are difficult to stop if you don't offer her a concrete plan] (30). These include 'slapping one hand over the other,' 'knocking her right hand against her chin with index finger extended,' clapping, 'making strange circles in the air with her finger,' and so on (all illustrated on page 30).

But Gallardo also works to resituate autism not merely as a neurophysiological issue but as a social relation as well-linking content with formal expression. In one instance, Gallardo uses a full-page labeled 'Caras' [Faces] and divided vertically in half to oppose María's glowing happy face ('Cuando María se ríe, todo alrededor se ilumina, como si se contagiara' [When María laughs, everything around her is illuminated, as if it were contagious]) to the 'Caras que no me gusta ver en las personas que miran a María' [Faces I don't like to see in the people who look at María]. The strict formal division of this page into two halves points to the distance between his own fatherly connection (and his informed grasp of autism) and the lack of knowledge and lack of connection that comes to define the greater public. The top half of the following page elaborates on this through a traditionally framed if large panel wherein a rosy-cheeked (red-inked) María is barely visible within a crowd of seated restaurant guests as her (red-inked) scream 'Elia es guaapaa' [Elia is preeetty] rises up and breaks a section of the upper panel border (17). The bottom half reveals that although Miguel sometimes tries to stop María's perseverative screams, he would like, also, to stop the poor reactions of public onlookers ('A veces me gustaría decirles a ellos también: iNo, señora!' [Sometimes I would also like to tell them: No, madam!], 17). More importantly, he resorts to the metaphor of a dividing wall separating María from the world 'Un muro rodea a María' [A wall surrounds María]—but with a twist.

This wall is relational, dependent on social circumstances and most of all on the attitudes of others, and not necessarily on María:

Un muro invisible rodea a María cuando la gente la ve por primera vez o se cruza con ella. Un muro de miedo a lo desconocido y de extrañeza. Nadie sabe qué hacer ni cómo comportarse al principio, sin embargo, la gente que llega a conocerla, aunque sea fugazmente, queda encantada al ver que el muro que han levantado no es tan alto. Bien es cierto que María tiene los sentidos muy sensibles para el rechazo, sólo se acerca al que está dispuesto a prestarle un poco de atención y escucharla. He conocido a personas enamoradas de María tan sólo por hablar con ella un rato y ver como no es difícil comunicarse. (31)

[An invisible wall surrounds María when people see or run into her for the first time. A wall of fear of the unknown and of the surprise. No one knows what to do or how to behave at first, but then, the people who come to know her, even if fleetingly, are amazed to see that the wall they have built up isn't that tall. It is true that María is very sensitive to rejection, she only approaches those who are inclined to give her a bit of attention and listen to her. I have known people who fall in love with María only by speaking with her a little while and seeing that it isn't so difficult to communicate with her.]

The illustrations that accompany this necessarily pedagogical paragraph are just as striking, with a range of four faces drawn in black ink surrounding a central depiction of María's shining face, inked in red and surrounded by a black-dashed circle indicating the wall. While the relation of words to images on this page might best be described in McCloud's terminology as 'word-specific,' the image nevertheless more directly addresses the range of reactions that people may have when meeting María for the first time: a middle-aged woman and a middleaged man with glasses look skeptically at María from the left while a boy stares in childish wonder and a younger woman looks as if she might venture to communicate with María from the right side of the drawing. Here it is worth turning to the discussion of the abstract-iconic spectrum as it is mobilized in comics. As scholar Thierry Groensteen has noted. 'Indeed it is the distinctive feature of visual monstration to present the "particular" rather than the "general" (Groensteen, The System of Comics 123); and yet, as McCloud reminds us, it is best to speak of degrees of abstractness in cartoon icons (Understanding 28–31). The range of abstractness-iconicity used by Gallardo is reduced in comparison to other comics that present a more exaggerated difference

between one and the other end of the spectrum, and the level of iconicity he uses to draw the characters of María and Miguel is more or less comparable to that he employs in drawing certain German tourists or even the full cast of characters in the comics appendix. Here, however, Gallardo uses a slightly more abstract but nonetheless iconic style, which effectively conveys his sense of hesitant frustration when routinely faced with a series of social types who may react to seeing María for the first time in somewhat predictable ways.

One of the most striking aspects of the formal expression of the volume involves its page layout (see also Groensteen, The System of Comics 142-43). Whereas overall, Gallardo shows a marked aversion to the traditional strict panel divisions that have come to be synonymous with sequential art in the popular imagination, he sporadically incorporates this more traditional formal structure when making specific points. More often than not, he prefers a style in which images co-exist and almost float together on a white background. Simply put, what comics fans/ scholars call the 'gutter' between panels (see McCloud, Understanding 66; Groensteen, The System of Comics 114) is almost nonexistent in María y yo. Significantly, however, Gallardo returns to a traditional, sequential use of framed panels on pages 33-34 in the process of giving the reader a sense of what it is like to have, as the subsection title indicates, 'Una conversación con María' [A Conversation with María]. Each panel features Miguel's face in close-up on the left and María's face in closeup on the right, with no deviation from this pattern throughout the 24 panels comprising the sequence. While María greatly enjoys her time interacting with her father, as Gallardo notes on the previous page in a lengthy paragraph attempting to manage the reader's expectations if not educate him or her outright, 'Con María no tenemos conversaciones al uso, siguen siempre unas pautas rígidas que ella establece, una parte de su discurso son los nombres [...] Ella va soltando nombres que están ligados a sus recuerdos [...] Una memoria extraordinaria para la gente' [María and I have conversations that are unconventional, they routinely follow a strict structure that she establishes, names are a big part of her speech (...) She throws out names that are linked with her memories (...) She has an extraordinary ability to remember people] (32). Although the visual nature of the dialogue of their unconventional conversation is not necessarily linear, it goes something like this:

María: —Marcos

Miguel: —¿Quién? [Who?]

María: —Marcos Miguel: —¿Marcos?

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María: —¿Quién? [Who?]
Miguel: —Marcos... ¿Quién es? [Who is he?]
María: —Un amigo [A friend]
María: —iAlfredo!
Miguel: —Pero cómo es posible que te acuerdes de... [But how is it
          possible that you remember...]
María: —iTe acuerdas de Alfredo! [You remember Alfredo!]
Miguel: —Te acuerdas de Alfredo, ya veo... [You remember Alfredo, I
          see...1
María: —El Richar [Richard]
Miguel: —Pero yo no... Yo no sé quién es el Richar, María... [But I
          don't... I don't know who Richard is, María...]
María: —¿Quién? [Who?]
Miguel: —El Richar [Richard]
María: —Te acuerdas del Richar [You remember Richard]
Miguel: —Richar, claro [Richard, of course]
María: —iYopleidi!
Miguel: —Mmm Yopleidi... Síi [Hmm Yopleidi... Yes]
María: —iTe acuerdas de Yopleidi! [You remember Yopleidi!]
María: —Jose, Luis, Pilar, Leo, Susi, Simón, Pilarín, Yeremai, Ami,
          Keni, Machuca, Diana, Isra, Hanoch, Janet, Marta, Guasi,
          Fabi, Román, Paco, Ima, Ceiba...
Miguel: —Puf [Phew] (33)
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The strict and traditional panel divisions punctuating this dialogue reflect the 'pautas rígidas' [strict structure] established by María to great effect, visually highlighting the sense of order and routine that characterize the conversations between father and daughter. The next page similarly features another 'unconventional' conversation between the two: Miguel begins by asking María what she has eaten today, to which María continually responds that Lili hit her (panels 1–6, page 34), and once Miguel modifies his approach to ask about Lili, María once again changes the subject (twice) before finally telling him (in panel 11) that she has eaten spaghetti and chicken. The final panel shows both María and Miguel facing the reader head-on (still in characteristic close-up continued from page 33) with smiles on their faces as Miguel says '¿No somos la mejor pareja de comediantes que hayais visto?' [Aren't we they best comedic duo you have ever seen?].

Returning to the lengthy paragraph introducing the topic of conversations with María on page 32, it is important that Gallardo draws

the punctuating image of a key beneath the paragraph—it is as if he, here, intends to 'unlock' for the reader the secret of understanding how María's thinking works and of learning how to appreciate one's time with her. He writes:

Su especialidad son las listas de familias, primos, tíos, amigos y ... de pronto, surgido del fondo de uno de sus cajones, el nombre de alguien que hasta tú habías olvidado (algo nada extraño en mi caso) y la cara de alegría de María al ver que tú te asombras de su memoria, eso amigos, es *oro*. (32, the italics indicate red ink)

[Her specialty is making lists of family members, cousins, aunts and uncles, friends and ... suddenly, retrieved from the bottom of one of her drawers, the name of someone that even you had forgotten (nothing strange in my case) and the happy face she makes upon seeing that you are amazed at her memory, that, my friends, is *gold*.]

The notion that María has 'cajones' [drawers] in which she stores her numerous memories of people is an important one whose significance has been underscored earlier in the book (appearing, also, on the back cover), and one that will appear poignantly also in the documentary by Fernández de Castro. On page 23 there appears a sketch of 13 drawers with the labels 'Comida' [Food], 'Paseos' [Walks], 'Piscina' [Pool], 'Canarias' [Canary Islands], 'Fotos' [Photos], 'Barcelona,' 'Amigos' [Friends], 'Arena' [Sand], 'Nombres' [Names], 'Preguntas' [Questions], 'Cumpleaños' [Birthdays], 'Bañete' [Bathtub], and 'Otras cosas' [Other Things]—presumably an illustration of what is most important to María, weighted by increasing the space occupied by certain drawers, with 'Comida' being the largest and 'Arena' coming in a close second. Gallardo contextualizes this picture by refusing to allow autism to be the reader's only guide: 'Compartimos además manías y costumbres, las mías me las inventado yo, las suyas son mezcla de su discapacidad y de ser terca como su abuela. Somos los dos reacios a los cambios y queremos que las cosas estén en su sitio' [Moreover, we share manias and habits, I have invented my own, hers are a mixture of her disability and of being stubborn like her grandmother. We are both resistant to change and prefer it that things be in their place (23). Gallardo does well here in preventing María from being equated with her disability alone—it can be difficult for some unacquainted with people with disabilities to understand that a disability does not determine a person's behavior nor completely account for their personality or identity. Nonetheless, the metaphor of the drawers works as a way of pointing to those patterns of thinking and relating that are, perhaps, characteristic of autism while imbuing such qualities with an accessible, quotidian, familiar and even warm, cozy, and personalized feeling. While the recourse to strict, sequential panel divisions in the section focusing on conversations between Miguel and María (above, 33–34) may have been important to illustrate their repetitive nature, Gallardo's drawer metaphor is appealing for its relatability and potential pedagogical applications, becoming a good way of introducing autism to those unfamiliar with it without overly emphasizing the notion of difference.

Here it is worth returning to Grandin's text Thinking in Pictures to understand that '[d]iscussions with other autistic people reveal similar visual styles of thinking about tasks that most people do sequentially' (32). Paralleling, if not consciously building upon María's non-sequential, 'drawer-like' thinking, Gallardo's text also routinely exploits the visual nature of the comics format, arranging objects together on a page that are necessary for accomplishing a certain goal or engaging in a certain activity. The first page of the section entitled 'Peces' [Fish], wherein Gallardo focuses on pool-time play at the resort in Canarias, features an illustrated look at packing the backpack for María and Miguel's time at the pool. Items showcased include the backpack itself, two towels, hats to protect from the sun, sunblock, a notepad (for Miguel), a notepad of names (for María), wet wipes, and—displaying once again Gallardo's humorous tone—'gafas para el agua (la piscina tiene cloro para matar varios elefantes)' [underwater goggles (the pool has enough chlorine in it to kill a few elephants)] (28). The appendixlike section at the end of the comic bearing titles such as 'Reparto' [Cast] (42), 'Casting en Canarias' [Casting in the Canary Islands] (44), 'Casting in the Canary Islands - 2' [Casting in the Canary Islands -2] (45), 'Casting en Barcelona' [Casting in Barcelona] (46), '¿Quién vino a la fiesta de final de verano?' [Who came to the end of summer party?] (47), '¿Quién estaba en la cena de fin de año?' [Who was at the end of year dinner?] (48), and '¿Quiénes no pudieron venir a la cena pero vinieron después?' [Who didn't make it to dinner but showed up later?] (48) permit the reader a glimpse into María's love for the people close to her as well as what Gallardo describes as her staggering ability to remember people. The iconic drawings of people in María's life included here (which reach a grand total of 45) sprawl over the pages in tidy rows of varying numbers and without any sort of panel structure, each boasting their own name in black ink.

The significance of Gallardo's comics style as presented here is not solely visually 'autistic' of course. It is perhaps best to complement this interpretation by emphasizing at the same time the particular

characteristics of what Robin Varnum and Christina T. Gibbons call The Language of Comics. In the introduction to their edited volume, they cite the undeniable '[v]isual turn of our culture' (ix), alleging that 'Comics is one of the most popular and pervasive media forms of our increasingly visual age' (ix). Nonetheless, María y yo also includes a more explicitly pedagogical component emphasizing the importance of visuality for people with autism. A series of visual lists follows the various casting pictures at the end of the comic: the first, illustrating 'Los deberes de María' [María's chores] (49) is properly introduced as presenting 'pictogramas que utiliza María' [pictograms that María uses] (49). Of interest here, as Andy Bondy and Lori Frost mention in A Picture's Worth: PECS and Other Visual Communication Strategies in Autism, is the fact that 'aided symbols' such as 'Real Objects, Photographs, Line Drawing Symbols, Alphabet Symbols' (53-55) are of great use in communicating with people with autism. A system that the authors have developed known as the Picture Exchange Communication System (PECS) (67-94)—only one of many such systems that have been developed worldwide to aid in visual communication—can help with both 'Understanding Changes in Routine and Expected Outcomes' (131) as well as 'Understanding Transitions' (135; see also Boutot and Smith Myles, 125-27, for the importance of visual supports and visual schedules for populations with autism). Although he does not refer specifically to the system developed by Bondy and Frost, Gallardo takes a very similar pedagogically motivated approach in the final pages of his comic, noting the following:

Los niños con autismo son buenos procesadores visuales. Asimismo estos niños tienen problemas a la hora de anticipar lo que va a suceder, lo que les causa situaciones de angustia y frustración. Los *pictogramas* permiten la estructuración y planificación de sus actividades. Dispuestos por toda la casa ayudan a María a anticipar los acontecimientos que van a ocurrir durante el día. (49, italics indicate red ink)

[Children with autism process visual information well. These same children have problems anticipating what's going to happen next, which causes them to experience anxiety and frustration. *Pictograms* facilitate the structuring and planning of their activities. Postings throughout the house help María to anticipate the events that will occur over the course of a given day.]

The example on the same page as this description includes six traditionally framed panels with hard (seemingly non-hand-drawn)

borders: a car (indicating a trip out of the house), María's face next to a comb and scissors (indicating a haircut), a pizza pie, a young girl putting toys in a box, a young girl in a bathtub, and a young girl with her head on a pillow. The difference in style here—both in terms of the image borders and also the images themselves, which are drawn with a thicker black pen and a more expressly polished if formal approach—helps the reader to conclude that these images are more professionally pedagogical or communicational documents. Moreover, of the four human images, the first is clearly María's face while the others are noticeably not María but a more abstract young girl—a fact that visually allows the reader to intuit that although María uses these pictograms, they are not necessarily an individualized system but more broadly representative of varying types of visual communication. The nine framed images associated with '¿Qué haces cuando vas al lavabo?' [What do you do when you go to the bathroom?] elaborate on the process from raising the toilet cover (panel 1) to turning off the faucet after washing one's hands (panel 9, close-up) (50); and the next series depicts nine sequential activities associated with 'Miércoles -Agenda del día' [Wednesday - Daily Agenda] such as 'Vestirse' [Get dressed], 'Ir al colegio' [Go to school] and 'Ducharse' [Take a shower] (51). Whereas these pictograms introduce the reader to images that are destined for use by people with autism, here María, the last drawnimage series of the book mobilizes a visual pedagogical approach specifically designed to introduce readers to the general characteristics of autism, featuring specific traits illustrated by abstract solid-shade human figures such 'Accesos de risa en momentos inadecuados' [Outbursts of laughter at inappropriate times], 'Dificultades para interactuar con otros' [Difficulty interacting with others], and 'Dedicación obsesiva a juegos desacostumbrados o reiterativos' [Obsessive dedication to unconventional or reiterative activities] (53; cf. Grandin, above).

But as mentioned earlier, *María y yo* is far more than just a visual presentation of the traits often associated with autism. As an autobiographical comic, it is also an attempt to affectionately render Gallardo's relationship with María—and her endearing qualities—in visual form. Thus, accompanying the presentation of what are perhaps characteristically autistic behaviors in the comic are drawings of more idiosyncratic, personalized behaviors that constitute María's endearing traits. For example, after arriving from Barcelona at the Gran Canaria airport, she is 'contenta de llegar por fin y lo demuestra a su manera' [happy to have finally arrived and she shows it in her own way] (8). The red ink connecting objects and words—at other times linked to

sound as seen the above discussion of pages 4–5—is here used to show motion.¹¹ María and Miguel stand foregrounded from a lightly drawn crowd of bystanders with luggage; her t-shirt shirt is red and with her right hand she pinches Miguel's arm with affection as the explanatory nondiegetic words, also in red ink, specify: this is a 'pellizco de cariño' [affectionate pinch] (8). Two red asterisks connect with lines to Miguel's arm at the site of the pinch, and María is calm and smiling as her father looks around, perhaps somewhat perturbed by the crowd or thinking through the next stage of the journey. Similarly, later in the comic Gallardo reiterates that if María likes you she will give you a forceful pinch (31).

One of the most tender moments in the comic is the depiction of Miguel and María's time in the pool. Here, Gallardo is at his most playful as he visually renders both himself and his daughter as fish: 'Los dos somos peces. En el caso de María tiene que ser un poco templadita, es un pez algo delicado [...] iEn el agua somos felices!' [The two of us are fish. In María's case, the water must be lukewarm, she is a somewhat delicate fish (...) We are happy in the water! [(29, italics indicate red ink). We see profiles of two fish facing each other, with iconic features of the cartoon-María superimposed on the face of the fish on the left, and Miguel's characteristic glasses on the one on the right. In the image below, Gallardo superimposes Miguel's iconic characteristics on the face of a submerged turtle: 'A veces yo sumerjo y la llevo a mis espaldas como si fuera una tortuga de la polinesia' [Sometimes I submerge myself and carry her on my back as if I were a Polynesian turtle] (29; this image appears also the documentary film by Fernández de Castro). In addition to the concerted attempt to realistically (and autobiographically) portray the quotidian realities of autism, Gallardo is at pains to present the reader with a wider understanding of María, her likes and dislikes, her personality, her favorite activities and perhaps most importantly her beaming face (2, 8, 15, 16, 17, 19, 23, 24, 25, 31, 37, 43, 49, embedded). María's face is, notably, sometimes the only picture on an entire page (2, 43), many times tinged in red ink as a way of endowing the image with greater emotional weight. The comic narrative ends, appropriately enough, with the image of a single drawer labeled with the word 'Gracias' [Thank you] (55), thus calling up for the reader the previously established feelings of warmth associated with that image and also referring obliquely to the visual patterns of organization that have been associated with María. Gallardo is, perhaps, thanking the reader for two interconnected things at once—for taking part in his intimate portrayal of/tribute to his daughter and also for perhaps learning a thing or two about people with autism in the process.

Félix Fernández de Castro's Documentary María y yo (2010)

In general, the 2010 film directed by Fernández de Castro and Linspired by Gallardo's comic book is faithful to the original artist's dual goal of being both entertaining and educational. It is undeniable that, as discussed below, the film does well in incorporating as well as dramatizing specific sequences from the 2007 comic.¹² For example, the DVD menu for the film consists of a series of drawers (labeled 'Play,' 'Capítulos' [Chapters] and so on), and the first screen image (of the title and production information) is also a drawer seemingly drawn by Gallardo. I want to begin with a concise presentation of the way the film successfully translates many elements of the comic to the screen—noting in passing specific episodes that figure in both cultural products, and delving further into the way the film expands upon one episode in particular (María's sand-sifting on the beach). Here, however, we might also understand the documentary's visual contribution from a slightly different perspective, taking into account the more specifically cinematic aspects of the work and, finally, noting where Fernández de Castro's goals seem to diverge from those of Gallardo's original text. These differences notwithstanding, ultimately the film María y yo (2010) is overall true to the comic that inspired it an equally compelling presentation of a compelling personal story, one that notably foregrounds the day-to-day realities of life with a person with autism.

The limited press coverage of the film's 2010 release was generally positive. Although it did not win the 2011 Goya category for which it was nominated (that of Best Documentary Film; see the website: premiosgoya.academiadecine.com/finalistas), María y yo has routinely met with glowing reviews: for example, the film is characterized by a 'sinceridad apabullante que contagia al lector' [contagious sincerity that overwhelms the viewer] (Pons) and transmits 'optimismo, amor y el mensaje de que la esperanza puede ser una realidad en sí misma' [optimism, love and the message that hope can be a reality in itself] (Bonet Mojica). As if having expected the worst, one critic seems notably relieved that 'sales razonablemente contento [...], con la sensación de que los genéticamente perdidos y aislados pueden encontrar refugio, comprensión y comunicación [si] están protegidos por el amor, el conocimiento y la paciencia' [you leave reasonably content (...), with the sensation that those who are genetically lost and isolated are able to find refuge, comprehension and communication (if) they

are protected through love, knowledge and patience] (Boyero). Other reviews similarly attribute a generally 'positive' (and perhaps an uncritically anodyne) tenor to the film. 13 A review in La Vanguardia (a periodical to which Gallardo has regularly contributed) characterizes María y yo as 'un acercamiento pausado y realista a la problemática del autismo, capaz de analizarlo desde la visión que no renuncia al optimismo' [a cautious and realist approach to the question of autism, capable of portraying it from a perspective that doesn't do away with optimism] (Pons). References to other disabled screen protagonists (e.g. Rain Man in Boyero) and to Gallardo's previous work with Makoki (Pons) are overall de rigueur in this arena, as might be expected. 14 But reviewer Gregorio Belinchón—who perhaps follows suit by noting that the film is comprised of '[t]ernura y humor mezclados a partes iguales' [tenderness and humor mixed in equal parts] ('Otra cara')—nevertheless goes a bit further than other critics in that his praise is more informed as regards comic adaptations and also stronger. In one of his reviews published in El País, he highlights the film's uniqueness: 'No existe otra película parecida en el cine español, y pocas más en el cine mundial' [There exists no comparable film within Spanish cinema, and even in the world of global cinema no more than a handful of others] ('María'). Moreover, for Belinchón, María y yo stands with the aforementioned American Splendor (the Pekar biopic) as one of a small group of films based on autobiographical comics (see Hatfield, chapters 4, 5).

Of great interest here is the common claim—one largely supported by Pascal Lefèvre's essay 'Incompatible Visual Ontologies? The Problematic Adaptation of Drawn Images' (2007)—that both 'Cinema critics and comics fans seem to agree that it is hard to make a good movie of a comic' (1). As Lefèvre makes clear, complaints have taken many forms, such as arguing that that comics style does not translate well to the screen, that although both media are visual, the nature of narrative storytelling is widely different in each case, and that the nature of both spectatorship and production differs from comics to film (2-3). Some even invoke the more commonsensical notion of 'primacy'—the idea that 'usually people prefer the first version of a story they encounter' (3). Commenting specifically on the process of adaptation, the critic points to four problems that routinely loom large. All of these stem from the 'characteristics of the comics medium itself': 1) the deletion/addition process, 2) the nature of page layout vs. film screen, 3) the translating of drawings to photography, and 4) the sound of film vs. the silence of comics (Lefèvre 3–4). While the present focus is more generally on the documentary film's presentation of the theme

of disability and its link with *María y yo's* formal aspects—leaving these problems of adaptation largely unaddressed—I do discuss some very interesting choices made by Fernández de Castro in an attempt to preserve qualities of the original drawn text. Although, as Lefèvre makes clear, other cinema critics and comics fans may or may not find these decisions to be successful, that is not my concern here.

Similarly, although the discussion that follows treats the documentary largely as a continuation or re-narration (but not specifically as an adaptation) of Gallardo's comic book text—with little space to properly read the film within existing traditions of documentary filmmaking while discussing its treatment of disability at length—it is important to note in passing that the film squares with relatively recent trends, generally speaking. Noted documentary theorist Bill Nichols, for example, points to an increasingly blurred boundary between fiction and documentary (in chapter 5 of Blurred Boundaries), pointing to a 'shift of emphasis toward the poetic, expressive and rhetorical' in documentary film (99; Keith Beattie's more recent volume similarly emphasizes the 'expressive, evocative, entertaining and pleasurable capacities of documentary film,' 151).15 This issue, of course, while not addressed directly in this chapter, will certainly become clearly relevant to subsequent discussion of the film's more lyrical presentation and incorporation of animated sequences.

First and foremost, it is significant that Gallardo has collaborated with the documentary filmmaker in every sense, not merely as inspiration nor even as co-protagonist—nor yet for having allowed words and images from the original comic to appear in the film—but moreover for allowing the director access to his vast collection of personal drawings of María (featured from the third minute of the film). Félix Fernández de Castro is successful at incorporating these images—many of which do not appear in the comic book—into his film, and even at producing many wonderful animated sequences likewise clearly referring to Gallardo's work. 16 Many times in the film Gallardo's voice-over reads directly from the comic book text over the filmic images, and while the narrative action is very (but not completely) faithful to the spirit if not the letter of the comic, Fernández de Castro sometimes recreates actual drawings from the comic, modifying them to succeed as filmimages in their own right. This is the case, to give just one example, with the comic book's presentation of close-up iconic drawings of María and Gallardo on page 23, where the text mentions physical similarities between the two: strong and thick hair, and the same nose shape. In the film (beginning at 28:33), video-images of each of their faces are superimposed on an animated background—with the advantage that

exaggerated, animated hair can be drawn on each and that their faces can then be rotated to profile to allow an accurate comparison of nose shape (a common trait signaled by animated arrows, among other drawn images). As if illustrating the entire original comic book page, the film's animation then 'travels' down to show a recreated image of the drawers representing both Miguel and María's shared characteristic of being 'reacios a los cambios' [resistant to change] and wanting 'que las cosas estén en su sitio' [things to be in their place] (23). In a sense this entire page is faithfully presented on the cinematic screen, where it has been wonderfully imbued with a dynamic energy lacking from its static presentation on the original page.

In terms of content, both comic book and film prioritize María's love for the resort buffet (e.g. page 13 and minute 21:45), capture the onslaught of stares by strangers (e.g. pp. 26, 31; 48:59-49:20), evoke María's propensity to remember and talk about specific people (e.g. p. 33; 56:20), and depict her super-concentration while eating (e.g. p. 13; 48:39)—these being merely a sampling of such instances. Even the diegetic scenery is similar—as Belinchón notes, 'Tampoco dudó [Fernández de Castro] en rodar en los mismos sitios donde disfrutan Miguel y su Marieta' [Neither did (Fernández de Castro) hesitate to film in the same locations where Miguel and his Marieta vacation] ('María'). The sequence of the comic book discussed in the previous section entitled 'De Barcelona a Canarias' (4-5) is captured cinematically in the airport on a real SpanAir flight—although there is considerably less time-pressure here than in the comic book (one surmises that traveling with a film crew perhaps requires a bit more planning). The film goes a bit further than the comic by expanding upon the text with which Gallardo pokes fun at the resort-for example, the film refers to 'Una reserva natural de Guiris' [A nature reserve for foreigners] and at various times shows both Miguel and María wearing humorous t-shirts with English text (e.g. at approx. 1:08:08—Miguel's shirt: 'Warning: Tourist Area'; María's shirt: 'I'm not a tourist / give me a break'). Similarly, the comic's oft-repeated image of the series of drawers takes on new resonance in the film as the hotel at which the two are staying has balconies that look like actual drawers, complete with handles (it seems possible that this image has been digitally enhanced—and to wondrous effect—as a Google-image search reveals that neither of the hotels mentioned in the credits [the Hotel IFA Continental and the Hotel Parque] seems to have this appearance). The image of this hotel-consisting-of-drawers (e.g. 54:28-35; 54:45)—whether digitally manipulated or merely a well-chosen (non-)diegetic image—reveals a highly conscious grasp

of the importance of this drawer metaphor for understanding María's (and also Miguel's) need for a sort of structure, order, and organization. The film manages to suggest visually that the pair actually inhabit a drawer of the hotel themselves, a metaphor not merely for structure but also for the coziness and intimacy the pair share throughout the film and the comic book alike.

Whereas there are numerous episodes that figure in both texts—with relatively minor changes needed to bring them to life cinematically—I would like to focus on two in particular that seem to gain significantly greater resonance in the filmic version. One of the most notable ways in which the film expands on specific images inspired by the comic book is through its presentation of María's habit of sifting sand through her fingers on the beach. This image appears on the inside front cover of the comic book—a highly visible, memorable, and significant location. María sits at the bottom left corner of a two-page spread with a low horizon and mostly empty space, watching sand drop into a red bucket (a similar drawing occupies the two pages of the inside back cover, with María in the lower right-hand corner). Keeping in mind comics theorist Scott McCloud's discussion of the comic as necessarily having to resort to rendering time in terms of space (Understanding 95-103), the vast expanse of empty space employed by Gallardo in these images succeeds in imbuing them with an extended, even timeless quality. Even in the comic book this works at two levels at once: first, as an expression of both María's superconcentration when involved in this reiterative activity (qualitative, experienced time, Bergsonian time if you like) and also the length of time likely consumed by this activity (quantitative, measured time, Bergson's notion of spatialized time); and second, as an evocation of less character-driven and more universal themes associated with time. perhaps a meditation on the fleeting nature of time, the smallness of human experience and so on. Taking the comic book as a whole, it is clear that the first is privileged although both of these interpretive levels co-exist. The same cannot be said of the film, however.

The first reason for this perhaps nuanced shift in meaning when passing from the drawn to the filmic image is, quite simply, a matter of form. Film is, of course, a necessarily temporal medium, which contrasts with the purely spatial (flattened and two-dimensional) form of the comic. In the documentary version of *María y yo* the viewer is actually able to witness the sand falling through María's fingers in real time—there is no need to resort to spatial strategies for rendering time visible as on the inside front and back covers of the comic book. But this is not the only reason. In addition, Fernández de Castro

builds up to the emotional weight of this sequence from very early on in the film, thus exploiting the temporal aspect of film in order to create a certain familiarity with the sand as a filmic sign and a visual metaphor. A brief animated section from 11:30 to 11:46 shows a photo-image of María as she sits in shallow water on the animated image of the beach—the sand is not yet visible. Gallardo's voice-over references the parents' gradual understanding that María was different than other children (his ex-wife and the mother of María, May Suarez, figures much more prominently in the film than in the comic), and the sequence develops by showing the animated tide recede, leaving María seemingly stranded on the sand with (disembodied) adult footprints approaching María's image step by step. In this way, the sequence visually portrays the parents' feeling of a growing distance between María and the world around her.¹⁸ The director Fernández de Castro even comes off, here, as a savvy comics-insider—in a sense this sequence displays the 'interdependent' combination of words and images that is so germane to successful sequential art (McCloud, Understanding 155). 19 The message is clear either way—whether one listens to the voice-over or looks at the pictures alone.

As noted in numerous guides to understanding autism—such as *Autism in the Early Years: A Practical Guide* (2010) by Cumine et al.—autistic children may spend 'long periods intensely scrutinizing just one object or a single part of an object' (60). The authors go on to write that:

Children on the autism spectrum spend less time playing functionally than others matched for expressive language and general mental age. Such play is less varied and integrated and is characterised by repetitive manipulations such as continuously loading and unloading a truck or repeatedly crashing an aeroplane. (61)

Fernández de Castro—of course following Gallardo's lead—makes the decision to emphasize María's sand sifting over other behaviors, and he even turns it into a cinematic metaphor. Situated at a privileged point approximately halfway through the 80-minute documentary (37:07–38:38), the director effects a punctuating fade from black to lead into the content originally delivered on pages 18–19 of the comic book.

In general terms, this filmed sequence maintains the content of those pages—that is, in both comic and film, María watches the sand fall through her fingers into a red bucket, Gallardo's text/voice-over references the song 'Everything is Falling into Place' (by Kevin

Johansen), and he wonders what might be happening in his daughter's head while she engages in one of her favorite activities:

En mis fantasías (soy una persona muy imaginativa) tiendo a pensar que María puede ver la composición de los átomos de la arena, o quizás, ve mundos enteros o estrellas o... sólo arena cayendo. Pero cuando la arena pasa entre sus dedos, María es feliz. Horas y horas viendo caer granitos de arena... como un reloj. *Everything is falling into place*. (Italics indicate red ink, text from the comic book, which varies only slightly in the filmed version).

[In my imagination (I am a very creative person) I tend to think that María is able to see the composition of the sand's atoms, or maybe, whole worlds or stars or... just sand falling. But when the sand passes through her fingers, María is happy. Hours and hours watching grains of sand fall... like a clock. *Everything is falling into place*.]

The filmed sequence, while faithful to the original comic book, expands greatly upon the image of molecules drawn there (19) by cycling through superimposed black-and-white (seemingly Gallardo-styled) images of not only molecules but (through successive fades) also images of a solar system and finally a number of drawn constellations. But whereas Gallardo's text pulls the comic book reader out of Miguel's meditation on time and the infinite through a final image that re-establishes the priority of María's world (her day-to-day reality) over her father's momentary imagination (portraying her smiling face, and, through text, giving voice to her stereotyped enunciations), Fernández de Castro includes no such filmic equivalent.

That directorial decision seems to be made in preparation for a much more concertedly metaphorical (and cinematic) use of María's sand-play later on. Significantly marking the (approximate) three-quarter point of the 80-minute film (57:07–58:27), the director returns to another important sequence on the beach as a way of further pursuing the sand-play as a metaphor—in the process notably changing the tenor of the original comic-book narrative. Whereas the 2007 original gives perhaps equal weight to each aspect of the shared experience of María and Miguel—even if Gallardo is necessarily the one narrating the story—Fernández de Castro privileges Miguel's experience over that of his daughter, perhaps in order to have his film speak to a wider audience. This is most clear in the last quarter of the documentary as the film's intercalated interviews focus more than before on the parents' perspective (both Miguel and May

express their concerns for María's future, rather than talking about María herself), and this second sand scene in fact functions as the impetus for that shift. María is first seen against the beach landscape in an expansive general shot. She is much smaller in the expansive and mostly empty frame than ever before in the film—the frame approximately approaches the visual composition of the images on the inside front and back covers of the comic. Fernández de Castro incorporates many more eveline matches than before—when the emphasis was on portraying María immersed in her sand activity here connecting Miguel's gaze with María and with the sea, and even intimating that María herself is gazing out to the sea as does her father. These decisions imbue the sequence with a more generally pensive, thoughtful tone. The song employed here—starting at 57:54, 'La marea' (2007; by J.P. Martin, J.M. Latorre, A. Benito, D. García, J. González, and G. Galcan and interpreted by 'Vetusta Morla') intones the lyrics 'la marea me dejó arenas de plata que pone en el reloj el tiempo que no pasa...' [the tide left me silver grains of sand that time, standing still, deposits in the clock...]. There is a clear connection made here with the earlier animated sequence that portrays María left by the tide on an isolated beach, distanced from her parents—and in both, it is the parent's feeling of distance that is enunciated. The sequence ends as María and Miguel walk away hand in hand, but with the red bucket alone on the beach, a clear cinematic symbol for notions of loneliness, loss, and even the more metaphysical treatment of death toward which the director moves in the final stretch of the film.

Despite these subtle shifts from the comic book's more autobiographical format—and disability-specific theme—to a film that is more concerned with human universals, Fernández de Castro does also elaborate on the original's somewhat pedagogical treatment of autism. The fact that in an interview included with the DVD he categorically denies that the film is about autism should not be taken seriously:

Yo he dicho muchas veces que *María y yo* no es una película sobre autismo, no creo que el cómic lo sea tampoco. Para mi el autismo es como una circunstancia, es como el telón de fondo en el que se desarrolla la historia de los dos personajes. El autismo es una enfermedad o una condición de la que incluso la gente que sabe mucho, sabe relativamente poco, los estudios son relativamente recientes y la verdad es que todavía hay grandes incógnitas sobre el autismo y para mí hubiese sido una presunción pretender que ello podía aportar algo al tema del autismo en sí desde una perspectiva científica o médica o lo que fuera.

A mí me interesó más la historia sujetiva de estos dos personajes lideando con la discapacidad...

[I have said many times that the film *María y yo* is not about autism, and I don't think the comic was either. For me autism is like a circumstance, like the backdrop against which the story of the two characters develops. Autism is an illness or a condition about which even the people who know a lot know relatively little, the studies are relatively recent and the truth is that there are many things we still don't know about autism and for me it would have been presumptuous to think that it [the film] would be able to contribute something to the topic of autism itself from a scientific or medical perspective or anything like that. What interested me more was the subjective story of these two characters struggling with the disability...]

Having downplayed the 'contribution of the film to autism itself,' the director goes on in his interview to explain that his preference was to depict a love story (see also Pons; cf. *Yo, también* in chapter 1), the story of two characters overcoming obstacles, and even to deliver a film touching on the nature of communication in general. Even a cursory look at the documentary *María y yo*, however, reveals that this is, in essence, a distracting commentary (perhaps conscious on the director's part), as the film also greatly expands on the comic's treatment of autism in several respects: through substantial presentation of the parents' progressive realization that their daughter is autistic, through explicit (animated) instruction outlining the traits associated with autism, through sequences focusing on María's psycho-physical therapy sessions, and through the presentation of the use of pictograms in María's residence (with her mother and grandfather) in Canarias.

The indication that this is a film about parents dealing with autism and not merely a film about María and the world she shares with her father—breaking with the shared autobiographical day-to-day perspective that dominates the comic book—comes early on when Miguel reflects on the day of her birth in a voice-over while on the airplane (8:30). While the comic book mentions autism on page 3 in its introductory text, with the development of María's autism taking place largely simultaneously along with the development of its autobiographical narrative, the film very quickly takes time out from the adaptation of the 'De Barcelona a Canarias' travel segment to discuss María's birth, to present shots of Gallardo's notebook drawings of the newborn with her parents, and to show the artist-father's

characteristically upper-case journal text in close-up. An accompanying voice-over by Gallardo notes that 'May fue la primera que se dio cuenta de que algo no andaba bien' [May was the first to realize that something was wrong]. No such statement as this appears in the comic book, which avoids the tragic tone (one would presume deliberately), opting for a more matter-of-fact presentation that is unlike the film—neither tragic nor 'optimistic' (see the press reviews by Bonet Mojica, Boyero, above; also the interview by Fernández de Castro himself). Subsequent interview segments of the film continue to hammer home the narrative of 'coping with tragedy' begun here: May discusses how she told Miguel that 'María no me quería' [María didn't love me] in the same way as other children she had cared for (9:00–9:30), Miguel discusses his own later realization that something was wrong after talking with doctors (9:30–10:12), and May states that she had a feeling of being to blame (10:12–10:19). Much later, the film captures Miguel's candid description of how he realized that María was going to need to attend an alternative school (50:25), noting that this realization brought a knot to his throat ('nudo en la garganta').

Although it does so through a wonderfully playful animated style—and perhaps necessarily given the film's ambition of reaching a wider audience than the comic book—the film is more focused on providing viewers with a general(ized) introduction to autism than immersing them in María's world. In one instance, resorting to a narratologically 'objective' frame, a 'yes'/'no' checkbox list appears on the screen. The 'no' options toward the right margin of what looks like an animated piece of notebook paper are soon successively checked in red ink, drawing attention to those characteristic traits not typically displayed by children with autism: María showed a lack of 'abrazar [hugging], afectiva [affectionate (demonstrations)], jugar [playing], sonreir [smiling], utilizar brazos [using (one's) arms], cantar [voicing], (no responder al) cariciar [(being unresponsive to) caressing],' and Gallardo's voice-over punctuates this list with a seemingly definitive statement that María 'se quedaba como ausente' [seemed to be very distant] (10:20-10:30). Both Miguel and May here make reference to medical tests that were performed on María during childhood (10:30-11:31), thus imbuing the film with a medicalizing perspective on disability that is completely absent from the much more careful presentation of autism preferred throughout Gallardo's comic book. Similarly, in the film we learn of the moment when María was officially diagnosed (when she was eight years old, 13:30), a detail not appearing in the comic book and, I would argue, unnecessary for its full appreciation.

It must be said that, at times, the extra effort associated with the film's direct (if denied) attempt to portray the realities of living with autism can yield results that are quite cinematically engaging and educational for viewers unfamiliar with autism. From 52:15 to 53:54, for example, we witness María's work with a behavioral-physical therapist, as she is coached to balance herself on a tottering top-like platform for a count of ten—helping her with her balance and perhaps also with her upper limit of patience for activities for which she finds no immediate use. This and other instances of the direct presentation of disability are quite distanced from the paradigm of the medical model, having more to do with practical issues of developing physical and social autonomy just as communication. A sequence lasting more than a full minute (from 42:06 to 43:08, prompted by her mother's contextualization in an interview) documents how far María has come in terms of getting dressed by herself. She puts on her own pants and socks while helped and encouraged only minimally by a non-parent caretaker. Likewise a series of shots (beginning at 31:20) show her being coached to shave her own legs, and although the images shift after no less than a full minute, the sounds of both the shaver and María's conversation with her caretaker are gradually faded out over a period from 32:26 to 32:39. From 32:40 to 35:28 we watch as María is coached through setting the table (putting down her own placemat, getting her own napkin and silverware in preparation for a two-course dinner consisting of soup and meat); she later puts her dirty glass in the sink and her leftover bread in the bread box, demonstrating what, in light of her mother's previous remarks, is a remarkable degree of self-sufficiency that is directly attributable to María's concerted efforts to improve.

Importantly, these tasks occur immediately after a longer sequence (29:38–32:40) foregrounding the use of visual cues and pictograms that had been referenced in the appendix of the original comic (49–51). The first image that we see of a pictogram is on a bookshelf (29:38) in María's room during a sequence in which a caretaker uses a visual schedule (see Bondy and Frost) to walk María through the events of the day. Interestingly enough, that day is Wednesday, the same day of the week to which the original visual schedule in the comic was devoted (51), although the tasks here are different: 'depilar las piernas' [shave your legs], 'lavar las manos' [wash your hands], 'poner la mesa' [set the table], 'cenar' [eat dinner], 'la despedida' [goodnighttime], and so on. But from 32:26 to 32:39 (underneath the sound of the electric shaver) we see a series of pictograms as posted in various locations throughout the house (see the comic book text, p. 49). The

rhythmic relations of montage here are of a pointedly regular duration (approximately 2.5 seconds each), which is perhaps best understood as a semi-subjective cinematic technique wonderfully if indirectly referencing María's characteristically routine and well-ordered world.

Perhaps the most cinematically successful sequence of the film is also focused on a sort of general(ized) introduction to the topic of autism. This sequence seeks to render the characteristic overstimulation experienced by people with autism in visual terms accessible to a non-autistic audience. Gallardo's voice-over provides a context for the viewer: 'Muchas veces las personas que sufren del autismo reciben la información del exterior a través de canales no convencionales' [Frequently sufferers from autism receive information from outside through unconventional channels] (14:44–14:49):

Algunas teorías, por ejemplo, sostienen que las personas con T.E.A. [Trastornos del Espectro Autista] no son capaces de discriminar entre los distintos estimulos que reciben, o de ordenarlos en su cabeza en función de su importancia. Todos estos estimulos les llegan mezclados entre sí, creando una sensación de ruido, de confusión, como si estuviesen permanentemente delante de 20 televisores emitiendo a la vez 20 canales distintos. (14:49–15:06)

[Some theories, for example, maintain that people with T.E.A. (Autism Spectrum Disorders) are not capable of differentiating between the distinct stimuli they receive, or of organizing them in their head according to their importance. All of these stimuli reach them all mixed together, creating a sensation of noise, of confusion, as if they were permanently seated before 20 televisions each tuned into a different channel.]

This sequence (which is also noted by Carlos Boyero's review as being particularly effective) incorporates a number of visual images that connote some sort of visual or sonic disturbance: Miguel yelling out a nickname ('Mariota') from another room, an open window allowing sounds from children playing in the street below to enter the apartment, a teapot on the stove (in anticipation of its eventually whistling), an animated bull on a television seemingly charging directly at the viewer, and so on. As the sequence evolves, these images are put into alternation with each other through increasingly shorter takes and ever-faster rotation among the fixed set of images. The shots also evolve from being largely static at the beginning to becoming traveling shots and even zooms—forcing the visual images of the objects

represented to take up more and more of the screen. The bull snorts, the coffeepot whistles louder and louder, sirens begin to wail outside on the streets, Miguel repeatedly calls out to María from the other room... After a culminating point at which visual representations of animated explosions (notably without accompanying sound) yield to a return to the familiar image of María sifting bits of paper through her fingers, Gallardo's voice-over then explains for the viewer: 'Como resultado, muchos se vuelven hacia su interior, evitando el contacto con la gente' [As a result, many turn inward, avoiding contact with people].

The fact that the latter sequence is so effective and captivating, however, perhaps ultimately says something about what Fernández de Castro might have wanted to say with this film. That is, he would rather foreground this issue of communication between director and audience than, as is the case in the comic, plunge the reader into the world María shares with her father. Whereas the comic book does well in leaving many clinical and contextualizing explanations of autism to be deduced logically by the reader, if not ignored by him or her altogether, the film eschews the autobiographical nature of the original comic in favor of an overt tendency to 'teach' rather than represent disability on its own terms. In the end, while there is reason to see Fernández de Castro's unique product as a successful film in its own way—and certainly as a worthy tribute to Gallardo's original comic, if not also a faithful adaptation of it—its treatment of disability is not nearly as nuanced.

Notes

- I I write that this work on the theme of autism has 'appropriately' been produced by a graphic artist—this is because, as will be discussed shortly, the notion of visuality is particularly important for some people with autism.
- 2 See the *Arizona Journal of Hispanic Cultural Studies*, 14 (2009) for a special section of articles reflecting on the legacy of the Movida, edited by William Nichols and H. Rosi Song.
- 3 For a contextualization of the latter, see my recent review of *Carnal Inscriptions* (2009) by Susan Antebi in *Hispania*—a pathbreaking work focusing on disability and the body in canonical and less traditional Latin American cultural products.
- 4 The use of the term 'recovered' and 'recovering autistic' (5–6, foreword by Bernard Rimland) is a bit strange, but then, as Grandin herself writes in her own introduction, she is 'living proof' that 'the characteristics of autism can be modified and controlled' (13). I would rather not engage the theme of 'curing' autism—one that has been so pervasive in the American media

- in recent years—but it is certainly unquestionable that early intervention can lead to much better socialization, behavior modification, and ultimately successful lives for people with autism. I believe that this is what Grandin has in mind.
- 5 'However, not all people with autism are highly visual thinkers, nor do they all process information this way. People throughout the world are on a continuum of visualization skills ranging from next to none, to seeing vague generalized pictures, to seeing semi-specific pictures, to seeing, as in my case, in very specific pictures' (28).
- 6 'An image finally presented itself to me while I was washing the bay window in the cafeteria (students were required to do jobs in the dining room). I had no idea my job would take on symbolic significance when I started. The bay window consisted of three glass sliding doors enclosed by storm windows. To wash the inside of the bay window, I had to crawl through the sliding door. The door jammed while I was washing the inside panes, and I was imprisoned between the two windows. In order to get out without shattering the door, I had to ease it back very carefully. It struck me that relationships operate the same way. They also shatter easily and have to be approached carefully. I then made a further association about how the careful opening of doors was related to establishing relationships in the first place. While I was trapped between the windows, it was almost impossible to communicate through the glass. Being autistic is like being trapped like this. The windows symbolized my feelings of disconnection from other people and helped me cope with the isolation. Throughout my life, door and window symbols have enabled me to make progress and connections that are unheard of for some people with autism' (36-37).
- 7 Although the artist's textual comic style consists purely of upper-case letters, I have adapted it here and throughout in both upper- and lower-case. I should also point out that I use the name Gallardo when referring to the comics text as a cultural product and Miguel when referring to his autobiographical rendering of himself as a character within the sequential art of *María y yo*.
- 8 The pages throughout *María y yo* are unnumbered. In this chapter, I refer to my own numbering system, which starts with page 1 immediately after the book's publication information. Thus page 1 has a picture that matches the cover, in which we see the backs of both Miguel and María, the latter wearing her red shirt bearing the English words 'I'm unique just like everyone else.' Page 2 boasts only a centered picture of María, drawn in red and contained within a black-penned outline of a Polaroid picture. Page 3 begins with a small picture of an airplane and features the aforementioned text, which begins 'María vive con su madre.' All other pages follow from here.
- 9 Gallardo's previous publication of an illustrated guide introducing younger children to the topic of disability indicates that this motivation is not alien to his work.
- 10 On the origin of the drawings as a medium of a shared communication between father and daughter, Gallardo notes that 'Durante años he estado dibujando para María en libretas, papeles sueltos y papeles de envolver a todos los grupos de gente que le importan y le gustan: Familiares, niños del cole, amigos...' [For years I have been drawing for María all the groups of people that matter to her and that make her happy on notepads, loose-leaf

- and scrap paper: Family members, children from school, friends...] (42, full page panel), and also, 'Me gusta dibujar para ella y de que sea una forma de comunicarnos entre los dos' [I like drawing for her and that we have this form of communicating just between the two of us] (52).
- 11 The red ink works most frequently as a strategy of inflecting the necessarily two-dimensional form of comics with a dynamic/temporal quality. Sound and movement, of course, are necessarily temporal aspects of experience. But Gallardo also uses the color to add a further descriptive dimension to the static pictures—of the swimsuits worn by German tourists at the pool (11), for example, or as with the resort bracelet (10) that allows him to drink daiguiris by the pool in the afternoons. For an in-depth and illustrated discussion of how motion is represented in comics, see Gasca and Gubern (194-273). On the representation of temporality in general, see McCloud (Understanding 95-103). Douglas Wolk notes perspicaciously that, 'Comics suggest motion, but they're incapable of actually showing motion. They indicate sound, and even spell it out, but they're silent. They imply the passage of time, but their temporal experience is controlled by the reader more than by the artist. They convey continuous stories, but they're made up of a series of discrete moments. They're concerned with conveying an artist's perceptions, but one of their most crucial components is blank space' (125).
- 12 Selected pages of the comic as published by Astiberri appear in the extras section of the DVD menu, including some of those discussed above—particular in the 'De Barcelona a Canarias' sequence (pp. 4–5).
- 13 Interestingly, of course, such critics do little more than follow the director's own lead. In an interview included as a component of the DVD's 'extras' submenu, he remarked the following: 'el tono en el que estaba contada la historia: que podría ser dramática con descendiente triste, pesada, en cambio estaba tratada de una forma muy vital, muy positiva, muy optimista' [the tone in which the story is told: it might have been dramatic with a sad or heavy downward turn, instead it's been treated in a much more vital, more positive, more optimistic way].
- 14 Various influences on Gallardo's eclectic style are mentioned, including 'Segar, Wilson McCoy, Jack Kirby, Sempé, Robert Crumb, Quino, Peter Arno [...] U.P.A. [...] [the authors of] Tio Vivo y Pulgarcito [...] [illustrators like] Jim Flora, Miroslav Sasek [...] [and the elegant school of] The New Yorker' (Pons). Boyero does well in noting the drastic stylistic difference between María y yo and Gallardo's other work given that Gallardo himself voices this very distinction in the film of María y yo: 'Yo siempre he sido un dibujante muy meticuloso, muy... soy muy amante de las referencias de, de hacer pastiches de estilo, de trabajar mucho la técnica, ¿no? Y pronto, al empezar a dibujar con María, empecé a dibujar del natural o de la imaginación [...] y entonces me acostumbré a hacer un tipo de dibujo rápido [...] mis dibujos se fueron convirtiendo en algo muy icónico, muy simbolista' [I have always been a very meticulous graphic artist, very... I love making references (to other artists' work), making pastiches of style, focusing on technique, you see? And suddenly, when I began to draw with María, I started to draw more naturally or off the top of my head (...) and so I became accustomed to creating a type of rapid sketch (...) my drawing became something very iconic, very symbolist] (24:26-25:12).

- 15 There is a particularly interesting resonance between Nichols' earlier discussion of ethics in his book *Representing Reality* where he writes on the ethics of representation and the notion of proximity to documentary subjects (esp. pp. 91–92) and the comments reportedly made by the film crew for *María y yo* who cautioned first-time filmmaker Fernández de Castro that it was easier to approach and film María than it would be other protagonists—seemingly because her autism prevented her from changing her behaviors in response to being filmed or feeling like the crew was intruding (from speech reported by the director in the interview included as an extra on the DVD release).
- 16 The viewer will instantly notice a correlation between the style of the animated sequences and that employed by Gallardo in the comic book. Nonetheless, whereas Gallardo is explicitly mentioned as the inspiration for the film and credited as the sole entry under 'Creación personajes y story' [Creation of characters and story], he is, in fact, one of five names listed under the heading of 'Diseño producción grafismo' [Graphic Production Design]—indicating that the work of animating these sequences has not been his alone. The other credited names in this category are Karin du Croo, Mariona Omedes, Félix Fernández de Castro, and Carles Mora.
- 17 The text from that page detailing the physical comparisons has, here, been expanded to include also the mention of a 'coscola lisa,' which has been similarly bolstered by animation.
- 18 Boyero poignantly notes in his review that 'Es inquietante y lírica la comparación que hace de su hija con una isla a la que solo puedes acercarte unos instantes cuando baja a marea' [The comparison made—of his daughter with an island that you can only reach for a moment at a time during low tide—is disquieting and lyrical].
- 19 In fact, another interesting sequence of the film stunningly illustrates what comic theorist McCloud calls the 'montage' combination of words-and-images (*Understanding* 154), as various animated terms associated with autism rain down on the screen, pushing the image of both Miguel and May downward and ending with the word 'discapacidad' (13:05–13:12).

Narrating Childhood Disability

Salvador García Jiménez's Novel *Angelicomio* (1981)

En nuestro país, desgraciadamente, ninguna iniciativa institucional ha emprendido la tarea de aplicar una adecuada comprensión sociológica del fenómeno de la discapacidad, un intento de encuadrar la vivencia de la persona con discapacidad en el contexto de convivencia que marca los criterios tanto de definición como de adecuación de su existencia en tanto que persona con discapacidad.

[In our country, disgracefully, there has been no institutional initiative to take on the task of applying an adequate sociological understanding of the phenomenon of disability, no attempt to consider the life of the person with disability from a perspective attentive to the criteria of the definition and of the accommodation of his existence as a disabled person.]

Miguel A.V. Ferreira, 'Una aproximación sociológica a la discapacidad desde el modelo social: apuntes caracteriológicos' (148)

During recent years, the movement that seeks to obtain political rights for disabled people has echoed the advances of other civil and legal battles. In general terms, it has been important to call attention to disability as a form of marginalized subjectivity situated within specific socio-political contexts. Many have underscored a historical legacy through which the population of disabled people has suffered

due to harmful institutionalized perceptions. It has thus been important for research on disability to critique the 'medical model' of the disabled person, and thus to affirm that he or she is not merely a problem to be solved, but instead that he or she enjoys the same rights as the rest of society. Appropriately, critics in the field have emphasized a 'social model' of disability over the so-called 'medical model' (e.g. Brosco). The 'social model'—which Ferreira defines as a 'comprensión sociológica del fenómeno de la discapacidad' [sociological understanding of the phenomenon of disability]—does away with the medical focus on the disabled body itself in favor of an emphasis on environmental limitations and the importance of changing contemporary social attitudes and institutions.

Disability Studies scholars have emphasized the importance of obtaining human rights for this population (e.g. the comprehensive volume of Herr, Gostin, and Koh). In fact, the United Nations in 2006 promulgated an International Convention on the Rights of People with Disabilities with the hope that significant improvements would be carried out in participating countries, like Spain ('La Convención'; see also 'El CERMI' and 'Derechos'). In Spain, just as in other participating nations, the effort to reorganize contemporary society so that there might be greater equality for disabled populations hinges on basic and generalized concepts such as 'autonomy.' It is important to recognize that this concept boasts a rich Kantian philosophical inheritance (Shell; Reath) that has recently been called into question in other discussions regarding subjectivity and community (e.g. Esposito; Harvey, Cosmopolitanism). Nonetheless, in the area of disability, the term 'autonomy' possesses shades of meaning that are quite practical in nature. As many critical studies have demonstrated in recent years, disabled people generally struggle to gain an education and to find work both inside and outside of Spain (e.g. Chima; Hirtz; Marchesi; Moxley; Otón Hernández; Soto and Hetzroni; Vilà et al.), with it being difficult also to socialize and to form friendships (Abbott and McConkey).

In this context, the word 'autonomy' is invoked as a way of seeking to guarantee disabled people the right to live a life similar to that which we all have the right to live: to become educated, to find a useful job and to make money, to socialize and even fall in love.² This invocation of the word 'autonomy' does not necessarily call upon the complex Kantian inheritance that imbued it with a moral and even metaphysical meaning, but rather seeks to reassert the political dimension of the term that had existed prior to Kant (Shell 2). Here, 'autonomy' is not necessarily understood as the basis of morality

(Reath 122) nor as the intellectual capacity to reason or organize the world. In 'Understanding Autonomy in Light of Intellectual Disability,' Leslie P. Francis emphasizes that people with intellectual disabilities indeed possess autonomy in the sense of 'being able to value, being able to reason, being able to resist impulses, being able to imagine an ordered life, being able to order one's life, being able to put one's plans into practice, [and] being able to participate in moral deliberation of an idealized kind' even though they may lack 'autonomy in the political sense' (202). One of the barriers that prohibits disabled people from realizing a political autonomy in which they might make their own decisions in social life has been the problematic attitude that has generally accompanied the 'medical model,' something akin to what Harlan Lane calls the 'Mask of Benevolence.' As opposed to the 'social model,' which seeks to realize tangible social improvements for disabled people—in the areas of employment and education, for example—the 'medical model' supports a notion of disabled people as dependents. This harmful perspective stresses that it is more important to change the disabled person him or herself than it is to propose social changes that are more radical, global and enduring. Vague notions of tenderness and caring thus stand out as an expression of this mask of benevolence. This mask remains satisfied with the rhetoric of compassion toward disabled people and indisposed to attempt to change the material conditions of their socio-political lives.

Within the context of this discussion, this first part of this chapter proposes a continuation of 'una ardua tarea de salvamiento y rescate' [the arduous task of saving and rescuing] an 'autor de minorías' [author (writing on the topic of) minorities] (Cano Conesa 14). Salvador García Jiménez (b. 1944) is the author of some 15 novels, four books of poetry and many short stories, scholarly articles, and essays.3 The protagonists of his novel Angelicomio (1981) form a collective of adolescents 'compuesta por jorobados, mutilados, sordomudos, disminuidos psíquicos y sexuales, etc.' [composed of those with hunchbacks or physical deformities, of deaf mutes, and of those with reduced mental and sexual capacities] (Cano Conesa 171) who live together in a complex in a rural (fictionalized) corner of Spain. The novel in question acquires even more significance when seen in light of the history of the complex and still unfinished fight for the social and human rights of disabled people on the Spanish peninsula. In the case of the rights of deaf people—whose education was initiated in the sixteenth century—there has been much progress in recent years.⁴ In other areas pertinent to the topic of disability, however, there remains much work to be done.⁵ As Madeline Conway explains in her essay

from 2000 titled 'The Politics and Representation of Disability in Contemporary Spain':

Spain, in common with the rest of Europe, seems to lag behind the UK and US in response to disability politics. There is not the same strong, determined disability lobby fighting for disabled people's rights, nor the same situation of numerous respected charitable bodies funding research, raising awareness and providing assistance. (254)

It is clear that today there exist Spanish organizations quite committed to the fight-including ONCE (Gámez Fuentes), Down España (Fraser 'Toward'), the CNSE (Fraser 'Deaf Cultural') and many more. Nonetheless, what must be emphasized are the painful realities that disabled people faced before 1982, many of which still linger. Given that it was published in 1981—many years before the various substantial changes implemented during the 1980s, 1990s, and 2000s—García Jiménez's novel reflects the lack of support offered to this population over the span of the twentieth century (a situation that is of course and unfortunately—far from being unique to Spain). As Gloria Soto and Orit Hetzroni note, the first half of that century saw the establishment of segregated schools for children with disabilities in Spain, but it was not possible to implement the educational reforms needed until the final years of the Franco dictatorship (182). In fact, with the Spanish Constitution of 1978, the right to education was extended to all citizens without regard for their disabled status. Moreover, there was a need for the normalization of services and integrated education (183). With the establishment of the Ley de Integración de los Minusválidos (LISMI) in 1982, the road was finally being paved for future improvements in the realm of the education of disabled populations (183-87).6

Notwithstanding the important advances made during the 1980s and the 1990s, in the last five years it has become very clear that there is more work to do. In an essay written in 2008, Miguel Ferreira stressed the need to adopt the social model of disability from the US environment and apply it to the Spanish context. His article begins thus:

En el presente trabajo se propone el análisis de la discapacidad desde una perspectiva sociológica afín a la del modelo social anglosajón. Ello supone la puesta en cuestión de la perspectiva tradicional, según la cual la discapacidad es entendida como una insuficiencia padecida por un individuo, haciendo abstracción del contexto sociocultural en el que la misma cobra sentido (el modelo médico-fisiológico). (141)

[The present work proposes an analysis of disability from a sociological perspective in tune with the Anglo-Saxon social model. This presupposes placing in question that traditional perspective from which disability is understood as an insufficiency suffered by an individual, in the process extracting him from the socio-cultural context in which his disability is necessarily rooted (the medical-physiological model)].

It should be surprising to readers familiar with disability in the US context that in 2008 it was still possible to write that 'En España no existe, propiamente hablando, una Sociología de la Discapacidad como área de investigación reconocida ni reconocible' [In Spain, properly speaking, a sociology of disability does not exist as a recognized (or recognizable) field of research] (Ferreira 143 n.3). Similarly—and also in 2008—Mirón Canelo et al. stress that 'En la actualidad existen pocos estudios epidemiológicos dirigidos a conocer el estado de salud y evaluar la calidad de vida relacionada con la salud (CVRS) percibida por las personas con discapacidad intelectual en España' [Presently, there are few epidemiological studies focused on assessing the state of health or evaluating the quality of life related to health as perceived by people with intellectual disability in Spain] (337).

Along with interest in legislation directed toward the disabled population in Spain during recent decades and the corresponding effort to address more social perspectives (Vega Fuente), it is interesting to see disability represented as a cultural theme in widely viewed cultural products (such as the films addressed in chapters 1, 2, and 4 of this volume). In Conway's words, 'It is also possible to see an increasing number of positive representations of people with disabilities in contemporary Spanish cultural texts. This is particularly the case with cinema, perhaps due to the visible nature of many of the physical differences that constitute "disability" ('The Politics' 256). Although there have been a handful of critical articles written about the representation of disability in various cinematic texts, ⁷ there are very few indeed that explore the topic of disability within contemporary Spanish literature. The present analysis of a novel by this understudied Murcian author supposes a doubled effort—in the first place, to meditate on the problematic legacy of the institutionalization of disabled people in Spain, and secondly, to assert the literary value of an outstanding novel by an author who is surely destined to be a 'futuro miembro de la Real de Alfonso X' [future member of the Royal [Academy] of Alphonso X] (Salom).8 Published in 1981, the novel Angelicomio by García Jiménez depicts the common approach that characterized a neglectful period in the history of the education and social

integration of the disabled population—particularly the period before the promulgation of LISMI in 1982. Although this is clearly a fictional work—as opposed to the autobiographical novel *Quieto*, analyzed in the second half of this chapter—it is necessary to point out that there is nonetheless a slight autobiographical aspect to the fictionalized world *Angelicomio* depicts. More importantly, the author's novelistic critique of the inadequate support provided to disabled children in Spain (at least prior to 1982's LISMI legislation) and of the misguided notion that religion might 'cure' disability—although fictionalized—is a welcome contribution to general discussions of the problematic circumstances historically faced by disabled children living in institutions (see Carlson, *Faces*).

Salvador García Jiménez and the Creation of *Angelicomio*

Angelicomio was the sixth novel published by the Murcian author Salvador García Jiménez—following Puntarrón (1970), Por las horas oscuras (1974), Tres estrellas en la barba (1975, written eight years earlier), Coro de alucinados (1975), y Odio sobre cenizas (1977)—and is categorized as a 'novela vivencial' [novel of experience], and, along with Myrtia, with other 'novelas de colectivos marginales' [novels treating marginalized groups] (Cano Conesa 52, 62-63).9 The novel unfolds with a few light touches that accentuate its relation with the most experimental tendencies of contemporary Spanish literature—specifically, echoes of Valle-Inclán and Camilo José Cela (the novel also mentions Mariano José de Larra, 116; 'las Soledades gongorinas,' 137; a 'leyenda becqueriana,' 173; el Quijote, 178; Berceo, 182; and even Ionesco, 191; and Unamuno's Amor y pedagogía [Love and Pedagogy] casts a shadow over the whole work in an implicit way). In the chapter titled 'Paso por la literatura Ceheginera' [A Survey of Literature from Cehegin] of the book El cuento en Murcia en el siglo XX y otros ensayos [The Short Story in Murcia in the 20th Century and Other Essays], the scholar Ramón Jiménez Madrid notes that the novel 'roza el esperpento' [flirts with the esperpento] (263), and it is not difficult to see certain flourishes of tremendismo in Angelicomio.

Both of these terms—tremendismo and esperpento—enjoy a certain highbrow status in the field of Spanish literature and as such may not be familiar to some readers. Tremendismo is said to have originated with the 1942 novel La familia de Pascual Duarte by Spanish Nobel Laureate Camilo José Cela (prize awarded in 1989), although esteemed literary

critic Gonzalo Sobejano points out that its characteristic traits— 'aspectos de la realidad horribles por su violencia, por su fealdad o por su abyección' [aspects of reality that are horrible due to their violence, due to their ugliness, or due to their vileness] (70-71)—had already been well established with the Romantic movement of the nineteenth century. The term esperpento is generally equated with the work of Ramón del Valle-Inclán, whose Luces de bohemia of 1920 is, likewise, a canonical work of Spanish literature. In his substantial critical introduction to the 1988 reprint of that work, scholar Alonso Zamora Vicente notes that esperpento is 'Una voz traída del habla popular, que designa lo feo, lo ridículo, lo llamativo por escaparse de la norma hacia lo grotesco o monstruoso' [A term borrowed from common speech that designates that which is ugly, ridiculous, and showy by going beyond the normal toward the grotesque or the monstrous] (14). To highlight only one example from Angelicomio—and I leave the decision about whether this particular event is tremendista or an example of esperpento to others—in the chapter 'Obsesión en cuarto menguante' [Obsession during the Last Quarter] (69-82) one of the interned adolescents fornicates with a dog while the narrative voice oscillates among graphic descriptions of this event and the discourse of an administrator celebrating the institution's inauguration. In a sense, the inclusion of this event in the novel, although surely disturbing and possibly sensationalist as well, is not casual—instead it points to the interest in the sexual lives of the people with disabilities that motivated García Iiménez to write the novel. As Cano Conesa relates, 'el interés que le sucitó [al autor murciano] una conferencia en la que el ponente trataba sobre el derecho de la sexualidad de los deficientes, removió su curiosidad y puso en marcha los mecanismos de la reflexión creadora' [his interest was piqued by a conference in which a presenter discussed the right to sexuality held by disabled people, sparking his curiosity and initiating the mechanisms of creative reflection] (163).

From a contemporary perspective, from the novel *Angelicomio* there arise two questions of great importance with respect to the representation of people with disabilities—here adolescents in particular. The first is that of the literary treatment of this population that perhaps tends toward the stereotypical and toward a presentation of 'subnormal' beings who need to be kept isolated and away from society. The second is that of the problematic institutionalization of the disabled person, and the idea that Spanish society has not, up until now, been able to offer him or her sufficient help—the novel suggests that it is not enough to create complexes isolating children with disabilities (see Carlson, *Faces* 21–52); instead, they must be attended to

through well-thought-out forms of social integration. In fact, García Jiménez hits the mark precisely by way of the vanguardist form of the aforementioned narration—the complex narrative oscillation emphasizes the distance that separates the cold and congratulatory discourse of the administration of the complex of Aledra from the reality of the children with disabilities interned there—highlighting their social context, their educational formation, and the problem of their integration. The effect of this contrast between individual behavior and institutional discourse is precisely to situate the reader's reception of the disturbing event within a wider discourse on disability. The narration highlights the restrictions placed on populations with disabilities by a society that intends to 'normalize' the sexual conduct of an already marginalized population. As Conway points out,

Sexual activity is a normal part of 'normal' life. However, there is a tendency to think that the idea of people with mental or physical disabilities having sex (either with other disabled people or—worse—with a 'normal' member of society) is wrong. The concept of people with disabilities having sexual relations is an uncomfortable one for many people, and thus is seldom discussed. However, in order for full integration of all members of society to take place, it is must become acceptable for all members of that society to have the right to be sexually active. ('The Politics and Representation' 256)

Although the *tremendista* character of García Jiménez's narrative is far from constituting a reasoned contribution to this critical social discourse on disability and adolescent sexuality, it nonetheless suggests that the Spain of the 1980s (through the fictionalized location of Aledra) still did not possess sufficient resources to assure any type of social-sexual integration for disabled populations.¹⁰

Moreover, although there may be a tendency to judge the novel too much for this type of sensational scene, it is essential to contextualize it. The immense power of the novel is that it avoids an overly stereotypical treatment of disabled populations. This effect owes to the multifaceted presentation of a variety of disabled people—the novel is

centrada, sobre todo, en Patachicle, un muchacho cojo, dueño de una rudimentaria muleta carcomida; en Polifemo, personaje derforme que posee un solo ojo sobre la frente; en Nemesio el gorila, un grandullón cuyos órganos sexuales son tan diminutos que le ocasionan insalvables complejos psicológicos, y, por último, el Jíbaro, un chico microcéfalo. (Cano Conesa 165)

[centered, above all else, on Patachicle, a lame boy, owner of a rudimentary, decrepit crutch; on Polifemo, a deformed character possessing a lone eye on his forehead; on Nemesio the Gorilla, an overgrown boy whose sexual organs are so small so as to cause unavoidable psychological complexes, and last, Jíbaro, a microencephalitic boy.]

The extension and depth of the novelistic development of these varied characters of *Angelicomio* induces in the reader an appreciation of the diversity of the adolescent disabled population while also centering the novel on the important description of their everyday social lives and not necessarily on the medicalization of their identities as problems to be solved.

García Jiménez treats his disabled, interned characters with a marked degree of tenderness, something that should not be surprising given his relevant experiences. The autobiographical element of the text comes from the fact that García Jiménez has been an administrator in a similar institution, 11 and Cano Conesa suggests, based on interviews with the author himself, that Aledra is in fact Cañada de la Cruz, a town located in his native region of Cehegín (12, 38–39). The book acquires even more weight given the complex fusion of autobiography and fiction that forms the basis of the author's literary production in general terms. Cano Conesa characterizes certain aspects of his works as 'una especie de autobiografismo atormentado' [a type of tormented autobiography], commenting that 'el autor se inventa una vida ficticia y la incorpora a la literatura como si ésta fuera realmente vivida' [the author invents a fictional life and incorporates it into literature as if it were really lived [19, 20]. The most important thing is the high degree of emphasis placed on the disabled characters themselves—on their everyday lives and problems in a complex like that of Aledra, something that in my view makes it necessary for us to recognize the novelty and originality of Angelicomio within Spanish literature. The next section details the novel's contribution to a model of disability that rejects the simplistic notion of tenderness in favor of stressing the importance of autonomy and both family and community support of disabled populations.

Toward Autonomy—A Social Model of Disability

The narratological stylistics of the novel are themselves of interest—from the first chapter's leaning toward stream of consciousness to the cinematic crosscutting of the aforementioned chapter 'Obsesión.'

And yet the most noteworthy aspect of the book's structure must be its division into a multitude of brief chapters that, in the main, highlight the everyday life of one or another disabled intern in the Aledra complex. Cano Conesa is right when he writes that 'Al fin y al cabo, Angelicomio puede leerse perfectamente como una sucesión de cuentos con desenlaces parciales o abiertos' [In the end, it is appropriate to read Angelicomio as a string of stories with partial or open endings] (169), underscoring that the mere titling of each chapter 'responde a la determinación del escritor a organizar la materia narrativa de forma más o menos pedagógica' [responds to the author's decision to organize the narrative material in a more-or-less pedagogical form] (170). Nevertheless, this critic restricts himself to explaining the significance of this pedagogy briefly, focusing on 'la cuestión moral' [the moral question] and emphasizing only the tenderness expressed throughout the narrative of García Jiménez. It is, of course, useful to recognize the limits of tenderness. In a present-day context in which theorists conceive Disability Studies as a political project and as a rejection of the 'masks of benevolence' that avoid implementing improvements to the quality of life of disabled people (Lane), it is appropriate to approach the novel from an alternative perspective. From this alternative perspective, Angelicomio not only critiques a Spanish society that lacks sufficient tenderness to treat disabled adolescents better it also questions the limits of tenderness and begins to suggest that we consider the matter of disability in greater depth, as an inherently social matter.

It is true that in recent years theorists have repeatedly posed the question of affect (with its own philosophical inheritance and practical applications: see Sedgwick; Kittay Love's Labor, 'When Caring'). This concept is used by Eve Sedgwick, for example, when complementing the traditional paradigm that over-values the intellect and marginalizes people with intellectual disability (23). In her essay published in Hypatia, the feminist philosopher Licia Carlson proposes the term 'cognitively abled' as an inversion of 'cognitively disabled' in order to point to the way in which a disabled minority is marginalized following a rhetoric that enforces a certain conception of normality. In this way, the philosopher also draws attention to subjectivities not defined by the intellect but rather by other qualities that do not marginalize people who have been historically labeled as 'feeble-minded' (Carlson, 'Cognitive Ableism'). Nonetheless, it is crucial to distinguish between the recuperation of affect/emotions by Carlson, Kittay, and Sedgwick and the everyday meaning of what I will here call the discourse of tenderness. The use of this term does not refer to the psychic/emotional

lives of disabled adolescents but rather to a social attitude. This social attitude is satisfied with demonstrating tenderness to disabled people and avoids a more radical reorganization of society that might improve the lives of disabled people in the areas of education, work, and quality of life. In his recent book *La educación social ante la discapacidad* [Social Education in Light of Disability] (2003) Amando Vega Fuente points out that: 'Las personas con minusvalías reclaman su inclusión como derecho, el derecho a no ser excluidos, en lugar de depender de la buena voluntad de los demás' [people with disabilities demand their inclusion as a right, the right to not be excluded, instead of depending on the goodwill of others]—as he puts it, in simple terms, disabled people want 'derechos, no caridad' [rights, not charity] (79).

Clearly the novel dramatizes the importance of tenderness (and its lack among the complex's administration) through a series of abuses forced on the adolescent interns. As the text emphasizes, mentioning 'los brutales castigos que los rudos pedagogos del complejo descargaban mayormente sobre los mongoloides' [the brutal punishments that the coarse pedagogues of the complex would mete out on the mongoloids] (127), upon behaving badly, the interns are disciplined so strongly that the administrator of the complex, Don Gregorio '[expulsa] a los educadores que más se sobrepasaron en infligir castigos a los débiles internos' [(expels) the educators who went too far in inflicting punishments on the meek interns] (115).12 But whereas it is clear that the novel depicts and denounces the inhumane treatment of the disabled it also problematizes the question of tenderness. The character of Don Gregorio himself constitutes a representative case in the complex presentation of disability. Upon first glance, Don Gregorio is a symbol of the tenderness lacking in Spanish society, and a model for the parents of children with disability, given that he has 'un hijo sordomudo' [a deaf mute child] (31). As he explains in the novel's narration of his interview for the administrative position at Aledra:

Creo sentir una pasión singular por la cultura. Por ello me recluí en un pueblo labrándome con épicos sacrificios mi porvenir en la ciudad. Les he de confesar que, al principio, lo que me atraía era la literatura. Con posterioridad me nació un hijo sordomudo, y por amor desplacé mi interés a esa otra zona de pedagogía. Intentaba desmutizarlo yo mismo; intentaba insuflarle un gran optimismo ante la vida... (32)

[I feel a singular passion for culture. 'For that reason, I secluded myself in a town, working hard and making great sacrifices toward a future life in the city' I must confess to you that, in the beginning, what motivated

me was literature. Later on, I had a deaf mute son, and in the name of love I shifted my interest to that other zone of pedagogy. I attempted to demutize him myself; I attempted to imbue him with a great optimism for life...]

But it so happens that, with time, Don Gregorio becomes neglectful of his own deaf child and, heeding 'la llamada de Jesucristo, «deja todo lo que tienes...»' [the call of Jesus Christ, "leave all you have behind"], he distances himself from his own family under the pretext that 'los sordomudos de Aledra lo necesitaban mucho más' [the deaf mutes of Aledra needed him much more] (123), a fact that calls into question the notion of tenderness in that it leads to yet another example of social marginalization. Gregorio's eventual hypocrisy goes against what psycho-sociological theorists have signaled as the importance of the collaboration of the family in the life of disabled children (Vega Fuente 149-51) and, moreover, of the importance of the engaged role of the entire community (151–53).¹³ In this way, the novel contrasts the rhetoric of tenderness and compassion (the ubiquitous references to the 'subnormal' children as 'angels' throughout Angelicomio) with the limits of the shortsighted plan to merely found a complex—what is lacking in Aledra is a systematic and sustainable plan to facilitate the inclusion of disabled people within society. What García Jiménez denounces is not necessarily the lack of compassion (although this is part of it) but rather the illusion of tenderness—as is underscored in the text by the criticism of the region's parents for having interned their 'subnormal' children in the complex as an easy solution to the problems presented by disability in a society that provides insufficient support: the narrative comments that 'la ciudad les aguardaba con sus confortables cafeterías inglesas, con sus cócteles de champán y sus licores de whisky, que les distanciaban de sus hijos anormales, de la amargura de tener que recordarlos a cada instante por haberse entregado con entera filantropía al complejo' [the city awaited them with its comfortable English cafés, with its champagne cocktails and its whiskies, which distanced them from their abnormal children, from the bitterness of having to remember them at every instant on account of having turned them over to the complex under the pretext of philanthropy] (29). Through the brutal presentation of the lives of the adolescents interned in the complex of Aledra, Angelicomio emphasizes and even anticipates 'la necesidad de una lectura social del fenómeno de la discapacidad' [the necessity of a social reading of the phenomenon of disability], that is, the '[necesidad de] superar la marginación, la impotencia, la injusticia, y dar voz a los oprimidos'

[(necessity of) overcoming marginalization, impotence, injustice, and giving voice to the oppressed] (Vega Fuente 261), integrating them into the community and granting them a certain political autonomy.

While the rhetoric of tenderness and compassion might be touted as itself a social improvement, a solution to the poor social treatment of disabled people, through it there also operates a certain hidden and questionable ideology that contributes to the further marginalization of this population. Harlan Lane has written that 'Whenever a more powerful group undertakes to assist a less powerful one, whenever benefactors create institutions to aid beneficiaries, the relationship is fraught with peril' (33); the question is that of a system 'under which an authority undertakes to supply the needs and regulate the conduct of those under its control' (37). Such a system—one that recalls Michel Foucault's remarks on the panopticon in Discipline and Punish: The Birth of the Prison (chapter 3)—is clearly dramatized in the novel through the 'catalejo con trípode que mandó instalar don Gregorio decidido a ejercer sobre todos los aledaños una vigilancia escrupulosa' [telescope with tripod that Don Gregorio ordered be installed in order to exercise a scrupulous vigilance over the vicinity (155). The introduction of the telescope into the institution is revealing in that it points to the way in which institutions for disabled children are simultaneously centers for their control. In this sense, the book goes beyond the problematics of mere tenderness toward a recognition of the importance of individual autonomy-something decidedly absent in the lives of the interns of Aledra, and by extension, in the lives of the marginalized disabled populations before 1982.

It is useful here to continue to dialogue with the work of Foucault and Foucauldian scholar Didier Eribon—even if in passing—as a way of underscoring the relevance of their work on the asylum to the experience of Angelicomio's (albeit fictional) interned protagonists. In 'The Birth of the Asylum'—chapter 9 of Foucault's important work Madness and Civilization: A History of Insanity in the Age of Reason (see also his History of Madness)—the French thinker discusses the legacy of the nineteenth-century European asylum as one in essence defined by the 'phenomenon of observation' (250), by systems of 'surveillance and judgment' (251). Traditionally, religion was viewed as an integral part of life in the asylum, something that was necessary for populations who were considered 'mad':

religion can play the double role of nature and of rule, since it has assumed the depth of nature in ancestral habit, in education, in everyday exercise, and since it is at the same time a constant principle of coercion. It is both spontaneity and constraint, and to this degree it controls the only forces that can, in reason's eclipse, counterbalance the measureless violence of madness. (244)

As Foucault notes, religion thus mobilized functioned to control, and not to cure ('the religious and moral milieu was imposed from without, in such a way that madness was controlled, not cured,' 244). While it is important to recognize first that Foucault's analysis may be only partially applicable to an intensely Catholic Spanish national context (historically and comparatively speaking, of course), and second that his work on 'madness' in general may need to be reconfigured as part of the growing interest in studies of intellectual disability specifically (a project initiated, in part, by Licia Carlson's 2010 work *Faces*), the characters of *Angelicomio* must nonetheless persistently grapple with what Foucault calls the institution's devotion to 'the order of observation and classification' (250). As we will see in further discussion of the novel, religion functions as part of this perceived necessity to control the lives of *Angelicomio*'s characters.

In this light, the disabled institutionalized protagonists of *Angelicomio* face a situation very similar to that described by Eribon in regards to other marginalized populations. In the work *Insult and the Making of the Gay Self*, the Foucauldian critic explores the notion of a 'collective psyche, designating certain people as destined for shame' (xv) that may certainly also be relevant for disabled populations. Particularly in chapters 10 ('Caricature and Collective Insult') and 17 ('The Individual and the Group'), Eribon's comments foreground issues of autonomy faced by gays and lesbians that may certainly apply also to people with disabilities. He writes:

It is necessary and essential that gay men and lesbians be able to provide their own images of themselves to escape from the images that have been so long produced of and on them. In doing so they will offer more positive models (or at least more neutral ones or ones closer to reality) to those who have at hand only strongly negative images. The project is to produce one's own representations for oneself and thereby to produce oneself as a discursive subject who refuses to be the object of the Other's discourse. (75)

Just as with Eribon's discussion of the challenges faced by gay men and lesbians, disabled people have historically also 'been deprived of rights': 'the very possibility of personal autonomy is denied to them'; '[t]hey are limited by an external constraint; their consciousness has literally been invaded by discourses and images (in short, by a social order) that rejects them' (Eribon 77). And yet—as is clearly seen in *Angelicomio*—the interns lack the degree of social (political) autonomy to launch such a project of self-representation within the context of the institution. In lieu of the potential self-determination made possible through processes of what Eribon—following from Judith Butler's influential work *Bodies that Matter*—calls 'resignification' (7), the only option available to the novel's disabled characters is a physical escape from the constraints of the institution.

The chapter of García Jiménez's novel that treats the momentary escape from the complex organized by the character Ángel Patachicle ('Rabioso contra el mar' [Raging against the Sea] 127–39)14 points to the restrictions placed on the political autonomy of the interns. To contextualize the significance of this escape, it is important to understand the events that precede it—that is, to understand that after Don Gregorio finds out that the adolescents of the complex have fornicated with dogs, he orders that 'Operación Pureza' [Operation Purity] be carried out, in which 14 dogs are killed by the administration of Aledra while the adolescents themselves are forced to watch (119–21). Afterward, the cadavers of the dogs are burned so as to avoid the transmission of germs. While being forced to watch the dogs' burning, the narration comments that 'algunos subnormales vomitaban sobre su propio pecho antes de que concluyera el crepitar de la chamusquina' [some subnormals vomited on their own chests before the scorching pyre finished crackling (121), another event that points to the work's tremendist character. In the chapter 'Rabioso contra el mar,' Ángel Patachicle simulates dog noises in the areas outside the complex in order to confuse the administration (132)—demonstrating his rebellious nature—and later he escapes from the complex on a bicycle to see the sea (139). To realize this plan, it is necessary that Patachicle send an accomplice to distract the guards (128), that he prepare for the necessary physical feats that the escape will require of the paralyzed adolescent (130), and that he has already '[rumiado] su proeza y [preparado] los más nimios detalles de la evasión' [(thought over) his accomplishment and (prepared) the escape down to the tiniest detail] (130). At the chapter's end, a pair of Civil Guards see the two boys:

los bondadosos guardias, después de estudiar la pierna marcada por la polio de uno y la astillada del otro, sus cuerpos magullados y la sórdida lucidez de la cabeza reducida, tuvieron que establecer contacto telefónico con el internado para dar crédito a la aventura. Un taxi, en hora y cuarto, los reintegró a Aledra. (139)

[the good-natured guards, after eyeing the polio-scarred leg of one and the shattered leg of the other, their bruised bodies and the sordid lucidity of the one's small head, were obliged to establish contact by telephone with the complex to bring the adventure to an end. One and a half hours later, a taxi reintegrated them into Aledra].

Even though there may be dramatic aspects to this segment of the narration, it also poses interesting questions from the perspective of Disability Studies. First, here we confront a favorable representation of two clever, disabled adolescents, capable of formulating a complex plan and also of carrying it out; capable, too, of injecting the plan with a certain originality and even an iconoclastic message directed toward the institution in which they are interned. As scholar Leslie P. Francis might say (202-03), this passage stresses that they have one type of autonomy (intellectual/conceptual capacity) at the same time that they are withheld another (the political autonomy to make their own decisions). We have a plotline that points directly to the physical limitations placed on the boys by the institution with the implication that the total control of the Aledra complex is (in some if not all cases) to a certain point unnecessary and even an obstacle to the autonomy that the adventurers are capable and desirous of exercising. The compassion shown by the Civil Guards is presented as a secondary detail given the abrupt end of the trip to the sea and the narrative transition to the punishment of the children meted out by Don Gregorio. This punishment ('Don Gregorio les aguardaba con la prohibición de que fuesen diez sábados seguidos de permiso a sus casas' [Don Gregorio rewarded them with the prohibition that they not visit their homes for ten Saturdays in a row], 139) serves only to emphasize the lack of family and community resources devoted to the social well-being of the disabled children. García Jiménez does not depict a passive pair of disabled adolescents who depend on the tenderness and compassion offered them by society but rather two clever boys, active and capable, who are lacking underlying systems of social support just as sufficient (political) autonomy to create, direct, and live their own lives.

This lack of political autonomy can be seen also in the relationship that develops in the text between the character known as 'El Gorila' and the adolescent girl Primitiva in the chapter titled 'Comulgar con Primitiva' [Communion with Primitiva] (141–54). The boy eyes the girl during Mass:

Primitiva se hallaba sentada frente a él, de costado al altar, sin cesar de agitar su palidez resplandeciente, guapísima a pesar de unos ojos despegados de todos los detalles, con una baba cristalina que su madre, detrás, no dejaba caer hasta la barbilla frenándosela con un moquero bastante inferior de calidad respecto al del Obispo. (144)

[Primitiva was sitting in front of him, sideways to the altar, with her splendorous paleness never ceasing to agitate [him], quite beautiful despite eyes that wandered unfocused on any detail, a crystalline trail of drool that her mother, behind her, never let reach her chin, putting an end to it with a handkerchief that paled in quality to that of the Bishop.]

Upon seeing her for the first time, García Jiménez notes—in a classic mixture of third- and first-person narration that approaches the semi-subjective as analyzed by Bakhtin in the context of the nineteenth-century Russian novel, coaxing the reader to identity with the character— 'El Gorila se juró que la interna sería para él, porque estoy perdido si dejo que se me escabulla' [the Gorilla swore that the girl would be his, because I am lost if I let her slip out of my hands] (145). In what follows, the reader is told of the love he feels for her—we see El Gorila struggling to have Primitiva notice him during Mass (145), thinking that Primitiva is 'la muchacha que amaba' [the girl he loved] (148) and revealing that he has purposely burned himself, resulting in a tattoo in the shape of a heart bearing the initials P. and G. (148–49). Even though his amorous feelings are not properly sexual but rather romantic-El Gorila says that he would be content to receive a kiss in return (146)—when the pair are found alone together (151) El Gorila is punished just as if his love for Primitiva were something as unnatural as the aforementioned episode of the dogs. At the moment of discovering the two adolescents alone together, a guard comments: 'Como os hemos fusilado a los perros, andáis locos' [As we've shot all your dogs, you're running around crazy (151–52), and adds, 'si no os cojo de tiempo la conviertes en una desgraciada' [if I hadn't caught you in time, you would have defiled her] (152). When Primitiva is taken away from him, El Gorila 'permaneció sentado, bajo una nube blanca con forma de mariposa, incapaz de protestar para que le permitiesen amar por una vez a alguien' [remained seated, under a white butterflyshaped cloud, incapable of protesting that they let him love someone for once] (152)—and to demonstrate his feelings to Primitiva he has no other option than to make her a doll, 'para que sus brazos nerviosos se volvieran tibia cuna, y su baba fuese desapareciendo a fuerza de besos' [so that her nervous arms might become a makeshift cradle, and her trail of drool be replaced by kisses (152).

What allows this chapter focusing on El Gorila and Primitiva to have such a pathetic resonance15—in the Greek sense of the word (pathos)—is its frequent referencing of the misguided notions of disability propagated by religion. The institution of the Church is in fact one of García Jiménez's preferred targets (e.g. the Bishop denounced on page 141). Although another part of the novel had previously described parents who refer to their disabled child as 'endemoniado' [demonically possessed] (91), this chapter delves further into the idea of the Church as one origin of harmful beliefs about disability. Thinking about Primitiva, for example, El Gorila realizes that 'el demonio no la habitaba como le enseñaron las monjas, porque por la comisura de los labios no asomaban sangre ni otros líquidos escandalosos, ni la había volcado vahído alguno sobre las losas de mármol abrillantadas con cera para el acontecimiento' [the devil did not possess her as the nuns had taught him, because the corners of her mouth showed no sign of blood or other scandalous liquids, nor had she suffered fits that would have knocked her over on to the marble floors that had been polished with wax for the occasion (144). The narration contrasts this with the situation of other adolescents who hope—in vain, clearly—to be cured by some religious miracle:

los «drome» pensaban que por la hostia sus jorobas se transmutarían en alas de harina; los «muti» observaban con desproporcionado interés sus muñones con ansias de que se completasen; los «tapias» creían que pronto les ensordecería la naturaleza viva enmarcada por los mil ventanales del pabellón... (147)

[the "drome" thought that the eucharist would turn their humps into shimmering wings; the "muti" observed their stumps with disproportionate interest, wishing them to grow back; the "tapias" thought that they would soon be deafened by the sound of living nature funneling in through the pavilion's thousand large windows].

In this context, the amorous disenchantment suffered by El Gorila after Primitiva is taken away from him (152) implies that both religion and the institutionalization of the interns at Aledra create obstacles for adolescents who now must struggle to achieve a middling quality of life, perhaps never obtaining sufficient autonomy to guide their own lives and make their own decisions.

The pedagogical success of the novel lies in the fact that García Jiménez has attempted to combat the bases of the notion that disabled adolescents will benefit merely by being interned in a locked facility,

by being subjected to religious dogma and by being greatly stripped of their political autonomy by a discourse of compassion that—whether religious or more widely social—denies them the levels of family, community, and social support they need. The notion of a 'cure' for disability is directly contradicted in the text by the mention of the 'ineficacia de las curaciones científicas o sobrenaturales' [inefficiency of scientific or supernatural cures (24) and the implicit ridiculing of the idea that 'enfermos, ciegos, cojos, mancos, paralíticos, como vosotros' [the sick, the blind, the lame, the disfigured, the paralyzed, like you all] will ever be 'cured' by the Angel of God (95). Moreover, the Quixotic hopes of Don Gregorio that religion will save all the interns (e.g. 218-19) complement his refusal to support psychological evaluations of the adolescents (165) and thus his refusal to conceive of their health from an appropriately broad perspective. In this way, Angelicomio dispenses with the focus on the inadequacy of the body of the disabled person that has been so characteristically a part of the 'medical model' just as it does a religious discourse that will never lead to more radical changes in the perception of disability as a social matter. The novel's narration underscores the insufficient recognition of disability by the public at large ('El día de los subnormales no es el tuyo, ni el de los minusválidos; jamás se celebrará el día de los niños tristes con la cabeza menguante' [The Day of the Subnormal is not your day, nor is that of the Handicapped; the Day of the Sad Micro-Encephaletic Children will never be celebrated], 79; see also 217), and the insufficient funds available to sustain the Aledra complex (116–17, 155, 166)—just as it does the dehumanizing problems created by the institutionalization of a population that requires a variety of social resources and support systems.

Although its narrative action may be fictional, *Angeliocomio* remains a literary manifestation of the insufficiency of the 'medical model' of disability that reigned in Spain under the dictatorship and that continued through LISMI in 1982. Even in the new millennium, it is more important than ever to embrace the social model of disability that seeks to improve the quality of life of this marginalized population, not from within institutions of questionable character (like Aledra) but rather from the outside, in families, communities, and the already integrated educational systems that shine with the promise of a better future. This social model definitively refuses to see disability 'como una condición en sí misma' [as a condition in itself] (Vega Fuente 35) and instead emphasizes that it is a 'condición relacional [...] un producto en el cual una limitación funcional, en cualquier área del funcionamiento humano, queda sancionada por la sociedad,

como una desviación de escaso valor social' [relational condition (...) a production in which a functional limitation, in whatever area of human functioning, is sanctioned by society, as a marginality of little social value] (36, citing González Castañón; see also the remarks by María Garaña in this book's Introduction).

By way of concluding the first part of this chapter, it is important to briefly contrast García Jiménez's use of the term 'subnormal' with that of renowned author and critic Manuel Vázquez Montalbán. By the time that Angelicomio was published in 1981, Vázquez Montalbán had already, in 1970, coined the notion of 'escrito subnormal' [subnormal writing] as a way of confronting the hypocrisy of the vacuous de-politicized intellectual who thinks 'que ha entendido algo por el mero hecho de haber sido capaz de ordenar una determinada parcela del lenguaje' [he has understood something due to the mere fact of having been able to order a determined parcel of language].¹⁶ The label 'subnormal' became part of Vázquez Montalbán's poetic and political critique of existing Spanish institutions and was applied—as Hispanist critic Eugenia Afinoguénova notes—to many of his literary creations of the period 1965–75 (see 'La dialéctica' 24; also El idiota superviviente, chapter 2). I regard the author's appropriation of the term 'subnormal'—which is well known among scholars of contemporary Spanish literature and culture—to be unfortunate, although not entirely suspect. I say 'unfortunate' because it is used largely in the sense of denoting a 'deformation' of reality or of existing aesthetic (i.e. literary) practices. As critic José V. Saval notes, 'La estética subnormal guarda cierto parentesco con el surrealismo en cuanto a la forma' [The subnormal aesthetic sustains certain similarities to surrealism regarding the matter of (literary) form] (113; see also Bayó Belenguer; Lanz; Otero-Blanco). To a certain extent, this invocation of the term risks supporting a medicalizing perspective by portraying 'subnormal'—a Spanish word with a clear connotation of disability, as can be seen in the above discussion of Angelicomio—as a departure from an unquestioned state of normalcy. Yet I also believe that there is an explicit rebellious and even revolutionary aspect to the use of the term 'subnormal.' As Saval also notes, the subnormal aesthetic 'mantiene unos contenidos profundamente politizados y subversivos, sumergiéndose en toda una serie de aspectos contraculturales' [is supportive of content that is deeply political and subversive, immersing itself in an entire series of countercultural aspects (113). The social commitment that characterizes Vázquez Montalbán's work as a whole—seen clearly also in his book of essays titled La palabra libre en la ciudad libre (1976/2003)—places

a value on recovering the potential for the true democratic participation of all in a society that at present excludes large numbers of people. While analyzing his engagement of a 'subnormal aesthetic' from a Disability Studies perspective would require more space than this book permits, I would like to close this first half of the present chapter by attempting a concise reconciliation of Manuel Vázquez Montalbán's thoughts with the theme of *Angelicomio*.

Salvador García Jiménez does not hesitate to offer a novel that struggles with the topic of true 'subnormality,' and not merely with the term as a pretext or easy metaphor en route to another political goal. Vázquez Montalbán is right to point out that:

La sociedad distingue, ante todo, entre el subnormal recuperable y el subnormal no recuperable. En el primero invierte grandes dosis de solidaridad, y nunca hay más fiesta en el cielo burgués que cuando un subnormal regresa de la noche y vuelve al día de la lógica normativa. Para el subnormal no recuperable, la sociedad reserva un ghetto normalizado, reglamentado, controlado, reprimido, integrado. (Escritos subnormales 49)

[Society distinguishes, above all else, between the recoverable subnormal and the unrecoverable subnormal. It lavishes great amounts of attention upon the former, and there is never more celebration in bourgeois heaven than when a subnormal returns from the darkness to the daylight of normative logic. For the unrecoverable subnormal, society reserves a ghetto that is normalized, structured by law, controlled, repressed, total.]

Nonetheless, we might conclude that with this novel by Salvador García Jiménez, the line between the 'subnormal recuperable' and the 'subnormal no recuperable' finally begins to fade away—for the first time in contemporary Spanish literature, disability begins to be recognized as a problem of a necessarily social nature. Seen from this perspective—that is, within the context of the political project of disability—the novel points not toward the lack of compassion in Spanish society, but rather toward the lack of a greater systematic, sustainable plan to facilitate the inclusion of disabled people into society, that is, a move 'Hacia una sociedad no excluyente' [Toward a non-exclusive society] (Vega Fuente 231).

Màrius Serra's Autobiographical Novel Quieto (2008)

Tith Màrius Serra's recent autobiographical novel Quieto treating seven years in the life of his disabled son—we pass from an emphasis on one scale of analysis to another, from discourses of disability at the scale of the community to the more intimate scale of the family and even the quotidian emotions of the individual. We also pass from discussion of multiple children with disabilities to a single child with multiple disabilities. As the title Quieto [Calm/Quiet] subtly suggests, its title character Lluís (a.k.a. Llullu) is completely nonverbal. Born on March 14, 2000, he suffers from a severe neurological encephalopathy—cerebral palsy (36, 136) accompanied by epileptic seizures (13; reaching at times some 11 per day, 50)—one that was never fully diagnosed. Consequently, over many years his parents live in a perpetual state of frustration and even alarm (67, 70) as various diagnoses come and go (i.e. lipofusinosis, mucolipidosis, Refsum disease, and West syndrome were all false alarms). Very early on in Llullu's life, Serra tells us, the doctors would explain to the parents what their son would never be able to do. As his father explains, Lluís is 'Un niño que no camina ni gatea ni lloriquea ni ríe, que no dice ni mama ni papa ni caca ni mu, un niño, pues, que no levanta la cabeza aunque le pongan una teta delante' [A child who neither walks nor crawls nor cries nor laughs, who says neither mama nor papa nor poo nor anything at all, a child who doesn't even raise his head when you put a breast right in front of him] (69–70). Here—rather than using the word interdependence as is appropriate in other contexts where people with disabilities may indeed achieve a high level of autonomy despite the prejudices of a larger able-bodied majority society—dependence is the most appropriate word choice available. Throughout the novel Serra highlights his son's extreme vulnerability:

la fragilidad de mi hijo tiende al infinito. En un incendio no podría huir del fuego. En una evacuación masiva no movería ni un dedo. No bebería aunque se deshidratase, porque no sabe agarrar nada con las manos. No cerraría los ojos ante ninguna barbarie porque goza de la valentía infinita de los ignorantes. Ni tan sólo sabría expresar repulsa o pedir ayuda. Los peligros, que amenazan al común de los mortales son, en su caso, peligros de muerte. (135–36)

[My son's vulnerability is almost infinite. He couldn't flee from a fire.

He wouldn't wiggle a finger in the event of a massive evacuation. He couldn't drink even if he were dehydrating, because he can't grasp anything with his hands. He wouldn't close his eyes to avoid witnessing a tragedy because he enjoys the infinite courage of the ignorant. It wouldn't even occur to him to express condemnation or ask for help. The dangers that we all face are, in his case, life-threatening.]

Lluís's case requires that we recognize that the horizon of expectations for his relationships with other people is completely different from the cases of the protagonists of *Yo, también* and *León y Olvido* (chapter 1), that of Miguel Gallardo's daughter María (chapter 2) and even those of the young co-protagonists of *Angelicomio*. In this sense, Serra's necessarily frustrated desire to see his son run (discussed in depth in the final section of this chapter), does not represent the often unrealistic expectations that are placed on people with disabilities but rather functions as a reminder of the extreme nature of Llullu's individual circumstances.

Whereas Angelicomio is an important novel because it underscores the need for community support for disabled children in a wider sense (matters of educational policy, issues of resources, a social perspective on disability), Serra's prize-winning novel (see 'La asociación') delivers a more intimate picture of caring for an individual child whose disabilities are indeed severe—perhaps even severe enough to shift the discussion away from the strictly social focus on the discourse of autonomy and rights toward more personal and emotionally charged concerns. 17 This novel, it is important to point out, is not a fictionalized rendering of childhood disability. The preface to Quieto foregrounds the work's autobiographical nature through framing the narrative's episodes as 'rigurosamente literal' [rigorously literal] (7), seeking to portray in stark terms 'el ambivalente estado emocional que provoca tener un hijo que no progresa adecuadamente' [the ambivalent emotional state provoked by having a child who does not adequately progress] (8; see also 'Màrius Serra Interview,' henceforth 'MSI'). In his own words, Serra has approached the work as an adventure story ('MSI')—one in reality comprised of a series of episodes actually lived by himself and by his family: his wife Mercè and his daughter Carla, among other friends and characters—for example Aunt Mireia, who watches Lluís when his parents must take Carla to the hospital for her own severe ear problem (73). The episodes that vertebrate Quieto are framed by concise remembrances serving as chapter epigraphs and are punctuated with dates and place names as a diary of sorts: for example, the first such remembrance begins: 'Recuerdo en primer

plano el rostro desconocido de Lluís deformado por una mueca. Ojos muy abiertos cejas circunflejas manos arriba lengua hinchada boquiabierto. Recuerdo también la mirada preocupada del doctor Casanovas' [I remember in close-up Lluís's unfamiliar face, distorted by a grimace. Very open eyes arched eyebrows hands up large tongue open-mouthed. I also remember Doctor Casanovas' worried look] (11). The dates of these remembrance episodes range from April 30, 2000, to August 15, 2007—although the novel does not proceed in a strictly chronological fashion—as Serra narrates his own experiences of a seemingly endless series of doctors' and hospital visits, but also numerous non-medical anecdotes. Many episodes, for example, touch on their family trips to Canada (19, 105, 113), Rome (23), the north of Italy (89), Hawaii (109, 135), Eurodisney (Paris) (145) and even Finland (149), surely only a sampling from their extensive travels.

As opposed to other narratives of disability in which the writer takes on the voice of the disabled person him or herself (in the aforementioned interview the author mentions the 2001 novel Soy Julia by Antonio Martínez as an example, 'MSI'), in Quieto Màrius Serra does not pretend to speak for his son, Lluís: 'darle voz a alguien que no tiene, era fundamental [...] de todos modos, lo más importante no era lo que él emitía sino lo que nosotros comprendíamos, es decir nuestra descodificación de esos mensajes básicos y por tanto nuestra traducción al lenguaje verbal de nuestro entorno' [giving a voice to someone who doesn't have one, that was essential (...) at any rate, the most important thing was not what he might convey but rather what we understood, that is, our own decodification of those basic messages and thus our own translation to the verbal language that surrounds us] ('MSI').18 The intention is clearly that the specific case of Lluís speak to the issues of severely disabled children and their families more globally. It is significant, in this respect, that as novelist, journalist, and ludo-linguist Serra has cleverly coined the generalizing term 'un llullu' (9, 43, 126)—an intensely personalized metonomy for such children that he also uses in the plural as 'llullus' (38, 43 [twice], 83, 111). 19 The idea expressed through such neologisms (also the adjectival phrase 'de etnia llullu' [of the llullu tribe], 123) is that children with this sort of extreme disability comprise a diasporic community of sorts who both command public attention and also remain simultaneously invisible. The public attention is, of course, not always welcome—one of the first and foundational episodes of the novel (as the author makes clear in his interview, 'MSI') describes a visit to a restaurant in Italy where the hostess treats the family poorly, claiming that Lluís's wheelchair is a problem for the restaurant and also for other diners. Some

of the titles of the mini-chapters of the work ('Visibilidad' [Visibility], 105; 'Invisibilidad' [Invisibility], 109) draw attention to this disability-specific paradox of being the center of (often unwelcome) attention while also being rendered simultaneously invisible and concomitantly judged to be of little importance. In one instance while on vacation in Hawaii (111), Màrius himself even fails to notice another 'llullu' in a similar wheelchair and wonders how others would notice his son if even his own glances are so inattentive.

In passing to a discussion of the novel's themes—and their overlap with some of the themes of Angelicomio—it is important to reiterate that this is an extreme case. Màrius Serra's son Llullu is absolutely dependent on others. It is simply not relevant here—as it was in the case of the disabled characters of Salvador García Jiménez's novel—to argue for Lluís's autonomy. Children in his situation will never lead an independent life. But the extreme nature of his disability serves only to remind us of the need to insist that the discourses of autonomy and interdependence replace talk of dependency in the more prevalent (and less severe) cases of other people with disabilities. As we will see, however, the fact that the novel narrates Lluís's absolute and extreme dependency does not prevent Quieto from speaking to key questions of Disability Studies more generally considered. Even given the personal tone of Serra's work and the extreme nature of his son's individual circumstances, the novel still succeeds in advancing a critique of both the insufficiency of the medical model of disability and of a misguided approach content to read disability against the hope of a miraculous (religious) cure. In the end, the novel also ingeniously breathes life into its author's dream that his son will one day be able to run—as do other able-bodied children his age—through the inclusion of an intriguing folioscope (flip-book) rendered in the upper right-hand corner of pages 157-229. Written from the perspective of a loving father—certainly as a memorialization of his son's life (and perhaps, too, as a chronicle of anticipatory grief, given that Llullu died the year after publication; see also Cercas)—the novel constitutes a limit point of sorts for testing the application of more mainstream contemporary discourses of Disability Studies regarding dependency.

Insufficient Paradigms: Tilting against Religion and the Inefficiency of Medicine

We saw in *Angelicomio* how García Jiménez advanced a subtle but persistent critique of religious views of disability that tend to see the

disabled person as a problem to be solved by God. These same views appear in Quieto as Serra lambasts those who pray for miracles as an easy solution to the more difficult path of dealing with conflicting emotions and eventually reaching a kind of acceptance of severe disability. As the novel makes clear, the road to accepting the realities of this sort of severe difficulty is hard—to borrow Serra's neologism—for the parents of these 'llullus.' As the author relates in an interview, parents eventually reach a point where one of them accepts things as they are ('MSI')—whatever that may mean in a given case. Nevertheless, the path to that realization—to an acceptance that there will be no diagnosis and thus no treatment and ultimately of course no cure-tends to progress via all kinds of dead-ends. For Llullu's parents Màrius and Mercè, those dead-ends consist of energy and time misspent with a variety of doctors who ultimately can do nothing to change Lluís's future. Quieto humorously narrates the frustrations of seeking alternative diets with the understanding that such a change may result in an improvement (in 2007 Lluís is equipped with a 'sonda gástrica' [stomach pump], 88), just as it dramatizes to great effect an appointment with a magnetotherapist who gives them a shockingly deceptive visual image of hope for their son (he says something along the lines of 'I treated another girl like this and now she runs like a gazelle,' 64).20 The parents eventually come to accept their son as he is—and from the perspective of this acceptance the notion of a religious miracle becomes something to ridicule. This, Serra does quite well, indeed.

Already in the second, third, and fourth mini-chapters Serra takes aim at the simplistic and often offensive religious view of disability as a problem begging for Godly solution. On May 15, 2000—while he smokes a cigarette in the waiting room of the Hospital Vall d'Hebron, Barcelona (a frequent setting for the book's narrative action)—Màrius witnesses a quite curious scene. For two days a group of some 20 gypsies from Lleida have gathered in the waiting room to pray for the health of a baby girl who is suffering from severe problems in the same hospital (15). That night, a man whom the narrator refers to as a 'pastor evangélico' [Evangelical pastor] (16) undertakes to bless each part of the child's body in turn, raising her above the assembled crowd: 'Oh Señor, Vos que sois todopoderoso, haced que sanen estos ojos [...] Oh Dios omnipotente, Padre y Señor de todos los hombres, haced que sane esta nariz' [Oh Lord, You who are allpowerful, let these eyes be healed (...) Oh omnipotent God, Father and Lord of all men, let this nose be healed], and so on. After each body part ('Luego es el turno de las orejas la boca el cuello los hombros el pecho' [Later it is time for the ears the mouth the neck the shoulders the chest]) the crowd responds in unison: 'Te lo suplicamos, señor' [We implore you, Lord [16–17]. The matter-of-fact style in which this passage is narrated—in addition to the description of the rhythmic/ritualistic and exotic aspects of the prayer, its mechanical progression from one body part to another, and the way the word Señor is pronounced exaggeratedly by the pastor (17)—hints that this effort may be useless and merely for show, conceived perhaps to help the community rather than the girl herself. Serra markedly understates his ridicule of the event's pageantry itself, saying 'No se puede negar que el repaso anatómico al cuerpecito de la menor es muy completo. Exhaustivo, diría' [It can't be denied that the anatomical survey of the girl's tiny body is very complete. I would even say exhaustive (17), and he humorously intimates that the spectacle is relatively unimpressive and overly timeconsuming: 'Cuando llega a las rodillas ya me he fumado dos camels' By the time he gets to her knees I've already smoked two Camel cigarettes] (17). In subsequent remarks he makes clear that these hopes for miracles ring hollow for him, stating that:

Si yo supiera que las plegarias de este pastor pueden tener la más mínima eficacia, ahora mismo arrancaría todos los cables que lleva mi hijo, me haría evangelista por procedimiento de urgencia en el mismo pasillo y le haría pasar esa ITV espiritual, a ver si los coros de Yavhé conseguían sanarlo. (17)

[If I knew that the pastor's supplications were to have the most minimal effect, I wouldn't hesitate in ripping all the leads off of my son, I would convert to Evangelism in an instant right there in the hallway and I would subject him to those spiritual emissions, to see if the incantations of Yahweh would succeed in healing him.]

At the end of the second mini-chapter Serra candidly writes that he is beginning to realize that his son will never be healed (18)—which is, of course, the reality of things.

The third mini-chapter follows this episode up with a description of an encounter with a stranger who wants to pray for Llullu in New Brunswick, Canada (19–21). While they are sitting on the patio of a restaurant on August 12, 2005, an older English-speaking man approaches the family, saying that he noticed Llullu as he watched them exit their car an hour earlier and that he would like their permission to pray for him (20). Kneeling down next to the chair, the man

pronuncia una serie de invocaciones muy ruidosas que empiezan todas por un oh-Dios-mío y que llaman poderosamente la atención de Carla. El Llullu, como era de esperar, ni se inmuta, pero parece mirarlo de reojo, con los morros llenos de restos de comida. Las plegarias del hombre de corazón sencillo son largas y sentidas, pero difíciles de seguir. La verdad es que, más allá de los oh-Dios-míos, entiendo poca cosa. (20–21)

[voices a series of very noisy invocations that all begin with an 'Oh my Lord' and that forcefully draw Carla's attention. Llullu, as would be expected, seems unperturbed, but he seems to regard him with suspicion, his lips covered with traces of food. The simple man's prayers are long and heartfelt, but difficult to follow. The truth is that, apart from the 'Oh my Lords', I hardly understand anything.]

After having established the basic premise of a stranger performing a strange act, Serra ups the ante, further distancing himself explicitly from what he calls the old man's 'extreme faith' (21). Llullu almost goes into an epileptic seizure during the prayer (although the potential danger soon dissipates), and Serra takes this moment to wonder what might have happened if the seizure had in fact happened: '¿lo habría considerado una señal de algo? ¿De qué? ¿Lo sería?' [would he have considered it a sign of some kind? Of what? Would it be (a sign)?] (21). As the reader learns in the next mini-chapter (titled 'Señales' [Signs], 23), this incident has played an establishing role to set up a question that will be put to rest through discussion of a curious incident at the Vatican five years earlier in 2000.

The most damning indictment of the false hope promised by religion comes in this fourth mini-chapter in the form of what is possibly the book's most humorous anecdote (it has attracted the attention of two reviews in particular, one written by noted Spanish author Javier Cercas himself; see Blàzquez; Cercas). Through various circumstances described in detail over many pages (23–26), while Mercè and Carla remain outside, Màrius and Llullu are able to cut through lines to get inside the Vatican's famed Basilica of San Pietro ('¿Es una señal?' [Is it a sign?], the father initially wonders, 26). The narration of the visit is couched in the context of the intense parental questioning characteristic of the first year of Llullu's life. Serra writes, 'Desde que ha nacido el Llullu lo miramos cada día buscando señales de mejora' [Ever since Llullu was born we look for signs of improvement every day] (26). It is there in the Basilica that they will receive an answer of sorts. Gazing up at the awe-inspiring ceiling the father-author is moved to

start talking to his son, asking (pleading with) him to respond. Màrius promises to do anything—even go to church again and pray like his grandmother once taught him (28). All he wants is a sign, 'Envíame una sola señal y creeré en Dios para siempre [...] observaré todas las leyes de la Iglesia católica' [Send me one single sign and I will believe in God forever (...) I will observe all the teachings of the Catholic Church] (28–29). The narration here has its own prayer-like rhythm (referring the reader indirectly back to the previously narrated prayerepisodes of Quieto's mini-chapters 2 and 3) as Serra intones his desire repeatedly, incorporating textual reminders of his son's epilepsy and frailty, all seemingly testament to his fervent potential religious faith. The narration plays with the reader's expectations by making him or her wait through numerous iterations before delivering its final, punctuating, scatological attack on religion. That final sign comes, humorously enough, in the form of 'La mierda que expele mi hijo' [the excrement defecated by my son] (29)—the long-awaited answer turns out to be one that points to this world and not to the world beyond. This event is just as instructive on matters of disability as it is derisive of religion as a miracle cure.²¹ After all, what response could be more firmly grounded in material concerns and conditions of life in this earthly world than the one thus delivered by Llullu?

Serra is perhaps stronger in his rejection of religion than he is in his critique of medicine.²² It must be understood, however, that the treatment of medicine in *Quieto* necessarily differs greatly from that in other texts (like *Angelicomio*) due to Lluís's extreme circumstances. He depends on others for just about everything. Nonetheless, even Serra finds reason to debunk the inflated importance of medicine in his narration of Llullu's life. He makes fun of the overly bureaucratic processes associated with attempting to diagnose his son, portrays the inefficiency of diagnoses and medicine in general, and ultimately dispenses with the desire for a medical cure just as he does the idea of a religious one. The narration makes clear that Llullu requires a certain level of medical attention merely to go on living—even if this is not overemphasized. The text mentions the parental responsibilities of administering between two and four medicines every eight or 12 hours:

Esto te obliga a ir por el mundo cargando con cajetillas y frasquitos de nombres tan exóticos que parecen islas polinesias habitadas por tribus caníbales: Mysoline, Depakine, Sabrilex, Topamax, Noiafren, Kepra, Trileptal, Rivotril... Algunas medicaciones son líquidas y se administran fácilmente, gota a gota, pero la mayoría se presentan en pastillas

blancas como aspirinas que primero deben ser cortadas, molidas y disueltas en agua. (55)

[This obliges you to go everywhere carrying packets and bottles bearing names so exotic they seem to be Polynesian islands inhabited by cannibalistic tribes: Mysoline, Depakene, Sabrilex, Topamax, Noiafren, Keppra, Trileptal, Rivotril... Some medications are liquids and can be administered easily, one drop at a time, but the majority come as white aspirin-like pills that must be broken up, crushed, and dissolved in water first.]

Although Màrius may make light of the litany of pills his son has to take, there is no indication that these medicines are not, in fact, of some benefit to their son (as contrasted with their brief foray into magnetotherapy). The fact that Llullu must occasionally spend significant lengths of time being closely monitored in hospitals (e.g. a stay of five weeks is mentioned on p. 139) means that the importance of medicine for his life is never completely denied.

But the world of medicine is frustrating enough that Quieto's narrator is forced to look for small victories, for example that offered by a particularly useful four-level organizer/dispenser from the pharmacy that greatly alleviates the stress surrounding dosing (56). The narration's privileged description of the need to collect fecal samples from Lluís in order to send them for analysis to the 'Great Plains Laboratory' to determine possible food sensitivities (31–32) is notable in three respects: first, for its scatological resonance (a continuation of the work's characteristic humor); second, for the opportunity it provides to draw attention to the frustratingly excessive regulations that distance patients from potentially helpful treatments (Serra mines the confusion wrought by the necessity of attaching multiple copies of receipts to his mailings with verve, 33); and third, as it points to the arguable inadequacy of the national context regarding such medical matters (and Serra clarifies that 'national' refers to Spain and not Catalunya, 84). It seems that the closest center capable of analyzing Lluís's specimens is located in a place called Lanexa, near Kansas City, USA. After a stomach tube is surgically implanted in his son, Màrius refers to it not as something that changed their lives but merely as a source of humor. For example, he takes pleasure in the fact that, after the encounter with a poorly mannered hostess in Italy, the 250cc of the 'líquido lechoso y pegajoso Isosource' [milky and sticky Isosource liquid] has ended up on the floor instead of inside his son's stomach due to an error committed while connecting the tubes (103). Such

humorous narrations are, of course, merely outgrowths of the author's more fundamental distrust of the efficacy of medical science as a whole—at least in the case of Llullu. In a particularly lucid moment, Serra writes somewhat sarcastically that 'Cuando la medicina puede diagnosticar, tratar y derrotar las enfermedades deberíamos organizar una fiesta de celebración' [When medicine is able to diagnose, treat, and defeat disease we should throw a party in celebration] (75). In the final analysis, it is not that a social model of disability eclipses the need for medical treatment altogether in Quieto, but rather that a non-medical view helps to indicate where meaningful changes might be made in society whereas medicine itself is portrayed as largely inefficient if not entirely impotent in certain extreme cases. Serra realizes, as he makes clear in his interview, that 'el objetivo no es curar sino el bienestar, el día a día' [the goal is not a cure but rather wellbeing, the day-to-day] ('MSI')—here it is the excess of medicine that is harmful, not its very nature.

In lieu of embracing medical definitions of disability—or of maintaining a faith in medicine's ability to diagnose, treat, and cure certain illnesses—Serra promotes the shift in social perspective offered by sharing a meaningful life with a disabled child: 'detrás de una silla de ruedas es el mejor observatorio de la realidad, de las miradas ajenas de las miradas de otros que atrae alguien que es distinto, que es muy distinto' [behind a wheelchair is the best place from which to observe reality, to observe how someone who is different, who is very different, attracts the strange looks of others] ('MSI'). With the religious and medical worlds being held as suspect, the focus of Serra's work remains on the practical concerns, the social world of the here and now. He does share a perspective with others who are more critical of the medical model of disability. For example, as is important to some such scholars, he rejects the metaphorical understanding of disability outright (46),²³ preferring the perspective of the sympathetic realist over the escapism offered by the former approaches. If the book is indeed about a child who does not 'adequately progress' ('MSI'; see also the Anagrama book cover) there are also great social improvements to be made that may nonetheless remain invisible for those who do not share life with a person who has a disability.

The book points to problems of social attitudes and perceptions: not only the hostess in Italy who is unaccommodating (to put it mildly), but also the stares and gawking by strangers routinely encountered in public places (see also chapter 2 on *María y yo*). One such episode that is particularly developed in the novel centers on the street where Màrius and Lluís wait for the latter's bus. The father

describes the anger he feels as he honked at by a line of cars as his son and his wheelchair are loaded up on to the bus-in a moment of rage he yells at the honkers that the bus is for 'paralíticos, y concretamente paralíticos cerebrales, que es un término más desagradable que el oficial de discapacitados' [paralyzed (children), and specifically those with cerebral palsy, which is an even less desirable term than the more official term of disabled], 78). Similarly, the cars of parents with able-bodied children routinely and illegally park on the sidewalk near that spot, thus obstructing the passage of Lluís's wheelchair and limiting the area where the pair can wait together. The officers nearby seemingly have no interest in enforcing parking regulations that might benefit the pair, and instead chew out the bus driver herself for the time she spends loading up her disabled passenger. One able-bodied driver even yells at Màrius to move himself and his son's wheelchair so that he can park on the sidewalk and accompany his son to the gate of the school building that stands only meters away (80-81). If the city sidewalks are inadequately policed, elevators inside the city's buildings are routinely too small for Lluís's wheelchair to fit (83). Thus in addition to the problematic nature of social perceptions of disability, the modern urban environment of Barcelona is also in many ways inadequately designed for disabled populations. This situation provokes a great degree of frustration and anger that Màrius tries to control through the cultivation of a more relaxed mindset.²⁴ Thus, in response to the false hope of a religious miracle or a medical cure for Lluís's disability, Màrius Serra foregrounds the value of day-to-day realities: mixing an appreciation for small victories with the hope for a future society that pays more heed to the needs of disabled populations in general. In this light, the true value of Quieto comes not from Serra's specific critiques of religion, medicine, or even the inadequacy of existing social environments—although these are indispensable—but rather from its grounding in affect, its immersion in the personal emotions experienced by Lluís's father. The next section of this chapter reads the novel as an intimate portrait of a father's love for his son.

Llullu Runs: Readerly/Personal Engagement and Quieto's Folioscope

To the uncertainty offered by scarce, ineffective, and unreliable medical resources, to the false promise of a miraculous religious cure, and to the still unresolved social problems associated with the perception of

people with disabilities, Serra opposes the solid, emotional ground of the life he shares with his son. This fulfilling, intimate portrait foregrounds a number of profoundly meaningful events in their experiences together. Most moving, perhaps, is the novel's description of the way things changed when he realized for the first time (in the Vatican) that he could talk and have a relationship with his son even if Lluís couldn't respond, for example. He reminisces about that realization he had on a day in 2000:

Es la primera vez que tengo conciencia de haber hablado fluidamente con Lluís. Desde entonces ya no he parado. Al principio, resulta difícil hablar con quien no te contesta. Lo sabe quien haya intimado con bebés, animales o plantas. Pero al final te acostumbras. Haces clic y ya no callas. Yo hice clic aquel día, allí. Rodeado por las suntuosas riquezas del Vaticano empecé a hablar con mi hijo como si fuese a responderme en cualquier momento. (27)

[It is the first time I am conscious of having spoken fluently with Lluís. From that moment on I have never stopped. At first, it was difficult to speak with someone who doesn't answer you. People who have spoken to babies, animals, or plants know that as well. But in the end you get used to it. A light turns on and you never shut up. A light turned on for me that day, there. Surrounded by the sumptuous splendors of the Vatican I began talking with my son as if he was going to answer me at any moment].²⁵

In a way, the novel Quieto, itself, was made possible only following this moment. The question posed by Serra—of what it means to have a relationship with someone who cannot respond to you—is an anchor for the reader's experience of the binomial father-son relationship at the novel's core. Màrius attempts to bridge this distance in his own way, establishing communication (even if unidirectional) by speaking habitually to his son and eventually coming to fully accept his situation (even if this is narrated as a difficult road). But Quieto suggests to the reader that being the father of a child who is severely disabled (in Spanish a word often used to describe Llullu is *pluridiscapacitado*, which translates as multiply disabled) entails a certain splitting of the self. Just as part of Màrius is more and more able to face the fact that the horizon of expectations for his son differs largely from that pertaining to more able-bodied children, he is also understandably subject to a very basic desire to want a different life for Lluís. His acceptance of his son's circumstances does not prevent him from being entitled to

having his own dreams and hopes, however implausible they may be. Màrius, it seems, persistently dreams of his son being able to run.

Before continuing with the way this dream plays out in Quieto from the choice of cover art through the text's episodes to the unique folioscope of the final pages, it is important to see how the work is best contextualized within a literary tradition of father-child disability memoirs such as Japanese author Kenzaburo Oë's novel about a disabled newborn, A Personal Matter—itself cited in Quieto. Importantly, Serra's previous work as an author and journalist included interviews with notable people that he did for Channel 33—and on March 16, 2004, he interviewed Oë (129). Serra must have been thrilled to have this opportunity—he had already read Oë's A Personal Matter once (when Llullu was only a few months old), and would go on to read it a total of three times, and have the Japanese author autograph his copy. He describes the cover art for that work (in which Oë rides a bike along with his disabled son Hikari) with appreciation, cites its final lines in the Spanish edition translated by Yoonah Kim, and says that each time he reads it he likes the book more (129-30).²⁶ Quieto's author invokes Oë explicitly throughout the mini-chapter 'Vampirismo' [Vampirism] (129–34), but also in an extensive uncited (but implied) quotation, the length of a paragraph, that brings the previous chapter to a close (127; the review by Cercas is aware of the origin of this quotation). Like Serra's son, Oë's character (perhaps loosely modeled on Hikari) in the novel is severely disabled from birth. The second chapter dramatizes the reaction of the father character (named Bird, perhaps only loosely modeled on Oë) who is worried for his child, who he believes to be a monster. He finds out that the child, as a result of a brain hernia, appears to have two heads (A Personal Matter 25). The remainder of the book follows Bird as he reacts to the reality that he is responsible for this child, flirts with letting the child die (having been prompted by a nonetheless disapproving doctor), and ultimately accepts his responsibility if not also his child's disability at the novel's end.²⁷ The critic Yasuko Claremont sizes up A Personal Matter as 'a masterpiece in the psychology of withdrawal' (52). Even Bird's motive for saving his son from being murdered by an abortionist at the end of the novel is, for Claremont, 'a selfish one, without pity for the baby but instead aimed at restoring faith in himself through responsible action' (52). If Oë's novel treats a main character who is nothing if not the pinnacle of self-interest, Serra's autobiographical novel doesn't even come close to approximating such depths of human baseness. In Quieto, the most significant detail included in the digression about Oë is, to my mind, the offhand comment made by the Japanese author before the

interview with Serra (a comment not recorded by the cameras): 'El día de la entrevista, me dijo que el nacimiento de Hikari le había influido tanto que desde entonces se definía, en primer lugar, como padre de discapacitado' [The day of the interview, he told me that Hikari's birth had influenced him so much that ever since he identified himself, first and foremost, as the father of a disabled child] (130). Serra writes,

pienso en la definición de Oé. Yo no querría que Carla se definiese, en primer lugar, como hermana de discapacitado, ni tampoco me gustaría encabezar mi currículum como padre de discapacitado. Pero lo único cierto es que lo soy, que ejerzo de ello y que ahora mismo escribo estas líneas por una necesidad que sé imperiosa. (133)

[I think about Oë's definition. I wouldn't want Carla to identify herself, first and foremost, as the sister of a sibling with a disability, nor would I want to put the label of 'father of a disabled child' at the top of my resume. But the only sure thing is that I am such (the father of a disabled child), that I hold that office and that I now write these lines due to a necessity that I find to be urgent.]

Given the overall complexity of *Quieto*, the father-narrator's dream that his son should run is not forged from harmful expectations for disabled children that merely affirm the false promises of the medical paradigm; instead I suggest that it is an integral and compelling part of the emotional landscape of Serra's autobiography. In a sense, the contradictory feelings experienced by Oë's fictionalized character Bird (which are externalized in a much more disturbing way) are still present in Serra—it is only that he has channeled these feelings into a more poetic and certainly personally meaningful dream.

This dream that his son will run as do able-bodied children his age is so important to Màrius that the cover of the Anagrama novel features an image of Llullu on a track running across the 100 meter mark as if finishing a race. The notion of running is persistently highlighted throughout the text as Màrius includes it in the list of things his son will never be able to do (50–51)—a passage in which he is reduced to tears, mourning the loss of his own fatherly dreams.²⁸ Later he writes of how the very idea of running produces anger in him: 'Aplicado al Llullu, el verbo correr me provoca escalofríos. Es una palabra obscena' [Applied to Llullu, the verb 'to run' gives me shivers. It is an obscene word] (66). Much of the emotional weight of the thought of Llullu running may stem from the displaced need to compensate for the closeness that could never be reciprocated by his son. Serra writes at length

of his emotional vulnerability to music such as famed Catalan singer Pau Riba's song 'L'home estàtic' [The Immobile Man] (118–22)²⁹ and, continuing this line of thought, even to a statue outside the Barcelona hospital where he spends much time thinking about his son (139–43). If the play between the simultaneous visibility and invisibility of disabled populations is one of the key oppositions upon which the work hinges, then that between silence and communication is another, just as is that between stillness and mobility.

The title of the novel is well chosen: *Quieto* masterfully encapsulates both of these linked meanings. Regarding sound, Lluís is quiet and tranquil, producing hardly any noise. In that sense, the title also perhaps refers simultaneously to the metaphorical quiet of the narrative space in which Serra can compose and communicate his thoughts through his written text. But the choice of the word *Quieto* (in English meaning quiet, but also calm or still) also captures the absence of kinetic energy. Llullu is, of course, incapable of moving, let alone running; a reality that is curiously dramatized through the narration of a family visit to the Vancouver Science Museum (113–15). As part of an interactive and intriguing neurophysical science demonstration, two participants may sit on opposite sides of a table fitted with a channel in which there is a metal ball. Each wears a headset fitted with sensors that are designed to react to brainwaves of a certain frequency:

Según les he traducido del letrero explicativo, se trata de poner la mente en blanco para conseguir el grado máximo de relajación. Los cables que salen de nuestras cintas van a dar a una máquina que traslada la actividad cerebral a la bola de la mesa. Quien menos relaja, más atrae la bola. O, dicho de otro modo, si la bola va hacia ti significa que tu oponente está más relajado. Y en tal caso pierdes. (113)

[According to the explanatory sign I have translated for them, it is a matter of clearing your mind of thoughts to achieve the greatest degree of relaxation. Wires run from our headbands to a machine that translates cerebral activity to the ball on the table. Whoever relaxes less draws the ball toward him or her. Or, to put it another way, if the ball rolls toward you it means that your opponent is more relaxed. And in that case, you lose.]

In the first round, Màrius wins over Carla, due to a trick he learned from yoga class—placing all of your attention on the tip of your nose (114). Carla loses to her mom Mercè in the second round, but then finally plays Llullu, where she believes winning is assured from the

fact that her younger brother is 'un perdedor nato' [a natural-born loser] (114). Unexpectedly, however, he triumphs over her: 'Sin dudarlo ni un instante, la bola empieza a rodar decidida hacia la posición de Carla' [Without even a moment's hesitation, the ball begins to roll unequivocally in Carla's direction] (114). This greatly impresses Carla. As Serra writes, 'El Llullu es muy bueno en esta disciplina de la relajación total. El mejor. Da la impresión de que podría enfrentarse al campeón mundial de relajación e igualmente le vencería. Su capacidad para mantener inactivo el cerebro parece infinita' [Llullu is very skilled in the art of total relaxation. He gives the impression he could take on the world champion of relaxation and defeat him. His ability to keep his brain inactive seems to be infinite] (115).30 Llullu's instantaneous conversion from being a 'natural-born loser' to being a natural winner has obvious dramatic significance, for both family and readers alike. But the contrast between stillness and mobility that is rendered here through such a visual anecdote is an essential part of both Màrius's own emotional geography and also the book as a whole. His father's corrective to Lluís's cerebral paralysis and corporeal immobility is not only a fatherly dream but also a poetic and novelistic complement of sorts. As Lluís himself does not move, the energy of the novel pushes the reader ahead on his behalf.

This contrast between stillness and mobility is most significantly effected in the final section of the novel, labeled simply 'correr' [to run] (157-229). Here, photographic color stills of Llullu in various positions are situated in the upper right-hand corner of each right-hand page, constituting a folioscope (flip-book) that, when animated by the reader, actually breathes life into the images and gives the illusion that he is running.31 The process involved was made quite popular in nineteenth-century bourgeois mechanisms that functioned as precursors to the modern technique of cinema. The most famous example is undoubtedly Eadweard Muybridge's motion study of a running horse (not a flip-book, but static images designed to be viewed without motion). Muybridge placed numerous cameras at regular intervals in order to produce stills of the horse in various poses. In Quieto, although the character Lluís may not move physically on his own, the extradiegetic space of the final pages allow his image to come to life and fulfill his father's dream that he run. These pages are, of course, dependent on having a reader—perhaps just as Lluís was dependent on having an involved and loving family. The images beg for someone to actively flip the book's final pages and bring Lluís's image to life. There is a fitting analogy here between the personal energy supplied to make the flip-book section work and the personal engagement required in the real world to allow severely disabled populations to lead successful and meaningful lives. If *Angelicomio* tended to emphasize the need for support of disabled children at the national and community scale, *Quieto* points to the importance of individuals and families who will take on active roles in supporting children with disabilities.

Notes

- 1 For example, two authors advance a comparison between the population of disabled people and those of African-Americans, women, gays, and lesbians (Sulmasy 183; Shapiro 11). Moreover, of recent publication, *Crip Theory* by Robert McRuer presents a vision of Disability Studies that articulates explicit connections with the theoretical frameworks of feminists and queer theorists. See also Garland-Thomson.
- 2 See Fraser, 'Toward,' 'The Work.'
- 3 The reader may be interested in seeing the bibliography of works written by and about García Jiménez as published in the book by Juan Cano Conesa, published in 2004 (375–90). García Jiménez has also written critical works (for example a thesis on Kafka and Spanish literature, and a study/edition about Juan Quiroga Faxardo published in 2006 with an extensive introduction of 130 pages, reviewed in *The Bulletin of Hispanic Studies* 86.5 [2009], pp. 712–13). His most recent novel bears the title of *La voz imaginaria* (Salom) and he has also published *La sangre desgranada de Federico García Lorca*.
- 4 My edited volume (Deaf History and Culture in Spain, Editorial Gallaudet, 2009) traces the history and culture of deaf people in Spain from the sixteenth century through contemporary times. A brief summary of this progression tells us that Pedro Ponce de León (1524-82?), a Benedictine monk in the monastery of San Salvador en Oña (near Burgos), had begun to teach the deaf, those relatives of a royal family, in the sixteenth century. Soon after, the book Arte para enseñar a hablar los mudos was published by Juan Pablo Bonet in 1620. This educational practice soon spread to France, with the first chair for the education of the deaf being occupied by the Portuguese Jew Jacobo Pereira around 1750. Nonetheless, as the Benedictine monk Benito Jerónimo de Feijóo y Montenegro pointed out in the good spirit of eighteenth-century thought, the Spanish origin of this practice was soon overlooked ('News,' 'On the Invention'). As Harlan Lane puts forth in his Mask of Benevolence—rooted in the idea of a Deaf identity already extant in the Deaf communities of the United States and borrowed by Spanish Deaf communities during the 1990s (see Fraser, Deaf)—Deaf people want to be recognized as a linguistic minority and not necessarily as a disabled group. The languages of Spanish Deaf populations (LSE, LSC) are now officially recognized by the Spanish state (Fraser, 'Deaf Cultural').
- 5 It is necessary to highlight that some intellectual voices have for centuries noted that Spain is 'El furgón de cola' [The Caboose] (Goytisolo) of the European train, or that Spain has suffered from a characteristic national backwardness (Feijóo, 'Causas').
- 6 Spain has played a notable role as the epicenter of the discourse on the

- integration of disabled populations—'In June 1994 representatives of 92 governments and 25 international organizations met in Salamanca, Spain. They agreed on a new statement and a framework for action on the education of disabled children, which called for inclusion to be the norm' (Dunlea 17).
- 7 There are, for example, a handful of critical studies on the representation of disability in Spanish cinema—'Cryptic Triptych' by Ryan Prout, 'Life on Wheels' by Julie A. Minich, and the doctoral thesis 'Representing' by Conway herself. As a whole these publications discuss the films *El cochecito* (1960), *El jardín de las delicias* (1970), *Acción Mutante* (1993), *Carne trémula* (1997), *Planta cuarta* (2003), and *Mar adentro* (2004). As regards the representation of intellectual disability specifically, Fraser has written essays on the recent films ¿Qué tienes debajo del sombrero? (2006, Fraser, 'The Work') and *Yo también* (2009, Fraser, 'Toward').
- 8 It is important to point out that the Murcian author enjoys a certain fame in his native region—for example, that 'la propia Concejalía de Cultura del Ayuntamiento de Cehegín haya creado el Premio Salvador García Jiménez de literatura con dos fines muy claros: promover la literatura en castellano, y rendir homenaje al escritor ceheginero' [the Cultural Council of the Government of Cehegin has created the Salvador García Jiménez Prize with two clear goals in mind: to promote literature in Spanish and to pay homage to the writer from Cehegin] ('Salvador,' see also '500 cuentos'). Neither should it be surprising that there are a street and a library in the city of Cehegín that bear his name (Vivas). His writings are not completely unknown among certain Spanish circles, given that he has won a number of prizes between 1969 and 1999. On the prizes won by his novels Cano Conesa writes: 'las obras Puntarrón, Tres estrellas en la barba, Coro de alucionados, Por las horas oscuras, Odio sobre cenizas, Agobios de un vendedor de biblias, Las ínsulas extrañas y Sonajero de plata fueron distinguidas, respectivamente, con los siguientes galardones «Premio Nacional Universitario de Salamanca, 1969», «Ciudad de Palma, 1974», «Ciudad de Murcia, 1974», «Ateneo de Valladolid, 1974», «Armengot de Castellón, 1977», «Gabriel Sijé, 1984» de Orihuela, «Premio Casino de Lorca, 1999»' [las obras Puntarrón, Tres estrellas en la barba, Coro de alucionados, Por las horas oscuras, Odio sobre cenizas, Agobios de un vendedor de biblias, Las ínsulas extrañas and Sonajero de plata were awarded, respectively, with the following prizes "Premio Nacional Universitario de Salamanca, 1969", "Ciudad de Palma, 1974", "Ciudad de Murcia, 1974", "Ateneo de Valladolid, 1974", "Armengot de Castellón, 1977", "Gabriel Sijé, 1984" of Orihuela, "Premio Casino de Lorca, 1999"] (15)—and this does not include those won by his poetry and short stories.
- 9 In Cano Conesa's voluminous study (recently published, it should be stressed) there are only 11 pages dedicated to *Angelicomio* (163–73), despite the fact that *Angelicomio* was among the top ten of the Planeta prize (Cano Conesa 38).
- 10 The spirit of Conway's quotation seems to be even more relevant to the plot (and marketing campaign) of the recent film *Yo, también* (see Fraser, 'Toward').
- 11 'Así es que el escritor apeló a su capacidad de transformar la realidad y localizó la acción en un escenario inspirador: un complejo residencial, poblado de niños y ancianos, en donde el propio escritor ejerció la enseñanza' [Thus the writer drew on his capacity to transform reality and localized the action in an

- inspiring setting: a residential complex, populated by children and elders, in which the author himself taught] (Cano Conesa 163).
- 12 Among other punishments, the text mentions 'la expulsión de [...] Damián por la canallada que cometía al someter a los internos al sin sentido de cavar y rellenar zanjas, de propinar palizas brutales a las criaturas que examinaba si les descubría arañazos en las ingles' [the expulsion of (...) Damian on account of the dirty deed he committed upon subjecting the interns to the senseless digging and filling-in of ditches, of unleashing brutal beatings upon the creatures he watched over if he discovered scratches on their groins] (123).
- 13 Elsewhere, Angelicomio continues this unfavorable portrait of family involvement in the lives of disabled adolescents in the description of 'aquel hijo extraño que se apartaba de Dios y frecuentaba únicamente el hogar a la hora de comer' [that strange child that moved away from God and frequented the home only at mealtime] and in the feeling Don Gregorio has of being 'Todo un fracaso a pesar de sus apabullantes títulos y méritos pedagógicos' [An utter failure despite his impressive titles and pedagogical successes] (40). Reference is also made to the dissolution of entire families, for example in the anecdote of certain parents who have 'desparramado a sus ocho hijos en distintas instituciones de misericordia, privadas o estatales' [spread their eight children across different private or state institutions of mercy] (145).
- 14 An earlier version of this chapter, as Cano Conesa mentions, was published as the story 'Patachicle' in 1973 and was later re-edited for the 1981 collection titled *La paloma y el desencanto*.
- 15 Cano Conesa comments that 'Primitiva es un personaje dibujado con gran sensibilidad' [Primitiva is a character sketched with great sensitivity] and that the episode of the doll is 'es especialmente hermoso, imaginativo y tierno' [particularly beautiful, imaginative and tender] (171, n.93).
- 16 For Vázquez Montalbán the 'subnormal' is at once a mindless product of 'las tácticas de la conformidad universal' [the tactics of universal conformity] (*Escritos subnormales* 32), and a term that attempts to destabilize the hegemony of a reason appropriated by the bourgeoisie (38; see also Balibrea 52–60).
- 17 Both novels share a focus on the sexual lives of adolescents with disabilities, although that theme is more prevalent in *Angelicomio. Quieto* does, however, feature a chapter ('Sexo' [Sex], 36) devoted to stories of adolescent sexual awakening told by Jessica, the caretaker of another older boy with cerebral palsy. These stories, related by Màrius to his wife Mercè, provoke her to remark that 'si nuestro hijo pudiese gozar del sexo, aunque fuese mínimamente, querría que lo hiciese' [if our son were able to enjoy sex, even in the slightest, I would want him to] and, conjecturing about a future state of Lluís's adolescence, to suggest hiring a professional (39).
- 18 Introduced by a remembrance of his daughter's writing about Lluís for a school assignment, Màrius discusses his own writing in the text of *Quieto* in this way: 'Me doy cuenta de que escribir, para mí, siempre ha sido transcribir, transliterar, traducir. Incluso cuando lo baso en la invención, que es una pura transposición acrobática de experiencias' [I am realizing that to write, for me, has always been to transcribe, to transliterate, to translate. [This is true] [e] ven when I base it on invention, which is a purely acrobatic transposition of experiences] (132).
- 19 He also uses the term as an adjective ('la realidad luliana,' 69; 'el relato

- luliano,' 95; 'los gestos lulianos,' 122) and frequently digresses into linguistic tangents in the novel. The references to llullus are in the end about the recognition of commonalities and the notion of visibility and invisibility of such populations (naming something makes it easier to notice). The term llullu/llullus/luliano is an expression of his love of language in general as a writer and creator of crosswords (thus 'ludo-linguistics'/playing with words), a theme that is touched upon explicitly in the text (e.g. 27, 60, and a humorous play using the verb 'cenarlo' on 35).
- 20 The book ridicules magnetotherapy as one of many practices that seek to capitalize on the false hopes of parents of severely disabled children. During this phase, the couple buy numerous patches and three dark crystal bottles 'llenas de un líquido imprescindible para la terapia y que yo juraría que es agua destilada' [full of a liquid that is indispensable for therapy and that I would swear is distilled water] (65).
- 21 Serra also pokes fun at the way in which spiritual concerns are often trumped by seemingly bureaucratic issues when he writes: 'sólo quedan tres días para completar la visita a todas las basílicas que otorgan no sé cuántos puntos extra en la tarjeta de cliente del catolicismo' [only three days remain to complete the visits to all of the basilicas that come with who knows how many extra points on the customer (loyalty) card of Catholicism] (24).
- 22 On one occasion in particular, he mixes both critiques in one medical-religious comparison: describing a certain doctor, he writes that 'Si la medicina tuviese un centro de gravedad parecido al Vaticano, ella sería de la teología de la liberación; intestinal, en su caso' [If medicine had a gravitational center like the Vatican, she would be represented by the Theology of Liberation, (in her case, Intestinal Liberation)] (86).
- 23 'Un intelectual tal vez hallaría una manera de transformar su parálisis cerebral en una metáfora del mundo contemporáneo. En función de sus intereses proyectaría el colapso de un ser humano como él al futuro de Cataluña, el capitalismo, el machismo, la sociedad occidental o los derechos humanos. Yo siempre he vivido de mi intelecto, pero me di cuenta a tiempo de la vacuidad de las metáforas, creo. [...] las relaciones con mi Lluís son siempre a través de la piel. El intelecto no juega ningún papel. Ninguno. Y sin intelecto no puede haber intelectuales, ni pensamiento ni lengua ni metáforas ni metonimias ni sinécdoques ni ningún tipo de tropo, por más que a mí me entusiasme la vida tropical que las palabras permiten explicar' [An intellectual might find a way of transforming his cerebral paralysis into a metaphor for the contemporary world. Given his interests he might globalize the collapse of a human being such as himself to be the failure of Catalunya, of capitalism, machismo, Western society, or human rights. I have always made a living because of my intellect, but I realized soon enough that metaphors are, I think, vacuous. (...) my relationship with Lluís has always been grounded in the tactile. The intellect plays no role. None. And without intellect there can be no intellectuals, nor thought nor language nor metaphor nor metonymy nor synecdoche nor any type of trope, as much as I may enjoy the poetics of prose that language helps elucidate (46). Recalling the scatological ending to the incident at the Vatican, Serra also here opposes Lluís's burp to intellectualism, a reminder of the physicality of his life, of the importance of material conditions for disabled populations. Intriguingly, however, on a later page the author does manage

- to suggest the very intellectual metaphor he has so vigorously decried (and perhaps only partly in jest): he writes 'tal vez el punk surge de la parálisis cerebral, o viceversa' [perhaps punk (aesthetics) stems from cerebral palsy, or vice versa] (99).
- 24 'Cada mañana mi rabia aumenta. Hay días en que rayaría los coches aparcados en la acera sin contemplaciones. Otros días les rompería el retrovisor, les picharía las ruedas o las dos cosas a la vez' [Each morning my ire increases. There are days on which I would scratch the cars parked on the sidewalk without even thinking about it. On other days I would break their side mirrors, slice their tires, or both at the same time] (79).
- 25 *Quieto* also humorously features the story of the young niece of a family friend, who has complained that Llullu is keeping secrets from her.
- 'Cada vez me gusta más, esta novela [A Personal Matter], pero eso no me pasa con los otros textos que conozco de Oé en los que la presencia de su hijo tiene un peso específico' [Each time I like this book more, but I can't say the same regarding the other Oë texts I know of in which the presence of his son has a given weight] (130). The reader should note that A Personal Matter narrates the story of the son's birth and ends soon afterward. The other Oë novels mentioned by Serra include iDespertad oh jóvenes de la nueva era! [Rouse Up O Young Men of the New Age!], Dinos cómo sobrevivir a nuestra locura [Teach Us to Outgrow Our Madness] and El grito silencioso [The Silent Cry] (131). See also Oë's A Quiet Life.
- 27 See Claremont, chapter 3, for further discussion of the father–son pair in the novel, and also a discussion of *Rouse Up...* in which the fictionally reimagined son is rendered as an adult.
- 28 Màrius is brought to tears when at a larger family get-together he sees his nephew, Oriol, dancing to country music and running around: 'al ver correr a Oriol, aún me obsesiona más la idea clara de que Lluís nunca lo hará' [seeing Oriol run, I am driven to madness by the undeniable truth that Lluís will never do so] (51). During this passage, he relates that, unbeknown to his wife Mercè, tears are streaming down his cheeks.
- 29 Riba's lyrics are incorporated into the book, and the singer himself also collaborated with Serra in a benefit for people with multiple disabilities in 2009, after Llullu's death (see the article 'El escritor').
- 30 This episode may remind some readers of a case discussed by Oliver Sacks in *An Anthropologist on Mars* where a man with a brain tumor was thought to be very mellow and even a model of a sort of vaguely Eastern style of touching the infinite. Clearly this case differs substantially from that one.
- 31 The reader is prepared for the folioscope with numerous references earlier in the text to early cinema-esque machines (zootrope, mutoscope, 53–54) and also the word folioscope itself (155, 153–56). Serra thanks Jordi Ribó and Miquel Llach (on p. 8) for realizing his vision of the folioscope.

CHAPTER 4

Documenting Cognitive Disability

¿Qué tienes debajo del sombrero? (2006), by Lola Barrera and Iñaki Peñafiel

[Judith Scott] raises all kinds of questions. Is she making objects? Is she making art? Is she communicating?... Or is she merely unraveling... you know... all of her stories and everything that's been in her head for forty years that she's been trying to communicate but can't?

Tom di Maria, Executive Director of the Creative Growth Art Center, qtd. in ¿Qué tienes...?

Two of the most material among the many signs of [the paternalistic syndrome's] effects are the horrific unemployment figures for people with disabilities (hovering at a steady 80 percent even before the last recession) together with the dwindling ranks of disability-specific publications and programs.

Charles A. Riley, Disability & the Media: Prescriptions for Change (10)

While engaging the process of artistic creation at the Creative Growth Art Center (CGAC) in Oakland, California, Judith Scott produced numerous enigmatic three-dimensional fiber and mixed-media sculpture pieces that subsequently received international attention. Approaching Scott's life and art from the perspective of Disability Studies—once again understood as an expressly political project—takes us beyond the limitations of the label of *Art Brut/* Outsider Art and of questions of artistic communication to properly

situate her activities at the CGAC as work in both a social and economic sense. Scott's story—and her representation in a Spanish documentary film by directors Lola Barrera and Iñaki Peñafiel—suggests that in aspiring to achieve greater social and economic inclusion for such marginalized populations we must challenge the pervasive clinical paradigm that frames disability as lack and go further by cultivating sustainable, meaningful work experiences, such as that offered by the CGAC to people with developmental disabilities. Ultimately, creating art has the potential to be such a form of meaningful work. The first part of this chapter looks at the life, work, and filmic representation of American fiber artist Judith Scott (1943–2005) within the context of Disability Studies in order to accomplish a series of three nested goals.

First, discussion of her life and art provides the opportunity to assess the appropriate ways of talking about outsider and disability art, and in so doing broach the question of the limitations of traditional communicational approaches to art. In order to set up this discussion, it will be necessary to explore Scott's process of artistic creation as well as its resonance in the larger world of art and art interpretation and discourse. The first section of this chapter thus explores Scott's work within and beyond the category of Outsider Art/Art Brut, emphasizing her unique situation as a producing artist working at the Creative Growth Art Center. As a way of setting up this discussion, I rely on content drawn from two distinct textual accounts of Scott's work and life—art critic John MacGregor's superb book Metamorphosis: The Fiber Art of Judith Scott (Creative Growth Art Center, 1999) and a provocative documentary film dealing with both Scott and CGAC and directed by Spanish filmmakers Lola Barrera and Iñaki Peñafiel, titled ¿Qué tienes debajo del sombrero? (2006). Although the film is interesting in its own right on account of its intriguing formal properties, my intent is to here restrict discussion of the documentary to the level of content—mainly as a primary source of interviews with those who knew Scott best—saving a brief formal discussion of ¿Qué tienes...? for a later subsection.

Second, I want to situate discussion of Scott's artistic production within larger social processes that inform and all too often limit the day-to-day lives of people with developmental disabilities. This means going beyond long-standing views of outsider and disability art that perpetuate a certain view of the artistic product as autonomous—a world in and of itself—and recognizing the rich life experience of and the social restrictions frequently imposed on its creator. All too often, critics reduce the life of a person with developmental disabilities to fit squarely within the category of discapacity, perhaps believing that a

superficial brush with this category alone will suffice to add spice to the work of art's reception. Instead, I argue that the process of artistic creation undertaken by people with developmental disabilities may be simultaneously seen as a social and ultimately even an economic process without sacrificing any of the artistic content of their works. In Scott's case, this means moving from her art through her life history to the more immediate social (and economic) context in which her art was produced—the innovative and artistically nurturing environment of the CGAC. In the second section I argue that the requirement that art be understood in terms of communication is not merely limiting within the discourse of art as a whole, but is gravely inadequate when applied to the work of artists with developmental disabilities. As many scholars have indicated (Kittay, Love's Labor, 'When Caring,' 2002, 'When Caring,' 2001; Kittay et al., 'Dependency'; Sedgwick; Carlson, 'Cognitive Ableism,' for example), disabled populations are too often seen as a special case that serves an able-bodied majority whose enforced idea of 'normalcy' has lent support to 'the myth of the independent, unembodied subject' (Kittay et al., 'Dependency' 445). Dispensing with the bias of the 'cognitively abled' (Carlson) and heeding recent work on employment and disability (Chima; Citron et al.; Contardi; Kiernan; McGuire and Chicoine; Migliori et al.; Morris; Moxley; Parmenter, 'Living,' 'Quality'; Pardeck; Wehman, 'Supported,' 'Integrated'; Vilà et al.) and developmental disabilities in particular (Abbott and McConkey; Hartnett et al.; Lack; Morris; Ping-Ying Li et al.) suggests that Scott's unconventional experience at the CGAC may deserve more attention as one possible way to address the full social and economic integration of such marginalized populations.

Finally, I want to look more closely at the formal properties of Barrera and Peñafiel's documentary film ¿Qué tienes debajo del sombrero?, which fittingly achieves a sympathetic treatment of Scott's life, artistic work, and social/economic context as a whole. The documentary notably succeeds in avoiding some common pitfalls in the representation of people with developmental disabilities by presenting Scott first and foremost as an artist in her own right, and also by problematizing a purely aesthetic approach to her art by emphasizing the social conditions of her life. The final subsection of this chapter's first part relies on critical literature to address the commonly superficial portrayal of people with developmental disabilities in film (Enns and Smit; Rapley; Riley). Ultimately, Barrera and Peñafiel manage to avoid the typical portrayal of disability and instead pay appropriate attention to Scott's artistic production, the rich texture of her life, and also the larger social problems faced by people with developmental disabilities more

generally. The film also notably strives to challenge the clinical view of disability noted by scholar Mark Rapley (2004) in one of its most powerful sequences. Discussion of this sequence explores the way in which Scott's art—rather than her body—is subjected to an exaggerated clinical treatment (including numerous X-rays) by a number of technicians in white coats in order to draw attention to the way in which people with developmental disabilities are routinely marginalized through the discourse of illness.

Much as Judith Scott's fiber art spins multifarious everyday objects together into a coherent and beguiling mixed-media sculpture piece, this chapter's ultimate goal is to tie together both the artistic production and social/economic integration of people with intellectual disabilities in calling for the recognition of artistic process as itself productive work in its own right. This discussion thus seeks to call attention not to the 'work of art,' but rather to the 'work of (creating) art.'

Judith Scott, Fiber Artist

Judith Scott, who neither spoke nor used sign language (there is no mention of her deafness in institutional records until twenty years after her arrival), was a deaf person with Down syndrome who earned an international reputation as an artist for her mixed-media fiber sculptures. Fiber art sculptures created by Scott while at the innovative Creative Growth Art Center in Oakland have formed part of the collections at the San Francisco Museum of Modern Art, the American Folk Art Museum in New York and even the Collection l'Art Brut in Lausanne, Switzerland¹ (see www.creativegrowth.org/ gallery). Similarly, as a testament to how widespread appreciation of her work has become, there have been a number of insightful textual attempts to reconcile her art with her life story, perhaps most extensively in MacGregor's print account in his book Metamorphosis, but also in Barrera and Peñafiel's enlightening cinematic text ¿Qué tienes...?. I draw from the content of both in this section as a means of broaching the entwined subjects of Scott and the fiber art she produced while at the CGAC.

First and foremost it is important to understand the benefit and the limitations of the interpretive label through which many have traditionally viewed the production of art by people with disabilities. Scott was designated an outsider artist by art scholars and critics such as Roger Cardinal and John MacGregor, who themselves drew upon the French term *Art Brut*. As MacGregor notes 'The term Art Brut was

introduced by Jean Dubuffet in 1945. Outsider Art, the exactly equivalent English term, was introduced by Roger Cardinal in 1972' (3, n.6). A simple web search confirms the verve with which Judith Scott has been internationally labeled an outsider artist—even in such prestigious Spanish newspapers as *El País* and *El Mundo* (Luzán; 'Filmando la enfermedad'). Significantly, there is reason to view the term and its application with a modicum of approval, but also with suspicion.

Jean Dubuffet—the collector credited with the movement's origins—used the term *Art Brut* in his attempt to find art where people least expected it. This effort was intended to widen the traditional understanding of what constitutes art. Writing of marginalized artists whom he characterized as insane, Dubuffet stated that 'We see no reason to establish a special department for them, as some have done [...] From our point of view, the artistic function is identical in all cases, and there is no more an art of the insane than there is an art of dyspeptics or of those with knee problems' (33). Art is, after all, a form of communication—and to a certain extent, the term *Art Brut* and its application represented an attempt to reach out and communicate with artists who were not currently part of the conversation. Although he also somewhat predictably emphasizes the lonely worlds of outsider artists, Roger Cardinal aptly emphasizes the priority placed by the movement as a whole on questions of communication:

It has been said that outsider art at its most extreme would not be in dialogue at all with the outside world, because the urgent business has to do with self assertion. But when one looks at such work one becomes aware that that is actually what we're all dealing with, and what is important to us. And so beginnings of a dialogue emerge, and although the outsider work appears to be superficially self-enclosed and not talking to anybody, autistic, it does I think, perhaps necessarily contain the beginnings of communication. And indeed every expression in effect presupposes somebody listening, somebody that will interpret and respond. And so in the end I think that Outsider Art asks us to respond, and to do so we need to ourselves go through a similar engagement with these deep problems, with these deep difficulties. (qtd. from interview in ¿Qué tienes...?)

Although this perspective certainly has its flaws, as I will soon point out, it is important to see how the category of *Art Brut* in a sense advocates a more egalitarian model of social communication by extending an invitation for those previously marginalized from the discourse of art to participate in it. In this one sense, the arrival of *Art Brut/*Outsider

Art shook the greater art world to its core. As artists and critics struggled to redefine what constituted art they in effect took a step toward realizing a more inclusive notion of humanity, daring to go beyond the dismissive view that social pariahs such as the intellectually disabled were valueless, even if they were willing to do so—as the insular character of Cardinal's quote makes clear—only up to a certain point.

At the same time, it cannot be ignored that there is a fundamental problem with the label of Outsider Art and its application to people with intellectual disabilities, not to mention the problematic nature of the name itself and its application to other marginalized groups. The invitation extended to individuals with intellectual disabilities to participate in the discourse of art is offered only conditionally, under the proviso that they do so on terms that are not subject to their control and that do nothing to change the existing social limitations placed on those individuals. While perhaps working to expand the notion of who is capable of creating art, Art Brut/Outsider Art in a sense works against reaching a rich understanding of the lives of people with disabilities. It does this by suggesting that appreciating the outsider artist's product on purely aesthetic terms matters more than attending to the social conditions in which that art is produced and viewed. In all probability, the term ends up institutionalizing the marginalization of the artists on whose work it profits. Particularly as it relates to people with intellectual disabilities—as opposed to a more generalized stereotype of the insane hermetic artist—the term's utility breaks down. The label of Art Brut obscures the very process of exclusion, obfuscating differences among the 'insane,' lumping everyone together in a monolithic peripheral identity that merely reaffirms the central position of a socially mediated and produced 'normalcy' (Carlson, 'Cognitive Ableism').

Most important in this regard is that in prioritizing the art made by people with disabilities at the expense of the social conditions that necessarily inform their lives and work, we lose a sense of the larger picture. This means recognizing, as Charles Riley points out, that people with developmental disabilities suffer from unemployment figures he terms 'horrific [...] (hovering at a steady 80 percent even before the last recession)'; just as it means lamenting, as Riley does also, 'the dwindling ranks of disability-specific publications and programs' (10). Going beyond the artistic category of Outsider Art in approaching Judith Scott's creative expressions is a way of recognizing both those challenges that are unique to her and also the larger social processes in which her artistic production must necessarily be understood.

The Creative Growth Art Center, where Scott worked as an artist over a number of years, provides a notable example of how to remain attentive to both the challenges specific to individuals with developmental disabilities and the wider social and economic webs in which they live. Significantly, the Center's Art Gallery (formed in 1980) was the first gallery in the world established for artists with disabilities (www.creativegrowth.org), and offers day and afternoon programs, a tapestry workshop where clients earn an hourly wage, scholarships, and the opportunity for artists to exhibit and sell their art. It is important to note that the CGAC's artists 'receive a percentage of the proceeds from the sale of their art' (creativegrowth. org/program-overview),2 and that some of Scott's works have even sold for thousands of dollars ('she [Scott] sells for 5,000 to 15,000 [dollars],' qtd. from an interview with the Center's director Tom di Maria in ¿Qué tienes...?). Currently, the Center is staffed by Creative Growth Art Instructors, Artists in Residence and additional instructors who work alongside some 150 artists with physical, emotional, and developmental disabilities (creativegrowth.org/program-overview, creativegrowth.org/about-support). There are also visiting artists who periodically spend short periods at the Center, such as Silvia Seventy—the artist credited with introducing Scott to fiber art.3 Tom di Maria, the Executive Director of the CGAC, emphasizes in no uncertain terms that 'The Creative Growth Art Center is an art center' (original emphasis, interview included in ¿Qué tienes...?) He continues:

We are not a therapy or rehabilitation center. We... the model for our studio is that we have artists from the community who are all working artists come here as staff people and form a partnership with our artists with disabilities so it's a true artistic model. We do not have therapists who work here and we do not see ourselves as therapists. (qtd. from interview in ¿Oué tienes...?)

While the Center is no doubt 'conceived of neither as a school nor as a sheltered workshop' as MacGregor notes (6), I see the CGAC as a unique integrative space where select artists with and without developmental disabilities work alongside one another in pursuit of a goal that is at once both artistic and necessarily social.⁴

This social aspect of the Center stems from the fact that it provides a rich social atmosphere and work environment, but also from the opportunity it creates for people with and without developmental disabilities to work together in what is best understood as a non-clinical, even professional (artistic) environment. Stan Peterson, one of the Center's collaborating community artists (who features in the documentary by Barrera and Peñafiel), provides a glimpse into what happens there on a day-to-day basis. Of the many artists who create works of art at the Center,⁵ Peterson has been closely assisting Carl Hendrickson, an artist with severe cerebral palsy who makes chairs and furniture. As Peterson explains:

Carl's body is basically his measuring device, so he uses the length of his arm, the length of his leg, the length of his torso to determine his dimensions. He has a very clear kinda engineering-construction kinda mind inside a body that has a lot of physical limitations. And what Carl and I have developed over the years is a sort of communication system that's just totally individual... that indicates what he wants done, what he wants me to do for him, and how we work together. And I'm always amazed, I've known Carl for twenty years and I'm always amazed at the clear conception he has in his mind and how well he can communicate it without words and without using sign language, but just through gesture, pointing and his enthusiasm. (qtd. from interview in ¿Qué tienes...?)

In contrast to Hendrickson, Scott worked largely on her own. MacGregor noted in his critical artistic biography that 'Judith works alone, with the object she is making her only companion. It is not unusual for her to select a table where she is not only by herself, but facing the wall' (32).

The artistic process in which Judith Scott engaged at the CGAC took on greater and greater meaning for her as her work also gradually became more complex. Her work notably diverges from that traditionally done by other 'outsiders' in that Scott eschews representational forms in favor of 'seemingly abstract forms' (MacGregor 6). She began by wrapping fiber (yarn, string, thread, etc.) around common objects (sticks, cardboard spools, an umbrella handle, broken electric fan pieces) covering them completely and producing what MacGregor describes as objects with 'a hidden inside, and layers and layers beyond'; the end product is almost invariably something that is 'soft, warm, comfortable and comforting' (35). After spending hundreds of hours observing her at work, MacGregor has charted out three periods in the evolution of her work: early work, approximating nests and cocoons incorporating traces of the human body; a middle phase, centered around poles, pole groupings, pairs and doubled figures; and a late phrase constituted by reclining figures and body/head forms. Significantly, this ongoing artistic evolution was accompanied by Scott's own growing recognition of herself as an artist.

Her sister Joyce notes that Scott responded to her ongoing artistic endeavors by recreating herself visually—tailoring a new image for herself. Joyce speaks to her sister's fondness for wearing hats and scarves wrapped around her head:

She started wrapping the scarves around her head and wearing special hats and things when she started getting this sense of herself as an artist or that somehow those two things came together and it seemed that the more her art pieces grew and the more recognition she received the more elaborate her headpieces would become so that she sometimes would wrap, you know, *three* scarves and then some kind of very fancy thing on top of that so... I sometimes think of it as an expression of her self-esteem and her sense of herself as an artist. (qtd. from interview in ¿Qué tienes...?, original emphasis)

It is clear both from reading MacGregor's book and from watching Barrera and Peñafiel's documentary that Scott saw herself as an artist. The title of the Spanish directors' film—¿Qué tienes debajo del sombrero? [What is Under Your Hat?]—even emphasizes this by drawing attention to her hats, the representations of her artistic self-esteem.

Scott's situation—her identification and success as an artist and the pride she so clearly derived from this vocation—is, of course, not the norm for individuals with developmental disabilities. Scott's accomplishments are of great significance in a world in which, as the sociological literature commonly points out, 'Despite changes in public policy, across this country, the typical working-age adult with a developmental disability is not employed' (Morris 18). Read in this context, the CGAC has supported a novel path for the employment of such individuals that is all too infrequently made available. This path has directly confronted long-standing and limiting views of both artistic process and intellectual disability, and perhaps most importantly, it has provided a model that is attentive both to the art produced by people with developmental disabilities and also the social conditions of their lives. Andrea Lack writes that 'The more opportunities people with Down syndrome are given, the more they are able to achieve. Today, people with Down syndrome are musicians, writers, dancers, singers, actors, public speakers, advocates, business owners, homeowners, husbands, wives and much more' (444). Judith Scott's story calls for the addition of 'artists' to that list, and—all the more intriguingly—employed artists at that. While this section has sought

to characterize Scott as an artist, the next section engages Scott's life, artistic production, and work at the CGAC from a perspective that is more explicitly political. In doing so, it argues that her artistic work itself—and not solely the products of her creative efforts—should ultimately be seen both as a form of (non-linguistic) communication in its own right and also as an appropriate method of social/economic integration of which people with developmental disabilities are in dire need.

Disability Studies as Political Project: Art, Work, and Communication

One of the larger goals of this book is to draw attention to, denounce, and suggest alternatives to a constellation of ways in which people with developmental disabilities are marginalized. With this in mind, this section moves to understand Judith Scott as a producer engaged in what is necessarily work, specifically the meaningful process of artistic creation. Although it is pertinent to acknowledge Disability Studies as a point of intersection with a coalition of other political movements,6 I focus here largely on discourses of artistic production and developmental disabilities in particular. Scott's story, emerging as it does from a woman who is an artist and who at the same time has an intellectual disability, undoubtedly presents challenges to the definition, appreciation, and study of art. And yet it also simultaneously calls attention to the larger webs of capital from which people with intellectual disabilities are routinely marginalized. Whereas many attempts to advocate for people with intellectual disabilities make an explicit argument for altruistically coming to their aid, this argument is often content merely to request contributions or encourage volunteering among family or community members—balking when it comes to addressing the appropriate incorporation of individuals with intellectual disabilities into sustainable and meaningful working relationships.

Moving away from the stigmatizing view supported by the pervasive medical model, current approaches strive to recognize disability as 'a natural part of the human experience' (according to the Developmental Disabilities Act of 1984, P.L. 98-527 Section 101a; qtd. in Morris 19). Contemporary research has widely recognized the importance of employment for people with Down syndrome in particular, asserting that these populations 'can be adversely affected by the limited number of jobs available to them and by the lack of independence

and control they have over their own lives' (McGuire and Chicoine 227), and elsewhere critics point to the importance of work for people with developmental disabilities more generally (Wehman, 'Supported,' 'Integrated'). Although there has been a certain degree of progress made since the 1970s and 1980s (Kiernan; Wehman, 'Supported'), as a number of researchers have suggested in the last decade, there is much more to be done in order to more fully integrate these populations socially and economically (e.g. Citron et al.; Migliori et al.; Wehman, 'Integrated'; Vilà et al.) A recent article published by Citron et al. in the Journal of Vocational Rehabilitation underscores that 'employment and valued community participation appear to be frontline solutions for undoing the disempowerment and dependency cycle for people with disabilities' (170). This struggle becomes even more important in light of the suggestions that overall the power of the Americans with Disabilities Act has been of late substantially limited by U.S. Supreme Court decisions (Pardeck), such that people with disabilities may even face increasing challenges (Chima). Disability Studies seen as a political project thus necessarily requires the exploration of a number of strategies for improving the lives and social/economic conditions of people with developmental disability.

One such area, even if it is merely one aspect of a larger political project, concerns the realm of art. Disability scholar Roy I. Brown notes that

In recent years it has been recognized that the Arts have much to offer adults with Down syndrome. There are many examples of people with Down syndrome who paint, act and dance. A few reach professional standards and obtain employment at national and international levels. But the Arts also allow for the development of self-expression and modeling of behavior. They provide opportunities to explore ideas and imagine the future. They also provide opportunities for dealing with anger and other emotions, and can encourage positive self-image. (444–45)

In a context in which scholarship on disability is pushing not merely for work opportunities but for career development (Moxley) for people with disabilities, art presents a very real possibility for self-selecting individuals, provided they are given the opportunity to test the waters as Judith Scott was at the CGAC. Art as a vocation boasts a number of benefits (e.g. the opportunity for self-expression/creative outlet, minimization of obstacles related to the work environment), not least of which is that artistic creation offers an environment in

which the person with Down syndrome may very well experience a high degree of autonomy—a situation whose benefits are touted by Anna Contardi.

Nevertheless, one of the greatest obstacles to seeing artists with developmental disabilities as producers—as artists doing artistic work—lies in the priority given to questions of communication when dealing with such populations, whether on the part of art critics grounded in the paradigm of Art Brut/Outsider Art or by the larger society. Shifting the debate from the meaning of Outsider Art as a reified aesthetic product in itself to the social and economic model of integration suggested by the CGAC allows us to move from discussion of the ability or inability to communicate linguistically/artistically toward a more contextualized, meaningful, and immediate form of non-representational communication as expressed through the social and economic integration of people with developmental disabilities as producers. This is in itself can be seen as a way of shifting from the discourse favored by the cognitively abled, for whom the communicational model of sent-and-received messages is a day-to-day reality, to the everyday lives of the developmentally disabled, whose methods of communication tend less frequently to be so direct and which are sometimes non-verbal, as in the cases of CGAC workers Carl Hendrickson and Judith Scott.

Certainly the tendency exists, as Tom di Maria voices in the quotation that serves as an epigraph for this chapter, to try and make sense of Scott's work from a communicational framework. And yet even within the larger discourse of art there is reason to avoid putting too much stock in such communicational approaches. We thus might return to di Maria's questioning in order to state unequivocally that, yes, Scott is indeed communicating without needing to establish with precision 'what' she is communicating through her art—it is important to recognize that Scott was unable to influence the reception of her work through interviews, writings, or public lectures as other more cognitively abled artists have been able to do. Moreover, it is important to recognize that the question of artistic communication is limiting at an even more fundamental level. Consider critic Susan Sontag's assertion—in an essay written over forty years ago—that if we require artistic communication to be as clear and concise as an intended and received message, we fundamentally misunderstand art. In that famous essay, which she titled 'Against Interpretation,' she insisted that instead of overly rational approaches to art that in fact limit its meaning, relevance, and potential, 'we need an erotics of art' (23). Scott's artistically layered creations are no less meaningful on

account of their enigmatic connotations—they nonetheless have the capacity to move us.

But the most important reason to dispense with the primacy so frequently attributed to questions of communication when dealing with artists with developmental disabilities is that this approach reflects a wider social bias (not specific to the art world) that has been denounced by disability scholars. It is interesting in this regard that theorist Eve Sedgwick has gone so far as to use a photograph of Scott embracing one of her fiber art sculptures as the cover of her wonderful work Touching Feeling: Affect, Pedagogy, Performativity (2002). Although her work does not explore Scott's story extensively, the critic gives it a prominent position, discussing Scott at the close of her book's introduction (22-24) where she notes that the cover photograph of the noted fiber artist served as 'the catalyst that impelled me to assemble the book in its present form' (22). It is clear that the same traditional and overly intellectual paradigm that has 'repeatedly diagnosed [Scott and others] in terms of lack' (Sedgwick 23) has also made the more cognitively abled, in scholar Eva Kittay's words, 'captives of the myth of the independent, unembodied subject—not born, not developing, not ill, not disabled, and never growing old' ('Dependency' 445). Recognizing that we are, as Marx wrote, 'a species being' (qtd. in Kittay et al., 'Dependency' 445) entails that we acknowledge dependence—perhaps better said, interdependence—more pervasively as the primary characteristic of human social and economic life. Kittay points to the dependence that pervades all complex societies ('But who in any complex society is not dependent on others, for the production of our food, for our mobility, for a multitude of tasks that make it possible for each of us to function in our work and daily living?', 'When Caring' 2001 570), and even makes clear that we all are subject to periods where we are even more severely and 'inevitably dependent' (Kittay et al., 'Dependency' 443)—whether as young children, older adults, or as a result of other causes. Appreciating this requires stepping back from an overly intellectual and sterile clinical paradigm that seeks to find out 'What's in Judith's head' in order to articulate a model of human interdependence that does not sacrifice affect to intellect, caring to cognition.7 This move is made by scholars who advocate an approach that more closely examines the foundations of its own knowledge, as in Licia Carlson's use of the term 'cognitive ableism' to destabilize the colonializing ideology expressed through the marginalizing term 'feebleminded.'

Undertaking an appropriate theoretically informed approach to people with developmental disabilities, such as that provided by

Kittay, Sedgwick, Carlson, and others, is not a substitute for but rather a necessary precondition to revolutionizing the way in which these populations are situated in society socially, politically, and economically. Theory must inform practice. In this vein, one cannot ignore recent scholarly affirmations of the social and psychological importance of working environments for people with developmental disabilities. In their recent study in the Journal of Intellectual Disabilities, Hartnett et al. (2008) draw attention to the benefits of community programs for people living with intellectual disabilities, finding that 'new-found social roles and relationships [...] their hobbies and their work opportunities had a positive effect on their quality of life' (170). Similarly, it is clear that a work identity is one of the most important aspects of the lives of people with intellectual disabilities. One study's findings 'suggest that having employment enables people with intellectual disabilities to develop more positive self-concepts' (Ping-Ying Li et al. 30).

Here it may be appropriate to raise the objection that providing work environments for people with developmental disabilities may open them to a form of exploitation. As Eva Kittay suggests in 'When Caring is Just and Justice is Caring' (2002), an essay that blends her own experience as the mother of a daughter with developmental disability with a sophisticated academic treatment of the subject of care and dependency, we must be attentive to this possibility.8 As part of a larger argument, she raises the question of whose interest such 'work' or 'productivity' serves, suggesting that work should not be invoked as a priority outside of the meaning it has for the producer her or himself. I believe it is still possible to suggest that, as I mentioned above, many different forms of work may aid in the development of 'more positive self-concepts' among people with developmental disabilities. But what is clear beyond a doubt is that the form of work in which Scott produced her artistic creations is evidence of the possibility, remunerative potential, and advantages of community-supported artistic work in particular. The presentation of Scott's working life in both Barrera and Peñafiel's documentary and MacGregor's book makes clear that her foray into the world of artistic work was a self-directed and gradual journey that she chose for herself and from which she derived great satisfaction. The risk of exploitation in this type of situation is further mitigated if we consider exploitation from the perspective of Iris Marion Young (1990) as an enduring situation in which 'the results of labor of one social group [are used] to benefit another' (qtd. in Carlson, 'Cognitive Ableism' 130). It should not be ignored that the existence of a community-based art center such as the CGAC works

against the possibility of exploitation by returning profits from artistic work to the same social group whose labor has produced them.

In fact, the example of the CGAC comes to pose the novel idea that a more inclusive map of the circulation of capital—one that allows people living with developmental disabilities to engage in meaningful work as producers/work that is meaningful to the workers themselves—would be, under the current system, a form of improved social communication. In his classic work Capital (1867), written during the same decade as John Langdon Down's (1862/66) descriptions of what would come to be known as Down syndrome, Marx himself offered an explanation of capital as a relation (see Harvey, Spaces 27). Scott's art pieces in particular, and their remunerated incorporation into the international art circuit, provide the opportunity to see the current limitations regarding the extent and nature of the communication that takes place between people with and without intellectual disabilities in our society as well as the possibility of improving upon this current state of affairs. To put it simply, in the present context of capital true social communication cannot exist in the face of the limited access to resources/meaningful work and the vast income disparities that characterize the situations of people living with intellectual disabilities—people who, as Charles A. Riley writes, live with horrific unemployment figures that reach a staggering 80 percent and whose barriers to social inclusion are nothing if not complex. As Suzanne Abbott and Roy McConkey make clear in their article 'The Barriers to Social Inclusion as Perceived by People with Intellectual Disabilities' (2006), recent work has shown that previously applied purely social models of integration for people with developmental disabilities have been insufficient at best:

Social models of disability tend to emphasize the contribution of specialist services to this exclusion [of people with disabilities], which was particularly evident during the era of the long-stay hospitals. Even so, it has become apparent that physical presence within a community does not guarantee greater social inclusion. Taking part in activities, and using local facilities, does not necessarily lead to meaningful social contact with others, particularly the non-disabled population. (276)

As ¿Qué tienes...? informs us, Scott spent much of her life in a longstay institution in Ohio before moving to California and thriving as a result of contact with her sister and of course with the Creative Growth Art Center. One particularly significant way to make sense of this information (especially given the study by Ping-Ling Yi et al.) is to stress the social advantages of economic inclusion. Scott's work at the CGAC provides an opportunity to see that people with intellectual disabilities can be successfully incorporated into the economy not solely as hourly workers, but also as artistic producers engaged in meaningful work. The bottom line is that, as Scott's case proves, art is a form of work—and the tangible benefits of work for the population of people living with intellectual disabilities cannot be ignored.

The next section turns to Barrera and Peñafiel's documentary not merely as visual support for the work being done at the CGAC, but rather as a sophisticated critique in its own right. As evidenced through the film's content as well as its formal cinematic qualities, ¿Qué tienes...? avoids the common mistakes made when representing people with disabilities and also launches its own artistic challenge to the medical/clinical paradigm that sees such populations only in terms of disability. Part of the political project of Disability Studies entails challenging and creating alternatives to the limited fashion in which disabilities are all too often represented in the media.

Disability and Media Representation: ¿Qué tienes...?

Barrera and Peñafiel's splendid documentary ¿Qué tienes debajo del sombrero? (2006) allows us a compelling glimpse into Judith Scott's everyday life and artistic work that few print sources can provide. Perhaps more valuable than any written account of her creative process, the film's images allow us a real-time glimpse of Scott wrapping yarn around everyday objects (such as wood, spools, shoes), and coming to establish a comparison (made explicit in an on-screen sequence title) that frames her as 'la araña' [the spider].9 The film was produced by Julio Medem, who is one of Spain's most celebrated directors and also Barrera's ex-husband—in fact, Barrera and Medem's daughter Alicia, like Scott, is also a person with Down syndrome.¹⁰ Yet there is reason to go beyond considering the documentary film as a mere primary source from which to glean information regarding Scott's life and work. As regards the political project of Disability Studies, the documentary takes an important stance that places a high value on the social integration of people with developmental disabilities, challenging the common and reductive tendency of the media to portray that population in stereotypical terms and poignantly poking fun at the clinical discourse that is routinely used to marginalize them socially. Informed by the political discourse of Disability Studies, the present analysis of the film attempts 'to go beyond disability as a

simple metaphor' (Snyder, Brueggemann, and Garland-Thomson 2). To go beyond the metaphor is at once to go beyond the staid designs of an overly intellectual thought (that which characterizes the more 'cognitively abled') and move toward a more inclusive, affective approach to people with developmental disabilities.

Considering that often in film 'the disabled individual is effectively transformed into an object of cultural fascination, a fragment of humanity, the Other' (Enns and Smit ix), it is clear that ¿Qué tienes debajo del sombrero? is just as notable for what it does not do as for what it does. ¿Qué tienes...? refuses to portray Scott as either dependent on caregivers or a miraculous triumph of medical progress (see Riley 4). This is not to say that the film somehow 'goes beyond' the fact that she is a person with an intellectual disability—a cleansed or 'normalized' image that is all too frequent—but rather that it fully incorporates this aspect of her life while simultaneously making another more nuanced point regarding economic inclusion.

The film presents a challenge to the stereotypical view that equates people with developmental disabilities with their disabilities alone first and foremost by portraying Scott and other adults with developmental disabilities (e.g. Donald Mitchell, Dan Miller) in their capacity as artists. The opening scene of ¿Qué tienes...? undeniably presents us with the image of Judith Scott that comes to dominate the film. Significantly, going against the temptation to frame her life in terms of her disability alone, there is no framing narrative that emphasizes that she is a woman who is deaf and who has Down syndrome. Instead, from the very beginning she is introduced to the viewer as an artist engaged in the act of production. As Joyce Scott talks about her sister, the editing cuts to Judy Scott in the act of artistic production with her fiber art sculptures of yarns wrapped around a variety of found objects, all interspersed with a shuffled series of newspaper articles with headlines like 'Accidental Artist' and 'Berkeley Woman Gains Fame as Outsider Artist.' Joyce then invokes Scott's artist persona, stating plainly that 'getting [Judy] to leave her work is very difficult' (original emphasis, qtd. from interview in ¿Qué tienes...?). These initial edits reveal that, in the simplest terms, this is a film about an artist, her craft, her work environment, and, ultimately, even her economic remuneration.

The opening credits roll over a sequence depicting Scott's bus trip to the CGAC, and, as both the sequence and its overlaid musical track of an energetic operatic piece by Maurice Ravel draw to a close, we see the film's most pertinent and lasting image: Scott seated outside the Center, with hat and scarf atop her head. As she is presumably

waiting for the Center to open, the still camera accentuates her inner confidence as an accomplished artist. The importance of this image lies in the central role played by the artist's hat and scarf as indicators of positive self-esteem and a cultivated artistic persona. As Scott steps down from the bus, she wears a purple scarf over her hat. Just after we see her take a seat, a jump-cut makes her hat and scarf both instantly disappear off the top of her head. Next, we see Scott in the process of wrapping and tying the scarf directly around her forehead just above the eyes, and once again resituating her hat, this time above the scarf, and not below as before. This cinematic stunt is, in essence, the portrait of Scott as an artist: that is, Scott and her hat, the outward expression of her artist persona.

Whereas other films on people with intellectual disabilities have yielded to a biographical approach that risks allowing their disabilities to eclipse their own identities as people (Riley references this trend in chapter 4 of his book, titled 'I'd Like to Thank the Academy: Losing Focus on Disability in Movies and Television'), ¿Qué tienes...? expresses a subtle yet significant shift away from this position by focusing more broadly on the artistic production by Scott and numerous other artists at the CGAC.¹¹ This is not solely a story about Judith Scott (in this sense, it is noteworthy that the title, although it is drawn from Scott's story, does not even include her name).¹² Instead, the film captures the realities of a group of artists, focusing more on artistic process and the working environment unique to the CGAC than on the finished work of art. The filmmakers' interest seems to lie in the individuality of these processes, in discussions of artistic influences. Subsequently, the film comes to pose a question that goes beyond the often essentializing discourse of people with intellectual disabilities as infirm and engages the value of artistic production in terms that are at once social and economic—the artists we observe are indeed producers.

The very first words spoken about Scott after the opening credits of the film are, in this sense, quite telling. In fact, they emphasize her working identity as a producer and not the fact that she is a person living with an intellectual disability—it is the CGAC's Tom di Maria who plainly states that 'Judy Scott's worked here for I think twenty years now' (my emphasis). Of course a short biographical story follows, but importantly the viewer is encouraged to see this as filling in her character and not encapsulating it or completely defining her—just as one would expect to find in any other artist's biography. It helps that the Center's Executive Director presents this information in a matter-of-fact tone—how she was born in Ohio a twin, how (as was, and as perhaps still is, unfortunately all too common) at a young age Judy

was taken to a long-stay institution in the middle of the night straight from her bed. Yet significantly, in the middle of the biographical sketch delivered through the voices of sister Joyce and CGAC director di Maria, we are, in fact, seeing images of Scott's art. In the midst of Scott's chronological biography we watch as a series of eight professionally styled still photographs of Scott's art are intercalated in such a way as to emphasize that this is an artist's biography just as much as it is a condemnation of social marginalization (and also a more personal story of twins meeting again after a long period of time spent apart). In its presentation of Scott the film achieves a delicate balance between Judith Scott, producer, and Judith Scott, a person living with intellectual disability. Appropriately, given the directors' attempt to steer clear of a heroic 'supercrip' portrayal of Scott, many sequences in the film draw attention to her propensity to steal things (among those specifically mentioned are car keys and shoes). These sequences help to flesh out Scott's full range of personality traits—her thefts seem to be at the same time both an endearing and a frustrating trait to her family and the staff of the CGAC.

It is notable that rather than essentialize people with intellectual disabilities, the film is consistent in understanding intellectual disability as an interactional product, recalling Kittay's insistence that we are all dependent on others ('When Caring' 2001) as well as Carlson's use of the term 'cognitively abled'—that is, people with intellectual disabilities are produced, as their social identity is imposed, negotiated, and contested (Rapley). In his work, appropriately titled The Social Construction of Intellectual Disability, Rapley notes that people with intellectual disabilities are frequently observed clinically through the lens of standardized measures and interview procedures, and very rarely through 'naturally occurring social interaction' (3). As if responding directly to this clinical paradigm, the film notably makes an effort to show such naturally occurring social interaction from start to finish. ¿Qué tienes...? shows Scott walking into work, Scott waving hello with a smile on her face to someone offscreen, waving to someone else offscreen as she then walks to her workspace, watching TV on the couch where she interacts with another woman, greeting her sister with a hug, waving off a woman who touches her shoulder, eating ice cream at a communal table, peeling a banana while in the car with her niece, putting napkins on the dinner table, and so on. A somewhat longer sequence of shots of Scott late in the film uses the quotidian to great effect, filming her at a group table with her magazines, following her from the table as she washes her hands and repeatedly uses the automatic towel dispenser, 13 and ending climactically with her lifting

one of her larger pieces of art—thereby thoroughly immersing the viewer in her daily routine. Most significantly, the film's focus on the routines and interactions of everyday life eschews the approach used in many prime-time news specials on people with disabilities—it is lamentable that, as J.I. Charlton notes, 'In the United States surveys have shown that more people form attitudes about disabilities from telethons than from any other source' (qtd. in Riley 10). Instead of a more mainstream approach that uses footage of the everyday as the mere background for clinical or biographical narration, here there is no overdubbed narration at all. The footage of Scott's everyday life—a working life—is allowed to speak for itself. In this way, the documentary magnificently wages its own war in the sphere of the quotidian, employing the banality of everyday life as a significant contrast to the exaggerated highs and lows which tend to structure the more mainstream media's representation of people living with disabilities (Riley).

At other times the film's coverage of naturally occurring social interaction deals less with other people and centers on Scott's work environment-which is of course always already social: we see her unstacking the chairs from tables near her workspace, letting out a deep breath after some strenuous rearrangement of objects and materials in her workspace before scooting her chair in and getting down to work—and we most notably see her concentrating while interacting with her art in the very moment of producing it. In fact, as the film progresses, the sequences of Scott absorbed with her art become noticeably longer and more entrancing as the camera angle shifts at times to a bird's-eye view. In these numerous sequences and others, everyday content is used in a manner consistent with the overarching editing technique (intercalated images of her art and a marked lack of the extradiegetic narration that so often accompanies documentaries)—all to underscore her identity not merely as an artist, but moreover as a producer engaged in remunerated artistic work.

Perhaps the film's greatest feat is the cinematic challenge it presents to the medical/clinical discourse concerning intellectual disability (noted by Riley) by directly underscoring the inadequacy of clinical observation, measurement, and interview procedures to give us insight into the lives and experiences of people with developmental disabilities. One of the last sections of the documentary hammers this critique of medical discourse home through a captivating sequence in which many of Judith Scott's three-dimensional fiber art pieces, some resembling bodies or body parts, are serially subjected to imaging by an X-ray machine. The sequence, which exploits the cinema's capacity for suspense as well as any blockbuster action film does, starts with

CGAC collaborating artist Stan Peterson repeating and responding to a question presumably posed by the filmmakers: 'What is inside Judy's sculpture?... well, you know, there's all sorts of things.' This enigmatic answer is followed up by a statement by another CGAC community artist staff member, Michael Hall, who says 'We've often wanted to do an X-ray of her sculptures to see what is inside.' The sequence that follows is one of the most energetic of the film, contrasting with the slow pace of the previously shown un-narrated shots of Scott's's everyday working life. Here we have more rapid camera movement, mysterious music that builds and contributes to the tension inherent in the search for meaning behind Scott's work, frequent cuts from one person to another, and voiced statements all edited together to deliver a sequence that combines the speed of a car-chase with the excitement of an accelerating intellectual inquiry. The X-ray technician appears to set and re-set the machine at a dizzying pace while Peterson works from his previous knowledge toward a list of the possible objects that may lie in wait inside Scott's art:

It used to be the cones that wool came on, the skeins—ah—that wool's wrapped around, would be always a component. It used to be cut out pieces of pine, of wood, fabric scraps or pieces of cardboard... but also it's all kinds of things, like an electric fan that might be taken apart, maybe a bicycle wheel, it could be a chair, there's a children's chair here that she started wrapping, there was a grocery cart, off the street missing two wheels that a homeless person had left out in front at Creative Growth.

The rhythm of the sequence is astounding—we close in on monitor displays, the moving parts of the cumbersome X-ray machine shot from below, developed X-ray negatives showing the shapes of what appear to be zippers and other small metal objects, all in hopes of finally discovering once and for all the 'enigma that makes Judy's art interesting' (Peterson, qtd. in interview from ¿Qué tienes...?).

A powerful statement is made by the X-ray technician as he places one particular art piece on the X-ray bed: 'Look's like a little person this one, let's give it the treatment, just for fun.' Multiple camera shots from overhead and the side visually reinforce the idea that this piece is a person on a bed waiting to be X-rayed. But this seems to be the filmmakers' point precisely—whereas the medical paradigm and its limiting clinical view of people with intellectual disabilities would frame Scott herself as the ill body to be diagnosed, significantly it is not Scott whom we see on the X-ray table. Instead we see her

artwork waiting to be diagnosed, observed, and categorized by white-coated professionals. The numerous X-rays on the lighted wall-viewers display not her body but her art, leaving Scott out of the picture—and out of the examination room—free to continue her artistic work far away from the clinical gaze.

This tongue-in-cheek attempt to literally X-ray Scott's work and expose the enigma of her art is successful, indeed, in breaking free from limiting clinical views of people with intellectual disabilities. But it also affirms the properly non-rational role of art signaled by Sontag and encourages a more open and inclusive view of communication itself. The sequence's playful attack on the tendency to reach conclusions all-too-quickly, one that notably runs throughout both clinical and artistic discourses, manages to emphasize communication itself as an ongoing process, and in this sense it squares with other scenes in the film. Elsewhere, just as the directors largely refuse to portray Scott as either a 'sadcrip' or 'supercrip,' the documentary refuses also to tout the false benefits of what passes for 'facilitated communication' (see Riley 23). Rather than portray people with intellectual disabilities as the passive recipients of aid through a lens that borders on colonialism in which they are dependent on others to express themselves, the film overall supports the idea that people with intellectual disabilities are in fact already expressing themselves, that this expression needs to be valued—it is just that this form of expression is poorly understood through the traditional frameworks that guide clinical observation of people living with intellectual disabilities. By lampooning the clinical gaze so often directed at these populations, this important and truly cinematic sequence recalls director Tom di Maria's previous insistence that the CGAC is not a therapy center, but rather a 'true artistic model' (his words, ¿Qué tienes...?). The documentary about Scott's life and work is itself a complex artistic product that provides a reason to dwell on the connection between her life and work, but that goes beyond the limits of standard biography to engage the life and work options of people with developmental disabilities and to more broadly denounce an overly intellectual paradigm of disability. Most significantly, it provides visual evidence that people with developmental disabilities may even become (remunerated) career artists if they are provided with the proper opportunities.

So far, this chapter has gone beyond the limiting discourse of artistic communication in order to envision artistic creation as a form of work. In this way, it has resonated with a wider call for the reconciliation of social and economic battles for the integration of people with intellectual disabilities. Facilitated by the CGAC's attempt to

challenge both popular understandings of people with intellectual disabilities and traditional models for their social integration, Judith Scott found meaning in the work of (creating) art. Scott's story and circumstances suggest that there is no social progress without economic progress—and, provided we are talking about meaningful work, this is true for people with intellectual disabilities just as it is for us all. Ultimately, contemporary scholars working in the still emerging field of Disability Studies are in effect recuperating the original thrust of cultural studies research. It is worth remembering, as Raymond Williams reminded us in a lecture from 1986, that the forerunners of cultural studies demanded the relation of academic subjects to the 'life-situations which people were stressing outside the established educational systems' (152). Judith Scott's story, her work at the CGAC, and her depiction by Spanish directors Lola Barrera and Iñaki Peñafiel all point toward the complexity and significance of life-situations that have gone without scholarly attention for much too long. In the next section, this chapter turns to another intellectual disability that all too frequently goes unnoticed, visual agnosia.

Más allá del espejo (2007), by Joaquín Jordà

In May 2002, El País published an intriguing article by Rafael Méndez Ititled 'La chica que ve sin ver' [The Girl Who Sees without Seeing] that began with the simple sentence: 'Esther Chumillas no ve lo que ve' [Esther Chumillas doesn't see what she sees]. Strangely, writes Méndez, Esther—born in Cuenca 18 years previously—can read, write, and recognize colors, but her visual agnosia means that 'Ve, pero la información que llega a su cerebro se pierde y no llega a retener lo que ha visto' [she sees, but the information that reaches her brain gets lost and she can't retain what she has seen]. A poorly treated bout of viral meningitis left her occipital lobe affected—the part of the brain that is responsible for sight (she also lost her lateral vision and became epileptic). The film Más allá del espejo begins with a shot of director Joaquín Jordà citing the title and author of this El País article on Chumillas, after which he reads a few lines of its text. In this first shot, a still camera frames only the director at his desk. His reading is noticeably slow and perhaps a bit uneven as well. What we see as he begins reading is a scene that capitalizes on the over-abundance of visual stimuli that characterizes the cinematic image—as opposed to the relative economy of signs in written narrative. Due to what film

theorist Kristin Thompson calls 'cinematic excess'—or the almost infinite number of the cinema-signs that Pier Paolo Pasolini once baptized with the name of 'kinemes' (see Pasolini 201-03)—this initial scene overflows with numerous objects crowding his desk, and hundreds of books lining the shelves on the walls behind him. Hardly a single spot on the desk, wall, or floor—that we can see from our perspective as viewers—is clear of objects. Moreover, Jordà's shirt is perhaps purposely chaotic: it features a stylized print of seemingly African origin with dizzying rows of geometrical designs of alternating patterns and colors. The effect of this chaotic shot composition formed through the unique collaboration of set, mise-en-scene, and costume/props—is that the viewer struggles, initially, to make visual sense of what she or he is seeing. Whether this is intentional or not and I believe that Jordà's reputation as a filmmaker suggests that it is intentional, conceived to make the simple act of 'seeing' difficult—we nevertheless have here a wonderfully instructive beginning to a film whose focus is on the complexity of both visual fields and human relationships alike.

As has been noted by critics, Más allá is not merely a splendid documentary film, but also an autobiographical enterprise of sorts. The film's director had a stroke in 1997 that left him with a neuro-visual impairment generally similar to that of his film's protagonist: 'Jordà conoció a la chica y durante casi cuatro años la fue filmando, para dar cuenta de su evolución, pero también para contrastar los síntomas de Esther con los suyos propios' [Jordà met the young woman and filmed her over the course of almost four years, in order to understand her development, but also to contrast Esther's symptoms with his own] (Torreiro, 'El emotivo'; see also 'Más allá'). While Esther has agnosia, Jordà has alexia. Their disorders are presented, however, as points on a spectrum—an encounter with a Catalan woman named Paquita late in the film allows Esther to frame their overlap for the viewer: while Paquita is 'pure alexia,' and Esther represents 'pure agnosia,' Jordà has a mixture of both agnosia and alexia. 15 The film continually encourages the viewer to indulge in this sort of comparison through the introduction of several other minor characters who have complementary visual disturbances and through a persistent focus on both Esther and Jordà. Keeping the first shot of the film in mind, the inclusion of the word espejo [mirror] in the film's title points to the central trope of the documentary: Esther is a sort of mirror for Jordà, just as the documentary screen itself becomes a way for the viewer to reflect upon the human significance of the story they share. Going beyond a single reflection, Más allá del espejo functions as a three-way mirror of sorts, if such a

thing exists. Right from the start, our visual struggle to make sense of the chaotic composition of the initial shot nudges us ever so slightly to try and imagine what it would be like to be in either of their shoes. The result is a potentially humanizing appreciation of the complex worlds inhabited by people with such visual disturbances—and ultimately also a poetic reminder of the frailty of the human condition, more generally speaking.

Jordà, who was born in 1935 and who died of cancer in 2006, is known as 'Uno de los padres de la Escuela de Cine de Barcelona' [One of the fathers of the Barcelona School of Cinemal and counts the following among his noted film projects: Dante no es únicamente severo (1967, with Jacinto Esteva), Portogallo, paese tranquillo (1969), Lenin vivo (1970), Numax presenta (1979), El encargo del cazador (1990), the fiction film Un cos al bosc (1996), Monos como Becky (1999), and De niños (2004) (Torreiro, 'Joaquín'; see also EFE; Ibarz). 16 He was recognized for his substantial contributions to cinema by being posthumously awarded the coveted Premio Nacional de Cinematografía [National Prize in Cinematography] (EFE). Jordà died before Más allá del espejo was finished, and it was ultimately put together by the film's editor, Núria Esquerra (Torreiro, 'El emotivo'). Nevertheless, one sees that he has been largely responsible for the film's successful engagement with both the theme of neurological-visual disturbances and also its commentary on the more metaphorically visual theme of self-reflection. The first section that follows looks somewhat matter-of-factly at the film's presentation of Esther Chumillas's story and the dialogue that Jordà begins to establish between the portrayal of his protagonist, Esther, and the complementary narration of his own story. That is to say that, at the most obvious level of interpretation, the director clearly wants to bring the issues associated with Esther's agnosia and his own alexia to his viewer's attention. The second section, however, looks into the film's more universal, pointedly metaphorical, and specifically cinematic contribution by going—as the title itself instructs—Más allá del espejo [Beyond the Mirror]. Importantly, Jordà throughout uses the somewhat haunting and recurring image of a seemingly life-size, paper-mâché chess game to give the film a certain pensive, tense, and even dramatic tenor. Most of the pieces in fact bear sculpted, iconic representations that resemble the faces of specific characters in the documentary. As the chess match unfolds, these scenes parallel and ultimately heighten the challenging nature of the material as we grapple with the meaning of these visual disorders and struggle to put ourselves in the place of the protagonists—which is, in the end, just what Jordà wants us to do.

Esther Chumillas and Joaquín Jordà: Filmic Co-protagonists

Beginning with the initial scene—in which Jordà reads from the El País article describing Esther's unusual if not astonishing circumstances—Más allá del espejo presents the viewer with a puzzling series of questions. What is the nature of Esther's visual difficulty? How does it impact her life? How has she learned to cope? What does she have in common with Joaquín? What interests Joaquín about her case? In this sense, reading from Rafael Méndez's published El País piece meets certain practical goals—it sets up the problem in basic terms and gets the viewer thinking. But having Jordà the director read it to us himself on screen is also a sly way to anticipate the more overt introduction of his own story into the film at a later point. As we listen to his evenpaced and deliberate voice, he occasionally stumbles here and there, perhaps a product of his own difficulties with reading as a result of the alexia caused by his previous stroke (on the way reading is affected by alexia see Arguin and Bub 149; Coslett and Saffran). At this point, however, the viewer is being actively encouraged to identify with Jordà against Esther. It seems, at first, that it is she who is the topic of the film, not the director himself. Only as the documentary progresses will we be forced to challenge this misunderstanding. Here, it is provisionally permitted as a way of managing the viewer's expectations and making the shift toward the co-protagonism of Esther and Joaquín that is much more meaningful.

As the director reads from Méndez's article in the first sequence of the film, the visual editing cuts away to feature a still-camera long shot and a subsequent mid-shot pan of Esther walking from left to right against the backdrop of a high wall that seemingly provides a sort of anchor for her pre-conscious perception of her environment. Jordà's voice-over continues throughout: 'Padece agnosia visual, una rara enfermedad que no tiene tratamiento. Por eso, Esther camina sin problemas, pero no sabe por qué calle camine. Por eso no puede reconocer a su padre, ni describir el coche en el que se acaba de subir sin ayuda' [She suffers from visual agnosia, a rare problem for which there is no treatment. Because of it, Esther walks with no problems, but she does not know which street she is on. Because of it, she cannot recognize her father, nor describe the car from which she has just exited without any help whatsoever] (1:15-1:43). Through this editing, Jordà momentarily affirms the (falsely) objective premise of the camera—Esther is initially shown as if she, alone, were the problem to be analyzed. This sequence is both an illustration of and a visual anchor for the problem of her visual agnosia, but the way in which it is filmed—first framed by Jordà, then captured in still camera, and finally in a moving panoramic view—lends the problem a dynamic quality and a developing energy that will be pursued throughout the film.

In the next scene we accompany Jordà and his crew down a narrow street lined with white buildings as we go to visit Esther at home. The voice-over continues to feature text from Méndez's article: 'Lo más raro es que esta chica, nacida en Cuenca hace 18 años, puede leer y escribir, y reconocer los colores. Eso es lo único que le permite tener cierta autonomía' [The strangest thing is that this young woman, born in Cuenca 18 years ago, can read and write, and recognize colors. That is the only thing that allows her to have a certain autonomy]. It is significant, however, that the mention of color occurs along with the overwhelmingly white image of the buildings on either side of Esther's block, almost as if we are being purposely thrust into a world similar to hers—one in which color plays a huge role. At the moment when Jordà enters her building, he turns back to talk to the members of the film crew, one of whom responds, thus breaking down the illusion of documentary authority and objectivity (1:50). This challenge to the apparent objectivity of filmic images will be, in fact, routinely asserted throughout the film. As discussed below, Jordà not only figures more and more prominently on screen, many times addressing the camera directly, but his voice and visual image even interrupt a number of scenes where he is not the focus. Reaching Esther's floor of the apartment building in this first sequence of the film, Jordà continues to look back at and acknowledge the filming crew in the process of ringing first her neighbor's buzzer and then her own. This is perhaps another indication that Jordà's reading has been affected by his stroke—we learn later that he has difficulty reading numbers in particular—although this clue may be subtle enough to be disregarded by the viewer who is seeing the film for the first time.

At 8:48, however, the film finally reveals decidedly that Jordà is to be a co-protagonist. When, seated on a pair of yellow couches in a lobby, a woman asks him about his alexia, he responds at length:

El concepto global es de agnosia... Alexia es una manifestación de... Alexia... La alexia es la dificultad o la imposibilidad—o sea hay grados—en atribuir al signo-letra el valor que tiene comunmente. La cual se traduce en la dificultad o la imposibilidad, sobre esto hay grados, de leer. El origen es una dificultad de trasmisión entre el ojo que hace la entrada del objeto y la transmisión al cerebro—allí hay un barullo y esa trasmisión no se produce, o llega deformada [...] No tiene

curación porque sea por una infusión de sangre o una hermorragia sobre una zona, sea por un traumatismo que ha amputado o lesionado una zona del cerebro mínima—son zonas pequeñísimas, pero son las que contienen esta gracia, esta habilidad, esta cosa—sea porque sea el cerebro es una materia que es no recuperable.

[The global concept is agnosia... Alexia is a manifestation of... Alexia... Alexia is the difficulty or impossibility—which is to say there are degrees—of attributing to the letter-sign the value it normally has. Which translates to the difficulty or impossibility, there are degrees of it, in reading. Its cause is a difficulty in transmission between the eye that registers the object and the transmission to the brain—there is a disorder there and this transmission is not produced, or it arrives distorted (...) There is no cure because, whether it is on account of an influx of blood or hemorrhage in a zone, or because of a traumatic event that has cut off or lesioned a tiny part of the brain—they are really small areas, but they contain this gift, this ability, this thing—whatever the cause, brain matter is irrecoverable.]

Jordà's informative and lengthy reply (8:49–12:14)—in which he goes on to speak of a few isolated moments in which his reading ability has briefly, if ephemerally, returned—squarely positions him on an equal footing with Esther as yet another focal point of the documentary. He is not merely a seasoned director who is capable of framing our understanding of her unusual condition. In addition, he is also worthy of screen time in his own right. During what is, in essence, an on-screen interview with the director, his intermittent glances at the crew member holding the camera (9:00, 9:03, 9:18, 9:30, 9:34, 10:04, 10:22, 11:00, 11:15, 11:24) or even what seem to be stares straighton at the lens of the camera itself (9:07, 9:10, 9:27, 9:48, 9:57, 10:19, 10:36, 10:38, 10:50, 11:06, 11:10, 11:40) continue to acknowledge the film's direct communication with the viewer. One of the film's aims, it seems, is to educate the viewer in the variety of neuro-visual disturbances that exist. But Más allá... cannot be explained solely in terms of that aim.

Joaquín and Esther have an interesting relationship wherein he approximates not only the role of a peer sharing the experience of a permanent visual disturbance but also that of a father figure of sorts. Both of these roles become particularly clear in an important sequence at the approximate mid-point of the almost two-hour film (beginning at 52:25), when the crew spends time in a hospital as Esther undergoes a series of tests. We watch as Jordà's co-protagonist sits in front

of a mirror alongside an unnamed clinician clad in a white coat. The latter puts a card in front of Esther, but we cannot see what it depicts. As Esther tries to come up with an answer, we wonder ourselves what is on the card, and have no idea—yet another indication that Jordà wishes to thrust us somewhat unprepared into the uncertainty that characterizes Esther's world. The image on the card, one presumes, has been purposely hidden from our view by the staging of the scene and the camera's deliberate positioning. We listen and watch as she mounts what seems to be an educated guess of sorts—'a radio' she says. Only now are we shown that the image depicted is of a television—although her guess is close, the antennae have led her to the wrong conclusion. The next drawing is an iconic image of a loaf of bread, but she remains puzzled (for an in-depth discussion of this recognition problem associated with agnosia, see Koch 219; more generally see Farah, Visual). The next card contains photographs of a child's face, and Esther discusses how she only recognizes emotions through movement in faces but not the details inherent to the expressions themselves (with the next card she mistakes a picture of Clint Eastwood for Julio Iglesias, 55:33). When shown a photo of a waterfall she guesses that it is a Roman aqueduct, and even helped with clues by the clinician regarding the colors she sees—even when directly told that the image is that of a waterfall—she cannot recognize it (Jordà's voice can be heard offscreen here, an example of the way we are persistently reminded of his co-protagonism, 57:15).

At 1:01:28, it is Jordà's turn for the picture exercise, and we see him seated in front of the mirror. This time we see the image at the same time that Jordà does. He does well with geometrical shapes, but when shown a drawing of a pair of eyeglasses he thinks they are a bicycle. He gets the television picture without problems, but when shown a trumpet he talks himself through the musical instrument's parts and arrives at the erroneous conclusion that it is a saxophone. Only after this first incorrect guess does he begin to make gestures with his hands as if playing the instrument—a strategy he exaggeratedly models for Esther as a way of helping her work through her pre-conscious grasp of images—moving on to the conclusion that it is a trumpet. When shown a photograph of the cross-section of a lime, he thinks it is an orange (unlike her, he doesn't see colors).¹⁷ The clinician then disappears and we see both Joaquín and Esther working their way through a series of image-cards together—first a clock, then a dancer, and a strange final image we cannot yet see: is it a nut? a piece of cheese? Instead of these guesses, the camera finally shows that the image is that of a slice of watermelon (on agnosic disorders of object recognition see also Davidoff 92–94; cf. Humphreys et al. 65).

Throughout, Joaquín is a partner and peer to Esther—and yet he is greatly conscious, too, of his role supporting and encouraging her. The pair similarly work together as a team to support another minor character—a woman named Elvira whose specific disorder, although unspecified, must be a type of agnosia or alexia. When speaking with Elvira, Joaquín takes the opportunity to proudly boast of what Esther has been able to achieve, including her persistence at studying.¹⁸ When Esther must get blood drawn and have a brain scan, he tries to keep the mood lively by making jokes and prompting her to showcase her knowledge of agnosia for the viewers watching the film. Later on, we learn that she is moving in with a boyfriend and as they show Joaquín around the apartment he prompts them to talk about how they met and even prompts the pair to kiss on screen—perhaps as a father might embarrass his daughter while simultaneously showing his approval and acceptance of her choice of partner. Many of the final sequences of the film swell with a kind of fatherly pride as we see Esther take (and presumably pass) her exams, on the way to becoming a licensed special education teacher. The camera captures Joaquín interviewing a co-worker at the school where Esther works, proudly prompting her to say positive things about his co-protagonist. These scenes solidify an image that has been developing throughout the film—of the two of them as a nuclear unit of sorts, a mutually supportive and close couple: Joaquín and Esther are, simply put, the co-protagonists of Más allá del espejo.

Theirs is, however, not a relationship that is closed-in on itself, but rather one that turns outward to embrace and help many others with similar problems. The composition of a key shot in a scene featuring the aforementioned Elvira is a wonderful visual illustration of the meaning of the film's title. In this scene (1:14:26-1:16:51), Esther and Joaquín team up (joined by a few others) to provide encouragement, support, and even hope for Elvira, who has apparently not had much time to get used to the idea of having her own visual disturbance, one that is severe if unexplained. The camera captures Elvira against the backdrop of a mirror and more or less straight-on. Her neck and eyes are turned toward her interlocutors who sit in-off – off of the left-side of the screen. To the right of her image we see the reflection of both Esther and Joaquín, whose images face to the right, seemingly away from where Elvira is seated. At the far right of the screen we see the back of Elvira's head and her jacket, such that she appears doubled while the others appear only in the mirror reflection. While the scene may be relatively confusing visually, at the level of sound there can be no doubt that the three of them are having a discussion:

Joaquín (to Elvira): Hace un rato cuando has empezado a hablar has estado a punto de echarte a llorar [...] Y ahora no te costaría nada volver [...] Pues eso no está ni bien ni mal [...] Pero también quiero decirte que [...] con la práctica [...] dentro de un tiempo, o sea día a día, semana a semana [...] vas a notar que vas para adelante. [Just before when you started to talk you were about to start crying (...) And it wouldn't take much for you to do so now (...) Well, that is neither good nor bad (...) But I also want to tell you that (...) with practice (...) after a while, or rather day by day, week by week (...) you'll notice that you are moving forward.]

Esther (to Elvira): ¿Qué te he dicho yo antes? Yo te he dicho antes que, que no me acordaba hasta de multiplicar [...] Yo no sabía qué era eso [...] No sé pues, toca aprender.

[What did I tell you before? I was just telling you that, that I didn't even remember how to multiply (...) I didn't know what that was (...) I don't know, you just have to learn.]

Elvira: Ya pero... [Yes, but...]

Esther (to Elvira): No, 'ya pero' no. 'Ya pero'—después ponerse alguna vez, otra vez, y otra vez, y otra vez hasta que me salga.

[No, 'Yes but' nothing. 'Yes but'—and then try it again and again until you get it right.]

Elvira: Que te salga, claro. [Until you get it right, sure.]

Throughout the discussion, the mirror takes center stage, marking a border of sorts between Joaquín and Esther on one side (in the reflection) and Elvira on the other, closer to us in fact. The implication is that Joaquín and Esther have successfully passed on to the other side of the mirror—the titular *Más allá del espejo*, perhaps better translated for English readers as *The Other Side of the Mirror* or even the somewhat loaded but nonetheless accurate title *Through the Looking Glass*—while Elvira still remains on this side, our side. Whereas the co-protagonists have found each other—found a way to cope and also a supportive community—Elvira remains on this side of the mirror, feeling isolated and alone, not understanding the nature of her visual disturbance, unable to cope or perhaps even to hope for something better than what she is experiencing in that moment.

As viewers (the majority of whom do not have visual agnosia or alexia, one might presume—particularly given Jordà's intention to speak to a wider audience), we notably share Elvira's world, a world

in which agnosia/alexia is a complete rarity, an unfamiliar and seldom understood condition, even something to fear. Even so, at the same time we are afforded a privileged glance through to the other side for the duration of the documentary itself. Jordà is, as explored above, relentless in attempting to communicate with the viewer directly, modeling his own acceptance of what is, in effect, another kind of normal. In addition to his own appearances on camera and his focus on Esther, there are also numerous explanations of various personal experiences of living with certain visual disturbances given by other minor characters in the film—not only Elvira and the aforementioned Paquita but also an unnamed blind woman with a guide dog and another similarly unnamed woman who cannot see anything on her left side. Similarly, a scene filmed in the hospital gives the viewer a kind of brief educational lesson—featuring a clinician who uses color neural images to illustrate the bodily processes involved in various neuro-visual disorders. Jordà's communication with the viewer through the documentary is itself a form of education, as he strives to make people on this side of the mirror aware of what life is like on the other side. This film is in a sense relatively timely, as—perhaps like autism (see chapter 2, 'Envisioning Autism')—a better understanding of visual agnosia has only developed over the past few decades or so (see Farah, 'Specialization' 134, Visual 2-5; Humphreys et al. 63-64).¹⁹ Apart from its pedagogical aspects, however, another part of the success of Más allá del espejo lies in the way its director mobilizes a somewhat obtrusive chess-game metaphor as a way of rendering Esther's struggle in a more poetic fashion—and thus imbuing it with a wider human significance.

The Chess Game as Metaphor: From Disability to Human Universals

The numerous intercalated chess-game sequences are a reminder that Jordà's aim in Más allá del espejo is not solely pedagogical or informative. This is definitively not the filmic equivalent of a book like Martha J. Farah's extremely informative Visual Agnosia: Disorders of Object Recognition and What They Tell Us about Normal Vision. In no case does the director attempt an organized taxonomy of visual disorders, such that the film's viewer finds that the difference between agnosia and alexia, and their overlap in Jordà's case, is left imprecise and ultimately unexplained. Although there is some degree of information about visual disorders included in the film, the focus is not on the medical side of things, but on the social side—and it is here, of course,

that social-filmmaker Jordà is at his best. The chess-game sequences function to suggest the importance of the social context in which the mere matter of the individual cases of agnosia and alexia unfold. Certainly, however, the medical study of these disturbances has a wider significance, as noted by Farah: 'One of the reasons for studying the cognitive impairments that follow brain damage is for the clues they can give us about normal cognition' (*Visual* 1)—but Jordà delivers a film that attempts to say something, also, about human relationships in general. *Más allá del espejo* stands out as a meditation both social and personal: its deeper meaning pertains to the ways in which we are capable of providing mutual support to each other, or of standing in each other's way; and to the ways in which we confront and ultimately defeat the unknown.

The trope of the chessboard is more than merely a disposable sidestory. There are a total of 13 scenes that capture the board and the various movements of the pieces, and the sum of the duration of these scenes taken together totals over nine minutes (chessboard#1, 3:25–4:07; CB#2, 7:49–8:37; CB#3, 18:39–19:14; CB#4, 25:50–26:46; CB#5, 45:56–46:40; CB#6, 1:11:22–1:11:55; CB#7, 1:16:54–1:17:35; CB#8, 1:21:56–1:22:14; CB#9, 1:26:17–1:27:13; CB#10, 1:33:53–1:34:28; CB#11, 1:43:40–1:44:01; CB#12, 1:48:08–1:48:54; CB#13, 1:53:02–1:54:08). The scenes range in length from 0:18 seconds to 1:06 minutes, and the most time that goes by between any two of them is 24:42 minutes, such that they are relatively evenly spaced throughout the film's almost two-hour duration. Significantly, however, the time between the scenes is, on average, much reduced during the second hour of the documentary, effecting an ever-greater emphasis on the themes symbolized through the game as the film reaches its conclusion.

The chessboard is first prominently introduced along with the title screen, following the initial sequence described above in which we see Jordà reading from *El País* and ultimately hunting down Esther's apartment along with his crew. In CB#1, we see immediately that only a few pieces remain on the board, white seems to have a slight advantage over red, and checkmate appears to be only a few well-calculated moves away. While a solitary piano plays music with a vaguely traditional if vexing tenor that will accompany the chess scenes throughout the film (music that is reminiscent of well-known pieces for solo piano by Erik Satie, such as 'Gymnopédies'), white subtitles further direct the viewer to the significance of the match:

La partida empezó mucho tiempo atrás. Ya ha habido muchas bajas por ambas partes. En el momento en que Esther se incorpora al juego, bajo la apariencia de un peón blanco, la situación es la siguiente: Las rojas resisten con tres piezas: rey, reina y caballo: las blancas atacan con peón, caballo, torre, rey y reina.

[The match has been going on a long while. There have already been many losses on both sides. When Esther joins the game, appearing as a white pawn, the situation is the following: The reds resist with three pieces: king, queen, and knight: the whites attack with a pawn, knight, rook, king, and queen.]

The board is gigantic in size, and is set up in the middle of what appears to be the flat roof of a single-story, rectangular building overlooking the sea. A white fence surrounds the perimeter of the rooftop. Positioned against the sea, whose shoreline currents are in a state of perpetual but subtle agitation, the match seems to immediately take on a greater meaning, conjuring up in the mind the way that some cultures have throughout history imagined human struggles to be the result of dice rolls that are beyond our control. Shade—from a tree that is visible on the left and also from the two-story building from which the scene is presumably being shot—covers the bottom half of the railing around the rooftop and lends the scene a chiaroscuro effect, the presence of both light and dark reflecting the dualistic premise of the chess game as well as the human struggle with the beyond. Not a single human figure is present, and throughout the film the pieces will appear to move on their own. Finally, a single white bench sits at the far left border of the rooftop in the shade, while its counterpart sits on the far right in the strong sunlight. Both are unoccupied, and effect a curious reminder of the absence of humankind.

Whereas the first scene introducing the chessboard is filmed entirely as a general shot, establishing its physical location and context and providing a general overview of the current status of the game, CB#2 thrusts us immediately into a close-up of Esther, now rendered as the white pawn. The transition from the previous interview sequence with Esther provides a graphic bridge of sorts, allowing the reader to recognize her facial features and glasses in the papier-mâché likeness on the top of the pawn, anthropomorphizing the chess piece without giving it legs or arms. This tactic, while it perhaps has a commonsense logic (legs and arms would seem a bit strange on chess pieces), also does service to the fact that here we are dealing with neurological disorders, focusing also on thoughts, emotions, and vision rather than issues of mobility strictly speaking. The accompanying stylized Satie-esque piano music works with this face-only

representation to give the chess scenes a certain cognitive slant. The mood created is a somber one. Esther the white pawn turns deliberately to her right to face off with the red queen, who bears a face that we don't yet recognize, and turns toward Esther simultaneously. As if in a ballet of sorts, the movements of the pieces are important—their parallel turns evoke a certain sympathy between the two pieces. We come to find out through subsequent interviews that the red queen's human complement is a woman who has a blindness that affects the left side of her visual field.²⁰ Interestingly, she moves toward the end of the board, staking out a position that puts the white knight in jeopardy. The prominent reciprocal eyeline matches between these two chess pieces (and those that occur in many of the CB scenes) as well as the shift from a general shot in CB#1 to a series of close-ups and mid to long shots of the pieces help to ground the viewer in the specific relationships between the pieces—and of course the eyeline matches also highlight the importance of visuality for the film and for the protagonists.

In the third chess sequence we are introduced to a number of novel variables. First, while the largely still camera in the first two chess sequences only began to move toward the end of CB#2, here the camera begins to move almost immediately. Although CB#3 begins with another general shot of the board, it quickly shifts to a slow zoom as Esther the white pawn advances toward a point at the camera's right. This zoom is made more complex as it is combined with a pan and a slight travel of the camera upward to capture her almost from above as she takes her new position at the side of the red king. There is a cut to a towering high-angle shot from above the red king, dwarfing Esther the white pawn in the process and characterizing their relationship as definitively unequal. A drastic shift to a low-angle shot with the red king looming over Esther occurs, and a subsequent cut frames only the red king in a slow zoom as we gain the first chance to see his menacing face. In contrast to every other chess piece on the board, the red king is a terrifying figure, his face lacking a nose and mouth or any other human features save two deep, empty, and haunting eye sockets. The relationship between Esther and the red king is, in fact, the most important of the match. As the chess game plays out over the remaining scenes, Esther will ultimately make it across the board, become a queen and defeat the red king, thus ending the game and bringing the chess metaphor to a close in the final scene of Iordà's film.

In CB#4 Esther's white pawn interacts with the white queen, with whom she exchanges a glance. The latter chess piece bears the face

of another supporting character in the film: the unnamed lady with a canine companion. The nature of this character's visual disturbance, like that of the red queen, does not seem to be that important of a detail in the plot. Even so, once out of the chess sequence, Esther and this new character interact on a number of occasions. Back on the chessboard in CB#5, Esther advances by the white queen, who then advances by her with the red king in the background. At the end of the scene, Esther is nestled between the two kings and further protected by the white knight (who, in CB#6, is shown to have Joaquín's face) against the red queen's potential attack. In CB#6 Esther continues to move forward (just as she continues to progress in the documentary), here captured by the camera in a semi-circular traveling whose dynamic movement suggests that her interior life (motivations, aspirations, fortitude) is gaining confidence and strengthening over time. CB#7 reveals that Esther's pawn is now a mere two squares away from the opposite edge of the board, thus about to turn into a queen. There is a complex strategy playing out among the various chess pieces where Esther is protecting the white king, the white queen is shifting over to protect them both from the red queen and so on. It is as if all of the white pieces are collaborating to allow Esther to become the second white queen.21

In CB#8, the red knight's face is clearly seen to be that of the minor character with 'pure alexia' named Paquita. In CB# 9, alternating close-ups of both Joaquín (the white knight) and Paquita (the red knight) build tension as a way of indicating that he is about to knock her off the board, which comes to pass (1:26:31). Esther's pawn turns as if to acknowledge Joaquín's good deed and he looks at her before returning to his previous spot. Just then, the red king turns to stare at her, perhaps a moment of fear experienced by Esther, who in the next filmed scene will take her exams. Finally in CB#10, after having taken (and presumably passed) her exams, she advances and becomes another white queen. The red queen pulls up beside her, but it is too late. We soon see Esther moving into her new place with her boyfriend, David (portrayed as the white king in CB#11). In CB#12, she knocks over the red queen, and turns her attention to the menacing countenance of the red king.

The question of what this red king represents is one that is, perhaps, open to interpretation. Nevertheless, its non-human qualities together with the overarching context of the almost mythological space created by the location and filming of the chessboard suggest that it is not a person but rather some kind of intangible emotion or obstacle. One possible explanation for the red king's presence relates to something

we learn early on in the film (also in the article by Méndez): the fact that Esther cannot recognize the face of her own father. In light of this detail, the blurry and fearful visage of the red king symbolizes the way her formerly familiar visual world has been distorted on account of her agnosia. It is not that she cannot see at all—after all she can see colors, we are informed—but rather that sight has ceased to be clean, orderly, and reliable. It is now a reminder of the visual uncertainty in which she must live on a daily basis. Another explanation—one that does not vitiate the former—is that the red king represents any and all obstacles to Esther's creating a successful life for herself on her own terms, and undetermined by her visual issues. She does, of course, finally defeat the red king, placing him in checkmate (in CB#12). Her triumphant defeat of the red king coincides in the documentary's narrative with numerous personal successes: taking and presumably passing her exams, success in her job, successfully moving into an apartment with her boyfriend, and having given hope to other minor characters in the film (Elvira, Paquita, perhaps even Joaquín).

As we see the chessboard for one last time during the credit sequence at the end of the film (CB#13, 1:53:02–1:54:08), there are no longer any pieces on the board. The entire rooftop is devoid of shadows of any kind, and a calm sunlight warms the scene. As in the beginning, there is a general shot taken with a still camera. Once again the viewer's attention easily drifts to the ocean, its waves gently coming into the coast. The chess metaphor stands as an enduring visual legacy, a way of paying tribute both to the struggles faced by Esther Chumillas and also to her accomplishments. Significantly, although the chess game is throughout presented in a parallel diegetic space as a way of introducing new characters and even transitioning back into the documentary's action²²—there are numerous ways in which it visually echoes even through the non-chess-themed scenes of the film. For example, in a scene filmed in Cuenca, the floor of a hotel in which Joaquín delivers his outline of alexia is comprised of alternating white and black squares. Similarly, the stone pattern that forms the sidewalk upon which Esther walks in her native Cuenca also suggests a chessboard (this is most visible from 21:04 to 21:19, but also on other streets in the city, e.g. 23:18-23:30, 24:45-24:50). It is thus quite short-sighted to say, as one critic has, that the chess game is one of the film's flaws. The author of blogs&docs sees the chess metaphor as one of the film's 'varios aspectos fallidos' [various unsuccessful aspects]:

Por ejemplo, la metáfora del ajedrez: un tablero gigante y unas fichas con rostros esculpidos actúan a modo de separadores de los diferentes

fragmentos documentales a lo largo del film. Lo que en un principio parece una buena idea que aporta un vuelo poético refrescante, acaba resultando redundante, torpe, efectista. Y esas caras tan torpemente esculpidas... ('Más allá')

[For example, the chess game metaphor: a gigantic board and some pieces with sculpted faces function as a way of separating the various documentary fragments throughout the film. What at first seems to be a good idea that lends a refreshing and poetic touch [to the film], ends up being redundant, awkward, overdramatic. And those faces, which are so unconvincingly sculpted...]

Whether in the parallel papier-mâché sequences or in Cuenca's visual space, the pattern of the chessboard suggests the importance of intentional, deliberate movements, and of reflexive thought. Through patience, mental fortitude, and deliberate action—along with a supporting cast of characters, as dramatized in the chessboard scenes—Esther has in a sense triumphed over the threat that her visual agnosia originally posed to her at the age of 13. Jordà's understudied documentary is thus at once a biographical portrait of Esther Chumillas, a personal (autobiographical) meditation, and also a documentary film intent to foreground the connection between the struggles faced by its disabled protagonists and those we all face.

Notes

- 1 While the book *Collection de l'Art Brut Lausanne* (2001) by Michel Thévoz does not include a section on Scott's work, it is a good introduction to the movement's origins and conceptual framework, and splendidly details some of the many artists whose work is included in the Lausanne collection.
- 2 The store's online shop may be accessed at creativegrowth.myshopify.com.
- 3 An important interview sequence from ¿Qué tienes...? focuses on visiting CGAC artist Sylvia Seventy as an influence on Scott's work. MacGregor also mentions this influence and goes further by exploring Scott's relationship with another CGAC visiting artist Richard Elliott (114), something that is not explored in the film.
- 4 MacGregor points out that 'Since participation usually involves five full days per week of non-stop creative activity, only those individuals displaying an intense commitment to image-making are encouraged to become permanent members of the Center. Only when she discovered fiber and began to construct three-dimensional forms, did her interest intensify to an obsessional degree, after which she strenuously resisted all attempts to involve her with other media' (6).

- 5 Artists covered in Barrera and Peñafiel's documentary include Donald Mitchell, Dan Miller a.k.a. 'Danny,' and an unnamed artist who documents a fictitious place called 'chocolate city' (where people who do not like chocolate or music are not allowed) (see creativegrowth.org/gallery for more information on Mitchell and Miller).
- 6 See, for example, Davis's Enforcing Normalcy (1995), McRuer's Crip Theory (2006), Sedgwick's Touching Feeling (2002), and Carlson's article in Hypatia (2001).
- 7 Such is the model articulated by Kittay.
- 8 This essay appeared first in *Public Culture* (2001). See also Kittay with Jennings and Wasunna.
- 9 Perhaps because of this title decision by the filmmakers, this nickname has stuck in the Spanish press (see 'La mujer araña' [The Spider Woman], Luzán). MacGregor contributes to the idea of Scott as a spider in his earlier book.
- 10 A short film by Julio Medem focusing on Alicia's invisible friend 'Clecla' also appears on the DVD.
- 11 Complementing the focus on Scott's own artist persona, the film significantly incorporates the artistic identities and processes of other people with intellectual disabilities doing work at the CGAC and covers the opening of their artistic work at the Center's art gallery. Significant in this regard is that during the film's 37th minute—at the mid-way point of the film's approximately 75-minute narrative and therefore occupying an intentionally privileged position—we see the opening of work by Donald Mitchell.
- 12 Compare this with such works as MacGregor's *Metamorphosis: The Fiber Art of Judith Scott* and the film *Outsider: The Life and Art of Judith Scott* (Betsy Bayha, release pending)—which 'delves deeply into the life of a compelling, eccentric and talented individual who has survived in the face of daunting odds' (www. judithscottdocumentary.org/about.htm).
- 13 As MacGregor's book reveals, one of Scott's sculptures consists solely of numerous paper towels wrapped together around and through each other (111). This image was, in fact, chosen as the cover art for his book (also plate 33 on pages 112–13).
- 14 This is evident early on in the film when Joyce reads aloud from some of Judy's institutional records which state that 'she is reluctant to talk and is not too cooperative.' As stated above, although Judy was deaf (a fact which goes unnoticed in her records for some twenty years), Joyce reads for us how Judy was misdiagnosed on account of her non-response to the command 'point to the red circle,' even though she was not able to hear the instructions. The camera works to capture the documents in close-up in order to visually emphasize the inadequacy of such a clinical paradigm.
- 15 Christof Koch writes that 'Pure *agnosia*, a relatively rare condition, is defined as a failure of recognition that cannot be attributed to elementary sensory defects (e.g. retinal deficits), mental or linguistic deterioration, or attentional disturbances. It is often limited to one sensory modality. Typically a visual agnosia patient can't recognize a set of keys on a chain dangling in front of her. If she grasps them or if they are jingled, she immediately knows what they are' (217, original emphasis; see also Koch 217–20). On the other hand, 'The characteristic features of pure alexia include very slow but on the whole accurate reading and massive effects of word length on performance' (Arguin

- and Bub 149). The very limited amount of press on the documentary and the complete absence of critical essays devoted to the film specifically and to Jordà means that there are very few attempts to flesh out the film's presentation of agnosia or alexia. One critic mentions only that agnosia is 'una disfunción cerebral que impide relacionar los objetos que ven sus ojos con las palabras que usamos todos para designarlos' (Torreiro, 'El emotivo').
- 16 The last film mentioned, *De niños*, received much attention as it touched upon a case of pederasty in the Barcelona neighborhood of El Raval in 1997—specifically how this case was manipulated in the media to achieve aims of urbanistic remodeling. See the interview of Jordà by Anuschka Seifert and Adriana Castillo, 'Murmurar es desaprobar.'
- 17 This may indicate a specific subcategory of agnosia, noted by Christoph Koch, in which the patient has the inability to perceive color (Koch 219; see also 137–38 on *achromatopsia*).
- 18 In praising Esther, of course, he also places himself with her in an in-group, explaining that Esther was studying, she stopped but now she is studying again and about to graduate... and that similarly he used to make films, he stopped and now he is doing it again.
- 19 'For instance, writing in only 1972, Bender and Feldman claimed that visual agnosia did not exist, independent of problems in basic perceptual functions on in general cognitive function. Today [this was written in 1994], the case for the existence of visual agnosia as a clinical phenomenon is more secure. There exist several good single-case and group studies of patients with selective problems in particular perceptual processes mediating visual object recognition, which cannot be attributed to impaired basic perceptual or general cognitive functions' (Humphreys et al. 63). Esther's case is perhaps interesting to the authors of these sorts of studies—and its presentation in Jordà's documentary is potentially of interest to a wider viewing public (English subtitles are included on the DVD).
- 20 The white rook also turns toward Esther in CB#2, but I was not able to identify who he was. While I want to say it is a supportive figure such as Esther's father, it may actually belong to a person whose story didn't make it into the final edited version of the documentary put together by Núria Esquerra, for whatever reason.
- 21 A seemingly offhand comment by Joaquín in the documentary suggests to this viewer that the decision to create a parallel chessboard universe where Esther travels across the board to become a queen might have evolved along with the documentary itself, instead of being a decision made in post-production. Joaquín, helping her out of a car, says 'bájate, reina' [Step down, o queen].
- 22 One poignant example of this occurs at 1:17:30, where the chess scene closes with a semi-subjective shot of the white queen (inflected with a slow zoom) as she 'stares' out at the ocean. The camera zooms past the chess piece, soon showing only the ocean and its movement. The next scene we see is of the human counterpart of the white queen (the lady with the seeing-eye dog) staring our at a river. The graphic relation between the shot of the ocean and the shot of the river parallels the thematic relation between two scenes that foreground protagonists alone, meditating on the more philosophical aspects of experience.

Epilogue: Exhibiting Art

n March 14, 2011, El País ran a story titled 'Familiares y trabajadores protestan por el "cierre salvaje" de tres centros de discapacitados' [Family Members and Workers Protest the "Savage Closing" of Three Centers for the Disabled ('Familiares'). Three hundred and five people were booted out of the centers with less than 24 hours' notice. Protestors in the Puerta del Sol (and in one of the centers themselves) subsequently called for a re-opening of the centers—which had been allegedly closed because of structural issues—and denounced the lack of government planning and oversight that led to the abrupt closures and the redirecting of those affected to other overcrowded centers. This story points directly to the question of the continuing need to advocate for disabled populations, generally speaking. Following on the heels of this story—and taking advantage of the more intimate tone made possible through the choice of the title 'Epilogue' for these thoughts—I would like to briefly indulge in a personal anecdote as a way of introducing larger questions surrounding academic research on disability and the matters of advocacy signaled in this El País piece.

The following anecdote explores an anonymous (peer-evaluation) response to an earlier draft of the analysis of *Angelicomio* that appears in chapter 3. When I submitted that earlier essay to a journal in the field of Hispanic studies (not the *Bulletin of Spanish Studies*, where it was subsequently accepted), one reader recommended publication while the second reader voiced the following unexpected (in my view) concern:

Al final el problema es el mismo que Spivak trataba en su artículo clásico 'Can the subaltern speak?', aunque en este caso sería '¿Puede

hablar el discapacitado?' En la novela, obviamente, la respuesta es negativa, ya que es el autor el que le da voz; sin embargo, el artículo no toca este espinoso asunto, lo que crea el problema fundamental y básico de su trabajo.

[In the end the problem is one treated by Spivak in her classic essay 'Can the subaltern speak?,' although in this case it would be 'Can the disabled person speak?' In the novel, clearly, the answer is 'no,' given that it is the author who provides him with a voice; moreover, the article does not address this thorny issue, which constitutes the fundamental and basic problem of the (scholar's) work.]

This comment is quite a curious one.¹ While I will not attempt to compare the need for Disability Studies with the need for studies of other marginalized subjectivities too closely (this has been an important legacy of other Disability Studies scholars—e.g. McRuer), I will merely say that the need for studies of disability (specifically/on its own terms) in literature and film, as well as other cultural production, is great indeed.

When talking about disability in general—that is, as long as the discussion is (as is currently necessary) merely about getting Disability Studies to register on the radar of other scholars at all, let alone getting more specifically into the circumstances surrounding a given disability or the severity of an individual person's disability—it is important to point out that it is still the case that some disabled people simply cannot speak for themselves: Llullu, in chapter 3, is an extreme case, but other people with disabilities, for a variety of reasons, may be somewhat non-verbal (María from chapter 2) or even completely non-verbal (Judith from chapter 4). In these cases it is necessary that someone speak for the disabled person. This fact has spurred a lively debate within the community of disability-minded scholars (see recent essays by Nussbaum, Bérubé, and Stark). What many see as the necessity to speak on behalf of people with disabilities is underscored also—to elaborate upon content included in the Introduction to this book—in comments made by Spanish journalist Amparo Mendo, mother of a son with intellectual disability and contributor to the booklet accompanying the Capacitados documentary:

Desafortunadamente, la discapacidad intelectual es la que menos llega a la sociedad, pero por una cuestión muy simple: las personas con discapacidad sensorial o física tiene voz propia y se hacen oir. Las personas con discapacidad intelectual no tiene voz propia para llegar

a la sociedad, y tienen que ser las familias y las asociaciones las que hagan llegar su mensaje. (43).

[Unfortunately, intellectual disability is the least visible of all, socially, but for a very simple reason: people with sensory or physical disability have a voice, and they make themselves heard. People with intellectual disability lack a voice that might reach society, and their families and associations must be the ones to make their message heard].

Clearly the best situation is that populations of disabled people come together to speak for and advocate on behalf of each other, and this has been an important legacy of the international self-advocacy movement dating back to the 1960s. Such movements, however, may currently either be non-existent, or else difficult to initiate or sustain, due to various reasons touched upon elsewhere.² In the absence of strong and successful self-advocacy movements, arranging for social changes that may produce a world better attuned to the needs of people with disabilities will need to be a joint effort, as is evident in the aforementioned case cited by the *El País* article.

At its base, the above peer-reviewer comments seem to intimate that it is a fundamental problem that such (presumably 'able-bodied') authors as Salvador García Jiménez attempt to speak to the harmful treatment of people with disabilities. Such a perspective ignores the fact that one of the basic problems faced by disabled populations today is their social invisibility. The number of literary works written by recognized Spanish writers on the topic of disability is clearly not very large, and the books that have been published—such as Angelicomio—have been deprived of a larger readership for one reason or another. One of the basic aims of the field of Disability Studies in its intersection with cultural studies in particular—stated or not-involves bringing works that address the topic of disability to the public's attention. I would add that fictional works on disability that have achieved wide recognition within Spain more often than not use the theme of disability as a mere narrative device that ostensibly heightens the dramatic potential of the novel. This is the case, for example, with Torcuato Luca de Tena's otherwise intriguing Los renglones torcidos de Dios (1979)—which, when I first read it, bore a cover declaring 'Más de 150.000 ejemplares vendidos' [More than 150,000 copies sold] (Barcelona: Planeta, 2002). The novel—which details detective Alice Gould's experiences inside a mental institution—is, despite its more appealing aspects, a mystery novel that presents disability as a monstrous curiosity—something that is sadly far from being out of the ordinary. In contrast to this sort of pernicious treatment of disability, which so often obtains in popular novels and films, *Angelicomio* is a diamond in the rough, and the spirit of its fictional advocacy for disabled populations is surely worthy of more attention than the bare minimum that it has received in the present volume.

In the end, however, I came to see the point made by that aforementioned anonymous reviewer. I have to admit that it got me thinking and, ultimately, led to the structure of this epilogue. It is my hope that the next book I write on disability and Spanish culture will focus almost entirely on works (films, novels, comics, and more) produced by disabled people themselves. That has not been my intent here, however. Nevertheless, in what follows, I look at three cases in which the producers of paintings, comics, and written stories and poems are themselves people with disabilities. This echoes aspects of chapter 4's treatment of artist Judith Scott, but with a twist. Here, the artwork is taken on directly—without mediation by a documentary director or an able-bodied author—and, it must be stated, in clear opposition to Barrera and Peñafiel's ¿Qué tienes...? (in the previous chapter), we are now talking about artists who live in Spain.

'Trazos Singulares' (2011) at the Nuevos Ministerios Metro Station

While making a research trip to Madrid during May 2011 as a way of finalizing this book project I was pleased to learn that an exhibition titled 'Trazos Singulares' [Singular Strokes] was to be on display at the north-central metro station of Nuevos Ministerios until May 15. The exhibition comprised 60 works by 30 artists and, significantly, the work of artistic production was itself performed *in situ* between the 5th and the 8th of April. Speaking on behalf of 'Metro'—the organization that oversees Madrid's subway system (and even produces its own television programming)—José Ignacio Echeverría (Consejero de Transportes e Infraestructuras [Transportation and Infrastructure Adviser]) read the following press release on April 12 in the station of Nuevos Ministerios:

Con este acto de hoy, Metro quiere [inaudible due to sound editing] también a las personas que se ven afectadas por capacidades diferentes, porque Metro tiene vocación de dar cabida a todos. Y el modo que

hemos elegido, creo con acierto, es el arte, porque el arte es uno de esos medios en los que es posible poner de relieve las capacidades de las personas por encima de cualquier otra limitación. El arte no entiende diferencias ni conoce barreras sino que promueve la integración y la autonomía de las personas. A través de la expresión artística, todos podemos conocer mejor las capacidades, el talento y lo mucho que estos madrileños pueden aportar a nuestra sociedad. ('Inauguración')

[With today's event, Metro would like (inaudible due to sound editing) also people who are subject to different abilities, because Metro is in the practice of accommodating everyone. And the vehicle we have chosen, correctly I think, is that of art, because art is one of those areas in which it is possible to make the abilities of people stand out against any limitation whatsoever. Art recognizes neither differences nor barriers. Instead, it promotes the integration and autonomy of people. Through artistic expression, we can all come to better know the abilities, talent and, indeed, how much these Madrileñans can contribute to our society].

While I understand that there exists a certain kind of sporadic and somewhat showy form of outreach by companies using disabled populations for causes that have as much to do with their own public-relations plans as they do with the notion of 'accommodating' such marginalized communities—one that certainly does not obviate the need for sustainable and lasting financial and institutional support from governments—there is something unconventional and intriguing about this particular event.

Over four days in April, 2011, prior to the delivery of the event's inaugural speech, the 30 artists with developmental disabilities featured in the exhibition 'Trazos Singulares' actually painted their works in the Nuevos Ministerios metro station itself (brief clips of this appear in the online video 'Inauguración'). This simple decision, in my view, has an understated significance. Many times, of course, the public appearance of the artistic work is separated in space and time from the moment of its production such that the product of art takes on an existence separated from the producer. Those who appreciate art have become accustomed to this sort of disembodiment. Nonetheless, if we are to take the somewhat predictable rhetorical spirit of José Ignacio Echeverría's speech to heart—('El arte no entiende diferencias ni conoce barreras sino que promueve *la integración* y la autonomía de las personas' [Art recognizes neither differences nor barriers. Instead, it promotes *the integration* and autonomy of people], my emphasis)—the

artistic producers of the 'Trazos Singulares' exhibition are not merely being integrated symbolically through the inclusion and integration of their artwork into the daily fabric of Madrid's transportation system, they are also being integrated physically.

Although it may admittedly be a far cry from sustainable and unconditional support for disabled populations, this small-scale decision to have the artists paint in the metro station itself nonetheless reflects, I believe, a somewhat more sophisticated understanding of the historical legacy of the paradoxical visibility/invisibility of disability than would be reflected in the decision to showcase their works alone. Disability philosopher Licia Carlson writes in her work The Faces of Intellectual Disability (2010) of the way in which 'intellectual disability [...] has been made both socially visible and invisible' (46). Historically speaking, the institutionalized classification/codification of people with intellectual disabilities made them highly visible from a clinical (and social) standpoint just as their incarceration in 'institutions far from public view' was intended to render them seemingly invisible to the public at large (46; see also Davis, Enforcing Normalcy 73, 94-95, 173; Siebers, Disability Theory 99-109). 'Trazos Singulares' thus ultimately succeeds in that it renders the contributing artists socially visible, in the process heightening the embodied nature of all artistic production.

'Supergestor' (2011) and Other Comics by the Grupo AMÁS

The reader who goes to the website www.terelo.com/comic.pdf will be able to print, download. or even just read a series of four interesting comics created by people with intellectual disabilities. The 28-page color document's introduction foregrounds the nature of the work:

Este cómic que tienes en tus manos surge de nosotros, los autogestores del Grupo AMÁS. Los autogestores somos mujeres y hombres con disacapacidad intelectual que nos reunimos para trabajar por mejorar nuestra autodeterminación y autogestionar nuestras vidas. (Grupo AMÁS 2)

[The comic you hold in your hands comes from us, the self advocacy group AMÁS. As a self-advocacy group, we are women and men with

intellectual disabilities who get together in order to work on improving our ability to determine and govern our own lives.]

Collaborating with three artists external to the group—Alberto Ramírez, Adrián Navas, and Javier Pacheco (2)—and inspired by a visit to see works on display at the Museo Thyssen in Madrid, the Grupo AMÁS created these four comics as a way of achieving a higher degree of visibility for their group and allowing others to come to know their reality.³ The first comic, for example—titled 'Dibujando en el museo' [Drawing in the Museum] (3–6)—narrates the group's visit to the Thyssen through sequential art. Surely an example of autobiographical comic art (see chapter 2 of this book), the autobiographical aspect is reflected not merely in the descriptive content but also in the form, in which color photographic images of the group members' heads accompany black-ink line drawings of their bodies, presumably drawn by each member his or herself.

The second comic, 'Una periodista entre nosotros' [A Journalist Among Us] (7–12), builds on this already established autobiographical theme, featuring a journalist named Ana who visits the AFANDEM Association and ends up taking the group to a concert at the music venue named the 'Sala Loud' [Loud Auditorium]—where they are invited on stage to sing along with the group. Written by the group and drawn by Ramírez, the formal qualities of 'Una periodista entre nosotros' are also of interest. This is true of the full-page image on page 9 in particular. The single 7 x 10 in. frame contains 14 people (head and shoulders) drawn in black pen and facing the reader with no internal framing whatsoever. Some of the people introduce themselves and their group to the reader through embedded text balloons, which is in the end a splendid visual manifestation of their self-advocacy.4 Attending to the language of sequential art suggests that their appearance in a single-frame emphasizes the notion of their shared community, and the way that five of the figures cross over the left and top borders of the frame similar indicates a cohesiveness and forward-moving energy that may not have been communicated in the otherwise two-dimensional images on the page.

The third comic—titled 'Y recuerde, el futuro está en sus manos' [And Remember, the Future Is In Your Hands] and produced in collaboration with Adrián Navas—employs a dramatic science-fiction narrative to tell the story of Mario and Nuria who dream of having their own house and living together. The couple use a time machine to travel to a distant future 'donde nadie tenía miedo de ellos y donde, después de la confusión inicial, les ayudaron a integrarse' [where

nobody was afraid of them and where, after an initial period of confusion, the people helped them to become integrated [15]. Its first page notably appears as an art-deco propaganda poster boasting in large letters at the top border the message 'Está usted entrando en la ciudad de la autodeterminación' [You are entering the city of self-determination] (13). Once the couple properly integrate into the world of the future, the background shifts from a cold bluish-gray to warm sepia tones as a way of accompanying the nostalgic drawings of the couple sitting on the couch together and taking a walk by the water with their dog, thus enjoying an autonomy that is presumably not a part of their more contemporary (non-futuristic) experience (15). On one of their anniversaries, however, they are reminded of what they left behind in the past; the background shifts abruptly back to its original cold bluish-gray—conveying the difficulties continually faced by disabled people in a non-integrated life—as the couple use the time machine to travel back in time and share with their friends their knowledge that 'un mundo mejor era posible' [a better world was possible] (17).

The fourth and final comic, produced in collaboration with Pacheco, features the title character 'Supergestor' [Superadvocate] in three subsections: 'El origen' [The Origin] (20–21), 'El viaje' [The Trip] (22–24), and 'La batalla' [The Battle] (25–26).⁵ Although the name itself may appear to mark the character as a stereotype (Riley's 'supercrip'), the important difference here has to do with the fact that it is connected with the ideas of self-advocacy and self-representation and not with the stereotypical representation of people with disabilities by others. While the first two sections are drawn by Pacheco (even if the plot and implementation has been, throughout, a collaborative process—see the introductory description on page 2), the third incorporates drawings by the group members themselves. 'La batalla' shows Supergestor triumphing over the forces of evil, and specifically using his intelligence, as well as brute force, to accomplish this (26).

As a whole, the four comics included in the folio—in practice and in content—assert the right of disabled populations to make their own decisions and lead their own lives. And once again, this is accomplished through the discourse and the public exhibition (in this case virtual/web-based) of art.

Associación Argadini's Literary Contests (2008–2010)

The Argadini Association has, since 2008, held a series of annual literary contests (certámenes literarios) in which people with disabilities submit their own original work: short stories, poems, and drawings. The full title of the first contest was 'Primer Certamen Literario Rosetta para personas con discapacidad intelectual' [First Rosetta Literary Contest for people with intellectual disabilities], while that title was later amended as 'personas con discapacidad intelectual o trastornos del espectro del autismo' [people with intellectual disabilities or autism spectrum disorders] for subsequent contests in 2009 and 2010 (see Rosetta 1, Rosetta 2, and Rosetta 3).

Featuring categories such as 'poesía individual' [individual poetry], 'poesía grupal' [group poetry], 'narrativa individual' [individual narrative], 'narrativa grupal' [group narrative], 'otros formatos individual' [other individual formats], and 'otros formatos grupal' [other group formats]—and, in the third contest, with anywhere from three to five prizes awarded in each category—the Rosetta contests are a great way to encourage the production of creative works by people with disabilities in Spain. In the first three contests 68 prizes were awarded, and the prize-winning works have been published online in three files totalling 284 pages. The first contest alone drew over 200 submissions (Barrón).

Significantly, some but not all of the submissions deal explicitly with autobiographical issues of disability. For example, the poem titled 'Confession' [Confession], written by Cuba's Luis Lexandel Pita García—third honorable mention in the Individual Poetry section of Rosetta 2—seems to capture the unwanted attention the narrative voice attracts from those around him in the city. Comprising eight poetic lines separated into three grammatical sentences, the second four lines echo the first four, in the process marking a narrative shift from the objective paradigm to a more subjective one:

Los habitantes de mi ciudad dicen que soy una criatura terrible y despreciable y en verdad tienen razón.
Terrible y despreciable ha hecho de mí la poesía.
Pero tranquilos, señores habitantes, que sólo a mí suelo hacerme daño. (12)

[The people who live in my city say that I am a thing terrible and contemptible and in truth they are right.

Terrible and contemptible through poetry I have become.

But be still, good people of my city, for I commonly do harm only to myself.]

The first sentence delivers a concise snapshot of the social stigma attached to disability, much as described by the father-narrator in chapter 3's discussion of Quieto. Its matter-of-fact tone conveys the banality of the power often attributed to external definitions of the self and begs for/sets up the expectation of a complementary selfdefinition to come. The next two lines affirm this definition of being 'terrible y despreciable' [terrible and contemptible], but reappropriate it, now as a product of the narrator's connection with the threatening marginality of poetry. The final two lines bring the reader ever further into the subjective world of the poet by turning the social gaze initially expressed in lines 1-4 on its ear. Now speaking from a newly found power—perhaps, as line 3 of the Spanish intimates, the product of the self-definition and perspective offered by the poet's grounding in the world of poetry—the poetic voice is in the position of being able to offer advice to the people of his town. In this context, the solace subsequently offered—'Be still, good people, for I commonly do harm only to myself'—seems intended to threaten as much as calm the townspeople. It may, of course, be only natural to harbor resentment toward those who participate in limiting your autonomy and freedoms.

Other prize-winning submissions more directly grapple with issues of practical and juridical importance to disabled populations. The title of the first honorable mention in the category of Individual Narrative from 2008, 'La protección de las personas con discapacidad' [The Protection of People with Disability], by María Fernanda Zahinos López, strongly underscores the goal of self-advocacy. Divided into 15 parts spanning eight pages (Rosetta 1: 31–38), each section of the submission features a brief (auto)biography describing a different person with disabilities.⁶ Similarly, the fourth honorable mention in the same category, by Frolia Torres Triñanes, is titled 'La biografía de una chica con discapacidad intelectual' [Biography of a Girl with Intellectual Disability] (Rosetta 1: 45–50). The short story 'Dos mundos' [Two Worlds], by Purificación Campa Palacio ('Individual

Poetry,' Rosetta 2: 22–24), foregrounds the issue of autonomy in love, as did the film *Yo, también* (from chapter 1).

Although the topics of these contributions are too varied and their significance too great to be adequately covered in this epilogue, I draw this book to an end through one final reference. In the group poem 'Yo quiero,' submitted by the Centro Ocupacional Las Victorias-Afanias [Occupational Center of Las Victorias-Afanias] in Madrid, the verses speak to the basic desires of people with disabilities—one verse reads: 'Yo quiero disfrutar / reir llorar... / por el parque pasear / y con mi novio ligar' [I want to enjoy (life) / to laugh to cry... / to stroll through the park / and get it on with my boyfriend] (Rosetta 3: 22; compare the desires voiced by characters with Down syndrome in the classroom scene of *León y Olvido*, chapter 1).

As I have tried to show throughout this volume, these fundamental desires are often and perhaps even routinely frustrated by a Spanish society in which people with intellectual disabilities face difficult paths to social integration and enjoy relatively little autonomy. It is my hope that these brief vignettes—together with the four previous chapters—may lead to further publications in the Disability Studies subfield of Hispanic Studies.

Notes

- I I maintain that this sort of comment speaks to the paucity of readers capable of addressing cultural studies of disability within Hispanic Studies: there is no indication that the anonymous reader cited had any knowledge whatsoever of studies of disability, let alone the field of Disability Studies as such. The other anonymous reader did indeed seem to be familiar with the field and produced immensely helpful editorial comments, although the editor did not see it as appropriate to discount the first review.
- 2 See the volume written by Williams and Shoultz (We Can Speak For Ourselves) as well as the Self-Advocacy section of Down Syndrome: Visions for the 21st Century edited by Cohen, Nadel, and Madnick featuring essays by Burke, and Illarramendi et al. Note that these sources are integrated into chapter 1's discussion of the filmic representation of people with Down syndrome in Spain. See also Carlson, Faces 7.
- 3 In fact, the self-governors of Grupo AMÁS list six reasons for undertaking to create their comics: 1) 'Para que se nos vea' [So that we may be seen], 2) 'Para que se conozca nuestra realidad' [So that others may come to know our reality], 3) 'Para que se eschuchen nuestras demandas, nuestros sueños y nuestros anhelos' [So that our demands, our dreams, and our desires may be heard], 4) 'Para que se conozcan nuestros derechos y nuestros deberes' [So that others may come to know our rights and responsibilities], 5) 'Para que se conozcan qué son los grupos de autogestores y lo que pueden llegar a hacer'

- [So that others may know what self-advocacy groups are and what they are able to do], and 6) 'Para demonstrar que podemos hacer todo aquello que nos propongamos si creen en nosotros y con los apoyos suficientes' [In order to demonstrate that we can accomplish whatever we put our mind to if we are believed in and receive sufficient support] (2).
- 4 The text balloons read (from top to bottom): 'Nos reunimos cada semana para hablar de nuestras cosas' [We meet every week to talk about what we are doing], 'Queremos que la gente nos conozca' [We want people to get to know us], 'Somos iguales a todo el mundo' [We are just like everyone else], 'Queremos reivindicar nuestros derechos' [We want to defend our own interests], 'Dibujamos' [We draw], 'Hacemos visitas' [We go places], 'También hemos grabado un corto que se llama "Calcetines" [We've also created a short film titled 'Socks'] (9).
- 5 The character of Supergestor is first introduced in the second comic (p. 11), where he appears just in time to allow the group members to attend the concert smiling, his arms folded and taking up half of the frame.
- 6 Perhaps unexpectedly, each mini-narration begins with a name accompanied by a percentage of disability, such numbers being frequent in the clinical categorization and diagnosis of disabilities. For example, Lucía (1st part) has a 70% disability, Alba (2nd part) has a 67% disability, Jesús (3rd part) is blind and has an 80% cerebral paralysis, Ana María (4th part) is 33 years old and has a 66% disability, and so on.

- 1% esquizofrenia. Dir. Ione Hernández and Julio Medem. Alicia Produce, 2007. DVD.
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