Disability Studies and Spanish Culture

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Published by Liverpool University Press

Fraser, Benjamin. Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition. Liverpool University Press, 2013. Project MUSE. muse.jhu.edu/book/72699.

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CHAPTER 3

Narrating Childhood Disability


During recent years, the movement that seeks to obtain political rights for disabled people has echoed the advances of other civil and legal battles.1 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. 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. In other areas pertinent to the topic of disability, however, there remains much work to be done. As Madeline Conway explains in her essay
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).

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)
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[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, 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).6 Published in 1981, the novel Angeliacomio 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 Myrtía, with other ‘novelas de colectivos marginales’ [novels treating marginalized groups] (Cano Conesa 52, 62–63). 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 bequeriana,’ 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 Jiménez 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.

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 rudimen-
tary, 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 adminis-
trator in a similar institution, and Cano Conesa suggests, based on
interviews with the author himself, that Aledra is in fact Cañada de
da 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). 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). 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’
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[(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) 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 sordida 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)
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[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 butterfly-shaped 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 resonance—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’ [demoni
cally 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 habita
taba como le enseñaron las monjas, porque por la comisura de los labios no asomaban sangre ni otros líquidos escandalosos, ni la había volcado vahido 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 enordecería 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-
Encephalitic 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, Angelicomio 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 popu-
lation, 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 disa-
bility ‘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].

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. ([Escríitos 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)

With 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 non-verbal. 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.]
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. 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
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plano el rostro desconocido de Lluís deformado por una mueca. Ojos muy abiertos cejas circunplejas manos arriba lengua hinchada boquiabierto. Recuerdo también la mirada preocupada del doctor Casanovas’ [I remember in close-up Luís’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, Luís: ‘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’). The intention is clearly that the specific case of Luís 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 metonymy for such children that he also uses in the plural as ‘llullus’ (38, 43 [twice], 83, 111). 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 Luís’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 Lluis’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 Lluis’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). 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
Narrating Childhood Disability

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 time-consuming: ‘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 Blázquez; 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 prayer-episodes 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 derivative 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 frascritos 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, Sabrillex, 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), 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:

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.

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 Lluís 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 Oe’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 Oe (129). Serra must have been thrilled to have this opportunity—he had already read Oe’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 Oe 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). 

Quieto’s author invokes Oe 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, Oe’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 Oe) 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. 

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 Oe’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 Oe 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. 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) 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).

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 Lluis 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. 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 Lluis 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 Angelicamio 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 Cehegín 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 alucinados, Por las horas oscuras, Odio sobre cenizas, Agobios de un vendedor de biblias, Las insulas 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”’—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, Angelicomico 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 Angelicomico. 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 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
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luliano,’ 95; ‘los gestos lulianos,’ 122) and frequently digresses into linguistic tangents in the novel. The references to llulus 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 llulu/llulus/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 Catalonia, 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 aparados 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.

26 ‘Cada vez me gusta más, esta novela [A Personal Matter], pero eso no me pasa con los otros textos que conozco de Oë 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 ¡Despertad 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.