Disability Studies and Spanish Culture

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Epilogue: Exhibiting Art

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

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

> Al final el problema es el mismo que Spivak trataba en su artículo clásico ‘Can the subaltern speak?’, aunque en este caso sería ¿Puede
hablar el discapacitado?’ En la novela, obviamente, la respuesta es negativa, ya que es el autor el que le da voz; sin embargo, el artículo no toca este espinoso asunto, lo que crea el problema fundamental y básico de su trabajo.

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

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

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

Desafortunadamente, la discapacidad intelectual es la que menos llega a la sociedad, pero por una cuestión muy simple: las personas con discapacidad sensorial o física tiene voz propia y se hacen oír. Las personas con discapacidad intelectual no tiene voz propia para llegar
a la sociedad, y tienen que ser las familias y las asociaciones las que hagan llegar su mensaje. (43).

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

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

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

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

‘Trazos Singulares’ (2011) at the Nuevos Ministerios Metro Station

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

Con este acto de hoy, Metro quiere [inaudible due to sound editing] también a las personas que se ven afectadas por capacidades diferentes, porque Metro tiene vocación de dar cabida a todos. Y el modo que
hemos elegido, creo con acierto, es el arte, porque el arte es uno de esos medios en los que es posible poner de relieve las capacidades de las personas por encima de cualquier otra limitación. El arte no entiende diferencias ni conoce barreras sino que promueve la integración y la autonomía de las personas. A través de la expresión artística, todos podemos conocer mejor las capacidades, el talento y lo mucho que estos madrileños pueden aportar a nuestra sociedad. (‘Inauguración’)

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

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

Over four days in April, 2011, prior to the delivery of the event’s inaugural speech, the 30 artists with developmental disabilities featured in the exhibition ‘Trazos Singulares’ actually painted their works in the Nuevos Ministerios metro station itself (brief clips of this appear in the online video ‘Inauguración’). This simple decision, in my view, has an understated significance. Many times, of course, the public appearance of the artistic work is separated in space and time from the moment of its production such that the product of art takes on an existence separated from the producer. Those who appreciate art have become accustomed to this sort of disembodiment. Nonetheless, if we are to take the somewhat predictable rhetorical spirit of José Ignacio Echeverría’s speech to heart—(‘El arte no entiende diferencias ni conoce barreras sino que promueve la integración y la autonomía de las personas’ [Art recognizes neither differences nor barriers. Instead, it promotes the integration and autonomy of people], my emphasis)—the
artistic producers of the ‘Trazos Singulares’ exhibition are not merely being integrated symbolically through the inclusion and integration of their artwork into the daily fabric of Madrid’s transportation system, they are also being integrated physically.

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

‘Supergestor’ (2011) and Other Comics by the Grupo AMÁS

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

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

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

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

The third comic—titled ‘Y recuerde, el futuro está en sus manos’ [And Remember, the Future Is In Your Hands] and produced in collaboration with Adrián Navas—employs a dramatic science-fiction narrative to tell the story of Mario and Nuria who dream of having their own house and living together. The couple use a time machine to travel to a distant future ‘donde nadie tenía miedo de ellos y donde, después de la confusión inicial, les ayudaron a integrarse’ [where
nobody was afraid of them and where, after an initial period of confusion, the people helped them to become integrated] (15). Its first page notably appears as an art-deco propaganda poster boasting in large letters at the top border the message ‘Está usted entrando en la ciudad de la autodeterminación’ [You are entering the city of self-determination] (13). Once the couple properly integrate into the world of the future, the background shifts from a cold bluish-gray to warm sepia tones as a way of accompanying the nostalgic drawings of the couple sitting on the couch together and taking a walk by the water with their dog, thus enjoying an autonomy that is presumably not a part of their more contemporary (non-futuristic) experience (15). On one of their anniversaries, however, they are reminded of what they left behind in the past; the background shifts abruptly back to its original cold bluish-gray—conveying the difficulties continually faced by disabled people in a non-integrated life—as the couple use the time machine to travel back in time and share with their friends their knowledge that ‘un mundo mejor era posible’ [a better world was possible] (17).

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

As a whole, the four comics included in the folio—in practice and in content—assert the right of disabled populations to make their own decisions and lead their own lives. And once again, this is accomplished through the discourse and the public exhibition (in this case virtual/web-based) of art.
The Argadini Association has, since 2008, held a series of annual literary contests (certámenes literarios) in which people with disabilities submit their own original work: short stories, poems, and drawings. The full title of the first contest was ‘Primer Certamen Literario Rosetta para personas con discapacidad intelectual’ [First Rosetta Literary Contest for people with intellectual disabilities], while that title was later amended as ‘personas con discapacidad intelectual o trastornos del espectro del autismo’ [people with intellectual disabilities or autism spectrum disorders] for subsequent contests in 2009 and 2010 (see Rosetta 1, Rosetta 2, and Rosetta 3).

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

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

Los habitantes de mi ciudad
dicen que soy una criatura
terrible y despreciable
y en verdad tienen razón.
Terrible y despreciable
ha hecho de mí la poesía.
Pero tranquilos, señores habitantes,
que sólo a mí suelo hacerme daño. (12)
[The people who live in my city
say that I am a thing
terrible and contemptible
and in truth they are right.
Terrible and contemptible
through poetry I have become.
But be still, good people of my city,
for I commonly do harm only to myself.]

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

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

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

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

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

Notes

1 I maintain that this sort of comment speaks to the paucity of readers capable of addressing cultural studies of disability within Hispanic Studies: there is no indication that the anonymous reader cited had any knowledge whatsoever of studies of disability, let alone the field of Disability Studies as such. The other anonymous reader did indeed seem to be familiar with the field and produced immensely helpful editorial comments, although the editor did not see it as appropriate to discount the first review.

2 See the volume written by Williams and Shoultz (We Can Speak For Ourselves) as well as the Self-Advocacy section of Down Syndrome: Visions for the 21st Century edited by Cohen, Nadel, and Madnick featuring essays by Burke, and Illarramendi et al. Note that these sources are integrated into chapter 1’s discussion of the filmic representation of people with Down syndrome in Spain. See also Carlson, Faces 7.

3 In fact, the self-governors of Grupo AMÁS list six reasons for undertaking to create their comics: 1) ‘Para que se nos vea’ [So that we may be seen], 2) ‘Para que se conozca nuestra realidad’ [So that others may come to know our reality], 3) ‘Para que se eschuchen nuestras demandas, nuestros sueños y nuestros anhelos’ [So that our demands, our dreams, and our desires may be heard], 4) ‘Para que se conozcan nuestros derechos y nuestros deberes’ [So that others may come to know our rights and responsibilities], 5) ‘Para que se conozcan qué son los grupos de autogestores y lo que pueden llegar a hacer’
[So that others may know what self-advocacy groups are and what they are able to do], and 6) ‘Para demostrar que podemos hacer todo aquello que nos propongamos si creen en nosotros y con los apoyos suficientes’ [In order to demonstrate that we can accomplish whatever we put our mind to if we are believed in and receive sufficient support] (2).

4 The text balloons read (from top to bottom): ‘Nos reunimos cada semana para hablar de nuestras cosas’ [We meet every week to talk about what we are doing], ‘Queremos que la gente nos conozca’ [We want people to get to know us], ‘Somos iguales a todo el mundo’ [We are just like everyone else], ‘Queremos reivindicar nuestros derechos’ [We want to defend our own interests], ‘Dibujamos’ [We draw], ‘Hacemos visitas’ [We go places], ‘También hemos grabado un corto que se llama “Calcetines”’ [We've also created a short film titled 'Socks'] (9).

5 The character of Supergestor is first introduced in the second comic (p. 11), where he appears just in time to allow the group members to attend the concert smiling, his arms folded and taking up half of the frame.

6 Perhaps unexpectedly, each mini-narration begins with a name accompanied by a percentage of disability, such numbers being frequent in the clinical categorization and diagnosis of disabilities. For example, Lucía (1st part) has a 70% disability, Alba (2nd part) has a 67% disability, Jesús (3rd part) is blind and has an 80% cerebral paralysis, Ana María (4th part) is 33 years old and has a 66% disability, and so on.