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Interview by Pascale Antolin

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## EDITOR'S NOTE

This interview was carried out by email in April 2016.

*Pascale Antolin:* Tammy Berberi, you are an American specialist in "Disability Studies." How is it that you developed such an interest in this particular field?

*Tammy Berberi:* I am a person with a disability (Cerebral Palsy, or IMC in French) who spent two years in an incredible school environment before joining the ranks of kids whose abilities were more conventional than mine. My "special" ed. teacher was a political radical who was determined to equip us for life, and we did that through a lot of creative interdependence and play. Other formative experiences of course included studying French (and other languages) and traveling. The first time I traveled to France in 1983, I was fourteen and I only knew a few hundred words of French. I immediately noticed different attitudes toward me and gorgeously inaccessible architecture. These early instances of awareness and context certainly fed a sense that ideas and identity are contingent and confluent, rather than fixed. That to me seemed interesting from the start!

*PA:* When did disability studies appear in the US, and why?

*TB:* Disability studies emerged in the 1980s on the heels of the American civil rights and women's movements of the 1970s, as we began thinking more about America comprising specific histories, unique to groups of people. But, of course, disability history in the U.S. and France extend back much further than that. The influence of French disability history on U.S. history is quite clear: American Thomas Gallaudet traveled to France where he learned about Deaf and Blind education methods; his youngest son founded one of the only predominantly Deaf universities in the U.S., Gallaudet University. I recommend the work of American historian, Kim Nielsen, who

recently published a terrific intersectional history, *A Disability History of the United States* (2013).

PA: How do you define disability studies today?

TB: Simply put, disability studies seeks to challenge “deficit models” that define a person as “less than” based on some sort of physical or cognitive difference, and to afford full humanity, rights, and participation to people with disabilities. Deficit paradigms locate disability in the body, as a problem that ought to be remedied through medical, pharmaceutical, or other intervention. In contrast, the social model of disability locates the problem in an environment that is ill-suited to some people and calls for removing barriers in the broadest sense: these barriers may be physical (i.e. inaccessible buildings), economic, attitudinal, or other. In fact, these barriers mutually support each other: a lack of physical access is usually a symptom of preconceived notions of who “belongs” in society, who best represents the interests of the state or who is most productive. Likewise, a highly inaccessible environment serves to reinforce these preconceived notions. People simply aren’t called to question their own ideas until they encounter something or someone that challenges them. This has been true for millennia, as has been shown by French scholar Henri-Jacques Stiker, whose first book, *Corps infirmes et sociétés*, was published in 1982, translated as *A History of Disability* (1999), and other scholars working in French disability studies.

I should add that many have critiqued the social model, which does not adequately reckon with the experiences of disabled embodiment. Within disability studies, this does not imply a return to medical discourse. These are two predominant paradigms, but I see them as neither mutually exclusive nor adequate in themselves to the experiences of people with disabilities.

PA: Are there different specific fields in disability studies?

TB: Disability studies is a broad, interdisciplinary field spanning many academic disciplines: history, literature, rhetoric, life writing, film studies, anthropology, sociology, environmental studies. And of course, it intersects with vibrant work in religious studies, women’s studies, critical race studies, Native-American studies, migrant studies, queer studies, and Deaf and Blind studies. These perspectives neither sync nor completely agree with each other: it’s a lively area of the American academy that is growing quickly by every measure: each passing year marks the establishment of new book series and new graduate and undergraduate programs in disability studies in the U.S. Syracuse University keeps an up-to-date list here: <http://disabilitystudies.syr.edu/programs-list/> [archived: <https://web.archive.org/web/20190218212656/http://disabilitystudies.syr.edu/programs-list/>]

PA: How do you account for the recent development of this field of research in your country?

TB: This momentum has been building for some time. Of course, I am delighted with the increased infrastructure around disability studies in the U.S., not only in terms of programs of study, but also in the diversity of events fostering exchange: symposia, conferences, etc. A small group of scholars in the 1990s began building this field with a great sense of purpose and method, urging scholarly organizations such as the Modern Languages Association to revise and expand key research terms in order to

bring disability into being through lenses other than medical. We likewise urged scholarly organizations to improve and diversify access to knowledge and events.

The *Society for Disability Studies* (SDS, founded 1982) has had a transformative impact on the development of disability studies, seeding research and collaborations and setting the standard for access and full participation for attendees. An organization of some four hundred members, when SDS gets together, it's a big deal! We commandeer every single accessible sleeping room. SDS captions all plenaries and concurrent sessions and provides ASL [American Sign Language], revoicing, social facilitators, and print materials in alternative formats upon request. Members local to the annual conference typically prepare a guide to accessible venues around the conference as a way of raising awareness and encouraging local businesses to make improvements.

PA: Do you have any idea why disability studies does not exist in France and other European countries?

TB: I challenge the notion that disability studies does not exist in France or Europe, although it may enjoy less visibility in France than it does in the U.S. and in the UK simply because knowledge is organized differently. A relative lack of visibility is due to epistemological differences as well as the predominance of research—writ large—in English. There is a vibrant interest in disability issues and studies in France: in terms of timeline, its development more or less parallels that of disability studies in the U.S.

While a good many scholars have been working in French disability studies for decades, it has enjoyed renewed interest since Julia Kristeva's landmark appeal to then-President Jacques Chirac, *Lettre au Président de la République sur les citoyens en situation de handicap* (2002) and the 2005 "Loi handicap." It was around this time that American historian Cathy Kudlick published with Zina Weygand a translation of a memoir, *Reflections*, by Thérèse-Adèle Husson, a young blind woman living in post-revolutionary France (2002), a manuscript found serendipitously in the Library of the Association Valentin Haüy. There is also the 2007 special issue of *Scandinavian Journal in Disability Research* dedicated to *French Disability Studies: Differences and Similarities*; ALTER: a European research group in disability studies, and its journal, *European Journal of Disability Research*, have been around for quite some time.

Consider too the spate of recent French-European films thematizing disability that have garnered international acclaim: *The Diving Bell and the Butterfly* (2007), *The Intouchables* (2011), and *Amour* (2012).

On the whole, it seems to me that France's faith in republicanist values has resulted in a rejection of multiculturalism, American-style, that contributes to the invisibility of the field for scholars who are accustomed to navigating knowledge by a logic of affiliation, or so-called "identity politics." For example, although there is a great deal of research on, and by, women in France, one won't find a shelf dedicated to women's studies in France. Moreover, on the whole, one does not imagine that the research is undertaken "for" them. The specificities of disabilities and experiences calls for greater imaginative reach than current paradigms on either side of the Atlantic allow: in the U.S., analogies with the experiences of other minoritized groups consistently fall short, while in France, legislation did not until 2005 allow for the possibility of discrimination on the basis of disability.

PA: The first sentence of Tom Couser's 2004 book *Vulnerable Subjects. Ethics and Life Writing* goes as follows: "This is not a book about bioethics." What is the difference between bioethics and disability studies?

TB: Bioethics is one field within disability studies, and some ethicists take positions that are absolutely antithetical to any stance in disability studies. These fields overlap, they are in dialogue. I offer the captivating encounter of Australian bioethicist, Peter Singer, and author, lawyer, and disability activist Harriet McBryde Johnson (published in the *New York Times*, 2003). As something of a counterpoint, I offer the work of blind bioethicist, Adrienne Asch. French scholar Stiker also takes up disability and bioethics in his terrific book, *Les Métamorphoses du handicap de 1970 à nos jours* (2009).

PA: Trauma studies, by contrast, are popular in France. Do you have any idea why they have developed while disability studies have not?

TB: I'm not sure my answer—as a seasoned outsider—is adequate to the question, but to me, the experiences of Europeans in the First and Second World Wars—and the many authors and artists who were inspired by them—spurred an interest in trauma studies that may not be as salient in the U.S. because most Americans experienced these events quite differently. European scholarly traditions continue to rely upon psychoanalysis as a useful lens for understanding human actions and interactions. Unfortunately, in my view, an American perspective tends to emphasize self-determination at the expense of lenses that may seem outmoded to many in the U.S. I can think of a few exceptions: the influence of psychoanalysis in the work of scholars like Lennard Davis, Tobin Siebers, and Sander Gilman is manifest.

PA: What are the links—and differences—between disability studies and trauma studies

TB: They are two huge and various fields. Trauma studies and disability studies intersect, but they are not the same. Not everyone who experiences disability experiences trauma; not everyone who is traumatized experiences disability. I refer you on this point to a very interesting article by James Berger, "Trauma without Disability, Disability without Trauma, a Disciplinary Divide" (2004). <http://jaconlinejournal.com/archives/vol24.3/berger-trauma.pdf>

PA: From what I know, disability studies focus on life writing. Are there specialists in disability studies focusing on fiction? Or does this field of research belong in another category

TB: Sure, many people focus on disability in representation, including fiction. Consider the work of Hannah Thompson, a scholar of 19<sup>th</sup>-century French literature teaching at Royal Holloway in London. In France, the work of Simone Korff-Strauss has greatly impacted my own thinking about the representation of physical difference in literature. It seems to me that the work of Charles Gardou is also quite germane to literature, though the lens he takes up in formulating a collective cultural imaginary is broader. A forthcoming issue of the bilingual journal, *Esprit Créateur*, guest-edited by Steven Wilson at Queen's University, Belfast, is dedicated to French Autopathography (summer 2016). Many scholars in the U.S. and the UK likewise study disability in British and American fiction.

PA: Fiction is increasingly concerned with illness, be it mental or physical, and not just as a background phenomenon but as a major dramatic element—think of Jonathan Franzen's novel, *The Corrections*, Barry Levinson's movie, *Rain Man*, the TV series *The Good Wife*, Darryl

Cunningham's graphic stories, *Psychiatric Tales*, to name only a few. How do you account for this phenomenon?

**TB:** Twenty years ago, when I approached a graduate professor to let him know that I would be studying disability in one of the novels we had read, he quipped, "I can't think of any examples of disability in French literature." Of course, there are hundreds of examples worthy of analysis. I chose to study Hippolyte and the (failed) corrective surgery of his clubfoot as elements that are central to Flaubert's method and aesthetic in *Madame Bovary*. My professor, a Flaubert expert of considerable renown, had never noted Hippolyte's disability, even though the surgery itself is situated in the literal heart of the novel, midway between Homais' sycophantic triumphalism and Emma's suicide.

This is to say that I don't think this phenomenon is a particularly new aspect of literature and popular culture—we simply may not notice it as an element worthy of analysis. These examples suggest that an increasing number of people are taking note of its presence and impact on stories... but with varying degrees of ethical or political engagement. I'm a huge fan of *The Good Wife* and I am always glad to see Hollywood hire actors with disabilities. On the other hand, Michael J. Fox's character [as formidable lawyer Louis Canning and regular opponent of the leading character] seems to rest on so many clichéd assumptions about people with disabilities. Do viewers understand the self-reflexive irony in his goofy underhanded tactics [to garner the judge and jury's sympathy for his clients]? I'm not sure.

**PA:** What do you make of so-called memoirs like Lauren Slater's *Lying. A Metaphorical Memoir* (2000), in which the author both asserts and questions that she suffers from epilepsy? In Tom Couser's 2009 book, *Signifying Bodies. Disability in Contemporary Life Writing*, he calls Slater's book "a postmodern memoir." Isn't this phrase paradoxical? Does such a narrative belong in the category of disability studies?

**TB:** It seems to me that anyone who holds either authors or bodies to a standard of truth is bound to miss something. Disability studies strives precisely to be non-essentialist in its consideration of embodiment.

**PA:** America even had a disabled president—F. D. Roosevelt—would that be possible in another country? Or does America stand apart?

**TB:** FDR seems to have done what he could to minimize the visibility of his disability, and of course lived in an era predating media saturation, so it was easier for him to pass as conventionally able-bodied. As a *globe-trotteuse*, I question narratives of American exceptionalism... yet, as a nation, we may be exceptional because we haven't elected more of them! Leaders around the world cope with chronic health issues and disabilities, the symptoms of which may or not be as manifest as those of FDR's polio. His legacy around disability may be amplified by the paradox of his choosing to minimize his own impairment while engaging in highly visible advocacy for others with polio.

Your point about underrepresentation is well taken: it's not the same as garnering broad support among voters, but the Obama Administration has intentionally appointed many people with disabilities to various posts in the federal government and has improved access standards in federal programs in an effort to cultivate leaders with disabilities.

PA: How do you see the future of disability studies in the US? Is it likely to continue developing?

TB: Sure. What's interesting is how many job sectors are enriched by disability studies perspectives: education, health professions, social work, community outreach and organizing, etc. I think it's here to stay. On the other hand, given the political climate today in the U.S.—rhetoric is at the moment quite set against any notion of the “common good” or shared, public resources—any interdisciplinary field struggles to maintain recognition and funding, especially in the public university system.

PA: What about disability studies in Europe and other English-speaking countries—do you think disability studies has a future there?

TB: In my view, Europe is doing quite well! I have been absolutely bedazzled by the emergence over the past few years of collaborative efforts to make meaning through language difference. In 2012, CIEE organized a 10-day faculty seminar on disability in Paris. There I met many prolific scholars and activists and engaged in dialogue and exchange in four languages: French, English, *Langue des Signes française*, and British or American Sign language (BSL/ASL). I had a similar experience last November at a conference in Paris: we were active polyglots in our efforts to learn from each other and make meaning. As Quebecois scholar, Alexandre Baril, notes in his forthcoming essay, “Doctor, Am I an Anglophone Trapped in a Francophone Body?” (*JLCDS* summer 2016), language pluralities add a new dimension to “crip time.” As a language teacher, I feel quite “at home” in the ambiguity and effort of those exchanges.

Another example of these kinds of collaborations is the conference spearheaded by a group of scholars working in Blind Studies in France, the U.S. and the UK. Zina Weygand organized its first iteration, *Colloque Histoire de la cécité et des aveugles in Paris* (2013), and Hannah Thompson, its second, *Blind Creations*, in London (2015). Cathy Kudlick is slated to organize the third in San Francisco in 2018. It is this kind of collaboration and exchange that will spur new perspectives and greater equity in their representation within transnational, multilingual disability studies.

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## ABSTRACTS

This interview of Tammy Berberi, Associate Professor at the University of Minnesota, discusses the advent and challenges of disability studies in the United States and in Europe.

Cet entretien avec Tammy Berberi, *Associate Professor* à l'Université du Minnesota, aborde l'apparition et les défis posés par les études sur le handicap aux États-Unis et en Europe.

## INDEX

**Keywords:** disability studies, trauma studies, fiction, France, history, academia, research

**Mots-clés:** recherche sur le handicap, trauma, fiction, France, histoire, université

## AUTHORS

### TAMMY BERBERI

Dr. Tammy Berberi is an Associate Professor of French at the University of Minnesota, Morris, a liberal arts college in rural, western Minnesota, United States. She has engaged in disability advocacy in higher education since she served as the first graduate-student member on the MLA Committee on Disability Issues (1997-2000), and recently served a two-year term as president of the Society for Disability Studies (2012-2014). Along with Elizabeth Hamilton and Ian Sutherland, Berberi co-edited *Worlds Apart? Disability and Foreign Language Learning* (Yale UP, 2008) and has published a number of articles related to the representation of disability in the poetry of Tristan Corbière. With Christian Flaugh, Berberi also co-edited a forthcoming special issue of the *Journal of Literary and Cultural Disability Studies* on Disability in French and Francophone Worlds (summer 2016).

### PASCALE ANTOLIN

Pascale Antolin is Professor at the University of Bordeaux III.