*ÉTAT PRÉSENT*

FRENCH AND FRANCOPHONE DISABILITY STUDIES

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Disability studies is now recognized as a vibrant, interdisciplinary, and intersectional field of study that encompasses work from disciplines including history, sociology, anthropology, law, education, and medicine.[[1]](#footnote-1) But commentators agree that disabilitystudiesdoes not have an easy French equivalent.[[2]](#footnote-2) Indeed, as eminent French disability historian Henri-Jacques Stiker points out, disability studies — which is sometimes (unsatisfactorily) referred to as ‘les études sur le handicap’ — does not exist on an institutional level in France.[[3]](#footnote-3) Alexandre Baril agrees, explaining that ‘there are no […] disability studies departments or programs in French-speaking universities’, although, as Zina Weygand points out, French social scientists are beginning to include disability on their research agendas.[[4]](#footnote-4) It is precisely what Anglo-American academia values about disability studies, that is its inherent interdisciplinarity, which at least in part explains its apparent absence from French academia. Again according to Stiker, French academia’s heavy reliance on traditional disciplines means that when disability-centred work is produced, it is not valued and thus not well represented.[[5]](#footnote-5) In addition, unlike the ‘nothing about us without us’ adage embraced by Anglo-American disability scholars, many of whom also identify as disability activists, advocates, or allies, the relative paucity of user-led disability activism in France means that disabled people are not necessarily at the centre of research conducted about them.[[6]](#footnote-6) But despite these limitations, some works have been instrumental in the development of disability studies in France: as well as Stiker’s own seminal *Corps infirmes et sociétés*, we might cite Jean-Christophe Coffin’s *La Transmission de la folie* and Zina Weygand’s *Vivre sans voir* as particularly interesting examples of historical enquiry that put disability at their heart.[[7]](#footnote-7) The title of the special issue of *Corpus* edited by Marion Chottin, *Éléments pour une contre-histoire de la cécité et des aveugles*, is indicative of French disability history’s attempts to challenge established narratives of disability, whilst the Paris-based, peer-reviewed journal *ALTER: European Journal of Disability Research / Revue européenne de recherche sur le handicap* publishes cutting-edge disability research from the social sciences in both French and English, as does the *Canadian Journal of Disability Studies / Revue canadienne des études sur l’incapacité*. In their insightful Introduction to the 2007 special issue of the *Scandinavian Journal of Disability Research* devoted to French disability studies, Isabelle Ville and Jean-François Ravaud explain how the specificity of France’s Republican universalism has influenced its distinctive approach to disability. Like the vast majority of French-language articles published in *ALTER*, the research showcased in the *états présents* by Ville and Ravaud, and Albrecht, Ravaud, and Stiker comes from the social sciences.[[8]](#footnote-8) In a move that heralds a new direction in French disability studies, two graduate researchers, Céline Roussel and Soline Vennetier, organized in November 2015 the first major international colloquium in France to overtly encourage disability-studies-inflected readings of literature and art. This event showcased work that critiques, challenges, or foregrounds the representation of disability in culture.[[9]](#footnote-9) The forthcoming proceedings — in which work on the relationship between disability, culture, and representation by established disability studies scholars including Stiker, Tammy Berberi, and Pierre Ancet is presented alongside research by emerging scholars such as Anne-Lyse Chabert, Barbara Fougère, Marie Astier, and Olivier Schetrit — will demonstrate how French researchers are now engaging with disability studies in varied and important ways.[[10]](#footnote-10) It is to this specific sub-category of literary and cultural analysis which I now turn in the remainder of this *état présent*.

Critical disability studies, or the examination, analysis, and critique of literary and cultural representations of disability, is not always easily separated from the broader concerns of disability studies activism, especially in Anglo-American contexts, and has consequently remained relatively neglected or subsumed into broader discussions. But this disability-activism-informed concern with the critical analysis of texts (meant in its broadest sense) by and about disabled people is becoming an increasingly significant strand of disability studies, as demonstrated by the inauguration, in 2007, of the *Journal of Literary and Cultural Disability Studies* publishedby Liverpool University Press and edited by David Bolt, as well as the continued success of the University of Michigan Press’s long-running ‘Corporealities: Discourses of Disability’ monograph series, edited by David Mitchell and Sharon Snyder, and the recent inauguration of Palgrave Macmillan’s ‘Literary Disability Studies’ monograph series.

 Even with the increased visibility enabled by the above publishing ventures, readings of French texts that make overt reference to the growing body of (largely anglophone) critical disability studies scholarship remain rare. The most significant example of critical engagement with French literature through a disability perspective is Cathy Kudlick’s interpretation of Guy de Maupassant’s short story ‘L’Aveugle’ (1882) in which she provides a helpful illustration of how critical disability studies can inform literary analysis.[[11]](#footnote-11) By elucidating the ways in which Maupassant’s story reveals that the blind man ‘suffered more because of how he was treated by others than by what he failed to see’, Kudlick argues that despite operating almost exclusively from within a ‘pathology’ or ‘deficit’ model of disability, Maupassant’s text nonetheless reveals how disability can be understood as a socially constructed phenomenon.[[12]](#footnote-12) In a similar vein, Berberi provides a critical-disability-studies-informed reading of Tristan Corbière’s poetry where she argues that rather than being a marker of lack or incapacity, disability becomes a means of exploring subject-object relations whilst questioning the meaning of representation in the nineteenth century.[[13]](#footnote-13) Informed by Berberi’s and Kudlick’s attempts to deconstruct stereotypes of disability, my analysis of depictions of blindness in popular French literature shows how literary representation can both perpetuate and undermine certain myths of blindness.[[14]](#footnote-14) In the engaging and erudite Introduction to her new translation of Diderot’s *Lettre sur les aveugles à l’usage de ceux qui voient*, Kate Tunstall uses a playfully deconstructive approach reminiscent of aspects of critical disability studies to show how notions of ‘blindness’ and ‘enlightenment’ have been constructed by philosophers without necessarily referring to the lived experience of the blind people they encounter.[[15]](#footnote-15) Like Tunstall’s work, Chottin’s edited volume on blindness in French philosophical writing reminds us that from Diderot to Derrida, blindness has always had particular resonance in French thought.[[16]](#footnote-16) But works by Willian Paulson and Martin Jay demonstrate that not all scholars who engage with the enduring French philosophical fascination with blindness do so from a critical disability studies perspective.[[17]](#footnote-17)

 In France, a small number of scholars have recently begun to consider how literature, art, and philosophy engage with the representation of disability. While not always as overtly political as the critical disability studies model put forward by Berberi and Kudlick, the work of Simone Korff-Sausse, Pierre Ancet, Marcel Nuss, and Charles Gardou nonetheless goes some way towards calling into question the traditional ‘deficit’, ‘pathological’, and ‘medical’ models of disability that have tended to prevail in French thinking about disability.[[18]](#footnote-18)

As is also the case in Anglo-American disability studies, critical interest in disability in France has been triggered by social and political reform. It is no coincidence that the majority of works referred to thus far were produced after France’s 2005 *loi handicap*.[[19]](#footnote-19)This wide-ranging set of reformsheralded a shift in social attitudes to disability, reflected not only in increased critical interest in the representation of disability, but also in literary and cultural production by and about disabled people. Sam Haigh’s important article, ‘Personal or Political: Representations of Disability in Contemporary French Fiction’, exemplifies a critical disability studies approach that also takes account of the current political and social situation of disabled people.[[20]](#footnote-20) As well as providing a helpful explanation of the 2005 legislation and its impact on French society, Haigh’s article is particularly noteworthy in that it brings fictional representations of disability, notably Luc Leprêtre’s *Club VIP* and Arnauld Pontier’s *Équinoxe*, to the attention of critical disability studies scholars.[[21]](#footnote-21) By including work by disabled writers in its discussion, Haigh’s article is also an example of the branch of disability studies concerned with the exploration and analysis of disability culture. This belief that disability generates its own specific modes of cultural production, an idea which, as Stiker points out, originated in the field of Deafstudies,[[22]](#footnote-22) is explored in recent literary analysis of works by disabled writers and filmmakers.[[23]](#footnote-23)

Opinion remains divided as to whether Deaf studies, referred to in French as ‘les études sur la surdité’, is a branch of disability studies, or a discipline in its own right. Unlike disability studies more broadly, Deaf studies does have some institutional backing in France and in particular the École des hautes études en sciences sociales (EHESS) has a long history of engagement in this area. In the 1970s and 1980s, it was home to a series of groundbreaking seminars on the Deaf community and sign language by Bernard Mottez.[[24]](#footnote-24) In 2006 this seminar series was relaunched as a collective venture and in 2014 Deaf studies specialist Andrea Benvenuto was awarded a lectureship, thus placing Deaf studies firmly at the centre of the EHESS’s research agenda. Subsequent seminars on ‘Surdité et cinéma’ and ‘Langue des signes et pratiques artistiques’ demonstrate the importance accorded to Deaf studies by the institution, and several doctoral and post-doctoral researchers including Barbara Fougère, Olivier Schetrit, and Ruth Kitchen are currently engaged in research around Deaf culture, sign language, and cultural production. The EHESS’s ‘Programme handicaps et sociétés’, directed by Isabelle Ville, further supports research on disability across the institution’s disciplines. Like Haigh’s dual concern with disability politics and cultural representation, recent work in French Deaf studies engages with the politics of Deafness through discussion of cultural and artistic practices. Benvenuto’s unpublished thesis, ‘Qu’est-ce qu’un sourd? De la figure au sujet philosophique’, exemplifies French Deaf studies’ interest in the philosophical questions surrounding Deafness, whilst work on the history and politics of the cochlear implant anchors theoretical debates in the lived experience of Deaf people.[[25]](#footnote-25)

This politically engaged approach to cultural representations of disability found in work coming out of the EHESS, is also manifested in Haigh’s other works. In the largely historico-political ‘Mad Pride France’ she examines the shifting approach to issues around mental health in France — from illness via disability to distress.[[26]](#footnote-26) Vivienne Orchard’s work complements Haigh’s by providing a detailed discussion of the differences between Anglo-American and French approaches to mental health in society and culture. Orchard shows that the French psychiatric establishment’s heavy reliance on psychoanalysis has led to widespread resistance to an American model that would see autistic people as people with disabilities whose needs should be accommodated in mainstream educational and social settings. Instead, in France, autism is treated as an illness and autistic children and adults are routinely confined to psychiatric institutions.[[27]](#footnote-27) As well as highlighting culturally and historically specific differences between Anglo-American and French contexts, the works by Haigh and Orchard are important because they include detailed explanations of the main issues in disability studies, which provide readers new to this area with essential background information. In ‘Writing Disability’ for example, Haigh provides a useful overview of the rise of the social model and the rejection of the traditional ‘triumph over tragedy’ autobiographical narrative before analysing in detail how an example of disability life-writing by Swiss philosopher Alexandre Jollien resonates with the changing status of disability in France, particularly in its foreshadowing of several of the concerns raised by Julia Kristeva in her work on disability.[[28]](#footnote-28)

As Haigh’s interest in Jollien suggests, life-writing is a significant strand of disability studies.[[29]](#footnote-29) The discovery, and subsequent publication, by Kudlick and Weygand, of the memoirs of the nineteenth-century blind French novelist and early disability advocate, Thérèse-Adèle Husson, demonstrates that one of the functions of disability studies is to give voice to the hitherto-unheard words of under-represented minorities.[[30]](#footnote-30) Husson’s work, which critiques the ableist assumptions made by her sighted acquaintances, is an early example of a first-person text that subscribes to the ‘social model’ of disability, that is the belief that disability is a socially constructed entity rather than a medicalized pathology.[[31]](#footnote-31) More recently, a number of male-authored first-person disability narratives by Jean-Dominique Bauby, Philippe Vigand, and Philippe Pozzo di Borgo have been published, which form, according to Áine Larkin, ‘a relatively new tradition of male autopathography’.[[32]](#footnote-32) Like Kudlick’s work on Maupassant, my own reading of Bauby’s *Le Scaphandre et le papillon* uses insights from critical disability studies to argue that Bauby’s text seeks, through its inventive and playful use of language, to challenge readers’ largely negative assumptions about disability.[[33]](#footnote-33) Indeed, the critical interest generated by Bauby’s acerbic yet poetic memoir and Julian Schnabel’s 2007 film adaptation of the same name suggests that Bauby’s memoir can now be considered part of a French studies ‘canon’, which means that it has begun receiving critical attention from scholars who do not necessarily work in the field of disability studies.[[34]](#footnote-34) As well as celebrating an author’s hitherto-neglected disability pride, critical disability studies can also highlight a writer’s ableism. Larkin’s analysis of the first-person narratives by Vigand and Pozzo di Borgo suggests that, in both cases, the disabled narrator has not fully abandoned the ableist world view of their pre-accident personas. Whilst, according to Larkin, Pozzo di Borgo and Vigand are both right to highlight areas in which France still fails adequately to cater for disabled people, and to speak candidly about the lived realities of their conditions, both men nonetheless continue to subscribe to a troublingly ableist ideology. Larkin’s suggestion that this ‘adherence to and acceptance of ableist norms of masculinity’ might be interpreted as either a ‘positive willed resistance to the disabling effects of […] impairments’ or ‘a powerful state of denial’ demonstrates the ambiguous nature of much French disability-centred life-writing.[[35]](#footnote-35) Larkin’s combination of insights drawn from both gender studies and disability studies exemplifies the intersectionality of much disability studies research that knowingly considers disability as a culturally constructed identity akin to gender, race, and sexuality. Korff-Sausse’s article ‘Des “gender studies” aux “disability studies”’ provides a helpful French take on identity politics that also offers another reminder of the persistent presence of psychoanalysis in French thought.[[36]](#footnote-36)

Like Husson’s autobiography, critical disability studies seeks to resist the medical model that views disability as an affliction to be cured, a problem to be overcome, or a disease to be eliminated. Paradoxically perhaps, the recent emergence of the so-called ‘medical humanities’ has helped to intensify critical disability studies’ challenge to the medicalization of disability. Larry Duffy’s 2015 work on the intersections of medical and literary discourses in Flaubert and Zola is the best recent example of how medical humanities scholarship can occasion insightful rereadings of French texts.[[37]](#footnote-37) Through their interrogation of themes often expressed in disability life-writing, such as the hierarchical relationship between patient and doctor, and how patient-centred means of expression might improve this encounter, the medical humanities also have the potential to highlight the shortcomings of ableist medical discourse. As Steven Wilson puts it in the Introduction to his 2016 special issue of *L’Esprit Créateur* on French autopathography, ‘the humanities in general, and narrative in particular, have a valuable contribution to make to attempts to understand what it is *like* to be ill, to suffer, to experience a life-changing condition, and/or to be facing death’.[[38]](#footnote-38) By putting the patient’s narrative at the centre of the encounter, critical disability studies, like some medical humanities scholarship, reconfigures the often-vexed relationship that exists between the medical establishment and socially constructed notions of disability. Researchers in France are beginning to engage with disability studies in their own investigations of *l’écriture de soi*. Céline Roussel’s work on anglophone autobiographies of blindness reads works by John Hull and Helen Keller through Derrida to ask how the materiality of writing and reading in Braille might alter the blind writer’s relationship with language.[[39]](#footnote-39) It is often the case in Anglo-American disability studies that researchers openly self-identify as disabled, and interweave their scholarly work with more personal reflections on how their experiences of disability influence their academic practices. This kind of ‘confessional’ or ‘embodied’ academic life-writing might be said to run counter to the intellectual rigour and objectivity prized by French academia. But young researchers are increasingly using such experiential insights in their work. Anne-Lyse Chabert convincingly uses her experiences as a person with a physical disability to argue that physical disability can be used as an informative ‘grille de lecture’ that provides creative ways of understanding and engaging with our surroundings.[[40]](#footnote-40)

In a powerful call for a move away from France-focused narratives of disability, Berberi and Christian Flaugh assert that ‘sustaining world languages and cultures has everything to do with the future of disability and its study’, but according to Julie C. Van Dam, writing in the same special issue, francophone postcolonial studies has been slow to respond critically to images of disability in francophone African texts.[[41]](#footnote-41) Van Dam suggests that Flaugh is the only postcolonial researcher besides herself to consider disability as culturally, politically, or socially constructed.[[42]](#footnote-42) In her work on Senegalese filmmaker Ousmane Sembène, ‘Re-viewing Disability in Postcolonial West Africa’, Van Dam uses a close analysis of the 1975 film *Xala* to explore how disabled bodies might disrupt the dominant discourses of postcolonial studies.

This overview of current work at the intersection of disability studies and French studies reveals that disability is now being taken seriously as a valid trope through which to shed new light on French texts. Indeed, several recent works on the body more generally include disability in their remit. In their 2000 edited volume on English and French eighteenth-century literature, Helen Deutsch and Felicity Nussbaum engage with the then-emerging discipline of disability studies to consider a selection of non-normative bodies.[[43]](#footnote-43) Although less influenced by disability studies, Wes Williams also considers non-normative bodies in his work, and a chapter of my *Taboo: Corporeal Secrets in Nineteenth-Century France* is devoted to Victor Hugo’s disabled characters.[[44]](#footnote-44) In French medieval studies, Edward Wheatley’s 2007 reading of *Bérinus* mobilizes Robert McRuer’s notion of ‘crip theory’ to show how the author’s depictions of the queer and disabled nations on the island of Blandie creates ‘a crisis for able-bodied heterosexuality’.[[45]](#footnote-45) As this kind of scholarly interest in disability studies grows, it is hoped that disability-themed texts — and disability-studies-inflected readings of them — will find their way into undergraduate courses and graduate research projects. Much scholarly work remains to be done in this area and it is only by according French and francophone disability studies the space it needs that funding bodies, conference organizers, and publishers will encourage and enable this cutting-edge, interdisciplinary, and socially, culturally, and politically crucial research to flourish.

1. See Lennard J. Davis’s Introduction to the fourth edition of his *Disability Studies Reader* (New York: Routledge, 2010), pp. 1–15, for a comprehensive definition of disability studies; for a helpful explanation of disability studies in both its US and French contexts see also Pascale Antolin and Tammy Berberi, ‘Tammy Berberi on Disability Studies’, *Angles – The Journal* (20 July 2016) <http://angles.edel.univ-poitiers.fr/index.php?id=558> [accessed 27 December 2016]. [↑](#footnote-ref-1)
2. See Gary L. Albrecht, Jean-François Ravaud, and Henri-Jacques Stiker, ‘L’Émergence des disability studies: état des lieux et perspectives’, *Sciences sociales et santé*, 19 (2001), 43–73 (p. 45). [↑](#footnote-ref-2)
3. Catherine Kudlick, ‘An Interview with Henri-Jacques Stiker, Doyen of French Disability Studies’, in *Disability in French and Francophone Worlds*, ed. by Tammy Berberi and Christian Flaugh (= special issue of *Journal of Literary and Cultural Disability Studies*, 10 (2016)), 139–54 (pp. 146–47); see also Isabelle Ville and Jean-François Ravaud, ‘French Disability Studies: Differences and Similarities’, in *French Disability Studies*,ed. by Anders Gustavsson and Karin Barron (= special issue of *Scandinavian Journal of Disability Research*, 9 (2007)), 138–45 (p. 141), and Albrecht, Ravaud, and Stiker, ‘L’Émergence des disability studies’, p. 62. For a detailed, qualitative study of what and how the word ‘handicap’ signifies in French, see Alain Giami, Jean-Louis Korpes, and Chantal Lavigne, ‘Representations, Metaphors and Meanings of the Term “Handicap” in France’, in *French Disability Studies*,ed. by Gustavsson and Barron, 199–213. [↑](#footnote-ref-3)
4. Alexandre Baril, ‘Doctor, Am I an Anglophone Trapped in a Francophone Body?’, in *Disability in French and Francophone Worlds*, ed. by Berberi and Flaugh (= special issue of *Journal of Literary and Cultural Disability Studies*, 10 (2016)), 155–72 (p. 166); Zina Weygand, ‘Préface’, in *Éléments pour une contre-histoire de la cécité et des aveugles*, ed. by Marion Chottin (= special issue of *Corpus: revue de philosophie*, 67 (2014)), 5–9 (p. 7). [↑](#footnote-ref-4)
5. See Kudlick, ‘An Interview with Henri-Jacques Stiker’, p. 146. [↑](#footnote-ref-5)
6. Albrecht, Ravaud, and Stiker, ‘L’Émergence des disability studies’, pp. 50 and 62. [↑](#footnote-ref-6)
7. Henri-Jacques Stiker, *Corps infirmes et sociétés: essais d’anthropologie historique*, 3rd edn (Paris: Dunod, 2013); Jean-Christophe Coffin, *La Transmission de la folie: 1850–1914* (Paris: L’Harmattan, 2003); Zina Weygand, *Vivre sans voir: les aveugles dans la société française du moyen âge au siècle de Louis Braille*,2nd edn (Paris: Créaphis, 2013). [↑](#footnote-ref-7)
8. See Ville and Ravaud, ‘French Disability Studies: Differences and Similarities’, pp. 140–41. [↑](#footnote-ref-8)
9. See Université Paris-Sorbonne, ‘Représentations et discours du handicap’, <http://www.paris-sorbonne.fr/representations-et-handicap> [accessed 27 December 2016]. In June 2015 the ‘Blind Creations’ conference hosted a panel on representations of blindness in French fiction which also exhibited a critical disability studies approach. Podcasts of the talks by Pieter Verstraete (‘The Representation of Blindness in Maeterlinck’s Theatre Play *De blinden* and Johan van der Keuken’s Documentary *Herman Slobbe: Blind kind II*’), Sabine Gadrat-Cellou (‘L’Émergence d’un nouveau type de personnage(s) aveugle(s) dans la fiction’), and Bérengère Levet (‘Blindness or Femininity, That Is the Question: The Young Blind Girl in *The Two Orphans*, a Popular Novel by Adolphe d’Ennery (1887–1889)’) can be found at <http://backdoorbroadcasting.net/2015/07/blind-creations-conference> [accessed 27 December 2016]. [↑](#footnote-ref-9)
10. *Représentations et discours du handicap*, ed. by Céline Roussel and Soline Vennetier (Paris: Garnier, forthcoming 2017). [↑](#footnote-ref-10)
11. Catherine J. Kudlick, ‘Guy de Maupassant, Louisa May Alcott and Youth at Risk: Lessons from the New Paradigm of Disability’, *Paedagogica Historica*, 45 (2009), 37–49. [↑](#footnote-ref-11)
12. Kudlick, ‘Guy de Maupassant’, p. 40. [↑](#footnote-ref-12)
13. Tammy Berberi, ‘A Rhapsodist at Mid-Century: Refiguring Disability in the Poetry of Tristan Corbière’, *Journal of Literary and Cultural Disability Studies*, 3 (2009), 51–66*.* [↑](#footnote-ref-13)
14. Hannah Thompson, ‘Les Aveugles en France au dix-neuvième siècle: un regard littéraire’, in *Éléments pour une contre-histoire de la cécité et des aveugles*, ed. by Chottin (= special issue of *Corpus: revue de philosophie*, 67 (2014)), 69–90. [↑](#footnote-ref-14)
15. Kate Tunstall, *Blindness and Enlightenment: An Essay (with a New Translation of Diderot’s’Letter on the Blind’ (1794) and a Translation of La Mothe Le Vayer’s ‘Of a Man-Born-Blind’ (1633)* (New York: Continuum, 2011). [↑](#footnote-ref-15)
16. *L’Aveugle et le philosophe, ou, Comment la cécité donne à penser*, ed. by Marion Chottin(Paris: Publications de la Sorbonne, 2009). [↑](#footnote-ref-16)
17. Martin Jay, *Downcast Eyes: The Denigration of Vision in Twentieth-Century French Thought* (Berkeley: University of California Press, 1994); William R. Paulson, *Enlightenment, Romanticism and the Blind in France* (Princeton: Princeton University Press, 1987). [↑](#footnote-ref-17)
18. Pierre Ancet and Marcel Nuss, *Dialogues sur le handicap et l’altérité: ressemblances dans la différence* (Paris: Dunod, 2012); *Le Handicap dans notre imaginaire culturel*, ed. by Charles Gardon (Toulouse: Erès, 2015); Simone Korff-Sausse, *Figures du handicap: mythes, art, littérature* (Paris: Payot & Rivages, 2010). [↑](#footnote-ref-18)
19. Officially known as ‘**Loi no 2005–102 du 11 février 2005 pour l’égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées’.** [↑](#footnote-ref-19)
20. Sam Haigh, ‘Personal or Political: Representations of Disability in Contemporary French Fiction’, *Journal of Literary and Cultural Disability Studies*, 6 (2012), 307–25. [↑](#footnote-ref-20)
21. Luc Leprêtre, *Club VIP: Very Invalid Person* (Paris: Éditions Anne Carrière, 2009); Arnauld Pontier, *Équinoxe* (Paris: Actes Sud, 2006). [↑](#footnote-ref-21)
22. Within disability studies, the word ‘Deaf’ is capitalized when it refers to people for whom sign-language is their first language, because this group is considered a political or ethnic collective with a shared history and culture, akin to a nation or race. The word ‘deaf’ is used to refer to people with hearing loss, who have a hearing language such as English or French as their first language. [↑](#footnote-ref-22)
23. Kudlick, ‘An Interview with Henri-Jacques Stiker’, p. 143. [↑](#footnote-ref-23)
24. These lectures were subsequently published in Bernard Mottez, *Les Sourds existent-ils?*,ed. by Andrea Benvenuto (Paris: L’Harmattan, 2009). [↑](#footnote-ref-24)
25. Andrea Benvenuto, ‘Qu’est-ce qu’un sourd? De la figure au sujet philosophique’, unpublished doctoral thesis, Université Paris 8, 2009. See also Soline Vennetier and Andrea Benvenuto, ‘L’Implant cochléaire, entre technique, éthique et politique’, *Grief*, 3 (2016), 36–48; Soline Vennetier, ‘La Controverse autour des implants cochléaires: évaluer les “allures de vie” des personnes sourdes’, *Incidence*, 12 (2016), 187–205. [↑](#footnote-ref-25)
26. Sam Haigh, ‘“Mad Pride France”: Disability, Mental Distress, and Citizenship’, *Disability in French and Francophone Worlds*, ed. by Berberi and Flaugh (= special issue of *Journal of Literary and Cultural Disability Studies*, 10 (2016)), 191–206. [↑](#footnote-ref-26)
27. Vivienne Orchard, ‘The “Rendez-vous manqués” of Francophone and Anglophone Disability Studies: The Case of Autism in Cross-cultural Context’, *Synergies Royaume-Uni et Irlande*, 6 (2013), 53–73. [↑](#footnote-ref-27)
28. Sam Haigh, ‘Writing Disability: Alexandre Jollien’s *Éloge de la faiblesse*’, *Modern Language Review*, 105 (2010), 695–712. For Kristeva’s position, see Julia Kristeva, *Lettre au Président de la République sur les citoyens en situation de handicap, à l’usage de ceux qui le sont et de ceux qui ne le sont pas* (Paris: Fayard, 2003). [↑](#footnote-ref-28)
29. See also G. Thomas Couser, ‘Disability, Life Narrative, and Representation’, in *The* *Disability Studies Reader*, ed. by Davis, pp. 447–51. [↑](#footnote-ref-29)
30. Thérèse-Adèle Husson, *Reflections: The Life and Writings of a Young Blind Girl in Post-Revolutionary France*, ed. and trans. by Cathy Kudlick and Zina Weygand (New York: New York University Press, 2001). [↑](#footnote-ref-30)
31. On the history, definition, merits, and shortcomings of the social model, see Tom Shakespeare, ‘The Social Model of Disability’, in *The Disability Studies Reader*, ed. by Davis, pp. 207–15. [↑](#footnote-ref-31)
32. Áine Larkin, ‘Dependence and Masculinity in Contemporary French Writing about Disability’, in *French Autopathography*, ed. by Steven Wilson (= special issue of *L’Esprit Créateur*, 56 (2016)), 121–34 (p. 121). The texts in question are Jean-Dominique Bauby, *Le Scaphandre et le papillon* (Paris: Robert Laffont, 1997); Philippe Pozzo di Borgo, *Le Second Souffle, suivi du Diable gardien* (Paris: Bayard, 2011) ; and Philippe Vigand, *Légume vert* (Paris: Éditions Anne Carrière, 2011). [↑](#footnote-ref-32)
33. Hannah Thompson, ‘“De simple malade j’étais devenu un handicapé”: Interrogating the Construction of “Disability” in Jean-Dominique Bauby’s *Le Scaphandre et le papillon*’, in *French Autopathography*, ed. by Wilson (= special issue of *L’Esprit Créateur*, 56 (2016)), 79–92. [↑](#footnote-ref-33)
34. See Connie Canam, Gloria Nne Onyeoziri, James Overboe, Carla Paterson, and Valerie Raoul, ,‘Narrating the Unspeakable: Interdisciplinary Readings of Jean-Dominique Bauby’s *The Diving Bell and the Butterfly*’, *Literature and Medicine*,20 (2001), 183–208; Henry C. Stewart, ‘In the Blink of an Eye: Teaching Bauby’s *The Diving Bell and the Butterfly* while Learning from Eye Blinks’, *Journal of Literary and Cultural Disability Studies*, 4 (2010), 89–98; Simon Kemp, ‘Bergson, Bauby and the Neuroscience of Emotion’, *French Studies Bulletin*,31 (2011), 73–76; Tess Jewell, ‘Blinding the Screen: Visualizing Disability in *Le Scaphandre et le papillon*’, *Mosaic: A Journal for the Interdisciplinary Study of Literature*, 46 (2013), 109–24; and Claire Boyle, ‘*Le Scaphandre et le papillon*: Autopathography, the Locked-in Self, and Schnabel’s Cinema of Embodiment’, in *French Autopathography*, ed. by Wilson (= special issue of *L’Esprit Créateur*, 56 (2016)), 93–108, for examples of critical readings of Bauby which — sometimes wittingly, sometimes unwittingly — mobilize elements of disability studies. [↑](#footnote-ref-34)
35. Larkin, ‘Dependence and Masculinity’, pp. 133–34. [↑](#footnote-ref-35)
36. Simone Korff-Sausse, ‘Des “gender studies” aux “disability studies”: repenser les catégories’, in *Ce que le genre fait à la psychanalyse*, ed. by [Laurie Laufer](https://www.google.fr/search?hl=fr&tbo=p&tbm=bks&q=inauthor:%22Laurie+Laufer%22) and [Andréa Linhares](https://www.google.fr/search?hl=fr&tbo=p&tbm=bks&q=inauthor:%22Andr%C3%A9a+Linhares%22) (= special issue of  *Champ psychosomatique*, 58 (2010)), 37–52. [↑](#footnote-ref-36)
37. Larry Duffy, *Flaubert, Zola, and the Incorporation of Disciplinary Knowledge* (London: Palgrave Macmillan, 2015). [↑](#footnote-ref-37)
38. Steven Wilson, ‘Introduction: Embodiment, Identity, and the Patient’s Story’, in *French Autopathography*, ed. by Wilson (= special issue of *L’Esprit Créateur*, 56 (2016)), 1–11 (p. 2); original emphasis. [↑](#footnote-ref-38)
39. Céline Roussel, ‘Quand l’aveugle prend sa plume: dialectiques d’une écriture aveugle de soi’, *Revue de littérature comparée*, 353 (2015), 65–76. Roussel’s doctoral thesis, ‘Cécité, discours et représentations de soi dans les écrits autobiographiques d’aveugles du xixe au xxie siècle’, which she is completing at the Centre de recherche en littérature comparée at the Université Paris-Sorbonne under the supervision of Véronique Gély, also includes French-language autobiographical writings. [↑](#footnote-ref-39)
40. Anne-Lyse Chabert, ‘À chacun son monde, à chacun son chemin’, *Reliance*, 2 (2008), 83–90. [↑](#footnote-ref-40)
41. Tammy Berberi and Christian Flaugh, ‘Introduction: Disability in French and Francophone Worlds’, in *Disability in French and Francophone Worlds*, ed. by Berberi and Flaugh (= special issue of *Journal of Literary and Cultural Disability Studies*, 10 (2016)), 129–37; Julie C. Van Dam, ‘Re-viewing Disability in Postcolonial West Africa: Ousmane Sembène’s Early Resistant Bodies in *Xala*’, in *Disability in French and Francophone Worlds*, ed. by Berberi and Flaugh, 207–21 (p. 211). [↑](#footnote-ref-41)
42. As well as her own *Critical Conditions: Illness and Disability in Francophone African Women’s Writing* (Lanham: Rowman & Littlefield, 2011), Van Dam cites Christian Flaugh’s *Operation Freak: Narrative, Identity, and the Spectrum of Bodily Disability* (Montreal: McGill-Queens University Press, 2012) as an excellent example of French postcolonial work on disability. [↑](#footnote-ref-42)
43. *‘Defects’: Engendering the Modern Body*, ed. by Helen Deutsch and Felicity Nussbaum (Ann Arbor: University of Michigan Press, 2000). [↑](#footnote-ref-43)
44. Wes Williams, *Monsters and their Meanings in Early Modern Culture: Mighty Magic* (Oxford: Oxford University Press, 2011); Hannah Thompson, ‘Metaphors of the Monstrous: The Case of Victor Hugo’, in *Taboo: Corporeal Secrets in Nineteenth-Century France* (Oxford: Legenda, 2013), pp. 105–25. [↑](#footnote-ref-44)
45. Edward Wheatley, ‘A River Runs through It: Disability, Homosexuality, Queered/Disabled Discourse, and the Isle of Blandie in *Bérinus*’, *Exemplaria*, 19 (2007), 386–401 (p. 398). [↑](#footnote-ref-45)