

The Contribution of Disability Studies to the New Humanities

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Abstract

Disability studies is deeply connected with the disability rights movement, and some of the pioneers of the movement were disabled academics. It is an area of study that draws from different disciplines, especially the social sciences and the humanities, while having its own unique character. The insights gained from disability studies are embedded in the direct experiences of disabled people and their family members and are based on an understanding of disability as arising from the interaction between people with impairments and socially created material and cultural barriers. This understanding enables the study of disability through the different disciplines within the humanities, such as philosophy, history and literary studies. Disability studies unveils the complex nature of disability and the multifarious factors that create it and that impinge on the lived experience of disabled people. It also testifies to the many ways in which disabled people negotiate their lives and identities *as* disabled people. For this reason, disability studies has much to reveal about the human condition and can contribute to current and future developments in the humanities.

Keywords: *disabled people's movement, disability studies, interdisciplinarity, models of disability, cultural representations of disability*

The Dual Nature of Disability

Given that disability studies deals with an aspect of being human that most people would rather not experience or even witness, what can it contribute to the humanities?

This article analyses the relationship between disability studies and the humanities, with a focus on what these two areas have in common and how they can, and to some extent already do, inform each other. This relationship is analysed through examples of some of the most important works that straddle the two areas.¹ Analysing this relationship necessitates first an exploration of the roots of disability studies, which are firmly embedded in the disabled people's movement. In fact, disability studies has been primarily developed by academics who have a disability or have disabled family members and, importantly, the discipline remains grounded in the experiences and perspectives of disabled people themselves. The single most important contribution of these perspectives has been the realization that disability is not equivalent to physical or

¹ *Word and Text* explored an aspect of the relationship between disability studies and the humanities in the 2018 special issue on 'Encounters Between Disability Studies and Critical Trauma Studies'; available at http://jls1.upg-ploiesti.ro/No_1_2018.html [accessed 20 September 2020]. This special issue was followed by a presentation at the 8th Annual International Disability Rights Affirmation Conference organised by Virtual Ability, Inc.; available at <https://virtualability.org/idrac-2019/> [accessed 20 September 2020]. To some extent, this article builds on that work.

mental impairment but arises from the difficulties faced by people with impairments in societies that have traditionally given little account to catering for impairment-related needs.

This decoupling of impairment and socially-created disability has enabled socio-cultural analyses of disability, thus facilitating the emergence of disability studies. The article surveys how, from its inception in the early 1990s, disability studies has drawn from different disciplines, especially within the social sciences and the humanities. The focus is then placed on the role of humanities scholars in the development of disability studies. It discusses how insights from the work of these scholars have deepened and enriched understanding of the extent to which disability is socio-culturally created. The humanities have also enabled a more thorough appreciation of the shifting, and sometimes amorphous, nature of disability, and have increased awareness of myths and misconceptions about disability. Examples are given to illustrate how the humanities have enabled an appreciation of the ubiquity of disability in literature, the arts and in the human imagination more generally – simply because impairment is part of the human condition.

This discussion shows clearly the contribution of the humanities to the study of disability. However, while work within the humanities that takes a disability studies perspective is flourishing, it mostly remains a niche (even if growing) area. The insights and contributions to knowledge that have emerged from this area of studies do not seem to have penetrated extensively into mainstream debates within the humanities. Given current debates about the new humanities, to which this special issue of *Word and Text* is dedicated, a discussion of what disability studies can contribute to this debate and to the development of the humanities more widely is timely. The article argues that disability studies has much to contribute to the continued evolution and adaptation of the humanities.

The Roots of Disability Studies

Any consideration of the origins of disability studies is intricately linked to an exploration of what is meant by ‘disability’. The reason why this exploration is necessary is provided in the very description of disability that is found in the United Nations Convention on the Rights of Persons with Disabilities (the CRDP), which states

that disability is an *evolving concept* and that *disability results from the interaction* between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.² (my emphasis)

Disability is here recognised as a *concept*, the nature of which changes with time. Significantly, this quotation is a description from the Preamble rather than Article 2, which is where the definition of terms used in a piece of legislation is ordinarily placed.

A crucial aspect of this description of disability is that it is based on the recognition of disability as being not simply the equivalent of biological impairment,

² Taken from paragraph (e) of the Preamble to the Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly, 2006; available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [accessed 20 September 2020].

whether congenital or acquired. The reference to barriers that are external to the disabled person and the role they play in creating barriers is momentous and itself a marker of just how much ideas about the nature of disability have evolved. We owe this evolution to disabled people themselves, who first distinguished the difficulties engendered by physical or mental impairments on the one hand and, on the other hand, the difficulties created by societies that ‘take little to no account’ of the adjustments needed to cater for the needs of people with those impairments.³ The British disabled scholar, Mike Oliver, coined the phrase ‘the social model of disability’, to refer to the difficulties created by inaccessibility to places, information, communication, as well as by misconceptions, prejudice and stereotypes. Addressing these difficulties entails finding explanations for and solutions to removing the barriers created by lack of access and by negative attitudes.⁴

A difference can be noted in Oliver’s conceptualization of disability as being entirely created by society and the formulation used in the UNCRPD Preamble, where disability is seen as arising from the interaction between a person’s impairment and societal barriers. The UNCRPD’s formulation is based on what Carol Thomas calls the social relational model of disability, which takes the impairment into account.⁵ There are some disagreements amongst disability studies scholars as to the extent to which impairment should be focused on. On the one hand, focusing entirely on socially created barriers risks denying the day-to-day reality of those disabled people who live with chronic illness or debilitating conditions. On the other hand, bringing impairment into the picture can deviate attention away from disabling barriers.⁶ The focus however remains solidly on societal barriers, since the difficulties faced by disabled people cannot be explained solely in terms of their impairment. It is this shift from a sole focus on impairment (that falls under the medical gaze) to sociocultural factors that has enabled the study of disability through the lens of different disciplines, including those that are associated with the humanities, such as history, law, philosophy, literature and art.

The pioneers of the disability rights movement were primarily disabled people in the UK and the US.⁷ One of the critical points in British disabled people’s struggle for their rights was the battle by residents of the Le Court Cheshire Home in Hampshire, England, to have control over their lives. Paul Hunt describes how he and the other

³ The Union of the Physically Impaired Against Segregation (UPIAS), a British organization led by persons with physical disability, set out the ‘Fundamental Principles of Disability’, a key document in the history of the disabled people’s movement. In it they declared that: ‘Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society’, 4 (1976); available at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf> [accessed 20 September 2020].

⁴ The first recorded use of the term is in Mike Oliver’s *Social Work with Disabled People* (Basingstoke: Macmillan, 1983).

⁵ Carol Thomas, ‘How is Disability Understood? An Examination of Sociological Approaches’, *Disability and Society* 19.6 (2004): NP.

⁶ One of the authors who tackles these different standpoints is Jan Grue in his book *Disability and Discourse Analysis* (Farnham: Ashgate, 2015).

⁷ For detailed accounts of the inception and evolution of the pioneering disability rights movements in the US and the UK, see respectively Doris Fleischer Zames, and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia, PA: Temple University Press, 2011) as well as Jane Campbell, and Mike Oliver, *Disability Politics: Understanding Our Past, Changing Our Future* (London: Routledge, 1996).

residents with a physical disability had managed to achieve ‘hard-won extensions of control over personal life’ in the 1960s.⁸ The freedoms won were about being able ‘to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc’⁹, that is engaging in activities that non-disabled adults could more or less take for granted. As Hunt himself recounts, the Le Court residents lobbied for two social scientists from the Tavistock Clinic in London E. J. Miller and G. V. Gwynne to carry out a study on how conditions in this and similar residential institutions could improve for the disabled residents. What the latter wanted was a say on the management board that ran the home they lived in. What they got instead, as Hunt says in his scathing criticism in ‘Settling Accounts with the Parasite People’, was a reconfirmation of the status quo as Miller and Gwynne saw the residents’ situation as an inevitable outcome of having severe physical impairments which they had to resign themselves to. The solution that the researchers proposed was ‘to help the inmates make their transition from social death to physical death’.¹⁰ As a reaction to these conclusions, Hunt and his fellow ‘inmates’ started lobbying for the social change in Britain that was needed for them not to continue living a ‘social death’.

It was also in the 1960s that the American Ed Roberts, who had been very severely disabled by polio when he was fourteen, took the University of Berkeley in California to court to win the right to be admitted. Since he was paralysed and in need of an iron lung to breathe, the University had to find accessible and appropriate accommodation for him in a nearby rehabilitation hospital. Roberts was later joined by other physically disabled students and they became known as the Rolling Quads. Eventually, ‘[i]mpelled by their desire to be in charge of their own lives, the Rolling Quads moved out of the hospital and into the Berkeley community’ and grew into what would become known as the independent living movement.¹¹

Universities have therefore played a significant part in the development of the disability rights movement. Early on it was a reluctant and even counterproductive one. Ed Roberts and his Rolling Quads companions recognised the importance of having a university education to be able to fight for their rightful place in their society. Berkeley’s initial resistance gave way to one of the most important developments in this movement. Likewise, Paul Hunt and his fellow residents first turned to university-trained social scientists for support. Having been let down by Miller and Gwynne, Hunt and other disabled people took the struggle for their rights into their own hands. One of the disabled activists who joined them was Vic Finkelstein, a disabled white South African anti-apartheid activist who was given political asylum in the United Kingdom

⁸ Paul Hunt, “‘Settling Accounts with Parasite People’ – A Critique of “A Life Apart” by E J Miller and G V Gwynne”, *Disability Challenge*, UPIAS 1 (1981): 40; available at <https://tonybaldwinson.files.wordpress.com/2018/04/settling-accounts-with-the-parasite-people-a-critique-of-a-life-apart-by-ej-miller-and-gv-gwynne-by-paul-hunt-1981.pdf> [accessed 20 September].

⁹ Hunt, 40.

¹⁰ Cited by Vic Finkelstein in ‘Disability: An Administrative Challenge?’, originally published in *Social Work – Disabling People and Disabling Environments*, ed. Mike Oliver (London: Jessica Kingsley Publishers, 1991), 2; available at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-Administrative-Challenge-1.pdf> [accessed 20 September 2020].

¹¹ Cited by Doris Zames Fleischer, and Frieda Zames, in *The Disability Rights Movement*, 39.

in the late 1960s.¹² Amongst his most significant contributions is his leading role in the team that devised the first course at tertiary level that addressed the changes needed for society to be inclusive and for professionals working with disabled people to give the perspectives of the latter their due recognition.¹³

The work of Finkelstein and other disabled academics would eventually develop into what we refer to today as disability studies, with scholars from the social sciences and the humanities contributing significantly to its expansion. One of the most prominent was Mike Oliver. In his 1992 paper ‘Changing the social relations of research production’, he reacted to a survey carried out with disabled people in Britain by the Office of Population Surveys and Statistics in 1986. The survey included questions such as ‘Can you tell me what is wrong with you?’, and ‘Does your health problem/disability make it difficult for you to travel by bus?’.¹⁴ These questions, Oliver argues, should be changed to ‘Can you tell me what is wrong with society?’, and ‘Do poorly-designed buses make it difficult for someone with your health problem/disability to use them?’ The focus therefore turns to trying to make changes in society by identifying and removing the physical and attitudinal barriers encountered by disabled people within its institutions and practices. Important as rehabilitation and cure are for disabled people to have as much functional ability as possible, most impairments cannot be totally removed and if society does not take impairment-related needs into account, in its institutional and cultural practices, the inevitable consequences are segregation, isolation and the denial of rights.

The response to Mike Oliver’s criticism of the 1986 OPCS questionnaire was the commissioning of a survey of disability discrimination in Britain. Colin Barnes, another pioneer of the British disability movement, was selected to lead the research, in conjunction with the British Council of Organisations of Disabled Persons.¹⁵ This research was therefore carried out by disabled people who were academics or activists in the disabled people’s movement or both. The work in turn led to the creation of what today is the Centre for Disability Studies at the University of Leeds, the first of its kind, and still one of the leading academic bodies in the area of disability studies.¹⁶ Many universities in many countries across the world now have a centre dedicated to disability studies to which academics from different parts of that university belong. These arrangements mean that disability studies has continued to develop through input by scholars from various disciplines. The influences of the social sciences and the humanities are discussed in the next two sections.

¹² Mike Oliver’s obituary to Vic Finkelstein encapsulates Finkelstein’s contribution to the British disabled people’s movement. ‘Vic Finkelstein Obituary’, *The Guardian*, 22 December 2011; available at <https://www.theguardian.com/society/2011/dec/22/vic-finkelstein> [accessed 20 September].

¹³ The *Handicapped Persons in the Community* course was first delivered by the Open University in 1975 and was revised in 1981. The textbook for the revised course, Ann Brechin, Penny Liddiard, and John Swain, eds, *Handicap in a Social World* (Milton Keynes: Open University Press, 1981) remains a classic text.

¹⁴ Mike Oliver, ‘Changing the Social Relations of Research Production?’, *Disability, Handicap and Society* 7.2 (1992): 101-114.

¹⁵ Colin Barnes, *Disabled People in Britain and Discrimination* (London: Hurst, in association with the British Council of Organizations of Disabled People, 1991).

¹⁶ See ‘What Is the Centre for Disability Studies (CDS)’; available at <https://disability-studies.leeds.ac.uk/about/> [accessed 20 September 2020].

Disciplinary Influences on Disability Studies

The origins of disability studies as an academic area of study is thus closely linked to the development of the disabled people's movement. The crucial idea of the social model has not only led to social and legislative changes, it has also opened up disability as an area of study beyond medicine and health studies. It has enabled investigations into societal factors that create disability, into the different ways how disability is understood and into how it is represented in culture and the arts.

Research and writing about disability has of course existed for a long time, even in the social sciences. But, until a few decades ago, the vast majority of that work was based on an understanding of disability as an individual problem, even when looking at the situation of disabled people in society. In her discussion of what disability studies offers which is new when compared to sociological work about disability, Tanya Titchkovsky describes how the latter has, for a long time, treated disability as a 'symptom' whereas disability studies enables a 'more conversational view of disability'.¹⁷ The conversation is enabled through the identification of material and cultural barriers as being as significant a part of the experience of disability as the impairment. It is also enabled through the different explanations of the nature of these barriers, their causes and ways to address them that are expressed through the different models of disability that have developed. At the same time, there are sociological texts that were produced well before the emergence of disability studies as a discreet area of study that are used by scholars working in this area. These texts include the work of Erving Goffman and Irving Kenneth Zola, which is discussed in the edited collection by Sara E. Green and Sharon N. Barnartt *Sociology Looking At Disability: What Did We Know and When Did We Know It?*.¹⁸

However, as Titchkovsky argues, the presence of these and similar texts does not detract from the unique contribution of disability studies. This area of study is not simply an extension of previous sociological work on disability, for various reasons. First of all, it is an approach to the study of disability that has been primarily developed by academics who either have a disability themselves or have disabled family members, or who have worked very closely with disabled activists. Pivotal to their work are the insights and perspectives that have developed from disabled people's experiences, since no one can identify the nature and impact of disabling barriers better than those who live them day by day. Thus, disability studies is grounded in the experiences and perspectives of disabled people themselves.¹⁹

Secondly, the work of disability studies scholars has evolved as a means of addressing lacunae in research about and explanations of disability not only in sociology but also in other disciplines. Academics working in disability studies emerged from and work within many disciplines, including education, law, sociology,

¹⁷ Tanya Titchkovsky, 'Disability Studies: The Old and the New', *The Canadian Journal of Sociology/ Cahiers canadien de sociologie* 25.2 (2000): 210.

¹⁸ Sara E. Green, and Sharon N. Barnartt (eds.), *Sociology Looking at Disability: What Did We Know and When Did We Know It?* (Bingley: Emerald Publishing, 2017).

¹⁹ There are of course also people involved in disability studies who do not have a direct experience of disability personally or within the family. But, as Kulik remarks, many writers in the field of disability studies make 'some kind of statement about the author's personal relationship to disability'. Don Kulik, 'The Problem of Speaking for Others *Redux*: Insistence on Disclosure and the Ethics of Engagement', *Knowledge Cultures* 3.6 (2015): 14. This is an opportune moment for me to state that I do not have a disability nor am I closely related to a disabled person.

psychology, the health sciences and the humanities. For example, the US-based Society for Disability Studies states that:

Using interdisciplinary and multidisciplinary approaches, Disability Studies sits at the intersection of many overlapping disciplines in the humanities, sciences, and social sciences.²⁰

As seen above, disability studies originated in the UK and the US, and the sites of major developments remain in Anglophone countries. There are, however, also developments in other countries, albeit in different ways. Lisa PhafI and Justin Powell, for instance, discuss the emergence of disability studies scholarship in Germany, Austria and Switzerland.²¹ They note how, while there are scholars whose work is grounded in the ethos of disability studies, the dominance of the established disciplines such as sociology and political science curbs developments in these areas. They also note ‘the paucity of intellectual homes that are genuinely multidisciplinary and devoted to (critical) DS’ in these three countries.²² Disability studies, therefore, has to adapt to already-existing academic infrastructures. In France, meanwhile, according to Isabelle Ville and Jean-François Ravaud, work in disability studies is mostly done through research institutes.²³ This approach enables transdisciplinary work to be carried out but makes it difficult for centres, programmes or other entities specific to disability studies to be established in universities themselves. According to Stiker, this situation limits the potential for the development of disability studies in France.²⁴ Away from the global North, developments in disability studies have to contend with lack of financial resources and the need to nurture approaches to the study of disability that are attuned to the socioeconomic and cultural realities of developing countries.²⁵

Thirdly, and perhaps most importantly, disability studies does not see the presence of impairments in human beings as a problem that needs to be solved. It takes impairment as a given, as an inherent part of the human condition – especially when there is no medical intervention that can address it. The framework within which work in disability studies is carried out is always focused on societal and cultural issues, which mainly fall within the sphere of the social sciences and of the humanities respectively.

This focus provides coherence to a range of work which is located in different ontological and epistemological standpoints. For example, the title of Oliver’s article, cited above, with its reference to changing the social relations of research production,

²⁰ Society for Disability Studies, ‘What Is Disability Studies?’, available at <https://disstudies.org/index.php/about-sds/what-is-disability-studies/> [accessed 20 September].

²¹ Lisa PhafI, and Justin J.W. Powell, ‘Subversive Status: Disability Studies in Germany, Austria and Switzerland’, *Disability Studies Quarterly* 34.4 (2014): NP; available at <https://dsq-sds.org/article/view/4256/3596Building> [accessed 20 September 2020].

²² PhafI and Powell, NP.

²³ Isabelle Ville, and Jean-François Ravaud, ‘French Disability Studies: Differences and Similarities’, *Scandinavian Journal of Disability Research* 9.3-4 (2007): 138-45.

²⁴ Henri-Jacques Stiker, ‘The Contribution of Human Sciences to the Field of Disability in France over Recent Decades’, *Scandinavian Journal of Disability Research* 9.3-4 (2007): 146-59.

²⁵ See, for example, Negin H. Goodrich, ‘A Persian Alice in Disability Literature Wonderland: Disability Studies in Iran’, *Disability Studies Quarterly* 32.2 (2014): NP; available at <https://dsq-sds.org/article/view/4255/3595> [accessed 20 September 2020] and Karen Soldatic, and Shaun Grech, ‘Transnationalising Disability Studies: Rights, Justice and Impairment’, *Disability Studies Quarterly* 32.2 (2014): NP; available at <https://dsq-sds.org/article/view/4249/3588> [accessed 20 September 2020].

places his research squarely within the Marxist tradition. In fact, proponents of the social model often work within a dialectical materialist epistemological framework and focus on material disabling barriers and lack of accessibility, while also taking into account the disabling barriers created by negative attitudes towards disability and disabled people.²⁶ Apart from Oliver, the work of other British disability studies pioneers – especially Vic Finkelstein, Colin Barnes and Geoff Mercer – is also located in dialectical materialism. Female disability studies scholars, among them Jenny Morris, Carol Thomas and Susan Wendell, have also brought feminist theories to bear on the study of disability.

More recently, many disability studies scholars are being increasingly influenced by post-structuralist perspectives, with a focus on the analysis of discourse and how it shapes – and even creates – our ideas about disability.²⁷ The work of Michel Foucault has come under particular attention in disability studies, as evinced, for example, by the work of Shelley Tremain.²⁸ These approaches are examples of the contribution that the humanities have made to the development of disability studies. It is on the relationship between the two that the rest of this article focuses.

Disability Studies and the Humanities

In the same way that there were precursors to the sociological study of disability before the arrival of disability studies, there were also studies within the humanities that heralded approaches to studying the cultural aspects of disability which are part and parcel of contemporary disability studies. Clare Barker and Stuart Murray present a ‘Chronology of Literary and Cultural Disability Studies’ in which they identified works such as Susan Sontag’s *Illness as Metaphor*, published in 1978 and Arthur Kleinman’s *The Illness Narratives: Suffering, Healing and the Human Condition*, published in 1988.²⁹ Barker and Murray then identify Lennard Davis’ *Enforcing Normalcy: Disability, Deafness, and the Body*, published in 1995, as ‘the founding text that marked the emergence of literary and cultural disability studies’.³⁰ Literary criticism, cultural studies as well as visual studies and film studies have given rise to the most fruitful contributions of the humanities to disability studies yet.³¹ However, before taking a closer look at these contributions, it is worth exploring how some other disciplines within the humanities have been used by disability studies scholars. The examples of

²⁶ Colin Barnes, and Geoff Mercer, *Exploring Disability*, 2nd ed. (Cambridge: Polity, 2010).

²⁷ Dan Goodley provides a very good introduction to the different approaches used in disability studies: *Disability Studies: An Interdisciplinary Introduction* (Thousand Oaks, CA: Sage, 2011).

²⁸ Shelley Tremain (ed.), *Foucault and the Government of Disability*, 2nd ed. (Ann Arbor, MI: University of Michigan Press, 2015).

²⁹ Clare Barker, and Stuart Murray (eds.), *The Cambridge Companion to Literature and Disability* (Cambridge and New York: Cambridge University Press, 2018).

³⁰ Barker and Murray, ‘Introduction: On Reading Disability and Literature’, in *The Cambridge Companion to Literature and Disability*, eds. Barker and Murray, xv.

³¹ David Bolt, Director of the Centre for Literary and Cultural Disability Studies at Liverpool Hope University, traces developments of cultural disability studies in ‘The Metanarrative of Disability: Social Encounters, Cultural Representation and Critical Avoidance’, in *Routledge Handbook of Disability Studies*, eds. Nick Watson, and Simo Vehmas, 2nd ed. (London: Routledge, 2020), 337-47. Another useful source of information is the chronology compiled by Clare Barker, and Stuart Murray, in *The Cambridge Companion to Literature and Disability* mentioned earlier. The work of the Centre led by David Bolt, including an annual conference, a book series and the *Journal for Literary and Cultural Disability Studies* are also worthy of attention.

philosophy and history show how these interdisciplinary encounters can be mutually beneficial with insights from the humanities informing disability studies and vice versa.

The work of philosophers like Foucault, mentioned earlier, as well as Jacques Derrida, Jacques Lacan, Jacques Rancière, Gilles Deleuze and Félix Guattari is frequently referred to by disability studies scholars. These and other works in philosophy are used in disability studies, as Simo Vehmas and Christopher A. Riddle write, ‘to question and carefully examine its essential concepts and conceptions, their rational credibility, logical tenability and normative soundness’.³² They identify ontology and moral and political philosophy as being particularly useful for disability studies. Using philosophical approaches to study the nature of disability and the meanings attributed to it can also enrich philosophy itself. For example, the Kantian notion of rational autonomy and concepts of what constitutes moral personhood are predicated on the ability to take rational decisions and act on them unsupported. This ability cannot be taken for granted for all disabled persons. Eva Kittay (whose philosophical work is directly influenced by her experience of having a daughter with severe intellectual disability), Licia Carlson and Laura Davy, among others, challenge the ways in which moral philosophy can overlook a whole sector of the population from its consideration.³³ Similarly, both Kittay in *Love’s Labour* and Martha Nussbaum in *Frontiers of Justice* critique John Rawls’ concept of the social contract since it leaves out, among others, people with physical and mental disabilities who are not necessarily able to contribute equally to any social contract, hypothetical or otherwise, while also often being more dependent on others in the day-to-day.³⁴ In this regard, disability studies helps to amplify evolving reflections about moral personhood, especially by developing the notion of relational autonomy, that is ‘a model of autonomy [...] that takes the vulnerable individual as its starting point and emphasises relations of support and advocacy’.³⁵

History is another discipline which enriches, and is enriched by disability studies, as Michael Rembis states in his discussion of disability history.³⁶ Disability history throws light on the situation of disabled people in different historical periods. But, as Rembis argues, it does more than that. History can also bring to life disabled people’s experience of living with their impairments in different historical periods. As an example, Rembis refers to Catherine Kudlick’s history of smallpox which takes into account the lives of those affected by the disease.³⁷ One notable figure in Kudlick’s

³² Simo Vehmas, and Christopher A. Riddle, ‘What Can Philosophy Tell Us about Disability?’, in *Routledge Handbook of Disability Studies*, eds Watson and Vehmas, 348-9.

³³ Eva Feder Kittay and Licia Carlson’s edited collection *Cognitive Disability and its Challenges to Moral Philosophy* (Malden, MA and Oxford: Wiley-Blackwell, 2010) provides a comprehensive exploration of the issues around this subject.

³⁴ Eva Feder Kittay, *Love’s Labour: Essays on Women, Equality and Dependence* (New York: Routledge, 1999); Martha Nussbaum. *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge, MA: Harvard University Press, 2006).

³⁵ Laura Davy, ‘Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Moral and Political Theory’, *Hypatia* 30.1 (2015): 146.

³⁶ Michael Rembis, ‘Challenging the Impairment/Disability Divide: Disability History and the Social Model of Disability’, in *Routledge Handbook of Disability Studies*, eds. Nick Watson, and Simo Vehmas, 377-90.

³⁷ Rembis cites different works by Catherine Kudlick. Husson’s life is discussed in her chapter ‘Smallpox, Disability, and Survival in Nineteenth-Century France: Rewriting Paradigms from a New Epidemic Script’, in *Disability Histories*, eds. Susan Burch, and Michael Rembis, (Urbana, IL: University of Illinois Press, 2014), 185-200.

work is Thérèse-Adèle Husson, a woman who lived in nineteenth-century Nancy in France, who was blinded by smallpox when she was a baby and grew up to become a writer. Rembis comments that '[w]ritten by disability historians, the history of smallpox in France becomes one not merely of outbreak and eradication, but also one of survival, artistic production and social commentary'.³⁸ Similarly, Anne Finger's *Elegy for a Disease* extends the history of polio far beyond the story of the Salk vaccine.³⁹ Finger recounts her own experience of contracting polio, being treated for it and living with it, and weaves this personal account with a medical history of the disease and the cultural narratives built around it. Taking a much wider purview, from the Biblical representations of disability to twentieth-century discourse surrounding rehabilitation, Henri-Jacques Stiker's *Corps infirmes et sociétés*⁴⁰ analyses how disability has been interpreted in Western civilization and what these interpretations reveal about the cultures from which they arose.⁴¹

These examples of philosophical and historical approaches to the study of disability show that, as Sharon Snyder, Brenda Brueggermann and Rosemary Garland-Thompson write in *Disability Studies: Enabling the Humanities*,

Disability [...] expands our ways of thinking about the form, function, and appearance of the body; it complicates the ways we imagine national, communal, and individual identities; it challenges assumptions about what is normative and what is marginal; it adds further dimension to historical, psychological, and aesthetic inquiries.⁴²

These approaches, therefore, in turn enrich philosophy and history, among other disciplines with the humanities. Aesthetic inquiries are also enhanced through disability studies by expanding our appreciation of how disabled people are represented in literature (and narratives – including film – more widely), the visual arts and other forms of cultural expression. One of the most influential books in this regard is David Mitchell and Sharon Snyder's *Narrative Prosthesis: Disability and the Dependencies of Discourse*.⁴³ Their central thesis is that, while disability is ubiquitous in narrative, the lives of disabled people are very rarely narrated in the complexity of the social and material realities in which they are situated. In their analyses, Mitchell and Snyder show how narratives repeatedly use disability as a plot device while the lived experience of disabled people remains largely invisible. Similarly, in *Aesthetic Nervousness: Disability and the Crisis of Representation*, Ato Quayson writes of 'the moral panic that has historically obtained in social encounters between disabled and nondisabled people'.⁴⁴ His analyses of different types of representations of disability in literature

³⁸ Rembis, 382.

³⁹ Anne Finger, *Elegy for a Disease: A Personal and Cultural History of Polio* (New York: St Martin's Press, 2006).

⁴⁰ Henri-Jacques Stiker, *A History of Disability*, trans. William Sayers as (Ann Arbor, MI: University of Michigan Press, 1999).

⁴¹ Catherine J. Kudlick also provides a useful review of books that contribute to disability history in 'Disability History: Why We Need Another "Other"', *The American Historical Review* 108.3 (2003): 763-93.

⁴² Sharon L. Snyder, Brenda J. Brueggermann, and Rosemary Garland-Thompson (eds.), *Disability Studies: Enabling the Humanities* (New York: Modern Language Association of America, 2002), 94.

⁴³ David T. Mitchell, and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor, MI: University of Michigan Press, 2000).

⁴⁴ Ato Quayson, *Aesthetic Nervousness: Disability and the Crisis of Representation* (New York: Columbia University Press, 2007), 33.

show how this panic manifests itself in the way that disability is used to represent violence and pain at a symbolic level, while the day-to-day realities of disabled people's lives often fail to be written into the narrative. Tobin Siebers also presents a similar argument, this time in relation to the visual arts, especially modern art.⁴⁵ In *Disability Aesthetics*, he argues that modern art moves us because of 'its refusal of harmony, bodily integrity, and perfect health' and 'its embrace of disability as a distinct version of the beautiful'.⁴⁶ However, the depiction of distorted bodies in paintings and sculptures is not usually connected with the deformities that some impairments produce in disabled people's bodies. Siebers uses Anita Silvers' point that, while for example the distorted bodies in Picasso's paintings are appreciated and considered aesthetic, deformed bodies of real people continue to be rejected and shunned.⁴⁷ Although one can safely say that disabled people whose bodies are anomalous find more welcoming spaces than was the case before the rise of the disabled people's movement, they still experience exclusion, prejudice and rejection based on the way they look.

The theories expounded in these three and similar books do not only throw light on the pervasiveness of disability representation and the concurrent absence of disabled people's lives in different cultural forms of cultural expression, including the visual arts, literature and narratives in general. They also provide an analytical framework for literary criticism, visual studies, film studies and other forms of cultural analyses which is based on theories of disability and concepts developed within disability studies. These analyses help us realise that, as Michael Bérubé states, in his pleasingly playful tone, in *The Secret Life of Stories*, 'disability has a funny way of popping up everywhere without announcing itself as disability'.⁴⁸ Bérubé in fact discusses 'deployments' rather than 'depictions' of disability. Focusing on intellectual disability, Bérubé shows how disability is found not only in stories which feature disabled characters but are also 'devices for exploring vast domains of human thought, experience, and action'. In novels such as Cervantes's *Don Quixote*, Philip K. Dick's *Martian Time Slip* and J. K. Rowling's *Harry Potter and the Deathly Hallows*, Bérubé argues, the 'deployment' of disability creates 'powerful meditations on what it means to be a social being, a sentient creature with an awareness of time, mortality, causality, and sentience itself'.⁴⁹

In these works, the analyses and critiques presented are informed by the perspectives of disabled people themselves. The study of cultural representations of disability, in the visual and performing arts, in literature, film and documentary, and so on, produces a rich body of research that explores the meanings attributed to disability in these various cultural forms. Insights from the humanities, and the analytic tools associated with disciplines related to the humanities, are combined with the insights and

⁴⁵ Tobin Siebers, *Disability Aesthetics* (Ann Arbor, MI: University of Michigan Press, 2010).

⁴⁶ Siebers, *Disability Aesthetics*, 5, 9.

⁴⁷ Siebers here refers to Anita Silver's chapter 'From the Crooked Timber of Humanity, Beautiful Things Can be Made', in *Beauty Matters*, ed. Peg Zeglin Brand (Bloomington, IN: Indiana University Press, 2000, 197-221).

⁴⁸ Michael Bérubé, *The Secret Life of Stories: From Don Quixote to Harry Potter, How Understanding Intellectual Disability Transforms the Way We Read* (New York: New York University Press, 2016), 1.

⁴⁹ The way that concepts related to disability can be 'deployed' (to use Bérubé's term) can also be seen in Mieke Bal's video art installation 'Don Quichotte – Sad Countenances'. Information about this work is available at <https://www.leeds-art.ac.uk/news-events/events-exhibitions/mieke-bal-don-quichotte-sad-countenances/> [accessed 20 September 2020]. See also Bal's chapter 'Improving Public Space: Trauma Art and Retrospective – Futuristic Healing', in *Arts of Healing: Cultural Narratives of Trauma*, eds. Arleen Ionescu, and Maria Margaroni (London: Rowman and Littlefield International, 2020), 73-98.

perspectives that spring from disabled people's experiences. It is no coincidence that the humanities scholars whose books have been presented in this section are either disabled persons or the parents of disabled persons. Among the latter, there is also Ralph Savarese who, in *See It Feelingly*, presents his discussion of works of fiction with autistic persons.⁵⁰ Savarese not only challenges misguided assumptions about the inability of those who are on the autism spectrum to understand figurative language and engage in imaginative play. He also presents a re-reading of various novels from the rarely-voiced perspective of autistic persons. Thus, Melville's *Moby Dick* becomes a multisensory experience and the empathy test in Dick's *Do Androids Dream of Electric Sheep* is discussed in the context of the misconception that autistic people lack empathy.

This overview shows how much insight and knowledge the humanities contribute to disability studies. However, they have yet to enrich themselves fully with what has emerged from their application to disability studies. One reason for this imbalance, put forward by Hannah Thompson, may be the intimate link of disability studies with the disability rights movement and with campaigning for social and legislative change which, at face value, may seem to be outside the scope of the humanities.⁵¹ Another reason can be the fact that, while decades of campaigning by disabled people and the various analyses of cultural representations of disability brought disability as a human rights issue to the forefront, deep-seated stereotypes and misconceptions about what it is like to live with a disability have yet to be unravelled. Mistaken ideas of life with a disability not being one worth living can lead to what Quayson neatly terms 'aesthetic nervousness'.⁵²

Disability and the Arts

The 'critical avoidance' (as David Bolt terms it⁵³) of disability by many humanities scholars is, ironically enough, counterbalanced by its pervasive presence in all things cultural. 'Disability as both image and concept pervades language and literature' as Snyder, Brueggermann and Garland-Thompson say.⁵⁴ It is present in the figurative expressions we use, invariably signalling negativity: lame ducks, being blindsided, crippling debts, moronic arguments. It is present in literature: Richard III, Mr Rochester and his first wife Bertha Mason, Quasimodo, Captain Ahab. It is present in those who produce art: Beethoven, Alexander Pope, Milton, Toulouse-Lautrec, Frida Kahlo, Virginia Woolf. It is there almost inevitably, by virtue of the fact that disability is very much part of the human condition.

But disability's presence is not always acknowledged. How often is the Venus de Milo thought of as an amputee?, Siebers asks in *Disability Aesthetics*. And yet, her incomplete arms do not in any way detract from her beauty.⁵⁵

In *Narrative Prosthesis*, Mitchell and Snyder show how the fact that Oedipus limped was key to his unravelling the sphinx's riddle. He himself was already aware of

⁵⁰ Ralph James Savarese, *See It Feelingly: Classic Novels, Autistic Readers, and the Schooling of a No-Good English Professor* (Durham, NC: Duke University Press, 2018).

⁵¹ Hannah Thompson, 'French and Francophone Disability Studies', *French Studies* 71.2 (2017): 243-51.

⁵² Quayson, *Aesthetic Nervousness*.

⁵³ Bolt, 'The Metanarrative of Disability', 30.

⁵⁴ Snyder, Brueggermann, and Garland-Thompson, 'Introduction: Integrating Disability into Teaching and Scholarship' in *Disability Studies: Enabling the Humanities*, eds. Snyder, Brueggermann, and Garland-Thompson, 2.

⁵⁵ Siebers, *Disability Theory* (Ann Arbor, MI: University of Michigan Press, 2008), 48.

the need to rely on extraneous support to walk. Apart from Sophocles' *Oedipus Rex*, Mitchell and Snyder also analyse works as diverse as Hans Christian Andersen's *The Steadfast Tin Soldier*, Shakespeare's *Richard III*, Herman Melville's *Moby Dick* and Katherine Dunn's *Geek Love*. They argue that disability is often a metaphor for the deviance and conflict in a plot that must be resolved, one of the clearest examples being Captain Ahab's amputation, for which he seeks revenge. Mitchell and Snyder's analysis, together with that of Quayson's of Nobel-prize winning literature, Sieber's of modern art, as well as the many other books, articles and conference presentations that fall within the scope of cultural disability studies, provide ample evidence of the unique contribution that a disability studies perspective can give to critiques of creative work. This perspective also uncovers ableist assumptions that are often made by non-disabled critics about cultural representations of disabled people.

An example of this type of work is Ria Cheyne's article on Anne McCaffrey's science-fiction story *The Ship Who Sang*. She shows how, although it has been read as a story that enables disabled people, it is actually one which reinforces ideas about the worthlessness of a disabled life. The infant Helva is born with severe physical disabilities. Her parents are given the option that, instead of killing her (as is the usual practice in their Sparta-like society), she is transformed into a cyborg and thus becomes a spaceship. Cheyne shows that to see this story as an enabling one for disabled people is to be rooted in a view of disability as tragedy, as something that needs to be fixed, and the disabled life as not worth living unless it can be fixed.⁵⁶ This outlook on disability prevails in many contemporary societies and translates itself into the abortion of disabled embryos and fetuses⁵⁷ and, at the other end of the lifespan, increased acceptance of assisted suicide for severely disabled people. As the British disabled actress Liz Carr observes

when a healthy, non-disabled person wants to kill themselves [sic] it's seen as a tragedy, and support and prevention tools are provided. ... Suicide is not seen as socially desirable – so why is assisted suicide seen as compassionate when it's for ill or disabled people?⁵⁸

While disability is often used by artists and writers whose viewpoint is not informed by the lived experience of disability, there are also exceptions. When the writer or artist does have that experience, it tends to influence their work, even if not always explicitly. To take an example from popular culture, there are probably fewer people who think of The Drifters' 'Save the Last Dance for Me' as a song inspired by disability, than there are those who think of the Venus de Milo as a double amputee. The song was composed by Doc Pomus, who was paralysed from polio and who, on his wedding night, had to watch his new bride dance with male guests from his wheelchair. But he tells her to save the last dance for him, because he is the one who will be taking

⁵⁶ Ria Cheyne, "'She Was Born a Thing': Disability, the Cyborg and the Posthuman in Anne McCaffrey's *The Ship Who Sang*", *Journal of Modern Literature* 36.3 (2013): 138-56.

⁵⁷ Bernard G. Prusak, 'Rethinking "Liberal Eugenics": Reflections and Questions on Habermas on Bioethics', *Hastings Center Report* 35.6 (2005): 31-42.

⁵⁸ Carr, Liz, 'Legalising Assisted Dying Is Dangerous for Disabled People. Not Compassionate', *The Guardian*, 9th September 2016; available at <https://www.theguardian.com/commentisfree/2016/sep/09/legalising-assisted-dying-dangerous-for-disabled-not-compassionate>. [accessed 10 October 2020].

her home and in whose arms she's going to be.⁵⁹ A more obvious example comes from the literary canon in Virginia Woolf's description of Septimus Warren Smith's mental breakdown and eventual suicide in *Mrs Dalloway*.⁶⁰ The insensitivity and ignorance of Dr Holmes and Sir William Bradshaw who see Septimus could very well have been inspired by Woolf's own unfortunate encounters with medical professionals, and Septimus's choice to jump from the window rather than go to a mental institution poignantly presages Woolf's own suicide when she could not face another round of therapies and interventions as she sensed the onset of another acute phase of her mental illness.⁶¹

However, inspired as these and many other examples are by the experience of disability, the contribution of disability to artistic and cultural expressions is taken much further through disability arts. Disability arts refers to art that is created by disabled people and that advances the agenda of disability activism.⁶² Disabled people who are involved in disability arts embrace what Swain and French⁶³ call the affirmation model of disability which turns on its head the personal tragedy view of impairment by affirming the experience of having an impairment as something to be celebrated, as an intrinsic part of a person's identity. Among many others, cultural expressions that can be subsumed under disability arts vary widely and include the Deaf⁶⁴ artist Susan Dupor whose paintings regularly feature people surrounded by multiple hands and arms that represent the spatial nature of words uttered in sign language,⁶⁵ the performance artist Claire Cunningham, who uses her crutches as an integral part of her dance and performances,⁶⁶ and poems, fiction and other types of writings about disabled people by disabled people.⁶⁷

A very important genre to take into account when considering disabled people's work is life writing, which G. Thomas Couser – one of the most important contributors to this area of disability studies – calls 'autosomatography', describing it as 'first-person

⁵⁹ William Hetcher, and Peter Miller, *A.K.A. Doc Pomus* (Clear Lake Historical Productions, 2012).

⁶⁰ Virginia Woolf, *Mrs Dalloway* (London: Grafton Books, 1978).

⁶¹ Rebecca Beatrice Brooks, 'Virginia Woolf's Misquoted Suicide Note', 2012; available at <http://viriniawoolfblog.com/virginia-woolfs-misquoted-suicide-note/> [accessed 20 September].

⁶² See 'Introduction, Background and History' by Elizabeth Brewer, Brenda Jo Brueggemann, Nicholas Hetrick, and Melaine Yergeau, in *Arts and Humanities (Disability Key Issues and Future Directions)*, ed. Brenda Brueggemann (Thousand Oaks, CA: Sage 2012).

⁶³ John Swain, and Sally French, 'Towards an Affirmation Model of Disability', *Disability & Society* 15.4 (2000): 569-82.

⁶⁴ Deaf people whose first language is sign language refer to themselves as Deaf (with a capital D), as explained by Carol Padden and Tom Humphries, *Inside Deaf Culture* (Cambridge, MA: Harvard University Press, 2005).

⁶⁵ Some of her art can be viewed on her website: <http://duporart.com/> [accessed 20 September]. See also works by Dupor and other Deaf artists displayed on the Deaf Arts website <https://deaf-art.org> [accessed 20 September].

⁶⁶ Cunningham's website can be accessed at <https://www.clairecunningham.co.uk> [accessed 20 September]. The trailer to 'Ménage à Trois' by Claire Cunningham and Gail Sneddon can be viewed at: <https://www.youtube.com/watch?v=oXppF9vUMQY> [accessed 20, September]. The third 'person' in the relationship is Cunningham's crutch.

⁶⁷ For example, *Word Gathering: A Journal of Disability Poetry and Literature*; available at <https://wordgathering.com> [accessed 20 September]; Victoria Ann Lewis, ed., *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights* (New York: Theatre Communications Group 2006); *Call Me Ahab*, an anthology of short stories by Anne Finger (Lincoln, NE: University of Nebraska Press, 2009); and *Staring Back: The Disability Experience from the Inside Out*, ed. Kenny Fries (New York: Plume, 1997).

life writing about illness and disability'.⁶⁸ There are also documentaries by and about disabled people. What is significant about this type of work is the 'warts and all' depictions of living with a disability: the limitations, pains and frustrations imposed by the impairment and those created by the people around the disabled person and society more generally, the joys and fulfilments experienced, and the different, and often ordinary, ways that these disabled persons get on with their lives.⁶⁹

Considering the works mentioned in this section, together with many other similar ones, is not only about comparing the representations of disability by disabled and non-disabled people, although such comparisons are in themselves worth making and can be very insightful. These considerations are also about what the lived experience of disability says about the human condition. They therefore fall very much within the remit of the humanities.

The Humanities and Disability Studies in the Twenty-First Century

Mitchell and Snyder write that '[t]he humanities component of disability studies offers scholars and students the ability to return to a history of representations to reassess our understanding of disability and thus of ourselves'.⁷⁰ The discussion and examples presented in the two foregoing sections provide ample evidence of the contribution of the humanities to disability studies. Given that disability is part of the human condition, it stands to reason that what we learn about disability contributes to the humanities and, ultimately, to our understanding of ourselves as Mitchell and Snyder write. What remains to be explored therefore is the contribution that disability studies can make to the debate about the humanities in the twenty-first century, a debate to which many humanities scholars have contributed. The focus here is on contributions by Jacques Derrida who developed the idea of the new humanities, Stefan Collini who is acknowledged as one of the foremost commentators on the humanities in the twenty-first century and Michael Bérubé who, as seen above, bridges the humanities and disability studies.

In 'The University Without Condition', Derrida says that '[t]he university professes the truth [...] It declares and promises an unlimited commitment to the truth.'⁷¹ It is precisely in the humanities, he continues, that discussions about the truth, about 'the concept of man, the figure of humanity' take place.⁷² These discussions naturally also entail questioning the nature of truth, what constitutes it and its effects. Using J. L. Austin's speech act theory, Derrida calls for work within the humanities that is done

⁶⁸ G. Thomas Couser, 'Body Language: Illness, Disability, and Life Writing', *Life Writing* 13.1 (2016): 3-10. This article is the introduction to a special issue of the journal on life writing about illness and disability, 3.

⁶⁹ Among the many autobiographies by disabled people, two excellent examples, both by blind men, are Stephen Kuusisto's *Planet of the Blind* (New York, NY: Random House, 1998) and Tommaso Di Gesaro's *Colori Nella Penombra* (Palermo: Spazio Cultura Edizioni, 2018). For analyses of documentaries about disabled people's lives see Catalin Brylla, and Helen Hughes's edited volume *Documentary and Disability* (London: Palgrave Macmillan, 2017).

⁷⁰ Mitchell and Snyder, 9.

⁷¹ Jacques Derrida, 'The University Without Condition', in *Without Alibi*, trans. Peggy Kamuf (Stanford, CA: Stanford University Press, 2002), 202, emphasis in the original.

⁷² Derrida, 207.

affirmatively and performatively, that is, by producing events (for example, by writing) and by giving rise to singular oeuvres [...] making something happen to this concept of truth and of humanity.⁷³

Furthermore, Derrida states that this work should take place in what he calls the “new” Humanities [...] to find the best access to a new public space transformed by new techniques of communication, information, archiving, and knowledge production.⁷⁴

What then could disability studies offer to these new humanities and the commitment to the truth? Any answers to this question entail a crossing of disciplinary boundaries. Derrida considers such crossings as necessary, although he cautions against ‘dissolving the specificity of each discipline into what is called, often in a confused way, “interdisciplinarity”’.⁷⁵ This specific crossing involves moving between disability studies – which draws from different disciplines while having its own ethos and character – and the humanities – a branch of learning that incorporates many disciplines. Encounters between the two can be fruitful while avoiding any dilution of their respective attributes. After all, Stefan Collini discusses the various social and cultural forces that have shaped the humanities while upholding the importance of specializations within disciplines.⁷⁶ Collini refers to the ways in which different disciplines (such as history, law and anthropology) have or have not been considered part of the humanities at different junctures in time and in different countries.

Locating the evolution of the humanities in specific contexts, as Collini does, throws light on the relationship between the disciplines within the humanities and other disciplines, branches of learning and areas of studies, and opens up further the already existing dialogue between them. A dialogue of the humanities with disability studies is a dialogue with an interdisciplinary area of study that is at once outside the humanities and directly informed by them. This dialogue can bring the humanities closer to the direct experiences of disabled people and those who live closely with them. The perspectives that arise from these experiences enrich analyses of cultural representations of and discourse about disability. They add an often-neglected dimension to the subjects that come under scrutiny in the humanities. And they uncover unquestioned assumptions that critiques about the nature of disability.

An example from a recent report in the news can illustrate the potential of such contributions. Towards the end of August 2020, the World Health Organisation announced the eradication of wild polio in Africa.⁷⁷ Like COVID-19, the polio virus leaves many of the people it affects asymptomatic or only mildly and temporarily ill, but has a devastating effect on some people. It starts in the guts but can move to the central nervous system and the respiratory system. Its eradication in an entire continent is therefore very welcome news. But celebrating this eradication needs to co-exist with another kind of celebration, that of the lives of people affected by polio, their

⁷³ Derrida, 204.

⁷⁴ Derrida, 203.

⁷⁵ Derrida, 230.

⁷⁶ Stefan Collini, ‘Seeing a Specialist: The Humanities as Academic Disciplines’, *Past and Present* 229 (2015): 271-81; ‘On Not “Justifying” the Humanities’, *The Humanities in the World Seminar* hosted by the Carlsberg Foundation, 10 January 2018; available at <https://www.youtube.com/watch?v=3nGEEW12usE> [accessed 20 September 2020].

⁷⁷ World Health Organisation, ‘Global Polio Eradication Initiative Applauds WHO African Region For Wild Polio-Free Certification’, 25 August 2020; available at <https://www.who.int/news-room/detail/25-08-2020-global-polio-eradication-initiative-applauds-who-african-region-for-wild-polio-free-certification> [accessed 20 September].

experiences, their tribulations and their achievements. That such a celebration can happen is evinced by books such as Finger's *Elegy for a Disease*,⁷⁸ referred to earlier, and the film *Breathe*, a biopic about Robin Cavendish. Paralysed from the neck down and in need of a mechanical respirator after contracting polio in his late twenties in the 1950s, Cavendish became a disabled advocate and a pioneer in the development of devices that enabled people with severe physical disabilities to lead more independent lives.

It is perhaps easy to see how the lives of a published author and a disabled pioneer can be celebrated. But the same applies to the lives of most people affected by polio, or other medical conditions, even if they are not marked by outstanding achievements. These lives, and the perspectives of those who live them, also fall within the scope of the humanities. In *University Without Condition*, Derrida calls for '[t]he Humanities of tomorrow ... to study their history, the history of concepts that, by constructing them, instituted the disciplines and were coextensive with them'.⁷⁹ Surely, if a study of the histories that Derrida goes on to list includes a study of disability as an integral part of the human condition, it will be more complete.

The relevance of disability studies to the humanities lies not only in the study of its own history, and in the analyses of current events and the current state of humanity. It also lies in the appreciation of works of the human imagination, which is one of the most important undertakings in the humanities. Whether it is the study of fiction, poetry, paintings, sculpture, film or other types of art, or whether it is the study of the aesthetic and the sublime, the theories developed by disability studies scholars – such as those referred to earlier – provide new dimensions of critique within the humanities. A disability studies angle enriches literary criticism, art appreciation and other discourses and practices, because it introduces ideas and insights that can be so overlooked that their absence is not even felt. These critiques are not only valid for the analysis of characters who have, or are purported to have, a disability. They also lend themselves to fruitful analyses of literature, art and creative work more widely. In fact, in *The Humanities, Higher Education and Academic Freedoms*, Bérubé brings in disability, and more specifically intellectual disability, in his discussion of the worth of studying the humanities, especially literary studies. He states that

We should [...] see the humanities as the study of what it means and has meant and might yet mean to be human, in a world where 'the human' itself is a variable term, its definition challenged and revised time and time again. We should say that what we offer is not the prospect of a better life but the (ancient, and ever-changing) promise of an examined life: and just as the universal has not yet received a final articulation, we might say that the study of the humanities has no final examination.⁸⁰

Bringing a more comprehensive disability studies angle into the study of the humanities can only enrich the examined life, and not only that of disabled people themselves. Bringing in this angle is a performative act since it takes on board the politics of the disability rights movement which foregrounds the multiple and complex

⁷⁸ Finger is also a novelist and short-story writer. Her most remarkable work of fiction is *Call Me Ahab: A Short Story Collection* (referred to earlier).

⁷⁹ Derrida, 230.

⁸⁰ Michael Bérubé, 'Value and Values', in Michael Bérubé, and Jennifer Ruth, *The Humanities, Higher Education and Academic Freedoms: Three Necessary Arguments* (London: Palgrave Macmillan, 2015), 54.

(and often avoidable) barriers that disabled people meet on a daily basis, and considers impairment as only a part of what it means to have a disability. It also means appreciating that a life lived with a disability can be as good a life as any other, by not only investigating the social and cultural forces that create disability but also understanding impairment as part of human beings' identity. 'New humanities' informed by the insights of disability studies can be a kind of humanities that is more aware than ever of the vulnerability and frailty, and the concomitant strength and resilience, that are inherent in the human condition and of the multifarious and multivalent ways in which these aspects of humanity have been and are being lived and expressed.

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Contribuția studiilor despre dizabilitate la noile științe umaniste

Rezumat

Studiile despre dizabilitate sunt într-o legătură directă cu mișcarea drepturilor persoanelor cu dizabilități și câțiva dintre pionierii acestui domeniu sunt profesori universitari care sunt persoane cu dizabilități. Acestea reprezintă un domeniu de studiu care își are originea în diverse discipline, în special din științele sociale și umaniste, dar care își păstrează unicitatea. Cunoașterea dobândită din studiile despre dizabilitate încorporează experiențele directe ale persoanelor cu dizabilități și ale membrilor familiilor acestora și se bazează pe înțelegerea dizabilității ca provenind din interacțiunea dintre persoanele cu deficiențe și barierele sociale pe care aceștia trebuie să le depășească. Această înțelegere face ca studiile despre dizabilitate să poată să fie analizate prin intermediul științelor umaniste, cu ajutorul unor discipline precum filosofia, istoria și studiile literare. Studiile despre dizabilitate dezvăluie natura complexă a dizabilității și factorii multipli care o creează și care au efecte asupra experienței de viață a persoanelor cu dizabilități. De asemenea, ele confirmă multiplele moduri în care persoanele cu dizabilități își negociază propriile vieți și identități ca persoane cu dizabilități. Din acest motiv, studiile despre dizabilitate au mult de spus despre condiția umană și pot contribui la evoluția științelor umaniste din prezent și din viitor.