Encounters between Disability Studies and Critical Trauma Studies

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Arleen Ionescu and Anne-Marie Callus

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Encounters between Disability Studies and Critical Trauma Studies: Introduction

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When setting up the premises for a dialogue between disability studies and critical trauma studies and embarking on editing this pilot issue on ‘encounters’ between the two disciplines, we necessarily welcomed interdisciplinary approaches, ranging across disability studies, trauma studies, literary and cultural studies, media studies, as well as many other disciplines in the humanities.

The first step in introducing this issue to our readers will be to present the histories of both disability studies and trauma studies in order to see how they evolved and see why our proposal that they should meet half way or at least more often can be considered a valid one.

Disability Studies

The single most important achievement of the disabled people’s movement has been gaining recognition of the fact that the difficulties encountered by disabled people in their daily lives are not so much a direct and inevitable result of biological or mental impairment but rather a consequence of barriers created by societies that take little to no account of the impairment-related needs of disabled people.¹ As Barnes and Mercer point out,² disabled people had been protesting about their situation for a good part of the twentieth century, but it was in the 1970s that the disabled people’s movement gained momentum, especially in the US and the UK, but also in other European countries. The recognition of the part played by society in the creation of disability is neatly encapsulated in the term the ‘social model’ of disability which was coined by Mike Oliver.³ This model is contrasted by Oliver with the ‘medical model’ of disability, which he later also calls the ‘individual model’.⁴ Adopting a social model approach to considerations of disability means acknowledging that the response to the difficulties encountered by disabled people cannot be restricted to medical treatment and social welfare. Important as these interventions are, they are not sufficient, simply because they do not tackle all the sources of disabled people’s difficulties, that is they do not address the obstacles and barriers that are created by society itself. Taking into account these hindrances also means seeing disability as a human rights issue and disabled

³ The term was first used by Mike Oliver in *Social Work and Disabled People* (Basingstoke: Macmillan, 1983).
⁴ Mike Oliver, *Understanding Disability: From Theory to Practice*, 2nd ed. (Basingstoke: Palgrave, 2009).
people on a par with other socially-disadvantaged minorities.\(^5\) The first piece of legislation to acknowledge societal obligations to remove disabling obstacles was the Americans with Disability Act in 1990.\(^6\)

The social model of disability is thus a few decades old. Prior to that, for centuries and even millennia, disability was considered to be located solely within the individual and equated with biological impairment. As Henri-Jacques Stiker shows in *A History of Disability*, the conceptualisation of disability has accrued different meanings and elicited varied responses across the centuries, which range from fear to charity to rehabilitation.\(^7\) The disabled activists who first made the clear distinction between impairment – which is caused by biological or psychological factors – and disability – which is located in society – were reacting to and countering a very long history of conflating impairment and disability. For this reason, on the one hand, many have for a long time stayed away from a consideration of how impairment impinges on the life of a disabled person. Barnes and Mercer write

> Those who assert the importance of the conceptual distinction between impairment and disability respond that ‘bringing impairment in’ clouds both the crucial question of causality and the source of disability discrimination and prejudice … Far from denying the ‘reality’ of impairment and its impact on disabled people’s lives, the emphasis on separating impairment and disability is a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or other professional treatments.\(^8\)

On the other hand, those who have critiqued the social model point out that the separation of impairment and disability has led to a focus on the latter at the expense of the former and at the expense of considering the interaction between the two. Carol Thomas discusses how in Britain, the early disabled activists, especially Paul Hunt and Vic Finkelstein, worked on a social relational understanding of disability, that is one that considers the relationship between the individual’s impairment and socially imposed disability, and that this model was eventually replaced by the social model. Thomas argues for a return to the social relational model of disability, by acknowledging the restrictions caused by impairment and chronic illness – what she terms ‘impairment effects’ – while at the same time keeping one’s focus on socially created disabling barriers:

> If this kind of social relational understanding of disability could be adhered to within disability studies, that is, if the commonplace view that disability equates with restrictions of activity could be broken away from, then there would be no need for futile and time-wasting disputes about whether or not impairment or chronic illness cause some restrictions of activity. We can say, ‘Yes, of course impairment causes some restrictions of activity – but these are not what is of interest in studying and combating disability’. Disability is a form of social oppression on a par with other forms of oppression in our society associated with gender, race, class, and sexuality.\(^9\)


\(^{8}\) Barnes and Mercer, 96.

\(^{9}\) Carol Thomas, ‘How is Disability Understood? An Examination of Sociological Approaches’, *Disability and Society* 19.6 (2004): 581.
Tom Shakespeare and Nick Watson even went so far as to consider the social model outdated at the turn of the century and called for it to be discarded.\textsuperscript{10} The fact that it has not been discarded is indicative of the resonance it has for many disabled people to explain the difficulties that they encounter in societies that do not habitually take into account their impairment-related needs. That said, when in 2006 the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD), it was the social relational model of disability that was used. The Preamble to the CRPD in fact recognises disability as the interaction between impairment and disability.\textsuperscript{11} In effect, whether one upholds the social or social relational model of disability, one is in agreement that disability can no longer be equated with impairment and that society must play its part in removing, or at least attenuating the effect of, disabling obstacles.\textsuperscript{12}

It was mainly through the work of disabled sociologists, including Oliver and Barnes, that disability studies was established as an academic discipline, shifting the focus of the study of disability from embodied differences – as was the case especially for medical sociology – onto societal structures. Across the Atlantic, sociology too played a part in the development of disability studies. As the contributors to Green and Barnartt’s edited volume \textit{Sociology Looking at Disability} show, the work of American sociologists such as Talcott Parsons and Erving Goffman had a profound effect in developing a sociological approach to studying disability.\textsuperscript{13} In her 1998 monograph \textit{Claiming Disability}, Simi Linton traces the history of the development of disability studies, especially in the United States. As she states,

\begin{quote}
it is the authors who deliberately set out to place ideas about disability in more specifically contingent relationships to the social situation of disabled people and to the disability rights movement who form the core group of disability studies scholars. Many in this group view the establishment of disability studies as part of an overt agenda to gain power for disabled people through organizing and coalescing people, resources, and knowledge.\textsuperscript{14}
\end{quote}


\textsuperscript{12} There are also other models of disability, among them the Scandinavian gap model, the American minority model, as well as the human rights model and, as seen below, the affirmation model and critical disability studies. As Mike Oliver quips in \textit{Understanding Disability: From Theory to Practice}, there are enough of them to set up a modelling agency. Therefore, while disability studies is a much broader church now than it ever was, the consideration of disability as a social and political issue always remains. Latterly, critical disability studies has been developed as a way of focusing on disability as identity. In their critique of this approach in ‘Moral Wrongs, Disadvantages, and Disability: A Critique of Critical Disability Studies’ (\textit{Disability and Society} 29.4 (2014): 638-50), Simo Vehmas and Nick Watson insist that any study of disability ‘must involve an engagement with moral and political issues, and must be sensitive to individual experiences as well as the social, material and economic circumstances.’ (638). See Dan Goodley’s \textit{Disability Studies: An Interdisciplinary Introduction} (Thousand Oaks, CA: Sage, 2011) and Jan Grue’s \textit{Disability and Discourse Analysis} (Surrey: Ashgate, 2015) for in-depth analyses of various models and approaches to disability studies.

\textsuperscript{13} \textit{Sociology Looking at Disability: What Did We Know and When Did We Know it}, ed. and intr. Sara E. Green and Sharon N. Barnartt (Bingley: Emerald Publishing, 2016).

Significantly, most of the disability studies scholars being referred to in this Introduction are themselves disabled people. In fact, aside from achieving recognition of the disabling effects of society, the second most important achievement of the disabled people’s movement has been the battle cry of ‘nothing about us without us’.\(^\text{15}\) It was not only against the centuries-old conception of disability as the equivalent of impairment that the early disabled activists were up against, but also against firmly entrenched practices of professionals, especially those working in the health sector, deciding for them what they needed and what interventions were best for them.

There are two watershed moments in this regard. The first was Miller and Gwynne’s study with the disabled residents of Le Court Homes in London, which was commissioned after the residents themselves suggested that research be carried out in how they could gain more control over their lives.\(^\text{16}\) Paul Hunt, one of the residents, wrote a seminal critique of their book, which provides an extensive analysis of all that is wrong about this study.\(^\text{17}\) Despite having requested the research in a bid to bring about improvement in the quality of services provided, the residents (all of whom had physical impairments) were left in pretty much the same situation they had been in before. Hunt criticises Miller and Gwynne because, in the name of scientific objectivity and detachment, they did not seek to expose the causes of what they themselves saw as the residents’ pitiful state and ‘social death sentence’.\(^\text{18}\) Instead, they recommended better training for staff, thus maintaining the status quo and, Hunt argues, advancing their own career through the publication of their research. The second watershed moment occurred in the same year on the other side of the Atlantic, with the founding of Disabled People’s International by a group of disabled people who walked out of the Rehabilitation International Conference in Canada after they were not allowed to speak by the professionals participating in the conference.\(^\text{19}\) The importance of disabled people being involved in decisions affecting them is upheld in the CRPD, while the role of non-disabled people in the disabled people’s movement and disability studies remains a subject of debate.\(^\text{20}\)

While disability studies fills in gaps that have been left largely unaddressed by other disciplines in their consideration of disability, not least by giving primacy to the voice of those who have a lived experience of disability, it can be said to have created its own gaps. One of these gaps is related, as seen above, to the almost exclusive focus on socially-created disability and the deliberate move away from considering the effects of living with activity-living impairments. This move was a reaction to centuries of focusing on impairments and to research which, like that carried out by Miller and Gwynne, did much to enhance the researchers’ professional status but very little to improve the situation of disabled people—hence Paul Hunt’s label of ‘parasite people’. However, this move has meant that some people have for a long time felt left out of


\(^{18}\) Hunt, 41.

\(^{19}\) See Driedger.

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Disability studies, including those living with chronic illness and/or chronic pain. Moving away from a focus on impairment also brought with it the need to emphasise that disabled people are not ill. People who are ill need doctors. But if medical treatment is not sufficient to address disabled people’s problems, then one needs to stay away from any talk about health-related issues. On the other hand, the need for medical treatment is a reality for many people who are ill and who are also disabled by society. Susan Wendell makes a distinction between ‘healthy’ and ‘unhealthy’ disabled people, that is those who have impairments but do not require ongoing medical treatment, and those whose impairments originate from an illness that requires regular medical intervention. For the latter, the distinction between the effect of their impairment and the effect of disabling barriers may become blurred. Alison Kafer, cited by Welch, writes: ‘[p]eople with chronic illness, pain, and fatigue have been among the most critical of this aspect of the social model, rightly noting that social and structural changes will do little to make one’s joint stop aching or to alleviate back pain.’

Interestingly, it is feminist scholars who are themselves disabled who have mostly voiced concerns about the difficulties that arise from the distinction. With reference to these scholars, Welch writes that they ‘have criticized this body/society divide as impractical and inadequate for describing their lived experiences with chronic illness, impairment, and disability.’ Welch refers to Liz Crow, Sally French, Alison Kafer, Rosemary Garland-Thomson, Simi Linton, Jenny Morris, Carol Thomas and Susan Wendell. As a solution to the impasse created by a rigid distinction between impairment and disability, Welch presents the work of the disabled American medical sociologist Irving Zola, one of the pioneers of disability studies in the United States, who sought to deal with the disabling barriers created by society while at the same time speaking about his impairments and illness as part of his identity.

Another approach to considering disability that takes identity issues into account is the affirmation model of disability, first developed by John Swain and Sally French. This model takes individual impairment into account, while deliberately moving away from a conceptualising of impairment as tragedy. Through this model, Swain and French sought to include disabled people who have chronic illness and those who live with chronic pain. Living with activity-limiting conditions becomes part of one’s identity. This view sees impairment as ‘physical, sensory and intellectual difference to be expected and respected on its own terms in a diverse society.’ Rather than being seen as an abnormal occurrence, impairment (and also illness) are considered as part of the human condition. Moreover, they are considered by the person as an integral part of their selfhood. This position is described well by Sharon Dale Stone when writing about living with osteoarthritis, among other conditions:

23 Welch, 123.
I regard it less as an illness and more as something that prevents me from doing all that I might otherwise do. On a day-to-day basis, I do not ‘feel’ that my osteoarthritis is an illness so much as an attribute of my body, much the way other impairments I live with are attributes of my body. The pain that arthritis can cause is something I would be happy to live without, but this does not mean that I am unhappy to live with pain. Yet the idea of having an impairment caused by arthritis resonates with my experience. Rather than experiencing my arthritic knee in terms of suffering, I experience it in terms of (permanent) bodily impairment. As such, it is neither good nor bad, it just is.

For some disabled people, impairment is not only something that ‘just is’ but is also something to celebrate. In fact, the affirmation model is based on the premise that for many disabled people, the impairment itself is a positive aspect of their identity. This position may seem counterintuitive to those who equate impairment and illness with tragedy, and even a fate worse than death. A prime example of this position is the concept of ‘Deaf Gain’, a term which is the polar opposite of ‘hearing loss’. Deaf Gain refers to the visual skills developed by Deaf people as they negotiate their way in the world, and the experiences and knowledge they acquire by virtue of being Deaf.

Affirming, and even celebrating, one’s identity as a disabled person also finds expression in Disability Arts, that is performances and other artistic output by disabled people that includes direct reference their impairment and is based on a socially-oriented understanding of disability. French and Swain in fact state that the affirmation model was developed directly from what disabled people have produced through Disability Arts. Among others, they cite a poem by Colin Cameron, ‘Sub Rosa’, which ends with the following lines:

But proud and privileged to be who we are ...  
Exactly as we are.

Disability is therefore conceptualised in a variety of ways. Indeed, the location of disability in social contexts makes it mutable and open to interpretation, and a consideration of these different conceptualisations and interpretations is an important area of study. The paragraph of the Preamble to the CRPD quoted above begins by recognizing ‘that disability is an evolving concept’. Disability, therefore, is not only not equivalent to impairment and not only caused by socially created barriers, but it is also a fluid and ever-changing concept. Conceptualisations of disability, however abstract, have real impact on the lives of disabled people. When these conceptualisations are negative and deficit-oriented, the impact can be devastating. All too often, disabled people have been regarded as having something missing and even as not being fully human. These views translate into death-related practices, such as the abortion of disabled foetuses and the support of assisted dying for those with long-term disabilities.

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27 Petra Kuppers, Studying Disability Arts and Culture: An Introduction (Hampshire: Palgrave Macmillan, 2014). The word ‘Deaf’, with an initial capital, refers to people who are born profoundly deaf and for whom sign language is the first language and Deaf culture the one they identify most with.
Studying disability as an abstract concept is therefore also a very important aspect in disability studies. In *Claiming Disability*, Linton identified a gap in ‘the study of disability as idea, as abstract concept, and it is in the humanities that these gaps are most apparent. It is there that the meanings attributed to disability and the process of meaning-making could be examined.’ In fact, it has been in the humanities that an examination of the meanings attributed to disability has developed most extensively. This development has been most marked in the United States with many scholars weaving their work on disability studies with analyses of literature, film and the visual and performance arts. Similarly to the British disability studies scholars mentioned above, most of them are disabled or are closely related to a disabled person. Apart from Simi Linton, these scholars include, among others, Brenda Brueggemann, Lennard Davis, Rosemary Garland-Thompson, Georgina Kleege, David Mitchell, Ralph Savarese, Sharon Snyder and the late Tobin Siebers. One of the seminal books is *Narrative Prosthesis* by David Mitchell, himself a disabled person, and Sharon Snyder in which they show how in many narratives the presence of disabled characters is a metaphor for a disruption that needs to be fixed and how prevalent is the practice of using disability as a prop to move the plot forward. These tendencies of authors to use disabled characters as a means to end, Mitchell and Snyder forcefully argue, are in stark contrast to the failure of these same narratives to represent disabled characters as human beings in their own right, and to do justice to the representation of the lived experience of disability.

The most important interpretations of disability remain those articulated by persons who themselves live disability on a personal basis. In their theoretical and autobiographical writing, as well as through creative writing, disabled scholars analyse how they negotiate their way through life and through the obstacles created by socially and culturally disabling factors. These writings conceptualise disability as an aspect of the human condition that is inevitable and navigable. In some cases, the personal experience of disability informs the text without it being directly autobiographical, as in the case of *Narrative Prosthesis* as well as *Extraordinary Bodies* by Rosemary Garland-Thompson and *Disability Theory* and *Disability Aesthetics* by Tobin Siebers. In other books, the autobiographical is directly merged with the theoretical. This is the case for Susan Wendell’s reading of feminism from a disability angle in *The Rejected Body* and Rod Michalko’s *The Difference That Disability Makes* which combines his memoir of his experience of becoming progressively blind in his childhood and adolescence with an extensive discussion of how blind people have to navigate their way through a world made for the sighted. Then there is Anne Finger’s history of polio in *Elegy for a Disease*, in which she interweaves her own experience, of contracting the disease and living with its aftermath, with the impact that the disease had on American culture.

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29 Linton, 87.
Others have written their autobiography through a social relational understanding of their experience of disability, and with an awareness of disability politics. Such autobiographies include Stephen Kuusisto’s *Planet of the Blind* and *Eavesdropping: A Memoir of Blindness and Listening*, and Robert Murphy’s *The Body Silent*. In addition, there are *Notes on the Flesh* by Shahd Al-Shammari and *Re-Membering* by Ann Millett-Gallant, two of the contributors to this special issue.

Furthermore, Michalko, Kuusisto and Finger are among the many disabled people who also use their creative writing skills to put forward disabled people’s agenda, through short stories, poetry, novels and plays. Examples include Michalko’s and Anne Finger’s anthologies of short stories (*Things Are Difference Here* and *Call Me Ahab* respectively), and Kuusisto’s poetry collections (*Only Bread, Only Light* and *Letters to Borges*). Of note also is Kenzaburō Ōe, the Japanese laureate for the 1994 Nobel Prize for Literature, whose work has been heavily influenced by his experiences as the father to Hikari, his son who has an intellectual disability. To these, we can add disabled playwrights who have combined their personal experience of disability with their knowledge and awareness of disability politics in their writings and productions. Victoria Ann Lewis’s *Beyond Victims and Villains* brings together excerpts from plays by David Freeman, Lynn Manning, and Susan Nussbaum among others. Another disabled playwright worthy of note is James MacDonald, who combines his personal experience of disability with his interest in Russian culture, as can be seen in his anthology *Russia, Freaks and Foreigners*. This list is by no means exhaustive and does not take into account the work of other disabled artists, such as painters, sculptors and dancers, which is part of Disability Arts. It is a list that is merely indicative of the wealth of literary output produced by disabled people which counters the age-old tendency to use disabled people as props for a narrative and to rely almost exclusively on stereotypical representations of disability without taking into consideration how disability emerges in the experience of those who live it on a daily basis.

These representations have been the subject of analysis by various authors, whether or not they themselves are disabled. These analyses highlight how disability has always permeated narrative, even in mythology as witnessed by the presence of


38 *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights*, ed. and intr. by Victoria Ann Lewis (New York: Theatre Communications Group, 2006). As the title of the book implies, the aim is to present narratives where disabled people are fully rounded characters and not simply cast in the stereotypical roles of either victims or villains.

disabled gods and other disabled figures such as Hephaestus and Tiresias in Greek mythology and Odin in Norse mythology. For example, Charles Gardou discusses how disability permeates French popular culture, Patrick McDonagh delves into a cultural history of the representation of intellectual disability, and Ato Quayson adds further to the analysis of disabled characters in American literature contributed by David Mitchell and Sharon Snyder, and by Rosemary Garland-Thomson, cited above. Similar aspects become the focus of several articles included in our issue. There is also much more work that can be referred to, including articles in disability studies and in humanities journals; presentations in conferences within both disciplines, most notably the annual Modern Language Association Convention held in the US; and the work of the Centre for Culture and Disability Studies at Liverpool Hope University which bridges the two disciplines and which includes *The Journal of Literary and Cultural Disability Studies* and various books, a taught Masters in Disability Studies that has a substantial focus on the cultural representation of disability, and an annual interdisciplinary conference.

It can thus be seen how the work of disability studies scholars within the humanities reinforces, complements and at times merges with work in disability studies that is situated within sociology or other disciplines. The possibility for these collaborations emerges from a consideration of disability as arising from social and cultural factors and of disability as a political issue. The study of both individual and social factors and the interplay between them also creates the possibility of disability studies and critical trauma studies meeting, with the latter bringing into focus the experience of going through traumatic events which leave not only physical but also psychological marks and the former emphasizing the consideration of sociocultural factors that impinge on how trauma is experienced by the individual.

**From Trauma Studies to Critical Trauma Studies**

As Jean Laplanche and Jean-Bertrand Pontalis showed in *The Language of Psychoanalysis*, ‘trauma’, coming from the Greek τϱα茌μα (meaning ‘wound’ and deriving from τϱο茌σχω, ‘to pierce’), is a term that has long been used in medicine and surgery that generally designates ‘any injury where the skin is broken as a consequence of external violence, and the effects of such an injury upon the organism as a whole’, and whose implications were extended to other types of injuries (like the ones that cannot be seen on the skin, but are internal). All the three ideas implicit in the term to the psychical level were carried in psychoanalysis: ‘the idea of a violent shock, the idea of a wound and the idea of consequences affecting the whole organisation.’

If we are to attempt to write a short history of trauma, perhaps the best to start with is Sigmund Freud, the father of psychoanalysis, for whom our emotions were always about the other. Freud used the term ‘repression’ as a key concept in psychoanalysis that signifies a defence mechanism, by which he understood ‘a defence

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of the mind under normal and abnormal conditions to neutralize or put out of action unwelcome and unpleasant thoughts.” Freud would later call the theory of repression ‘the corner-stone on which the whole structure of psychoanalysis rests.’ Early in his career, Freud assumed that neurotic symptoms are provoked by a history of sexual seduction in one’s childhood. His observations on the relationship between the external and internal world, which were later on reformulated in more nuanced terms referring to the conscious/unconscious, referred explicitly to what he called “traumatic” hysteria or ‘traumatic neurosis’ and ‘precipitating trauma’ whose symptoms he described in detail: ‘neuralgias and anaesthesias of very various kinds, many of which had persisted for years, contractures and paralyses, hysterical attacks and epileptoid convulsions, which every observer regarded as true epilepsy, petit mal and disorders in the nature of tic, chronic vomiting and anorexia, carried to the pitch of rejection of all nourishment, various forms of disturbance of vision, constantly recurrent visual hallucinations, etc.’

Freud was the first to talk about female hysteria, explained by his theory on the Oedipal complex and which is nowadays the equivalent of trauma linked to childhood sexual abuse (incest, rape). After WW1, Freud returned to his theories on trauma, analysing men returning from the battlefield with trauma. Thus, following Freudian psychoanalysis, trauma became a key concept in clinical psychology that diagnosed a psychological injury that resulted from experiencing an external event that damaged the individual’s self, and went on producing belated negative effects manifested as involuntary symptoms such as compulsive repetitive behaviour, nightmares and flashbacks.

In the sixties, a separation from Freud’s ideas about emotions and repression took place and affect scholars (especially psychologist Silvan Tomkins and his follower, Paul Ekman) put forward the theory according to which the relationship between affect and ideas or meaning seem arbitrary or contingent. They believed that affective processes appear independently of intention or meaning, thus going into the opposite direction of Freud and ‘appraisal theorists’, who claimed that emotions are embodied and related to our desires and beliefs. In 1962, Tomkins published the first volume of *Affect Imagery Consciousness*, followed by the second volume a year later, and two more, one in 1991 and one that was published posthumously in which he coined the term ‘affect’ by which we understand subjectively experienced feelings.

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47 These feelings can be positive (such as enjoyment/joy and interest/excitement), neutral (like surprise) or negative (like anger/rage, disgust, distress or anguish, fear/terror and shame/humiliation). Asked by the editors of the book why he failed to put a comma between the three nouns in his title, he explained that the concepts are interlocked: ‘Affect produces attention that brings its trigger into consciousness, and the world we know is a dream, a series of images colored by our life experience of whatever scenes affect brought to our attention and assembled as scripts.’ (Tomkins quoted in ‘Prologue’, by Donald L. Nathanson (ed.), in *Affect Imagery Consciousness*, vol. 1, xi). In a sense, Tomkins’s explanation makes us
has been taken up both in social science disciplines, like psychology and psychoanalysis, and the humanities (especially critical theory and gender studies), but also in medicine or neuroscience.

By the time Affect theory appeared, trauma studies had rather a clinical than a cultural meaning. Yet, let us not forget that the second half of the twentieth century came with catastrophes (the Holocaust, the Vietnam War), as well as a series of controversies in the United States around the issue of childhood physical and sexual abuse, rape and sexual violence that became public once feminists in the arts and literature decided to break the silence around this topic, after the publication of Susan Brownmiller’s book Against Our Will that shattered beyond belief what human beings pretended to know about themselves. As Jane Goodall and Christopher Lee mentioned in Trauma and Public Memory, a book that is reviewed in the present issue, clinical studies of psychological trauma intensified following WW2, with the first Diagnostic and Statistical Manual of the American Psychiatric Association in 1952 referring to a syndrome that was ‘known as “gross stress reaction”, described as a response to the exceptional physical or mental stresses of war and other catastrophic situations.’ Of note is that the Holocaust and the Vietnam War were the two events leading to the medical recognition of the diagnosis of Posttraumatic Stress Disorder (PTSD) into the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (1980). This recognition is also due to ‘the intense lobbying’ (that was ‘much a political as a medical and sociological campaign’) by mental health workers and lay activists on behalf of Vietnam War veterans. The condition of the ones suffering from this sort of recurrent psycho-physiological state of crisis and ‘disorder’ described as ‘post-’ (i.e. after) relates to what they face at a present that recalls a past, thus violating temporality; it is characterized, as Goodall and Lee show, ‘precisely by an ongoing relationship to traumatic experience not as “post” but as current, as something that continues to make itself present in sensory and physiological terms, through the flashback experience.’ Survivor guilt was included among the symptoms of PTSD, a symptom that in the latest editions has disappeared from the official list of criteria for PTSD and has been replaced by shame. The new clinical specialty named psychotraumatology appeared and in 1985 The Society for Traumatic Stress was founded, followed by the Journal of Traumatic Stress several years later and ‘more

meditate upon the fact that one cannot really consider any factor in isolation, which is also the guiding thread of our issue.

51 Goodall and Lee, 12.
53 Goodall and Lee, 3.
recent eruptions of nationalistic and genocidal violence, events that psychiatrists have labeled “massive psychic traumata”.55

In 1979, television journalist Laurel Vlock from New Haven, Connecticut interviewed the practicing psychoanalyst Dori Laub, a former victim of the Transnistrian camps where Romanian Jews were sent by Marshall Antonescu in 1942. His interview became the first in a huge testimonial enterprise, nowadays known as The Fortunoff Video Archive for Holocaust Testimonies at Yale. Vlock and Laub became the co-founders of The Holocaust Survivors Film Project,56 a project in which they conducted fourteen hundred videotaped interviews of Holocaust survivors and witnesses. The archive was moved to Yale University in 1981 and was opened to the public one year later. In 1982, Lawrence Langer published his Versions of Survival that focused on the interpretation of survivor memoirs from the archive; here he called for a post-Holocaust revision of ethics, arguing vehemently that traditional ethics is incapable of judging Holocaust victims’ dilemmas and contradictions of their unheroic ‘choiceless choices’, that he defined in his ‘The Dilemma of Choice in the Death-Camps’ as those situations ‘where critical decisions did not reflect options between life and death, but between one form of “abnormal” response and another, both imposed by a situation that in no way was of the victim’s own choosing’.57 In 1985, Claude Lanzmann’s Shoah, totalizing nine hours and resulting from Lanzmann’s work for 11 years was released. It contained the interviews with survivors, witnesses and perpetrators that he conducted in the many visits to four sites across Poland.58

With such a background, at the beginning of the eighties, we can speak of the development of trauma theory that initially derived from Freudian psychoanalysis and was a theory of subjective dissociation.59 Since a large number of the best-known trauma scholars were psychoanalysts who worked with Holocaust survivors, the Holocaust can be considered germinal for trauma theory. However, trauma theory was also largely fed by medicine, psychology, sociology, law, theology, feminist theory and genocide studies. What really inscribed trauma studies within the humanities instead of the social sciences is the huge interest people in the humanities and, in particular, in literary studies invested in it. Langer’s volume, Holocaust Testimonies: The Ruins of Memory performed an analysis of about three hundred of the videotaped interviews existent in the Yale archive. Emphasizing the role of oral Holocaust memories, that of complementing historical studies, Langer explored both what he called ‘common memory’, a mediating type of memory (which normalizes the camp experience so that the survivor can cope with trauma, that mediates ‘atrocity, to reassure us that in spite of the ordeal some human bonds [among the Victims] were inviolable’) and ‘deep

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56 The project was joined by William Rosenberg, President of the New Haven Farband (the only survivor of his Polish-Jewish family of seven children, who was an inmate of seven concentration camps) and Geoffrey Hartman, Sterling Professor of English and Comparative Literature, born in Frankfurt, in 1929 and saved from Hitler’s hell on a Kindertransport to England in 1939 where he spent the war years.
58 The sites are Chełmno extermination camp, where gas vans were used to exterminate Jews, Jews, the death camps of Treblinka and Auschwitz-Birkenau, as well as the Warsaw Ghetto.
memory’ which recalled ‘the Auschwitz self as it was then.’ His subsequent volumes: *Preempting the Holocaust* examining Holocaust themes in literature and memoirs (with an emphasis on authors like Primo Levi, Elie Wiesel, Cynthia Ozick, Art Spiegelman, Simon Wiesenthal), painting and art installations (Samuel Bak, Judy Chicago) and film (*Undzere Kinder*) and *Using and Abusing the Holocaust* in which, for instance, he revisited Ann Frank’s diary and criticised Benigni’s film *Life is Beautiful*, made him probably the best known literary critic of Holocaust literature and art and circumscribed once more trauma studies to the Humanities.

The Yale literary critic Shoshana Felman joined Dori Laub (as she modestly confessed, ‘a professional interpreter of texts’ joined ‘a professional interpreter of people’ in the effort to write for six years *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History* which became a capital trauma studies text that moves from the literary to the visual, embarking on autobiography, psychoanalysis and history. In the very preface of their book, they mentioned that with the exception of some texts, the major literary works, films and documents analysed (Camus’s novels, de Man’s essays, Celan’s poetic project, videotaped Holocaust testimonies and Claude Lanzmann’s film *Shoah*) were ‘all written and produced consequent to the historic trauma of the Second World War’, a trauma they considered ‘as the watershed’ of their times and which their book came ‘to view not as an event encapsulated in the past, but as a history which was essentially not over, a history whose repercussions were not simply omnipresent […] but whose traumatic consequences were still actively evolving’ in the political, historical, cultural and artistic scene of the nineties. In Chapter 3 (‘An Event Without A Witness: Truth, Testimony and Survival’), moving from the practice of the testimonial, Laub attempted to come up with the first theory of testimony, with all its historical and philosophical lessons and exploration of their psychoanalytic implications.

Two years after this remarkable volume, Dominick LaCapra published his *Representing the Holocaust: History, Theory, Trauma*, in which, starting from Freud, he distinguished between two forms of remembering trauma: ‘working through’ and ‘acting out’. While the former means gaining critical distance from the traumatic event one had experienced, being able to continue living in the present, putting the past behind although one could not disengage completely from the traumas of the past, the latter is related to repetition. According to LaCapra, people who have undergone a trauma, have the tendency to relive their past without being capable of living in the present. Their flashbacks, nightmares, sometimes words that were compulsively repeated because of past connotations in relation to trauma are proof that they have not managed to work

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62 Here we may note his criticism of the sporadic impulse to shift the emphasis from the crime, the criminals and the victimized to the question of forgiveness and the need for healing.
65 The texts were from Freud, Dostoevsky and Mallarmé.
66 Felman and Laub, xiv.
through their trauma, but they are acting it out. LaCapra examines the transference relationship between scholars and their subjects and also proposes a radical solution to the methodological problem of analogical articulations between concepts of psychological and cultural trauma, pointing out that psychoanalysis could be a discourse that has more affinity with the social and cultural realm than with the level of the individual psyche. His subsequent Writing History, Writing Trauma, whose purpose was ‘to treat trauma and post-traumatic symptoms in a manner that links them to inquiry into other significant problems, including the relations between the individual and society, the political implications of a research orientation, and the limitations and possibilities of an emphasis on melancholia, the sublime, the transhistorical, mourning, acting out, and working through problems that bear on social and political issues’, looked at examples from testimonies from the Holocaust, with a chapter focusing on Claude Lanzmann’s Shoah and the role of the interviewer in survivor testimonies, whose position LaCapra compared with that of the oral historian.

After her edited collection Trauma: Explorations in Memory, one year later Cathy Caruth published Unclaimed Experience: Trauma, Narrative, a pioneer psychoanalytic book on trauma, starting from Lacan and originating also from Paul de Man’s deconstruction to explain the aporia in consciousness and representation that outlines the traumatic experience. Caruth’s theory was built on the work of renowned contemporary psychologists and psychiatrists such as Judith Herman and Bessel van der Kolk. Caruth explored a number of literary texts and Alain Resnais’s and Marguerite Duras’s film, Hiroshima mon amour. Bringing in the idea of ‘belatedness’ at the centre of a theory of trauma and arguing that a traumatic event is accessible only in its return, Caruth suggested that trauma is an experience so intensely painful that the mind of the survivor who was exposed to trauma is unable to process the event under normal circumstances; in Caruth’s view, the narration written by the witness of a trauma is both amnesic and ‘unspeakable’, thus demonstrating that speaking trauma is an unsolvable problem of the unconscious and illuminating the inherent contradictions of experience and language. With Caruth’s discoveries, trauma studies gained significant attention for literary scholars and scholars interested in film, photography, media studies and museum studies, cultural studies, sociology, anthropology, Affect theory and especially memory studies which developed in close partnership with trauma studies.

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69 LaCapra, Representing the Holocaust, 173-4.
70 Dominick LaCapra, Writing History, Writing Trauma (Baltimore: Johns Hopkins University Press, 2014), ix.
71 LaCapra, Writing History, Writing Trauma, 86-113.
72 Cathy Caruth, Unclaimed Experience: Trauma, Narrative, and History (Baltimore: Johns Hopkins University Press, 1996).
73 Although it is impossible to make an exhaustive list, of note are Paul Antze and Michael Lambek’s edited volume Tense Past: Cultural Essays in Trauma and Memory gathering contributions from anthropology, history and philosophy of science and psychiatry, that looked into the role of memory, identity and society in trauma studies (New York: Routledge, 1996) and Avishai Margalit’s The Ethics of Memory that asks the question of the responsibility we have to remember the past, concluding that one particular community can have, and ought to have, collective memories and venturing a tentative belief in
In 2000, Ruth Leys’s *Trauma: A Genealogy* divided trauma studies in two different directions depending on the way the experience of trauma victims is conceptualized: ‘mimetic’ or ‘anti-mimetic.’ According to the first model, trauma victims were regarded as behaving rather like hypnotized people who are unable to distance themselves from the traumatic events they lived through and thus are prone to compulsive repetition of the respective event (or the unconscious imitation of the aggressor or other). In this case, Ruth explains, there are two major disadvantages: on the one hand, the validity of the victim’s testimony is questioned: ‘because victims are understood as traumatized into a state of imitative-identificatory suggestibility, the mimetic model can’t help worrying about the question of hypnotic suggestion and the fabrication of more or less false memories’; on the other hand, the victim is held to be identified with the aggressor and in a sense he/she becomes complicitous with the violence that was directed against him/her. The second ‘anti-mimetic’ model offers a different interpretation of imitation in the sense that victims are allowed to see and represent to themselves the trauma that they have experienced, thus not identifying themselves with the perpetrator but rather remaining a spectator to the scene of violence in which they were implicated. In Leys’s words,

> The antimimetic theory is compatible with, and often gives way to, the idea that trauma is a purely external event that befalls a fully constituted if passive subject. [...] In contrast to the mimetic theory’s assumption of an unconscious identification with the aggressor, the antimimetic theory depicts violence as simply an assault from without. This has the advantage of portraying the victim of terror as in no way mimetically collusive with the violence directed against him, even as the absence of hypnotic

the power of healing: ‘making the traumatic, repressed communal memories open, explicit, and conscious is said to have healing power,’ a belief that otherwise was at the heart of the Truth and Reconciliation Committee in South Africa (evoked by several articles included in this issue) which ‘was established with the hope that it will lead to social catharsis — that the truth about the past will, by being revealed, bring reconciliation.’ (Cambridge, MA and London: Harvard University Press, 2004). 5. One should also mention also the fact that ‘trauma studies and memory studies constantly intersect each other is possibly due to an inherent affinity between their subjects: although not all memory is traumatic, trauma generally is described as a kind of memory (from this view, trauma studies would have to be postulated as a department of memory studies)’ (Traverso and Broderick, 5). Kali Tal’s *Worlds of Hurt: Reading the Literatures of Trauma* concentrates on survivors of trauma of the Holocaust, the Vietnam War and sexual abuse and incest and the critical debate in the United States around them. (Cambridge: Cambridge University Press, 2004 [1996]). Marianne Hirsch’s *Family Frames: Photography Narrative and Postmemory* (Cambridge, MA: Harvard University Press, 1997) analyses the way in which collective memory is constructed from photographic images and develops her own theory on post-memory that reveals the complex relations between witnesses or survivors of trauma and the generations that succeeded them and related to the traumatic events of their ancestors. James E. Young’s *The Texture of Memory: Holocaust Memorials and Meaning* (New Haven and London: Yale University Press, 1993) and *At Memory’s Edge: After-Images of the Holocaust in Contemporary Art and Architecture* (New Haven and London: Yale University Press, 2000) as well as Silke Arnold-de Simine’s *Mediating Memory in the Museum: Trauma, Empathy, Nostalgia* (Houndmills, Basingstoke: Palgrave Macmillan, 2013) look at a range of museums at the interface between memory and museum studies. See also, Paul Williams, *Memorial Museums: The Global Rush to Commemorate Atrocities* (Oxford and New York: Berg, 2007) and Arleen Ionescu, *The Memorial Ethics of Libeskind’s Berlin Jewish Museum* (London: Palgrave Macmillan, 2017). 74 Ruth Leys, *Trauma: A Genealogy* (Chicago: University of Chicago Press, 2000). 75 Ruth Leys and Marlene Goldman, ‘Navigating the Genealogies of Trauma, Guilt, and Affect: An Interview with Ruth Leys’, *University of Toronto Quarterly* 79.2 (Spring 2010): 658.
complication as regards the reliability of his testimony shores up the notion of the unproblematic actuality of the traumatic event.\textsuperscript{76}

In \textit{Trauma: A Genealogy}, Leys puts forward a critique of Caruth’s theory, that she associates with affect programme theorists and in particular to Bessel van der Kolk’s work. Caruth asserted that trauma cannot be generalized but seen from the different positions the ones involved in the traumatic event had: victims, perpetrators and witnesses. Leys urges for the revision of the classical model of trauma foregrounded in the unrepresentability of the traumatic event in an attempt to move beyond an aporetic understanding of trauma, investigating both intersubjective and intrasubjective psychic processes of healing. In Leys’s opinion, although coming from different angles, Caruth, Van der Kolk and de Man shared ‘a commitment to the idea that trauma lies outside all representation because under conditions of trauma the ordinary mechanisms of consciousness and memory are temporarily destroyed’, with the result of what they claimed to be ‘an undistorted, material, or “literal” registration of the traumatic event […] that cannot be known or represented but returns belatedly in the form of “flashbacks” and other repetition phenomena’; showing that ‘today’s affect theorists similarly espouse an anti-intentionalist or materialist position’, making trauma theory and affect theory overlap.\textsuperscript{77} Leys also takes distance from the implications of Affect theory for artistic and literary criticism and its adoption in approaches to trauma theory.\textsuperscript{78}

The new millennium brought about cataclysms\textsuperscript{79} (environmental catastrophes such as tsunamis, floods, earthquakes and fires) and new traumas in the mental collective: 9/11, other terrorist attacks, the post-9/11 war on terror as well as the advancement of knowledge in medicine, psychiatry, psychoanalysis in exploring traumas of patients suffering from neurodegenerative disorders, such as Alzheimer or Parkinson that, even if they were existent before, were neither understood nor talked about at the end of the century.\textsuperscript{80} Trauma started to be interrogated, to make use of

\textsuperscript{76} Leys, \textit{From Guilt to Shame}, 9.
\textsuperscript{77} Leys and Goldman, 677. Also, in a sense, taking distance from classical trauma studies, \textit{The Journal of Literary Studies} recently published a special issue on ‘Mending Wounds? Healing, Working Through, or Staying in Trauma: An Introduction’, co-edited by John Masterson, David Watson and Merle Williams. This issue raised the question whether cultural narratives of trauma can contradict classical trauma theory which failed in discussing the efficacy of working through traumas and explore the endurance of trauma without looking at the possibilities for its resolution. Proclaiming autobiographies as the accounts that allow ‘victims to rewrite the histories that their interrogators have written for and of them, only to find themselves rewritten again by their readers,’ the editors put forward the narratives of the contributors to the special issue concerning the healing and mending of wounds suggesting ‘that trauma theory has given premature closure to discussions concerning the efficacy of working through traumas.’ (29.2 (2013): 4 and 2).
\textsuperscript{80} Of note are the works of Catherine Malabou who published her first work (\textit{Que faire de notre cerveau?}) in 2004, in which she coined the term \textit{plasticity} (\textit{What Should We Do with Our Brain?} Foreword by Marc Jeannerod, trans. Sebastian Rand (New York: Fordham University Press, 2008), 4). Her next book, \textit{Les nouveaux blessés: De Freud à la neurologie; penser les traumatismes contemporains} in 2007 introduces a radically new framework that stages a confrontation between psychoanalysis and contemporary neurobiology, within which to conceptualize traumatic events and their impact on the cartography of an individual’s brain. Malabou works on those that she calls ‘the new wounded,’ brain lesion patients who were victims of accidental traumatisms, chronic degenerative maladies or different forms of extreme violence devoid of reason, patients whose brain was affected and who cannot
Traverso and Broderick’s term in their issue dedicated to the turn of trauma towards critical trauma studies, a branch of trauma studies which considers both those who study trauma and those who experience and narrate it as a personal and embodied event, looking at the way in which the two parties inform each other. Critical trauma studies deals with how social relations and cultural meanings produce trauma in two ways: on the one hand, through class, gender, race, sexuality, social relations can denigrate and oppress individuals, on the other hand, trauma can be socially constructed. On the outset of their issue, the two editors underlined that interrogation ‘does not involve a blind rejection of this theory,’ but rather an awareness of the fact that ‘[t]rauma has progressively become a key notion in discussions that interrogate the links between social history, subjective experience, and cultural representation.’ Acknowledging important voices in the field, they stressed the ‘urgent need to reassess the study of the cultural engagement with historical suffering caused by political conflict, in terms of new inter-disciplinary and inter-cultural methodological perspectives’, a need that was reflected in their ‘movement beyond trauma – not in the ethically and politically unsustainable sense of turning away from a humanistic concern with social suffering and social justice but in the sense of opening up the scope of interpretation most familiar to trauma studies.’

Monica Casper and Eric Wertheimer’s edited collection Critical Trauma Studies: Understanding Violence, Conflict and Memory in Everyday Life dealing with war scenes in Afghanistan and Chechnya, Iran’s Evin Prison, the Holocaust, sexual assault and racial violence in America, the devastation of Hurricane Katrina made a step forward towards surpassing the different intellectual boundaries of trauma studies. The editors claim ‘to seek to foster a new humanities’, which is ‘keen to meld the scientific with the affective’, yet in spite of holding the view that ‘neuro-stories are rapidly becoming hegemonic explanations and depictions of human life’ do not include a chapter on neuroscience but keep a certain subjectivity especially in the middle section communicate their trauma through language, as the very centre of their psychical life was destroyed. As she states, in the case of a brain lesion, the external character of the accident remains external to the psyche itself. It remains exterior to the interior. It is constitutively inassimilable.’ (The New Wounded: From Neurosis to Brain Damage, trans. Steven Miller (New York: Fordham University Press, 2012), 5.)

81 These definitions also paraphrase Maurice Stevens, From the Past Imperfect: Towards a Critical Trauma Theory, which is a forthcoming book. See The Semiannual Newsletter of the Robert Penn Warren Center for The Humanities, Vanderbilt University, 17.2 (Spring 2009): 1-5; https://www.vanderbilt.edu/rpw_center/Letters/letterss09.pdf [accessed 24 September 2018]. Stevens explains the evolution of the concept of trauma as follows: ‘[r]ather than thinking of trauma as an identifiable and discrete event that must have occurred at some specific point in time and place, it can be more usefully understood as a cultural object whose meanings far exceed the boundaries of any particular shock or disruption; rather than being restricted by the common sense ideas we possess that allow us to think of trauma as authentic evidence of something “having happened there”, a snapshot whose silver plate and photon are analogues to the psyche and impressions fixed in embodied symptoms, the real force of trauma flowers in disparate and unexpected places’ (3).

82 Traverso and Broderick, 4.


84 Traverso and Broderick, 9.


86 Casper and Wertheimer, 2.

87 Casper and Wertheimer, 5.
on ‘Poetics’, which, as Christopher Powell ventured to warn, may challenge and frustrate sociologists with their ‘intense subjectivity’, yet which ‘are worth wrestling with for the insights they offer into the affective experience of trauma’. 88

In a sense, Casper and Wertheimer’s idea that ‘critical trauma studies suggests a radical inquiry into how social systems, personal experience, and biophysical (including neurological) mechanisms all co-produce each other’ 89 is also the one on which our issue is based in our belief that an inquiry into the encounters between disability studies and critical trauma studies could reflexively map how both the traumatizing experiences of disability and the concept of trauma can produce new social orders. It is perhaps time now to make a new step forward and suggest an opening of critical trauma studies towards disability studies, a suggestion that was tentative in the work of Casper before, as will be shown in the following part.

Apart from Tobin Sieber’s analysis of ‘trauma art’ in a chapter of his 2010 book Disability Aesthetics that also refers to Caruth’s work, Daniel R. Morrison and Monica J. Casper are among the first specialists to suggest that trauma and disability may be fruitfully conceptualized as embodied manifestations of social classification systems. 90 Their proposal was that disability studies have created the possibility to meet trauma studies, due to the work of disability scholars in ‘moving disability beyond the body to the broader social, political, and cultural contexts in which bodies are located and which give them meaning’. 91 Such a relocation of disability studies together with recasting ‘disability as something more than inherently traumatic and traumatizing’ created the possibility of looking at disability through the lens of trauma studies in spite of the fear of a refocus on ‘acts of disabling’, those ‘moments of bodily breach and psychic tear’. 92 For Morrison and Casper, it was precisely within such ‘moments of wounding and their aftermath’ that human bodies become the ideal corporeal screen upon which are inscribed notions of the normal and the pathological’, an issue that was investigated by other disability studies scholars like Lennard J. Davis 93 and Monica J. Casper herself in collaboration with Heather Laine Talley 94 and has elements in common with critical trauma studies that also ‘theorized disruptions, breaks, shocks, and ruptures that mark deviation from situations perceived as normal or mundane.’

The trauma of brain injury, with its related impairments, will never completely disappear after the event that caused it and will forever remain inscribed upon the body and the mind of the wounded. For Maurice Stevens, such ‘marks’ (broken bodies, forever alienated minds) became part of incomplete narratives that are also investigated by trauma studies in order to better understand the way in which ‘ruination’ was

89 Powell, 443.
91 Morrison and Casper.
92 Morrison and Casper.
achieved. Thus, intersecting the two apparently disconnected fields of disability and critical trauma studies could create the premise of moving us ‘beyond stigma and its necessary amelioration and beyond curb cuts to a broader recognition of the temporal and socio-historical aspects (e.g., geopolitics, social suffering, lack of adequate health care, social and economic injustice) that are instantiated through the categories of disability and trauma and the classifications of people into these categories.’

Morrison and Casper show that, by focusing on stigma, especially when in relation to the ‘pathological’ body, disability studies ironically, while working ‘to expunge definitions of abnormal from the body’, maintained them precisely because of their attempt to erase from their discourse ‘wounds, impairment and pain’ and focussing on a disabled body that is ‘socially constructed (not material) and whose agency is posited as being in struggle and resistance against the normative culture.’ This is why they propose a refocus on the body as ‘a link between the categories of “disability” and “trauma”’, on wounding, on ‘the larger social forces that produce “trauma”, that damage bodies, and that continue to shape what the traumatized body read as “disabled” can be and do.’ This refocus is in fact in line with that called for by some disability studies scholars to engage with issues of embodiment. Another refocus they suggest is connected to the notions of time and space in disability versus trauma studies. While for disability studies, especially for its early proponents, disability was ‘an acute, singular thing, static in time and place’, critical trauma studies were always interested in examining not only the present but also the ‘pre- and post-wounding conditions’, a concern that we share as editors of this issue and that many authors of the different articles included here have tackled to.

Moreover, Alison Kafer has argued that the failure to engage the traumatic effects of disability constricts the work of specialists in disability studies, stressing the necessity of disability theories of trauma, mourning and loss. Disability studies scholars like James Berger point out that the origin of the impairment is not important, since disability studies relates in the same way to both congenital or trauma-induced impairment. In the same direction, Daniel Morrison and Monica Casper focus on the silence around the traumatic origins of many disabilities. Unlike them, Kafer suggests that ‘attending to violence and trauma does not run counter to but is actually an essential part of critical theories of disability.’ Kafer, the victim of a fire when she was very young, identified herself with a community of disabled people who had to keep to herself the trauma of the accident that produced her disability. Thus, she feels the need to speak her trauma out loud:

96 Morrison and Casper.
97 Morrison and Casper.
98 Morrison and Casper.
99 Morrison and Casper.
102 Morrison and Casper.
103 Kafer, 6.
Too often we act as if the celebration of crip communities and identities, the imagining of crip futures, somehow erased the histories of trauma that many of us bear alongside disability, but sometimes all it does is repress them, cover them over, shut them up. We act as if how we became disabled, or how we may have been traumatized by our encounters with medicine, no longer matters, or does not matter in such spaces. 104

Thus, she feels not only to relate her disability to ‘the pain or distress of stigma’ 105 noting in passing what Elizabeth J. Donaldson and Catherine Prendergast remarked: ‘there is definitely no crying in Disability Studies.’ 106 Kafer believes in the possibility to heal the psychological effects of the wounds that disabled bodies, because, as she quotes Susan Brison, ‘attempting to limit traumatic memories does not make them go away’ but ‘narrating a traumatic memory can help to defuse it’. 107

Encounters between Disability Studies and Critical Trauma Studies

What Kafer suggests, to ‘make room for explorations of how we discuss and respond to’ histories of trauma and/or mental disability 108 and to advocate ‘a deep reckoning with it [trauma] – theoretically, politically, personally, collectively’ 109 was the core of our call for articles that emphasized that the meeting of disability studies and critical trauma studies provides the opportunity to focus both on sociocultural factors as well as the wounds, impairment and pain of the disabled person, categories which are more important for trauma studies. Such a meeting can also ensure that those who in the past have felt left out of disability studies, and have not felt that they were represented by the disabled people’s movement, can find a place within the former and can benefit from the achievements of the latter. At the same time, we believe that trauma studies should open up towards disability studies, since there are many disabling effects that need to be treated not only as naïve ‘trigger warnings or naïve calls for safe spaces, but that require political and theoretical attention.’ 110

This issue takes its cue from the links between the categories of disability and trauma, redirecting attention to bodies and minds and their un/seen wounds and the intersection with un/seen wounds and trauma inflicted by society and culture. The call for articles for our issue sought to bring together reflections on experiences of disability and trauma, taking into account the manifold interpretations and theories, inviting an examination of topics of interest like: the lived experience of pain, reflections on acquiring a disability and/or undergoing trauma, voicing the experience of disability and trauma, auto/biographical and fictional narratives featuring disability and trauma, embodiment and enmindment, wounds as representations of disability, stigma related to the gendered/racialized/disabled body, hierarchies of empathy in relation to physical and mental disability or trauma, affinities between literary/critical theory and disability studies and critical trauma studies, cultural meanings of trauma and disability, disability

104 Kafer, 9.
105 Kafer, 12.
108 Kafer, 17.
109 Kafer, 18.
110 Kafer, 18.
and trauma in the arts, literary explorations of disability studies and critical trauma studies and their correspondences and differences, cinematic, TV and documentary representations of disability studies, critical trauma studies and their articulations, questioning intersections between disability studies and critical trauma studies, representations of disability in the works of critical theorists.

The present issue deals with human experiences associated with abuse, war and violence, disaster and accident and raise fundamental questions about how traumatic events may register upon a wider public. It is structured in three major sections: the first section Autoethnographies Voicing Experiences of Disability through the Lens of Trauma Studies, the second, Fictional Narratives Featuring Encounters between Disability Studies and Critical Trauma Studies in Films and in Literature and the third, Biographic Accounts at the Intersection between Disability Studies and Critical Trauma Studies, focusing on several case studies and followed by a section comprising an article-review on two major books in the field of Disability Studies.

The first section, Autoethnographies Voicing Experiences of Disability through the Lens of Trauma Studies, combines the clinical and the personal of two authors who experienced both disability and trauma and maintained their subjectivity in navigating through the experiences they encountered and contributors who (although relating to their own story) approached it from an intellectual point of view, preferring detachment to the personal. The section is entitled ‘autoethnographies’, since all articles included here are based on the research method known as autodethnography (‘auto-’ from the Greek αὐτός meaning ‘self’, about one’s self, ‘ethno-’ from the Greek ἔθνος that means ‘people, nation, class, caste, tribe; a number of people accustomed to live together’ and ‘graphy-‘ from or suggested by the Greek γράφω and the Latin graphia that is ‘writing’), a term that was coined by Walter Goldschmidt for whom any ‘autoethnography’ focuses around the self and reveals, ‘personal investments, interpretations, and analyses’. Although it is only Douglas E. Kidd who explicitly names his method of research autoethnography, all contributors of this section navigate through their personal experiences, traumatic memories characterized by involuntary incoherent sensations, often accompanied by a sense of pointlessness that they find overwhelming and sometimes hard to narrate. They cast views on the way into which their autobiographies became part of a narrative dealing with disability /trauma and engaging with cultural, social and political aspects. As Laura Ellingson and Carolyn Ellis emphasized, since autoethnography is a broad and ambiguous ‘category that

111 Walter Goldschmidt, ‘Anthropology and the Coming Crisis: An Autoethnographic Appraisal’, Anthropologist 79.2 (1977): 293-308. Autoethnography started to be employed fully in 1994, when Norman K Denzin and Yvonna S. Lincoln published the first Handbook of Qualitative Research with Sage Handbooks to better explain the importance of autoethnographic use and when Altamira Press initiated the series entitled Ethnographic Alternatives, edited by Arthur Bochner and Carolyn Ellis, with the purpose of setting up and at the same time highlighting ‘experimental forms of writing, in response to the ever-present “crisis of representation” that affects all qualitative research’ (See also Jean Rath, ‘Review Essay: Ethnographic Alternatives’, Qualitative Research 1.1 (2001): 111-14). From the many definitions given to autoethnography, we retain one more that points out the subjectivity of the one who employs it, thus moving away completely from limiting the self: for Garance Maréchal, ‘autoethnography is a form or method of research that involves self-observation and reflexive investigation in the context of ethnographic field work and writing’. See ‘Autoethnography’, in Encyclopedia of Case Study Research, eds Albert J. Mills, Gabrielle Durepos and Elden Wiebe, vol. 2 (Thousand Oaks, CA: Sage Publications, 2010), 43.
encompasses a wide array of practices', there are two ways in which one can divide it: analytic autoethnography (by which the researcher develops theoretical explanations of broader social phenomena) and evocative autoethnography, centred more on narrative presentations evocative of emotional responses. Thus, while Ann Millet-Gallant’s collage-essay, Douglas E. Kidd’s article and Shahd Alshammari’s account are evocative autoethnographies (otherwise the order in which they are aligned in the table of contents responds anti-climatically to the degree of subjectivity and emotional response to their lived experiences of impairment and disability coming with all their traumas, ruptures that produce fragmentations in their narratives), Sarah Redikopp’s essay is an analytical autoethnography on Borderline Personality Disorder (BPD) in which her own story can be only seen in an explanatory note on the positionality and epistemic orientation of the essay: ‘I enter into this work as a queer borderline advocating for borderline knowing and for recognition of our lived experience and our uncontrollable emotions as valid forms of counter-knowledge – for lack of a better term, an ‘outsider within’; a borderline in the academy’.

Responding to the question of how art can have a therapeutic effect for the ones who have sustained injuries, in ‘Mind and Body Transformations through Visual Art’, Ann Millett-Gallant proposes to her readers a close reading of disability and trauma through the lens of her own story. She admits that through art history and art therapy, she has ‘cathartically mediated conscious and corporeal loss’. Her essay is written in the form of a collage-like analysis of her life after the accident in which she lost her memory, part of her skull, much muscular movement and her mobility in parallel with the composition of a mixed media artwork entitled Re-Membering and engaging with Cathy Caruth’s theories of trauma and different theories on art therapy put forward by Margaret Nauremburg, Edith Kramer, Judith Rubin, Elinor Ulman and Bernard Levy, Mayra Levick and others. The key visual examples analysed by Ann Millet help the reader understand better issues of disability, trauma and mind/body transformations.

Douglas E. Kidd’s ‘Neurodivergence Enminded/Embodied: Living with Severe Traumatic Brain Injury’ is an evocative autoethnographical account, combined with accounts on his brother, Richard Kidd’s story, that evokes the experiences of people who survived severe traumatic brain injury (TBI) in the context of persons with disabilities (PWDs) living in the United States and the world. While Richard’s experience is one of abuse and neglect coming from the society, Douglas’s is one of recovering and enhancing his abilities (both physical and emotional) to meet challenges of the nondisabled society. In a highly subtle narration of different episodes of emotional instability, temporal dissonance, Kidd highlights the main changes his person had to come to terms with after the automobile collision he was involved in and shows how after his identity was reduced ‘to a collection of cells struggling for survival in an indifferent universe’ (49), he moved through trauma, coma and amnesia to a new life in which the works of disability scholars like Ervin Goffman, Nancy Eiesland, Rosemary Garland-Thomson had an impact in his deciphering his very own condition and relation to the outside world. With their help, he started to express his cognitive, emotional, psychological and physical impairments being positive about how much they enriched the expression of his humanity.


113 See Ellingson and Ellis, 445.
Shahd Alshammari’s ‘On Being Woman, Other and Disabled: Navigating Identity’ interrogates disability and trauma studies by focusing on the different psychological traumas of a woman of mixed origin (with a Bedouin father and a Palestinian mother), diagnosed with Multiple Sclerosis (MS), ‘an illness that called into question every definition of “self”’ (37). Concentrating on the stigmatization of one’s body, and from here engaging with discursive discussions on stigma and shame, she engages with themes such as shame, exclusion and, ultimately healing, writing herself and her body into a larger narrative that lays at the border between disability studies and trauma studies in her search for liberation from the oppressive social structures of society.

Sarah Redikopp’s ‘Borderline Knowing: (Re)Valuing Borderline Personality Disorder as (Counter) Knowledge’ is a case study of Borderline Personality Disorder (BPD) from the perspectives of feminist, critical psychiatry and Mad critiques that medicalize trauma which intends to ameliorate the different critiques presented in the essay by engaging BPD as both a psychiatric diagnosis and as a (non-pathological) response to traumatic experiences. Engaging with concepts such as ‘borderline standpoint’ as a subversive epistemology, ‘cripistemology’, queer-crip trauma time, the author engages with the borderline standpoint, arguing that an engagement with borderline knowing/feeling must be contextualized and trauma-informed. Redikopp’s conclusion is that ‘witnessing and valuing the borderline is a fundamental challenge to Western epistemic regimes which would rather have the borderline medicalized, erased and silenced’ (91).

The second section offers thought-provoking insights into several films, a theatre representation, an 18th century literary work and an autobiography.

Sasha Dilan Krugman’s article ‘Reclamation of the Disabled Body: A Textual Analysis of Browning’s Freaks (1932) vs Modern Media’s Sideshow Generation’ scrutinizes Tod Browning’s 1932 film Freaks, in relation with contemporary texts such as American Horror Story: Freakshow and the reality television series Freakshow, via the works of trauma and disability studies scholars like Judith Butler, Rosemarie Garland-Thomson, Adrianna Cavarero and Lennard Davis. Krugman’s conclusion is that although in time freakshows changed their approach to ‘the intelligible gaze and the unintelligible body’, these ones ‘remain at odds’ and in the sphere of trauma.

Josephine Barnett’s ‘Setting the Stage for Bridging Disability and Trauma Studies: Reclaiming Narrative in Amy and the Orphans’ focuses on the world of the theatre. Amy and the Orphans, a play written by Lindsey Ferrentino, brings to the fore the encounters between disability studies and critical trauma studies from the point of view of the social construction of meaning and identity. Barnett attempts to demonstrate that defining Amy, a character with Down Syndrome whose experiences of abuse are essential for the understanding of the character, through both disability studies and trauma studies will enable the viewer of this play to reflect upon matters such as the origins of stigma and will reveal how theatre can be used as a tool of resistance to reclaim agency through performances that challenge conventional ‘disability’ stereotypes.

Tracy Anne Travis’s ‘To Leap First Down into The Trench: Tristram Shandy’s Critique of The Wounds of War’ is an excellent close-reading of Laurence Sterne’s novel from the perspective of the theory of Moral Injury (which the author considers ‘long present but largely unnamed in war literature’) and trauma studies that, in the author’s view, offers a better perspective on the ambiguous trauma suffered as a
soldier, thus becoming ‘a critical commentary on the social structures and circumstances that lead to the experiences of wounded veterans’ (149). Approaching the novel from such an angle, rather than the tempting diagnosis of Post-Traumatic Stress Disorder (PTSD), Travis’s analysis ‘allows for a more holistic understanding’ of Uncle Toby’s critical commentary on the mysterious a wound he has got in the groin during the Nine Years War (149).

Kurt Borg’s ‘Narrating Disability, Trauma and Pain: The Doing and Undoing of the Self in Language’ is a close reading of Christina Crosby’s disability memoir A Body, Undone: Living On after Great Pain, through the philosophical works of Judith Butler. Borg defines the memoir as a ‘bold portrayal of living with chronic neurological pain’ that ‘provides a critique of dominant disability discourses that affect the social formation and reception of disability narratives’ (169). The author brings the works of Crosby and Butler together for their complementary ideas on corporeal vulnerability, the precariousness of life, relationality and interdependence. He shows how the social model of disability studies has failed to account for the traumatic dimension embedded in experiences of pain and loss brought about by physical impairments. Borg investigates the ‘unsharable and uncommunicable’ (177) dimension of Crosby’s disability which is not a narrative unilaterally characterizing the disabled subject as strong, resilient, autonomous and which does not bracket the traumatic dimension of disability but on the contrary emphasizes the debilitating physical pain that the accident she was involved in brought about as well as many traumatic aspects of her disability consisting in the intense grief for lost bodily functions, abilities and life possibilities. Concluding that Crosby ‘continually highlights the rich meanings that grief continues to have in her life’ and that ‘she can only live on through grief, not as something she must overcome but as hope that guides her onward’ (183), Borg reflects on the therapeutic nature of Crosby’s memoir and the relation between disability studies and trauma theory.

Katherine E. Smith’s ‘“It’s a Pity and a Sin”: Images of Disability, Trauma and Subverted Power in Disney’s Beauty and the Beast’ explores parallels between society’s treatment of those with disabilities and the characters in Disney’s 1991 and 2017 versions of Beauty and the Beast. Mirroring the line ‘it’s a pity, it’s a sin’ in order to show how Disney used the Beast in order ‘to showcase antiquated stereotypes of the disabled body’ (111), such the perception of The Beast as a creature that became disabled due to its moral deficiencies, Smith compares Gabrielle de Villeneuve’s text with the films and points out those deviations from the text in order to connect with a disability stereotype. Smith does not stop only at pointing out the shortcomings of using such stereotypes, but, with the help of Wolf Wolfensberger’s classifications of deviancy and disability, seeks to demonstrate that Disney ‘continues to promote pejorative images of the disabled body’ (111). Using trauma theory, Smith illustrates how the curse of the Beast is a source of trauma and reveals how Disney ‘skips the recovery period of a traumatic experience because aftereffects of trauma don’t make for immediate resolution’ (125), which would be in contradiction with the happy ending spectators of Beauty and the Beast would expect.

Nontsasa Nako’s ‘Invincible yet Vulnerable: Race, Disability and Trauma in South Africa after Oscar Pistorius’ presents one of the most mediatized cases of a trial of a disabled person in South Africa and worldwide. Everybody must have heard of Paralympian and Olympian Oscar Pistorius’s trial in which he was accused of killing his girlfriend, Reeva Steenkamp on the morning of Valentine’s Day in 2013. Nako presents
the multiple faces of one of his many defences that was related to his disability that made him ‘over-react’ on that night. Nako analyses this defence as the link between the two extremes claimed by Pistorius’s public persona, that of ‘invincibility and vulnerability – extreme physical ability epitomized by sterling sporting prowess and fear of victimisation because of his physical limitation’ and at the prevailing social attitudes toward disability and disabled people, particularly in post-apartheid South Africa, a country which set up the Truth and Reconciliation Commission (TRC) in 1995 in order to ‘enable South Africans to come to terms with their past on a morally accepted basis and to advance the cause of reconciliation.’

In Nako’s opinion, ‘the corrosive legacy of TRC created rich ground for white victimization and popularised the medical model of trauma’ (187).

Although Sharon D. Raynor’s ‘The Double Consciousness and Disability Dilemma: Trauma and the African American Veteran’ that presents the story of the author’s own father does not directly invoke Ellen Samuel’s work, it certainly goes into the direction she suggested: moving away from the contradictory medico-administrative definitions of disability. Louis Raynor, an African American drafted into the U.S. Army at the age of eighteen in 1966 and serving in Vietnam with the 3rd Squad/5th Cavalry, 9th Infantry Division (Black Knights) during the Tet Offensive between 1967 and 1968, stands for the many veterans who never imagined themselves ‘maturing into a disabled veteran at the age of forty-three with an identity based on a myriad of social constructions’. Sharon D. Raynor takes the hard exercise of detaching herself as a witness of all the wounds of her father, presenting to us a case study in which she advocates the need of bridging the gap between disability studies and critical trauma studies via W.E.B. DuBois’s ideology of double-consciousness, critical race theory and cultural studies in order to address how the traumatized and disabled African American Vietnam war veterans are further marginalized by society in relation to issues of race, class and gender.

The mixture of subjects that have been examined by the contributors to this special issue is testimony to the rich potential inherent in encounters between disability studies and critical trauma studies. The issue includes authors who analyse their own experiences of disability and trauma, others who analyse other people’s experiences, whether it is about a family member, about a celebrity or simply an autobiographical account written by a disabled person. Still others have focused on novels, films or the theatre. There is also much more to consider and it is hoped that this special issue will also serve as an invitation for other authors to delve into these encounters.

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Encounters between Disability Studies and Critical Trauma Studies: Introduction

Autoethnographies Voicing Experiences of Disability through the Lens of Trauma Studies
On Being Woman, Other and Disabled: Navigating Identity

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Abstract

This article addresses disability in a Middle Eastern context. It interrogates disability and identity from a Bedouin perspective. The author relays her experiences with a physical disability and society’s stigmatization of different bodies. More often than not, this usually creates psychological traumas and a complex terrain of emotional tensions when dealing with society’s oppression of individuals with disability. The author engages with a discursive discussion of the struggles of navigating spaces of shame, the traumas of stigma, and ultimately healing in finding a voice that is separate from the collective.

Keywords: personal narrative, disability, shame, identity, Bedouin, women, autoethnography

Narrating Identity

This essay is part of a long coming-out process. As a woman with a disability, I have struggled with hiding my illness and remaining silent about it. Because I am a woman who comes from a Bedouin tribe, there are specific notions and stigma concerning disability that arise when I choose to claim my disability. There has been little scholarly attention focusing on Eastern perceptions and understandings of disability. There is hardly any work discussing specific and qualitative and/or ethnographic experiences of Arab women with disability. This essay attempts to be corrective of this lack of attention to perceptions of disability outside of the West. I shed light on an altogether different understanding of disability and what it means to be a disabled ‘Eastern’ woman, using my own experience as a starting point as well as a feminist disability studies theoretical framework.

Growing up, I was always reminded that I was a woman, that I was not a man, my rights were not equal to a man’s, my experience of life would be restricted and limited, and that I would not have access to the public sphere. I was also a hybrid, born to a Bedouin father and a Palestinian mother. A hybrid identity immediately cast me as ‘other’; as a mixed-breed woman, neither fully Bedouin, nor fully Palestinian. My identity as a hybrid was unusual for my Bedouin father’s culture, because marrying from outside the tribe was highly frowned upon. At the age of seven, my father sat me down, and explained that I was now a ‘woman’. And not just any woman, for that matter, because my identity was tied to the tribe’s; I did not represent myself, I was not an individual, but rather, I was a symbol, a representative of the tribe itself. As a child, my sense of identity was largely eradicated. About a decade later, I was diagnosed with Multiple Sclerosis (MS), an illness that called into question every definition of ‘self’ that I had acquired over the years. I was now a woman, and a hybrid, with a disability.
It goes without saying that in a heteronormative, ableist global culture, the experience of illness and disability is already marginalizing. In smaller communities, and specifically tribal communities, ideologies of exclusion are even more intense and bodies are regulated in different ways. I do not claim to speak for a general Middle Eastern perspective, nor do I wish to homogenize or overlook all the different cultures within the Middle East. My experience as a woman living with MS has been affected by the public sphere and I have been negotiating different labels for my identity. For what does it mean to be woman, and does it by definition mean a heterosexual non-disabled woman, and what does it mean to be defined as ‘other’ and what of the elusive category of the ‘disabled’? Must my experience of disability necessarily constitute a visible disability? These three disparate and marginalized identities (of being a woman, a hybrid, and disabled) have shaped my sense of self, a self that is always in a state of transformation and ambiguity.

Negotiating Disability Definitions

First, I would like to consider the usage of the term ‘disability’. In his groundbreaking study *Enforcing Normalcy*, Lennard J. Davis explains that this term includes those ‘who are regarded as having a limitation or interference with daily life activities such as hearing, speaking, seeing, walking, moving, thinking, breathing, and learning. Under this definition, one now has to include people with invisible impairments such as arthritis, diabetes, epilepsy … multiple sclerosis, heart and respiratory problems, cancer…and so on.’¹ Davis reminds us that we need to think of disability ‘as a descriptive term and not as an absolute category’.² I use the term in the same way that Davis urges us to use it – it becomes an inclusive category, one that is not fixated on the extent of disability, but rather, the presence of it.

In the same vein, Rosemarie Garland-Thomson situates disability as a social construction and examines the disabled body’s position in the world. She asserts that ‘[d]isability, perhaps more than other differences, demands a reckoning with the messiness of bodily variety…Disability is defined not as a set of observable, predictable traits – like racialized or gendered features – but rather as any departure from an unstated physical and functional form, disability highlights individual differences.’³ As such, disability cannot be restricted to medical definitions. Impairment usually means the condition itself, while disability may constitute the lack of functionality caused by the impairment itself. the Susan Wendell’s highly acclaimed work *The Rejected Body* puts forward a few ‘good’ definitions of impairment and disability, recognizing that speaking of disability and disabled individuals is a complex issue and demands recognition of people’s lived realities as well as a language that is adequate and accommodates different experiences of disability. Wendell summarizes a few characteristics of possible definitions:

Good definitions of impairment and disability should recognize that normal (i.e., unimpaired) physical structure and function, as well as normal (i.e, not-disabled) ability to perform activities, depend on some extent on the physical, social, and cultural

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² Davis, 8.
environment in which a person is living, and are influenced by such factors as what activities are necessary to survival in an environment and what abilities a culture considers more essential to a participant.4

Given the pervasiveness of society and the environment’s effects on the lives of people living with disabilities, it becomes necessary to situate different cultural and social understandings of disability. Race and gender cannot be ignored when articulating disability experiences. Recent scholarship addresses identity politics and is concerned with situating lived experiences of disability. What is it like for women with disabilities living in different societies with particular understandings (and stigma) of disability? Disability in Local and Global Worlds maps these very specific experiences of disability in different parts of the world, bearing in mind what makes these experiences similar and different. The editors of this collection state that they ‘are interested in people’s own experiences of what is disabling in their world rather than some universal definition.’5 Disability studies requires a cross-cultural theoretical understanding, shifting between ethnographies, anthropology, autobiographies, and a dialogue between activists, individuals with disabilities, and scholars.

Feminist disability studies calls for the intersection of gender and disability, and recent scholarship is urging for race to be included in the discussion. Intersectionality becomes the only possibility in engaging with gender and disability. Nirmala Erevelles defines a transnational feminist disability studies perspective as a:

perspective that engages gender and disability and their intersection with race, class, and sexuality within the material context of the post/neocolonial state…this perspective maps both the continuities and discontinuities across different historical periods that have both separated and connected women along the axes of race, class, disability, sexuality, ethnicity, and nationality, by foregrounding not just discursive representations but also the material (read actual) conditions of their lives.6

Similarly, I argue that transnational feminist disability studies is the only way disability studies can become inclusive. Disability definitions and stigma vary from culture to culture and are either challenged or reproduced by scholarly research. This paper, then, is only a glimpse into a Bedouin-Middle Eastern perspective, grounded in my own experiences, and by no means do I claim to speak for all Bedouin and/or Middle Eastern women. In a sense, this paper is inspired by critical autoethnography as a method of qualitative and self-inquiry. Critical autoethnography is about reflecting on one’s lived experience by examining the effects of culture and institutions that govern us. Critical autoethnography is not a simple telling of one’s own story but rather engages with multiple discourses of thought and looks at the lived experience through different lenses. According to Linn and Pruyn:

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Critical autoethnographers view their work as a means of pointing out the politics of their positioning, explicitly acknowledging the inevitable privileges and marginalizations they experience…They do so by creating accounts of intersectionality, a term coined by legal, feminist, and critical race theory scholar Kimberlé Crenshaw. Intersectionality calls to attention to how oppressive institutions, attitudes, and actions in cultures including racism, xenophobia, sexism, heteronormativity, classism, religious and spiritual fundamentalism, ageism, and ableism do not function independently but instead are connected and mutually influencing (5).7

As the above definition illustrates, I have recognized the significance of telling the story from a specific standpoint, through the body, from the body, and exploring race, culture, and social structures that come into play when negotiating what it means to live with disability. I stand as both the observer and the traumatized, the silent body and the researcher, and the authoritative voice on my experiences attempting to derive meaning and formulate an identity I can claim.

**Disability Narratives and Belonging**

For the purpose of this essay, I want to discuss Nancy Mair’s work and its role in guiding me through Disability Studies, disability, and writing. Nancy Mair’s work in *Carnal Acts*. When I first read Mair’s work, I found myself trying to make sense of the feelings of shame which were suddenly replaced by – dare I say it – pride. I was proud to be connected in some way to Nancy Mair’s, the writer, this woman who was reclaiming her womanhood, her disability, her ‘voice’ as she so elegantly puts it. Mair’s work spoke to me on many levels. She was able to describe the experience of having MS in a way that no medical terminology had managed to do, and no neurologist had taken the time to explain to me. Mair’s description of the mechanisms of MS is as follows:

> The hypothesis is that the disease process, in which the protective covering of the nerves in the brain and spinal cord is eaten away and replaced by scar tissue…is caused by an autoimmune reaction to a slow-acting virus…In effect, living with this mysterious mechanism feels like having your present self, and the past selves it embodies, haunted by a capricious and meanspirited ghost, unseen except for its footprints, which trips you even when you’re watching where you’re going…and weights your whole body with a weariness no amount of rest can relieve. An alien invader must be at work. But of course it’s not. It’s your own body. That is, it’s you.8

MS, then, almost seems non-existent, a ghost that attacks your body, its exact origins science and medicine are still unable to identify. All we know is that it is degenerative, and the body attacks itself. Because it is my body which has somehow decided to plot against my corporeal self, my ethereal self and my self-image is shaken. This ‘self’ of mine is called into question. MS itself originates in the central nervous system, the brain, the greatest powerhouse, yet it manifests itself mainly as bodily symptoms. The brain, then, destroys the body, or is it the body that is destroying the brain?

I find MS an almost always ambiguous state of being, ambivalent, unclear; a

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hybridized disease, if you will. MS is, sometimes, a disability that manifests itself during numerous times of one’s life, and may or may not disappear momentarily. You may lose function of your hearing, eyesight, and may identify as ‘deaf’ or ‘blind’ for the time being, until you regain functionality. Not everyone who loses one of their senses will identify as disabled. Not everyone with invisible symptoms will identify as disabled, and, to complicate this further, one may identify as disabled because of invisible symptoms which others do not perceive as a disability. With MS, a disease that presents multiple symptoms, it is nearly impossible to always claim a ‘disabled’ identity on the MS continuum. For instance, when I attended an MS support group, I found that I was not only the youngest woman at the meeting, but I was also part of the minority that was still able to walk. Everyone’s disability status/impairment differed; and, of course, this is not to discredit any of these disability experiences. Disability experiences are always diverse and there is a whole spectrum of ability/disability. I was not in a wheelchair, and I did not use a cane, yet I could not feel my legs at all because they were numb. But that was an invisible ailment, and I felt both guilty and selfish, for I had felt as though my own pain had to be measured next to theirs. I did not feel like I belonged and that I had no place amongst those who were really suffering, those who were truly in pain. What did I know of their pain? How would I connect with them, how would I belong with them? I felt varying degrees of shame, of not belonging, and this was further intensified with the way my family (and to a larger extent society) dealt with illness. The reason I had sought out an MS support group was namely that I was in great need of a place to belong to; I felt the incessant need to belong to a community. What hurt me the most was when other MS patients told me I was too young (ageism of course) and thus I would not suffer as much; that I should feel blessed. As I tried to find myself amidst the community, I realized that illness and disability were negotiated in different ways.

Illness and/or disability (or any affliction) may be understood in various religious and superstitious ways. Superstitious beliefs insist that illness is caused by black magic, demonic possession of the ‘weak’ self, or by the ‘evil eye’. Superstitious ideologies such as these work to exclude the weak (and yet also deviant body) from the social order and the tribe. Illness and disability may also be recognized as a form of punishment of the individual. In Islamic theology, disability has been interpreted in various ways. Mohammed Ghaly’s Islam and Disability: Perspectives in Theory and Jurisprudence examines the intersections of disability and Islam, and of a concept of a loving and merciful Allah. Ghaly’s study is one of the extremely rare examinations of the concept of disability in the Muslim and Arab world. Ghaly emphasizes that ‘disabilities may be but need not necessarily be the result of committing sins … Disabilities or misfortunes as punishment befall those who…make no effort to return to the straight path, declare no repentance to God and continue their disobedience.’ As such, upon recognizing that illness must have a reason, the family or those closest to the individual urge him or her to find Allah, to go back to a ‘straight path’ and avoid whatever sin committed in the past.

As an eighteen-year-old struggling with MS, I could not fathom the reason for my sudden illness. What sinful act could my body have committed? I had lost function

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of both my hands and legs, upon waking up one morning, a morning after I had graduated from high school. Some family members proclaimed I had been affected by the dreaded ‘evil eye’ (since not every Bedouin girl graduates high school, and my privileged position was one that supposedly sparked envy). Another understanding, perhaps with less negative connotations, is the one that my mother chose to embrace. It is one of purification and it dictates that illness/disability is a way for the self to become whole, to be purified, cleansed; in other words, the ill/disabled body is marked as a chosen one. Ghaly refers to this as an ‘elevated rank’, one that brings the sufferer closer to heaven: ‘Disability as a form of affliction and concomitant suffering were seen as possible means of attaining a lofty rank in a Paradise that would have been unattainable by good deeds only.’

The disabled or ill person becomes the chosen someone, someone who is unaware of the blissfulness of this affliction. Suffering is seen as necessary for reaching the best rank in Paradise, thus emphasis is placed on the afterlife. This view is supposed to be consoling and refreshing, and is adopted by most individuals. The more thankful one is for the disability/illness, the better the reward. Once you inquire as to why this has happened to you out of all people, then you are questioning your chosen status, and pushing the reward further away. My mother urged me not to ask Allah why this had happened to me, and just fully accept the condition. I spent a decade living with MS and fighting every day, on both a physical and an emotional level. My identity was constantly negotiated. I was unable to find a solid reason or a justification for my illness. Mostly, I felt overwhelmed.

Bloodlines and Bodies

As a Bedouin woman, my individual identity was closely tied to the collective and the idea of ‘asl’ or bloodline and purity. In Veiled Sentiments, Lila Abu-Lughod examines the concept of bloodline in Egyptian Bedouin societies. Abu-Lughod’s work is crucial for explaining critical concepts of Bedouin ideologies. I adopt Abu-Lughod’s theoretical framework to consider the same concept of purity in Bedouin Middle Eastern society and culture. Abu-Lughod defines ‘asl’ as ‘nobility of origin or ancestry.’ Although I was a hybrid, and my mother was not Bedouin, my identity was largely my father’s. As Abu-Lughod explains; ‘Children take their father’s tribal affiliation, although their mother’s affiliation affects their status.’ My status as a hybrid remains affected, I am othered, but at the same time, I carry a Bedouin, collective identity. Negotiating such conflicting ideologies had always been difficult, but even more so when MS decided to add itself to the mix.

Illness in a Bedouin context is primarily regarded as a subject to be avoided, and disabled subjects, especially women, are to be silenced. Abu-Lughod reminds us of the Bedouin code of honor: ‘The final element in the Bedouin network of honor-linked values is self-mastery, one aspect of which is physical stoicism. Bedouins think physical pain and discomfort should be borne without complaint.’ Mastery over the mind and body is crucial in establishing a good, moral self, a self that is fit to belong within the

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10 Ghaly, 46.
12 Abu-Lughod, 53.
13 Abu-Lughod, 90.
pure and noble tribe. The identity of the disabled person, or the disabled woman, is called into question. To come out with the illness, to speak out, to claim the illness, is to taint the purity of the tribe’s collective identity. This brings shame to the family, and by extension, the tribe. This idea of shame in illness stems from a concept of ideal femininity, ideal purity (asl), and the lack of mastery over the body. Women occupy lower positions on the social hierarchy, and people with illnesses or disabilities are even more excluded and marginalized.

I had to learn to absorb all these different public understandings of my MS and find my own personal reasoning to this new identity that had become me. Rosemarie Garland-Thomson reminds us that ‘[t]he ways that bodies interact with the socially engineered environment and conform to social expectations determine the varying degrees of disability or able-bodiedness.’\(^{14}\) I began to understand that my MS not only threatened and confused society, but it also marked me as a deviant and disabled body, as inferior on social hierarchies. My presence itself was unsettling, and my illness had become an issue to keep quiet about. If I had failed to perform my identity as a perfectly healthy, able-bodied, pure-blood woman, then I had also shamed the family and the tribe.

Perhaps my experience in a Middle Eastern, Bedouin culture caused a greater level of stigmatization when linked to ideologies of purity and asl. As such, my MS was to be hidden, concealed from the public sphere. People were never to know, and if I was going through a physical exacerbation, I was to avoid being seen in public. In *The Wounded Storyteller*, Arthur Frank reminds us of the double-burden that the person with the illness or disability must carry:

> When adult bodies lose control, they are expected to attempt to regain it if possible, and if not then at least to conceal the loss…Thus the work of the stigmatized person is not only to avoid embarrassing himself by being out of control in situations where control is expected. The person must also avoid embarrassing others, who should be protected from the specter of lost body control.\(^{15}\)

Frank writes from a Western perspective, but I find that this experience of stigma is universal; that the person suffering from illness or disability feels the same burden in different cultures (regardless of the intensity of the burden and/or shame). I was to maintain, as much as possible, a decent, ‘normal’ healthy image of a woman who was part of a certain family, and a family that was part of a ‘noble’ tribe. Not only was the experience of disability and illness difficult, but it was also complicated with cultural notions of normalcy.

**Disability and Identity**

Claiming the identity of a disabled woman has its consequences. Common beliefs about a disabled woman included various manifestations of lack: a disabled woman cannot hold a job, no man could possibly want to marry her, she cannot have children, and if

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she does, then she would somehow pass the disability onto them. Disability for a young woman can be emotionally crippling. The social stigma and being denied basic needs leave one outcast from the community and the family. The idea that you have failed to satisfy society’s expectations and the family’s marks you as incomplete, lacking, and as undesirable. The disabled female identity intersects with other social expectations of womanhood, namely reproduction and the ability to be a fully functional wife and a mother. The disabled woman fails to meet the definition of a ‘good woman’, one that is socially productive; in other words, fertile and possibly capable of breeding decent individuals. Associating with a disabled woman produces fear of contamination. It is a blurring of boundaries between abled/disabled, healthy/unhealthy. Disability is thus seen as polluting agent that is to be avoided. At a certain point in my life, I met someone who wished to marry me, until he informed his family that I was affected by MS. Needless to say, the reaction was an utter refusal of their son marrying into a family that had bred this disabled woman. Illness and disability marked me as unacceptable and not fit to be a wife or a mother.

The fear associated with illness revolves around not knowing what the condition entails, and whether contagion is possible. Because MS is a disease of the CNS, most people assume it is hereditary and that it is also a mental illness. I was perceived as not only disabled, but also dangerous, a threat to future generations and a body that would require constant care. As for the man who wanted to marry me – he felt that he did not mind sacrificing his youth for me. This so-called ‘sacrifice’, this concept of martyring one’s self in the pursuit of a disabled woman, simply did not appeal to me. I was nowhere near severely disabled, if anything, I suffered from slight ‘impairment’ and yet I had been denied the right to start a family with this specific person. I realized that regardless of the extent of disability, prejudice and discrimination against women with disabilities and/or illnesses constituted a whole new type of social disability. This cultural treatment of disabled women did not only affect me personally, but I quickly learned that there were many others who were subjected to the same social stigma.

Although Rosemarie Garland-Thomson speaks of western societies, she is right in maintaining that the disabled women ‘must sometimes defend against the assessment of their bodies as unfit for motherhood…disabled women are often denied or discouraged from the reproductive role.’16 Women are socially required to be capable of fulfilling many roles: maternal and familial duties, to be able to earn sufficient income to help support the family, and also to give birth to healthy children. In tribal communities such as my own, once one of the tasks is incomplete, then the woman’s value decreases. I spoke to several women who were married before MS decided to take control of their bodies. After being diagnosed with MS, they found no support from their husbands. A few were abandoned and divorced, while others had to suffer from a different kind of fate: having her husband re-marry. Since Islam allows polygamy, some men found that it was their right to re-marry and find a suitable and healthy woman instead. This did not mean complete discarding of the first wife, however, she was to share her husband with another woman, and give up her position and status within the family home. The new, healthy, able-bodied wife occupied a higher rank, while the disabled woman became even more marginalized and excluded. I was devastated when I spoke to these women, who soon became my friends. They had succumbed to their fate,

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accepted their multiple losses, and found that the husband reserved the right to re-marry, given that she had failed to satisfy him. Their sense of identity as women, as sexual beings, as complete and autonomous individuals, had been replaced with shame, feelings of failure, and acceptance of loss.

This acceptance of loss does not come from successfully embracing a new identity and a new body, but rather, from accepting the blame for this dysfunctional body. These women feel at fault. Society’s discrimination and uprooting of ableism is internalized within the self. As a disabled woman, she is denied social status, rendered invisible, and deemed sexually undesirable. Robert McRuer argues in *Crip Theory* that compulsory heterosexuality is synonymous to what he terms ‘compulsory able-bodiedness’.\(^{17}\) In a society that considers heterosexuality the only acceptable sexuality, it comes as no surprise that the discourse of ableism is as dominant and oppressive. There is no other alternative to living.

Although I understood that my gender and disability did not constitute my entire identity, I was still aware of the repercussions of claiming my body and illness. My identity was inextricably linked to my family and my tribe. Coming out with an illness is a process that is not purely personal, but affects the family and the tribe. The tribe itself extends across national borders. Kinship is based on sharing the same blood, the same roots, and as such, a bond that transcends nationalities and gender. For instance, a Kuwaiti tribe will share the same 
\textit{aslı} with a Saudi tribe, and by theory of kinship, they form a very strong, familial bond. As such, every action affects the entire tribe. One individual’s reputation and honor affects the collective, and vice versa. There have been numerous occasions where I have tried to ‘come out’ with my MS, and instead, faced reprimanding from my family. My action of claiming my identity as an MS patient, my speaking about it, was considered selfish, because I was not supposed to shame the family. The burden was mine to carry silently and deal with as invisibly as possible.

The disabled or ill body is the rejected body, the one made to feel ashamed, the body that is almost forced to conjure the negative feelings of both shame and guilt. Sara Ahmed, in *The Cultural Politics of Emotion* defines shame as the ‘intense and painful sensation that is bound up with how the self feels about itself, a self-feeling that is felt by and on the body.’\(^{18}\) She argues that if one feels shame, then the ‘desire to cover and to be covered presupposes the failure of cover; in shame, one desires cover precisely because one has already been exposed to others.’\(^{19}\) Shame, then, is inextricably linked to the experience of exposure, and rejection. Ahmed also aptly tells us that ‘family love may be conditional upon how one lives one’s life in relation to social ideals...Shame secures the form of the family by assigning to those who have failed its form the origin of bad feeling (‘You have brought shame on the family’).’\(^{20}\) Shame was an emotion I wished to rid myself of, but at a very high cost. If I had brought shame on the family, what had I brought onto myself?

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\(^{19}\) Ahmed, 104.

\(^{20}\) Ahmed, 107.
Moving Forward and Healing

Questions began formulating and my perception of my identity started to develop over time. Part of my academic career is my vexed interest in disability studies and I have struggled to find illness narratives from the Middle East, or narratives that I can relate to. As a way out of the traumas of living in a society that diminishes my agency as a woman living with a disability, I ended up writing my own illness narrative. It was a crucial part of my personal healing and to allow others in the same boat of marginalization to connect with this lived experience of disability in the Arab world, specifically Kuwait. Another reason I wrote the book was my scholarly and academic calling to address this gap in literature, a collection of short stories entitled *Notes on the Flesh*.21 *Notes on the Flesh* deals with love, disability, and identity in the Middle East. The protagonist of the book, Sara, is a recreation of my previous self, freshly diagnosed, and still learning the languages of disability and ableism. Sara serves as a stand-in for my experiences, however, she also represents the voices of marginalized identities. Other characters in the book must contend with their illness and their failed love lives. Love presents itself as a theme throughout the text. In the face of disability, what happens to love? How does one navigate a new relationship while also maintaining a sense of autonomy? How does society (in this case, Kuwaiti society) deal with different bodies and women with disabilities? Each hero and heroine of the various stories struggles with an ableist society that demands better bodies, better lives, and coherent identities. My characters are based loosely on people I have met during my quest to find a support group for disability. These voices are the unheard ones and I needed to articulate them. Because there is a lack in Arabic literature dealing with disabled female protagonists, I decided to correct this gap in the literature by writing from my body and other diverse bodies with different disabilities and overlapping identities: gender, social status, educational level, mothers, daughters, and significant others.

Illness and disability remain taboo subjects, in the same way that sexuality and the body is still a dangerous territory to discuss in Arabic cultures. The body is always shamed, whether it is ‘healthy’ or ‘unhealthy’. It is regarded as an immodest part of our selves, a part that should be covered, hidden, and avoided. The body in Arabic and Islamic cultures is one that should remain covered, both literally and symbolically. Any form of exposure is shameful and it is the mind that needs to be elevated and addressed. But a form of exorcism is in order. I choose to write about my disability, my body that has ‘failed’ to live up to society’s expectations. I choose to rid myself of shame, and I hope that, one day, my narrative will change the reception of women affected by illness in marginalized communities.

It goes without saying that I do not claim to speak for or represent all women with disabilities in the Middle East. This is, again, a personal narrative, an autoethnographical account, a story that has been informed by my interest in feminist disability studies. At this point in my life, I am starting to build a new sense of self, and see myself as an individual, claiming autonomy that is not altogether based on the collective; and finding new ways of expressing a sense of belonging. This embodied agency is a fundamental part of my academic career and pursuit of a change in global and feminist disability studies. By writing about the traumas of the stigmatized disabled body, I am able to find a voice amidst the shame and exclusion. I am writing myself and

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my body into the larger narrative and finding a sense of liberation from the oppressive social structures of society.

**Bibliography**


**Despre a fi femeie, alteritate și dizabilitate. Navigarea identității**

**Rezumat**

Acest articol abordează problematica dizabilității în contextul Orientului Mijlociu, punând întrebări despre dizabilitate și identitate dintr-o perspectivă beduină. Autoarea relatează experiențele personale legate de dizabilitatea fizică și de stigmatizarea de către societate a corporalității diferite. În cele mai multe cazuri, aceasta cauzează traume psihologice și creează un teren complex pentru tensiuni emoționale în cazul în care individul are de-a face cu opresiunea societății asupra persoanelor cu dizabilități. Autoarea se angajează într-o analiză discursivă a luptei de a învinge spațiile rușinii, traumele stigmatizării și, în final, de a ajunge la vindecare și la găsirea unei voci care să fie separată de cea colectivă.
Neurodivergence Enminded/Embodied:
Living with Severe Traumatic Brain Injury

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Abstract

This article positions my experiences as a severe traumatic brain injury (TBI) survivor relative to other TBI survivors and in context of persons with disabilities (PWDs) living in the United States and the world. This autoethnographical account (by autoethnography I understand a method or form of social research that serves the purpose of exploring personal experiences of the researcher) examines the life of a neurodivergent individual whose brain functions in ways that deviate significantly from social norms. I explore profound changes to my identity and the resultant social disconnection I encounter since acquiring a severe TBI more than a decade ago. The profound alterations to my identity affect my ability to process, and then adjust, to the demands of my surroundings. As I decode, decipher and process the world, at times my brain damage triggers and/or produces episodes of temporal dissonance. As these shifts in timing occur, they have tremendous impact on my emotional stability. Despite these outward difficulties, I celebrate my altered awareness of time and new identity as a disabled person. Connecting relevant critical trauma studies scholarship to the themes addressed here, the article examines how moving through trauma, coma and amnesia to a new life with cognitive, emotional, psychological, and physical impairments importantly enriches expression of my humanity. I will demonstrate the salient aspects of my new life – emotional sensitivity and volatility – may on the surface seem detrimental and undesirable; however, these qualities greatly enhance my identification with and empathy for others, which in turn drive my artistic, social, cultural and political expression, along with my quest for community.

Keywords: traumatic brain injury, acquired disability, identity

This article explores personal stories of trauma, coma/amnesia, physical-emotional injury and recovery from severe traumatic brain injury acquired during an automobile accident. I examine how the confluence of acquiring severe traumatic brain injury and exposure to disability studies concepts/paradigms, while pursuing a graduate degree, catalysed emergence and triggered establishment of my new identity as disabled.

First, I provide an analysis of the social context for my stories of survival. With an estimated 10 million occurring each year, the World Health Organization (WHO) projects traumatic brain injury (TBI) will surpass many diseases/disorders and become the major cause of death/disability by 2020. The WHO reported aetiology of traumatic brain injury is commonly referred to a loss of consciousness or coma greater than 24 hours, post-traumatic amnesia greater than 24 hours, or abnormal brain imaging results; available at http://www.northeastern.edu/traumaticbraininjury/what-is-tbi/severity-of-tbi/ [accessed 20 June 2018].

Neurodivergence Enminded/Embodied: Living with Severe Traumatic Brain Injury

Brain injuries are 60% road traffic accidents, 20% falls, 10% work/sport-related injuries, 10% violence.\(^3\) According to the international general medical journal *The Lancet*, Eurostat reported that in 24 European Union (EU) countries in 2012, TBI caused 1.4 million hospital discharges, more than 33 thousand fatalities and accounted for 37% of all injury-related deaths.\(^4\) In Malta in 2012, from the 53 injuries that caused death, 21 were fatalities from TBI.\(^5\) In the United States, according to the Centers for Disease Control and Prevention (CDC), TBI is a major cause of death/disability.\(^6\) The CDC reported in 2005, TBI caused 1.8 million emergency room visits and hospitalizations, with nearly 53 thousand deaths.\(^7\) Lastly, in the state of Ohio in 2005, the year of my accident, traumatic brain injury caused 8,674 hospitalizations, with 2,290 fatalities.\(^8\)

Returning to my own story, I submit simple questions to provide conceptual frameworks which illustrate how massive forces of an automobile collision erased conventional understandings of my essence/identity and reduced me to a collection of cells struggling for survival in an indifferent universe. The first question this article asks is: ‘what is reality?’ Reality may be seen as matter/energy existing within the space-time continuum. A second question: what is a human being? A human being can be regarded as a discrete mass of biological tissue – a matrix/factory where electrochemical exchanges, interchanges occur. Reality shapes/defines human beings as our biological tissue, awash in nutrient molecules, interacting with external matter, energy and gravity. Most human beings from birth acquire abilities to process reality. Imagine however, processing reality; but at a slower rate; so much slower, society leaves you behind… For weeks, my body existed, but I was separate, without a sense of time.

Longest day of 2005 swept past, with no awareness of self or time, I felt detached and apart. Vague impressions of the outside world: sounds, voices, some comforting/familiar, brought the world closer, then receded. Who am I? What am I? When did this happen? Why was I held captive? In an agitated state, I felt compelled to flee – ripped tubes from throat/body – left bed, only to hit the cold, antiseptic floor, hard. Subdued by staff – tears streaming – fought with every fibre of my being for release; until finally collapsing under the weight of strong hands, exhaustion, sedation; ensnared – entombed in my mind – enmeshed by a strait jacket, unable to escape, pinned to my bed. Few visible scars exist – others indelibly submerged. As memories surface, tears well in my eyes, splash down my face.

As delicate electro-chemical structures of my brain experienced massive damage and disorientation, I existed for months without a sense of time. In the days following my attempt to leave, I complied with treatment. Later, as machines healed me, noises...
and terrible odours emanating from the devices summoned me to surface. For months, adult cognition failed me. The operational fulcrum I developed for decision-making became damaged, diminished – reverted. Slowly, steadily I re-engaged my surroundings, but with the cognitive and emotional abilities of a young child. I am informed, my childlike curiosity developed an insatiable hunger for audio/visual stimulation. I would spend hours in bed absorbing the sounds and images of children’s programming on a small television held so close that it touched my nose. Days passed… friends read me children’s books. Others report, I would giggle and bounce my legs up and down in eager anticipation as pages turned. This stimulation helped me greatly as I first re-engaged the world.

Acquisition of spatial relationships, cognitive/psychological/emotional abilities gained in first days and years of life are small, incremental; individuals on neurotypical\textsuperscript{9} life trajectories experience a progression of days where knowledge gained from previous lessons is retained, enhanced, sharpened and cemented. This usual development over time creates the neural pathways that become tools, or lenses with which we learn to recognize, process, and navigate our surroundings. We are equipped at the cellular level to identify and interpret the world we encounter. The brain, encased inside dense bone, receives input from eyes, and sensory organs to process and understand external environments.\textsuperscript{10} Most take for granted the time required to navigate disparate elements of reality successfully – to process – make sense of the mélange of ordinary and extraordinary environments in which we find ourselves immersed. I took for granted the neurotypical development I enjoyed prior to my accident; then the disconnection from time and self I experienced, mark the beginning of my new life. As coma/amnesia subsided, somehow, as I filtered back through damaged brain tissues, enough neurons realigned, reactivated and I surfaced fully in late-July 2005. Without a clear understanding of what had occurred, disoriented, overwhelmed by emotion, overjoyed with simply being alive, I reunited with family/friends, then resumed life with my identity profoundly altered.

Brutally cold winter’s night, at home lying in bed, exhausted, I caught a reflection in the mirror, but did not recognize the stranger. Who is he? Looks familiar, but… Suddenly, the sinking realization: face in the mirror was I. Time then dilated for many intense minutes, body convulsed, mind collapsed, tears fell. Like falling from a great height, I shattered on the cold, hard ground of pitiless reality. The episode left me breathless.

My mental and physical decomposition that night was hardly surprising. Only eight months passed since 4:34 pm, Tuesday, May 17, 2005, when I initiated a call, then I failed to yield to an SUV travelling 50 mph and it smashed into me. My injuries were catastrophic. Severe traumatic brain injury with haemorrhaging precipitated states of coma and amnesia, lasting 70 days. In addition, my heart went twice into cardiac arrest, I experienced massive internal bleeding, with lacerations to rectum/liver, multiple hip

\textsuperscript{9} Neurotypical sometimes abbreviated NT, means having a style of neurocognitive functioning that falls within the dominant societal standards of ‘normal’.

\textsuperscript{10} Brain neurons or individual cells connect to form processing systems. These cellular networks are responsible for all action, thought, feeling and sensation. Each neuron shares connection with more than a thousand neurons and the adult brain has more than 60 trillion neuronal connections. See, for instance, Joan Stiles, Terry Jernigan, ‘The Basics of Brain Development’, Neuropsychology Review 20 (2010): 327.
I was discharged from hospital, September 15, 2005. Instead of daily workouts in hospital, I underwent 3 sessions per week of outpatient physical, occupational and speech therapy. By October 2005, I resumed my work as an industrial designer. In January 2006, eight months after the accident, I returned to university. All pressures combined to produce the episode. Like using a treadmill that suddenly spins too fast, I fell. Exhausted, brain ceased to process, overwhelmed by fear, shutdown, shuddered. Time sped by so fast – too fast – I could not breathe. I felt like I plummeted towards a bottomless pit looking to swallow me whole; hoped if enough fell, the pool of tears would break my fall; then gently I would float to the surface safe, whole, alive. Twelve and a half years removed as of this writing, searing remembrances of my first temporal dissonance remain. As memories surface, tears well in my eyes, splash down my face.

Pursuing a graduate degree in disability studies (DS) became crucial for my recovery from severe traumatic brain injury. It is doubtful that without exposure to DS I would have realized a way forward so compatible with my new fragile identity. I emerged from coma/amnesia with significant impairments, but with a non-disabled worldview; however, exposure to the socio/cultural/political histories of disabled people, led me to identify as member of a marginalized group. With an awareness of DS scholarship through works by Ervin Goffman, Paul Longmore, Mike Oliver, Ed Roberts, Nancy Eiesland, Simi Linton, Lennard Davis, Rosemary Garland-Thomson, Tom Couser, Simon Burch, Jim Ferris, Kim Nielsen, Ron Amundson, Alison Kafer, David Mitchell and Sharon Snyder, I gained an understanding of the lives of disabled people and their treatment/mistreatment through history. My new, fragile identity internalized DS paradigms and concepts as an organic process. In keeping with the notion of a natural progression for my brain’s recovery, if graduate school served as a trellis, I desperately clawed my way up, clung to and spread outward upon as my brain recovered cognitive, psychological and emotional abilities; then DS became the sun, air, minerals and water that nurtured, suffused within me and served as catalyst to construct my new identity as disabled.12 An example of how I internalized DS paradigms/concepts is demonstrated by the personal connection of lived experiences as severe traumatic brain injury survivor to the foundational scholarship concerning stigma by Erving Goffman. Goffman expounded Greek origins of the word stigma, ‘a mark made by a pointed instrument.’13 Goffman recalls the custom in ancient Greece to cut or burn into the flesh of slaves, criminals or traitors, marks signifying the individual is socially undesirable.14 People relegated in this fashion, were considered unusual, morally bad, ‘ritually polluted’ and avoided, especially in public. Goffman expands on this definition of stigma to describe, ‘[t]he process by which the reaction of others spoils normal identity’.15

While the stranger is present before us, evidence can arise of his possessing an attribute

11 MRSA is Methicillin-resistant Staphylococcus Aureus, an often-deadly type of staph bacteria that is resistant to several antibiotics; available at https://www.cdc.gov/mrsa/community/index.html [accessed 22 June 2018].
15 Goffman, 3.
that makes him different from others in the category of persons for him to be, and of a less desirable kind - in the extreme, a person who is quite thoroughly bad, dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap.\(^6\)

Based on Goffman’s description of the mistreatment of people regarded as different, or other, I have little doubt that if I had lived millennia ago, ancient people would have seen my scars, way of walking, how I expressed myself and thought of or called out ‘stigma’ when I came into view. To many, my scars would have associated me with evil. Likely, I would have fallen victim to shunning, assault or summary execution.

Nevertheless, in the first months of my reorientation to the world, perceptions of others to my physical disfigurements were of no concern. Almost as signs of passage, or evidence of courage or distinctiveness, I would openly display my scars. Carefree as I resumed my life in public, I wore my shirt open at the collar to reveal a nearly two centimetres in diameter scar left by the tracheostomy tube.\(^7\) However, as time passed, I noticed the scar on my throat elicited unwanted stares. For example, a woman made me feel uncomfortable when she stared at my neck as I was waiting on a gurney for my treatment. As I was in a hospital setting, unable to conceal the scar given the limitations of my hospital gown, I was not overly concerned with her stares and did not regard her gaze with alarm.

Nevertheless, all changed as I rode public transit on my way to university one day. As a passenger on the bus, I observed an elderly man with his attention fixed on my scar. Despite nonverbal cues signalling my discomfort to the man’s unwanted attentions, his gaze persisted. Some intensely uncomfortable moments later, I closed my shirt. In response to the stigma I experienced, I concealed the scar. It is certain my psyche is now strong enough to withstand the wilful intrusions of others; at the time, only eight months removed from the accident, my cognitive/emotional abilities were greatly diminished and highly sensitive. As demonstrated by the fact that unless I spend a day at the beach, concerns over unwanted attention and my hypersensitivity to stares the tracheostomy tube scar receives persist to the present day, I conceal the scar.

Another stigmatizing scar I have runs nearly the length of my abdomen. I have been informed that the surgical scar developed to address injuries sustained by massive forces generated by the SUV as it collided with me from the left and my body was thrown violently to the right coming hard up against the restraint. The forces caused massive abdominal bleeding and a ruptured spleen. Similarly, to the stigma I encounter with displays of the tracheostomy tube scar, I am sensitive to stares the scar on my abdomen elicits and I choose not display it. As an update and reflection on stigma I continue to experience in 2017, I had plastic surgery to reconstruct my abdominal scar. Nevertheless, while the disfigurement is dramatically decreased, I am still apprehensive over potential stares, so I hide the scar.

However, scars on my abdomen and throat pale in comparison to a dramatic scar on my leg. The scar – which is more than 1 centimetre deep, 5 centimetres wide and 30...
centimetres long – is the result of a fasciotomy18 to treat the compartment syndrome injury 19 to my lower right leg. It is curious that, during warmer months, I am comfortable displaying the scar. I proudly exhibit it as a signifier, or perhaps reminder of extraordinary experiences, which, in turn, feeds my positive self-image.20 However, in sharp contrast to the tracheostomy tube and abdominal scars, I associate no stigma with the scar on my leg. I find the contrasting views regarding embodiment of various scars, and stigma they induce and/or nullify, curious. Upon reflection, I choose to only display scars which project exceptionalism. Alternatively, scars that suggest what I perceive as weakness, stigmatize, cause me shame and urge me to hide from view.

The exchanges described above are similar to Nancy Eiesland’s reference to Goffman’s ‘rituals of degradation.’21 Goffman asserts for people with disabilities) they are particularly oppressive.22 Eiesland suggests that, in contrast to the stigma many people with disabilities typically encounter, such as physical avoidance, some non-disabled people are overly fascinated with embodied difference and feel empowered to freely engage people with disabilities in conversation. Many times, this fascination is expressed out of acts of seeming goodwill; yet Eiesland asserts it is inherent in the dominant-submissive paradigm that pervades nondisabled thought, and is an overt attempt to control the lives of people with disabilities.23 I will explore two interactions with strangers to illustrate Eiesland’s observation of ‘good-natured intrusions’ towards people with disabilities, based solely on perceived difference. In addition, they exemplify how lived experience enhanced my ability to internalize DS concept and paradigms.

One good-natured intrusion, regarding the differences I present, occurred when I was a student walking a university hallway. A young man coming the other direction, stopped as he drew near, looked full of concern, signalled for me to halt and asked without preamble, ‘What happened to you?’ and ‘Are you okay?’. The man did not begin with ‘Hello, please ease my concern, how are you?’ The fellow student chose to interrupt my progress and said in effect ‘I do not really care, but your scars and limp are intriguing, if not threatening, as well as mildly upsetting and that is why I disregard your privacy.’ I suppose I should learn to ignore rude intrusions from individuals that treat me this way; but it is difficult for me to speedily process comments from others and I have yet to figure out how to ignore them or politely refuse comment. Instead, and as evidence of a submissive posture, I feel obliged to be polite and answer the concerns of anyone I encounter. Therefore, I proceeded with brief description of events and reasons behind my walk. After this explanation, I assured the man I was not in pain when I walked; in fact, I added, given where I had been, I was proud of and felt very fortunate to have the ability to walk. As a check on reality of the interchange, but for my staggering walk, it is doubtful words would have passed between us.

18 Fasciotomy is a surgical procedure that cuts away the fascia to relieve tension or pressure. See https://medical-dictionary.thefreedictionary.com/fasciotomy [accessed 30 May 2018].
19 Compartment syndrome occurs when excessive pressure builds up inside an enclosed muscle space in the body. Compartment syndrome usually results from bleeding or swelling after an injury. For more details, see https://www.webmd.com/pain-management/guide/compartment-syndrome-causes-treatments #1 [accessed 30 May 2018].
22 Eiesland, 92.
23 Eiesland, 93.
Another ‘good-natured intrusion’ (to make use of Eiesland’s terminology) occurred when an individual perceived the deficiencies in my gait, then felt empowered to share their opinion with me. One day as I proceeded past a woman, without preamble she broke the customary silence with questions: ‘When will you resume physical therapy?’ and ‘Wouldn’t you like to walk normally again?’ As disability studies scholars/activists made me aware and sensitive to the significance and attendant baggage associated with the term ‘normal’, it was all I could do not to express disgust at the individual. In my daily life, it does not occur to me that I walk differently. I am simply moving though the world, living my life and proceeding with activities I desire. Yes, I will admit there are differences when I view myself walking in a mirror. Yes, I agree, I possess a significantly staggering lurch as I walk; but the fact that it took me eighteen months to regain the ability to walk, and in consideration of the wondrous variety of Homo sapiens on the planet, I feel my gait is well within the norm and should not provoke comment. However, many only see the exception and choose not to fight the urge to have difference explained. Another prominent way my fragile disabled identity internalized DS concepts and paradigms came once I was introduced to Rosemarie Garland-Thomson’s scholarship. The episodes described above are examples of staring. In her article, ‘Ways of Staring,’ Garland-Thomson’s asserts: ‘[p]art of our enormous communal vocabulary of the eyes, staring is a particularly emphatic way of expressing our response to others.’ 24 Garland-Thomson contends some non-disabled people feel empowered to express opinions on the difference disabled people present. She suggests staring is an automatic response dictated by perceived necessities of survival and writes: ‘[w]e are drawn by the unanticipated and the inexplicable in an effort to make sense of experience. We comfortably rely on the predictable, at the same time that we anxiously crave the unpredictable.’ 25 Furthermore, Garland-Thomson contends natural selection shaped the process of staring over millions of years of human evolution. Those who stare, then seek to engage their subject in conversation are well-meaning, yet, many cannot resist the need to have the unknown explained. 26

The following is an example of my lived experience, which illustrates Garland-Thomson’s ideas. One day waiting outside The Metropolitan Museum of Art in New York City, a stranger stared at me several times over the course of a few minutes, then crossed from where she stood and asked if I experienced pain. I said, ‘No, I am not in pain.’ When asked the reason for her question, she replied: ‘The scar running along your leg looks extremely painful.’ I thanked her for the concern, but responded, ‘I am not in pain, just waiting for a friend.’ We proceeded to have a 15-minute discussion. While preoccupied with the momentary arrival of my friend, I felt comfortable enough to explain my accident, scars and brain injury. As I engaged the woman in conversation, she became visibly less anxious about my appearance. Because of her decreased anxiety, soon I felt comfortable relating to her. The woman’s questions about my scars, and appearance originated from her uncertainty over the differences I presented. As staring led to her good-natured intrusion, which seemingly originated out of concern for my comfort and well-being, it is difficult to argue she attempted to oppress me; but rather she could not resist temptation and required exceptions in her environs explained. Confirmation of this notion is demonstrated by the fact that if the woman had not seen my scars, our exchange would have been unlikely.

The confluence of lived experience and pursuit of a graduate degree in disability studies greatly supported my nascent, fragile identity through natural assimilation of concepts/paradigms stigma, rituals of degradation and staring. However, these are but three of the many DS concepts/paradigms my new, disabled identity absorbed. I now examine further identity development gained from social interactions. Early during my recovery, I confronted significant aphasia, or the inability to produce and/or comprehend speech. Years passed before I regained the ability to speak comfortably outside of family/friends. Opportunities came as I met fellow TBI survivors. With complete acceptance, these understanding people led me to discover community. As interpersonal experiences expanded, I bonded and resonated fully with individuals classified as developmentally or intellectually disabled. When compared with more sophisticated disabled communities, members of this group live on the margin; yet I derive belonging from their presence. The only method one individual has to communicate is by striking himself in the face. If he feels hot or cold, or hungry, or wets himself, he moans, balls his hand into a fist, then hits. The louder he moans, the harder he hits, the more desperate he is for relief. It is difficult to know the borders of our one-time relationship; but it was my duty to attend to his needs, so it gave me great satisfaction to know I could contribute to his momentary peace. While many do not regard his life and speed away on their own missions, his humanity and lessons he teaches, shine.

Turning back to my identification with fellow TBI survivors, I will give a brief description of my own brother’s experience after an unfortunate accident. On December 31, 1987 as Richard Kidd attempted to cross a street in Indianapolis, a car without headlights ran through him. Richard acquired additional brain damage when he stopped breathing before rescue personnel arrived. Following his accident, brain damage caused Richard to experience a coma lasting nearly a year. Richard is hemiplegic, with only limited ability to process the world.27

The main lessons Richard teaches regard human fragility, strength, interdependence, neglect and abuse. For example, Richard’s life, post-accident, finds him subject to the expressed will of others. Decades of his inability to self-advocate for his health and well-being, nearly cost Richard his life one day. In the 1990s, nursing facility staff dropped Richard and caused his front teeth to shatter when his mouth smashed into the floor. We received the explanation Richard became combative, resisted treatment and his agitation caused the fall. As Richard is hemiplegic, possessing only the ability to yell loudly, he has limited ability to resist. Worse than the fall is that Richard never received follow-up dental care to repair or replace broken teeth. It is impossible to reconcile the fact Richard went decades without dental treatments, but he did. However, when I became a TBI survivor, my identification with and empathy for Richard meant disregard and neglect for his dental care ended. Given bureaucratic delays, what I thought would be routine dental treatment, took months to arrange. What happened next became disastrous for Richard. Due to prolonged lack of dental treatment, the dental surgeon decided to extract all 24 of Richard’s teeth in one session. I cannot argue with the dental surgeon’s assessment; but Richard’s sedentary lifestyle profoundly limited his ability to withstand what for him amounted to trauma. After the extractions were completed, hospital staff wrongly determined Richard stable enough and discharged him back to the nursing facility. Soon after returning to his home, Richard aspirated on

blood produced by the dental extractions. As the nursing facility was ill equipped, staff could not cope with the crisis, so Richard returned to the hospital, then slipped into a coma lasting three weeks. This tragedy confirms Richard’s fragility, yet ultimately exhibits his innate strength to withstand decades of extreme neglect and abuse by society.

While Richard’s journey is a series of disabling events, my experience is largely one of impairment. In other words, in stark contrast to the abuse and neglect of Richard’s experience; my journey is one of recovering and enhancing my physical, cognitive, psychological and emotional abilities to meet challenges by nondisabled society. The critical difference in our realities stems from Richard’s inability to self-advocate. Consequently, Richard is unable to resist the actions by others; vulnerable to whim, with his life is subject to chance. Especially early during my recovery, I shared similar circumstances and experiences with Richard. The core of common experiences forged bonds of identification, acceptance, draws me close and leads me to love Richard completely. Reflecting on our lives and my journey of self-discovery uses autoethnography and, in this context, poetry provides skills/methods to articulate and thereby position our experiences alongside other disabled people. The confluence of community, the acceptance of new realities I confront and the skill to relate personal experiences compel me to share, seek, and find belonging.

The drive to regain my former self and discover belonging embodies/enminds aspects of Amanda Wicks scholarship. The severe TBI I acquired produced extensive brain damage, which in turn precipitates temporal shifts. These shifts in timing generate profound gaps in my memory. In addition, residual brain damage makes difficult my ability to maintain pace, so I fall out of step, experience social dislocation. In addition, I have become perceived as ‘other’. As traumas established a significant void in memory, I struggle to recall and greatly yearn for the one-time integrated progression of my life. It is difficult for me to remember the hours, days and months surrounding the accident. Accordingly, I perceive this gap as an absence, or void that I dimly sense, yet is impossible for me to ignore. In favour of proceeding with more pressing activities of life, I am forced to push past traumas to the margins of my consciousness. Yet, I find myself compelled to reconcile and make sense of past experience. As Wicks suggests, ‘[t]hose who emerge into trauma’s after find themselves confronting endless repetitions of their experience.’ Like many trauma survivors, I endlessly replay the circumstances of my accident in vain hope of recalling memory; yet a wall of brain damage separates me from full understanding, which makes me live with outcomes, forever haunted, grasping after cause. In spite of these difficult to reconcile tensions, ever since returning to consciousness in my hospital bed I am compelled to recover as much as possible. As I moved through occupational, speech, physical therapies and psychological counselling, the greatest recuperative tool in support of my brain’s recovery are the writing skills I developed as well as opportunities to share my experiences with audiences. These recuperative efforts provide opportunities to compose narratives that build structures of understanding that nourish my need for intellectual/emotional

support and in effect, fill in the missing gaps. The narratives I’ve composed and shared is precisely the methodology I have used to examine my journey of self-rediscovery. The last aspect of Wicks’ scholarship I reference is: ‘[w]orking through trauma, therefore, ultimately becomes a narrativizing act, because the act of remembering and recounting structures through language what has occurred beyond language.’30 My journey to (re)discover and (re)claim my shattered identity is supported and bolstered by my efforts to compose articles and present them to audiences. Without these efforts, I am certain my brain would not have recovered, nor would my identity be fully realized. Brain damage affected and interrupted notions I had of my former self. There are times when I feel to have returned fully and recovered, yet in the core of my being I know how vastly different I now process my environs. Like a cloud or veil covering my past, I am forever struggling to reconcile memories of former functioning with new realities.

TBI shattered my identity, or the sense of who I am. The accident reset cognitive/emotional processes developed over the course of my life. Consequently, I am strangely disconnected from the past. Many long-term memories survive, but forces of trauma drastically altered my sense of self. While largely content with life, it is impossible to ignore how the accident completely disrupted my successive development, where first days turned to years, decades passed, I grew older with a continual/seamless awareness of my past-developed plans for the future. The accident caused the course of my life to depart radically from the usual ‘straight’ time progression most enjoy and experience.

Irrevocably severed from my past, the salient issue of TBI is grief over the loss of my former self. I generally move forward with life, but spend time trying to reclaim former ways of functioning. The drive to return to past methods of processing is innate and parallels neuronormative progression I achieved growing older. Intellectually, I understand I will never be the same person; however, I cannot ignore memories and the urge to regain former problem-solving methods and coping techniques. As my brain now processes, the pace of society at times frightens me. Often, tears occur as I manage the world speeding around me. For this reason, never do I intentionally refer to, nor conceive my brain injury as a past event. Brain damage is always with me. I cannot anticipate how my brain injury will express itself.

The crucible of surviving severe TBI proved fertile ground for the emergence of my neurodivergent31 identity. With great assistance from family, peers, medical professionals, I have grown, reconnected with others and largely reintegrated back into the larger world. While seeming to contradict negative descriptions regarding my neurodivergent life, difficult adjustments made on this side of trauma, injury, coma/amnesia, MRSA, awakening, recovering, reintegrating back into society, result with me happier, stronger, in celebration of neurodivergence. My response includes essays, articles, poetry, community service, political expression and presentations to international audiences.

My first opportunity to interact with others, find acceptance and discover community occurred when a friend asked me to participate on a panel discussion at the

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30 Wicks, 135.
31 Neurodivergent sometimes abbreviated ND, means having a brain that functions in ways that diverge significantly from the dominant societal standards of ‘normal’; available at http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/ [accessed 21 June 2018].
Society for Disability Studies\textsuperscript{32} annual meeting in 2014 in Minneapolis. Prior to this experience, I was unaware DS scholars and activists gathered to share community and research. As I never before relayed our story to an audience, apprehension over our story’s reception and acceptance made me anxious. This was demonstrated by the poor sleep I experienced for weeks prior to the conference. In addition, concerns over my diminished cognitive skills/abilities led me to feel out of place at such a prestigious and scholarly gathering. Nevertheless, I was surprised and overwhelmed by the warm reception, acceptance and animated response received when I delivered my paper. I recall enthusiastic smiles, bonding and sharing fellowship with fellow conference attendees, which lasted the remainder of our time together.

In the conferences I have participated ever since, I have encountered the same commitment to collegiality and willingness to serve as venues of cultural acceptance for embodied/enminded difference. Since my first conference four years ago, to the most recent facilitated by the University of Malta, I have presented eleven times. The personal growth I gain from these accepting forums, greatly promotes my recovery with opportunities to reduce stigma for severe traumatic brain injury survivors, discover meaning, share community and derive belonging.

Evidenced by my ability to work, service to non-profit boards, lead a support group and partner with a national safety organization, I have recovered a life, largely reclaimed adulthood, and adjusted to neuronormative expectation. Yet, I cannot ignore moments when I dissolve into cognitive misunderstandings and have difficulty processing the pace/breadth of normal/usual interactions. There are times when I find myself isolated, adrift, a stranger. Yet, despite seemingly detrimental and negative aspects described, alternatively, I possess renewed wonder in the world enveloping me, where even the ordinary is extraordinary. My new perception is the template with which I process/decode/decipher reality.

Human beings emerge from and exist within reality. Personal experience illustrates how sensitive the mind/body are as processing tools of reality. Envision the gelatine-like brain defined, ordered, separated by dense bone into compartments of knowing. Consider this working system suddenly, violently shaken so hard, brain damage ensues and total negation of self occurs. For a while, loss dominates. Time passes… Slowly brain tissues heal; they reconstitute, reassemble, restructure at the cellular level. Cognition flickers, self steals back, reclaiming the void. Now, examine one restored human being processing reality in space/time, but with a tendency to slip/disorient; yet throughout my recovery I possess a great desire to realize identity, uncover meaning, and discover belonging.

Bibliography


\textsuperscript{32} The Society for Disability Studies (SDS) is an international scholarly organization dedicated to promoting disability studies; available at https://disstudies.org/index.php/about-sds/mission-and-history/ [accessed 21 June 2018].


Neurodivergența din minte/ din corp. Trăind cu leziuni cerebrale traumatice severe

Rezumat

Acest articol relataază experiența mea ca individ care a suferit leziuni cerebrale traumatice în comparație cu alți supraviețuitori cu leziuni cerebrale traumatice și în contextual persoanelor cu dizabilități care trăiesc în Statele Unite ale Americii și în lume. Această relatăre autoetnografică (prin autoetnografie înțelegând metoda de cercetare socială care are scopul de a explora experiențele personale ale cercetătorului) exminează viața unui indiviz neurodivergent ale cărui funcții ale creierului deviază în mod semnificativ de la normele sociale. Explorez schimbările profunde asupra identității mele și excluderea socială cu care m-am confruntat din momentul în care am suferit leziuni cerebrale traumatice. Alterarea profună a identității mele afectează abilitatea mea de a procura informații și de a mă adapta la normele sociale din jurul meu. Pe măsură ce decodez, descifrez și procesez informațiile despre lumea care mă înconjoară, creierul meu declasează și produce episode de disonanță temporală și pe măsură ce aceste schimbări de temporalitate se petrec, ele au un impact devastator asupra stabilității mele emoționale. În ciuda acestor dificultăți externe, glorific modul în care creierul meu transformă conștientizarea timpului și noua mea identitate ca persoană cu dizabilități. Conectând studii critice ale traumei cu temele pe care articolul le propune, examinze cum trecând prin traumă, comă și amnезie către o nouă viață dominată de o deteriorare a proceselor cognitive și emoționale și de fragilitate fizică au avut rolul important de a îmbogăți exprimarea umanității mele. Articolul demonstrează că aspectele frapante ale noii vieți – sensibilitate emoțională și volatilitate – pot fi privite la suprafață ca fiind dăunătoare și nedorite. În ciuda acestei viziuni, aceste calități îmi intensifică consistent identificarea cu alții și empatia față de alții, care, la rândul lor, mă conduce spre a mă exprima artistic, social, cultural și politic și a căuta să mă încadrez în comunitate.
Mind and Body Transformations through Visual Art

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Abstract

This essay narrates my experiences as a congenital amputee and survivor of traumatic brain injury (TBI) through analysis of artwork. With art history and art therapy, I have cathartically mediated conscious and corporeal loss. I will analyse key visual examples to illustrate my disability, trauma and mind/body transformations. The article maintains that trauma is not an isolated event, but a conscious, collective and dynamic phenomenon.

Keywords: traumatic brain injury, congenital amputee, art therapy, modern and contemporary art, Disability Studies

I believe that art is a potent way to access the felt sense and the body’s memories of trauma as well as transform overwhelming emotions that result from crisis.1

Remembering

This essay composes a collage-like analysis parallel to the composition of a mixed media artwork entitled Re-Membering.2 Loss provides details about an accident that resulted in TBI and engages with Cathy Caruth’s theories of trauma.3 I combine medical information with personal details about falling, recuperating and benefitting from communal support. I present the cognitive and corporeal consequences of my injury and discuss how it disturbed memory and increased anxiety. I then turn to the physical and anatomical repercussions by discussing my corporeal pain and muscle contraction, work with a physical therapist, Abby and decision to discontinue using prosthetic legs. My experiences are not exceptional. According to the Centers for Disease Control and Prevention (CDC), TBI is the cause of 30% of all injury deaths in the United States and in 2013, the leading cause of TBI was falling.4 Additional statistics report that there is no cure for TBI, it is a major health and economic problem, globally and it has become the most prevalent injury associated with wars in Iraq and Afghanistan.5 TBI is a global

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4 Statistics published by the Centers for Disease Control and Prevention: https://www.cdc.gov/traumaticbraininjury/get_the_facts.html [accessed 17 May 2018].
5 Brainline, all about brain injury and PTSD: https://www.brainline.org/article/report-congress-toward-
occurrence and concern.

*Discovery* continues with my recovery by focusing on disability studies, art history and art therapy. As a congenital amputee, I self-identify as disabled and have been asymmetrical since birth. My right upper and lower limbs are longer than those on my left side, and I utilize some adaptive technology. Indoors, I ambulate on the floor in a seated position and I have used prosthetic legs. My history of personal and therapy-based practices is extensive, and, with repetition and available resources, I have defied many assumptions about what my body can accomplish. I incorporate art history, disability studies and my identity as a disabled woman into my teaching and writing. Disability studies scholar and performance artist Petra Kuppers served on my dissertation committee in 2005 after we shared several years of research, conference presentations and friendship. Her work influences my scholarship significantly and she continues to offer me encouragement and guidance. The work of disability scholars Tobin Siebers and Rosamarie-Garland Thompson have also influenced my academic work. In *Discovery* I focus on intellectual, emotional and physical transformations through visual art. I provide a brief introduction to art therapy and detail my art therapy practices concentrating on collage as a transformative media.

In *Forgiving and Forgetting*, I conclude on the adverse and regenerative ramifications of disability and trauma and underscore the power of art for healing.

**Loss**

For much of 2007, my existence may be characterised as loss. I lost memory, security, identity, part of my skull, much muscular movement and my mobility. I lost my sense of self.

In May of 2007, I was vacationing in San Francisco with my friend, Anna. We were exiting a café and I unexplainably shot ahead on my travel scooter and fell off of the sidewalk into the street. I was not obviously impaired by overexertion, sleep deprivation or any substance prior to this. I hit my head, began to bleed and an ambulance was called.

This was all knowledge I obtained after the event, as I have no recollection of the accident, the trip or even planning it. I have blocked many experiences out. Even as my memory congeals, much of my life takes place in stories and photographs but not in the sensations of *being* within the representations. I have no recollection of the six weeks I spent in Zuckerberg San Francisco General Hospital and Trauma Center (ZSFG). I cannot recall much of my time spent in Dodd Rehabilitation Hospital insuccessful-recovery-traumatic-brain-injury and https://www.brainline.org/military-veterans/military-brain-injury [accessed 17 May 2018].

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8 See https://zuckerbergsanfranciscogeneral.org [accessed 24 June 2018].
Columbus, Ohio, where I received physical, occupational and speech therapy. I moved in with my mother at the end of the summer in a place that I thought was her home I could not remember. Slowly my strength and endurance increased. I exercised, read, wrote in a diary, drew in a sketchbook and began to re-member – to put mind and body back together. I was content to remain in this sanctuary.

Surgery was performed on my skull to reconstruct the amputation in October. This surgery involved the puncture of my lungs as an IV was administered to my chest. I spent additional time in the hospital with tubes inserted in my sides to enable breathing as I awaited the procedure. Caregivers had suggested I would improve drastically following the reconstruction. I was more cognizant after my skull was made intact and began teaching an online class for the University of North Carolina Greensboro. My knowledge of art history, liberal studies and how to teach slowly reappeared and strengthened. I was able to concentrate and exert more authority. In December 2007 I moved back to my home in North Carolina and to Paul my boyfriend whose name I could then remember. As 2008 progressed, I was determined to halt procrastination. Below I detail my actions. My fear of injury dilutes with time while the corporeal and psychological effects of falling continue to oscillate.

Anxiety and depression are the most common results of traumatic brain injury, according to neuropsychologist Rudi Coetzer who further states that one specific expression of depression is guilt. For me the trauma of being lost and having lost control can be unbearable. I cannot sleep through the night without medication, my moods can fluctuate and I cannot recall various people and events. I can find duplicitous humour when I realize strangers are not figures from my past that I do not remember but people who look similar. I can periodically joke about loss while feeling consumed by the desire to know how and why my accident occurred. I grapple with guilt and questions of self-agency. I also discover countless lessons from this specific trauma – personally and academically. I conceive of feeling “loss” and “discovery,” not as absolutes, but as malleable states of being. They collide, overlap and intertwine. They can make falling asleep a chore and can produce ‘accidental masterpieces.’

Art critic and columnist Michael Kimmelman developed this term through essays published in The New York Times and later in a text. In The Accidental Masterpiece: On the Art of Life and Vice Versa, Kimmelman’s essays explore intersections between art and everyday life with the theme that art results from accidents. Accidents, in literal and figurative forms, catalyse discovery, creative production, unexpected and sometimes fortuitous masterpieces. I centre one of my courses on this vibrant book and require students to write an assignment about loss and discovery. The other required textbook is Rebecca Solnit’s A Field Guide to Getting Lost. Solnit’s works comment on cultural institutions and various material examples that she analyses through sensual details, personal anecdotes and storytelling. The class and its texts inform this essay.

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These analyses materialized when I created an accidental masterpiece in the form of collage on canvas. Its title, *Re-Membering* (2008), refers to processes of integrating the past with the present and synthesizing my mental, emotional and corporeal transformations. The collage format embodies my accident and recovery both visually and viscerally; visual fragments within it ‘collide, overlap, and intertwine’, as do my states of mind. I conceive of my memory as a collage of stories and pictures that are not enclosed by an overarching narrative. In comparison, the assemblage *Re-Membering*, juxtaposes images and words that resist amalgamation. Visual fragments render a story piece by piece in a chain of associations. Examples of get well cards frame the canvas and exhibit the range of people who reached out to and supported me. Within the collage are photographs of me in a coma from the San Francisco hospital, business cards and prescriptions. These medical references intermingle with personal photographs particularly of my wedding that signified moving forward and celebrating my life. Adhered to the canvas are sketches I made from pictures in magazines when I was consumed with my own private world and drawings I created on the surface of printed photographs, when the idea of creating an original drawing felt overwhelming.

In one example I sketched with scarlet ink over a printed photograph I took of my prosthetic feet at the beach and titled the composition *There’s No Place like the Beach* (c. 2004), with reference to *The Wizard of Oz* (because of the sparkling red shoes). The placement of this image in *Re-Membering* recalls the wounded and bleeding feet in Frida Kahlo’s magical realist painting, *What the Water Gave Me* (1938), where flashback images from her memory, history and fantasy float in the water surrounding her lower extremities.  

A public transportation accident impaired Kahlo at the age of eighteen, and she became a disabled artist by painting brilliant, passionate compositions about her embodied life. Kahlo is my favourite artist and now I conceive of further connections with her due to the accident.

A snapshot of me as a child in a gymnastics class resides in *Re-Membering*. Early in life, I was very active and physical activity is still a therapeutic tool. Following

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the 2007 accident, I began working with Abby, a physical therapist (PT) who has become a friend and personal trainer. The prescription on the assemblage is for PT. Additional body images on the canvas include smeared, hand painted representations of my amputee hands. One red hand sits on the edge of a page from my diary on which I transcribed Elizabeth Bishop’s poem, ‘Insomnia’ (1951). Sleep deprivation causes additional resonance for me with the poem. Although this mixed media collage is no masterpiece in the conventional sense it represents my energy, frustration and confusion. It illustrates many raw and random emotions. The collage is perpetually therapeutic in processing disability and trauma.

Literary theorist Cathy Caruth traces the etymology of ‘trauma’ in western philosophy that characteristically locates and contains trauma in and on the body (UETNH, 4). She expands the significance of trauma, elucidating how trauma affects and transforms collective consciousness, community and history. In her analysis of the work of philosopher Paul de Man, Caruth argues that de Man illustrates a contention between empiricism and embodied, perceptual experience, specifically through analogies of falling systems and bodies, suggesting that trauma is corporeal, philosophical and potentially transformative (UETNH, 76-93). My trauma impacts my mind, body and my immediate and extended families.

Relationships are paramount throughout this essay. Many that were established before the accident deepened, new friendships formed and tensions arose. Anna got on the phone just after the ambulance took me to the hospital and began a long chain of communications throughout my support system. She phoned Paul and then Brandee, my stepsister, who relayed news of my accident to my father. My father reached out to my mother, who immediately packed and caught a flight to San Francisco. I cannot imagine her state of mind when she arrived. She admits that for the next month or so, she often felt in a daze which aligns with the way Caruth articulates trauma: as an experience so intensely painful that the mind is unable to process the event, leaving the witness of a trauma in a disposition characterized by amnesia and ‘unspeakability’ (UETNH, 132).

My accident occurred close to a premier trauma centre (ZSFG). I entered the emergency room alert but was unconscious for ten minutes. I had a blown pupil and doctors assessed that I was within twenty minutes of dying. I recall nothing about being in San Francisco. Medical records state that I experienced a urinary tract infection, intermittent hypertension, pneumonia and a peptic ulcer. Reports list intricate details about the levels of every gas and vitamin in my blood. The staff evaluated all my organs and performed ultrasounds. My body was examined inside and out with diagnostic devices.

My mother took alarming snapshots of me in the hospital. Attached to devices by tubes and with my eyes closed I showed no signs of consciousness. I had a subdural hematoma of 1.8 cm. I received a right hemiceraniectomy (the removal of skull bones) and was made comatose, to allow my brain the space and time to swell. Progress reports state that I didn’t respond to stimuli following surgery, therapy was put on hold and a seventeen-gauge feeding tube was inserted into my abdomen. I remained in the intensive care unit until June 19. Then, on July 1, my mental status improved drastically. I began to respond to objects and commands and seemed to recognize my name. I knew I lived in North Carolina, but thought it was the 1980s. I subsequently maintained little awareness, and my doctors thought I may need more release from pressure in my brain. By July 22, I was more alert and responding to jokes, but it wasn’t until August 3 that I began to talk, recall names and be aware of my location. Mom says
that when Paul arrived at the bedside my eyes were wide open and that she recognized my love for him. Continuous records note rises in the number of platelets in my blood and more neurological activity, as the hospital staff weaned me off ventilation. They removed my catheter and I had to wear diapers. When awake, I was agitated and had painful muscle spasms. The medical team monitored my fluid collection, inflammation and rises in blood pressure and temperature, while my loved ones awaited my recognition of them.

I slowly recuperated. I left San Francisco at the end of the summer and went to Dodd Hall in Columbus, Ohio, where I had more therapy and lived with mom. She had to encourage me to leave this refuge. Any venture out required wearing a thick helmet. Surgical notes state that matter the size of a grapefruit had been removed and I wanted protection. As a congenital amputee, I have extensive experience being stared at but wearing such a helmet, projecting a public image of trauma and feeling uncomfortable around strangers brought averted looks and ones of pity. A surgeon reconstructed my skull in October using pliable and durable material after which I had more sense of being in time and space. I did not have medical insurance at the time as I was to begin a fulltime teaching position in a few months. I had no choice but to apply for Medicaid Disability Insurance. My dad spearheaded the process of applying and qualifying for this insurance, one that caused strain and disagreement. Soon, Columbus felt like a place for rehabilitation and conflicts arose about what I should be focusing on and doing. I longed for more independence and less structured routine. I returned to my home in Durham by December 2007.

Paul and I spent the holidays together at the end of that hard year and I enjoyed seeing friends. Later in January I taught multiple courses and continued teaching myself. I read many of the books on my shelves to refresh knowledge and my old diaries to reconnect with personal history and use of journaling as self-therapy. Artmaking, art history and art therapy would catalyse further healing.

**Discovery**

![Ann's Hands](image)

*Fig. 2: Ann’s Hands, acrylic on canvas, 25 x 20 cm, 2008*

Time spent in occupational therapy as a child involved drawing, painting, cutting and collaging. In 2008 I rediscovered my painting studio kept in a corner of the upstairs spare bed and band practice room. A small canvas with a sketch of my hands holding a
paint brush was resting against an easel. It became a symbolic re-entry into my identity as an artist and my scholarship on how and why disabled people represent themselves. As I applied thick brushstrokes and chose bright complimentary colours, a recognizable style emerged. I titled the work *Ann’s Hands* (2008). When I discuss my artwork with others, often their first question is about how I manipulate a brush. Such a painting was a means to demonstrate. Throughout 2008 I was determined to make up for lost time. I proposed to Paul in March and we were married in May. It was a whirlwind of experiences, emotions and corporeal pain.

Intellectual recovery began with teaching and studying books and visual culture intensely. I uncovered past ideas, made new connections and began to write, all with invigorate ambition. I returned to revising my 2005 dissertation and published it as my first book in 2010. As mentioned previously, Tobin Siebers’ s work influenced this book and he served as a mentor for me during its publication. He wrote a review to my book, which was quite an honour. Siebers called my monograph the first to integrate art history with disability studies. I began to lecture about my book during the 2010-2011 academic year. I felt more esteem as a scholar but trauma in the form of anxiety flared up. I would sometimes feel very nervous about everything and project these feelings onto smaller obsessions such that nothing unexpected could disrupt my precarious feelings of control.

Since 2007, I perceive everything strongly and this is a common result of TBI. Claudia L. Osborne defines ‘flooding’ as a prominent effect:

Flooding: overwhelmed by, or awash in, one’s emotions. This can take place even though the flooded individual does not appear upset or distraught or even consciously aware of being under emotional overload…. Flooding may be triggered by external events […] or from internal pressure—the awareness of one’s own confusion, a sense of helplessness, the pain of one’s loss of self.

I experience differing degrees of flooding by becoming overwhelmed by activities and responsibilities, many that I have created. Throughout diaries, I wrote about feeling anxious, worried and in a hurry. When I could not hear Paul snoring, I would check on him to make sure he was still breathing. I once wept because he got home later than usual and I was sure he had been in an accident. I could interpret everyday events darkly. I also felt guilty for being so self-absorbed, as neurologist Coetzer predicted. Since I cannot embody the person I was prior to the accident, it is hard to decipher what behaviours are results of it. I sense that every fear, disappointment and worry that might have existed before 2007 became intensely amplified. Contending with indecipherable anger, depression and defensiveness, I would grade myself on how well I performed every action and responsibility. For relief I made paintings, collages and lists during such periods of confusion and discomfort.

Paintings and collages were for me a world that helped me heal some of my emotional wounds. Making and talking about them in a therapeutic context became more concrete to me in 2009 as I began working with an art therapist, Ilene. I was

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17 Coetzer, xix, 4.
unsure about therapy but intellectually curious about art therapy and had confidence entering it. Art therapy sessions in office and at home transformed my life and my perceptions of my disability and trauma.

The practice of art therapy developed from the theories and practices of diverse professionals. This essay opened with a quotation by visual artist and art therapist Cathy A. Malchiodi expressing her philosophy about the role of art in trauma and transformation. Providing historical context, Malchiodi states that art therapy developed in the United States in the 1970s, although artmaking has been a part of healing rituals globally since ancient times. As a clinical practice, art therapy derives from ideas prevailing across cultures that art can be regarded as a form of communication and can express emotions and ideas that words cannot. Art helps people process their traumatic experiences and loss. Images and creativity are important components in psychoanalysis, in the works of Sigmund Freud and Carl Jung. Both theorists drew relationships between images and the psyche, personality, emotions and desire. Psychoanalysis analyzed dream imagery and visual symbols to access the unconscious in early twentieth century, as Western art work became more abstract to express in visual form the inner world. Relating art therapy to other mind/body theories and practices, Malchiodi states that people who undergo art therapy can achieve conceptualizations of being ‘healed rather than cured’ (ATS, 39). Trauma, specifically, is a phenomenon that can be neither cured nor overcome. Art therapy is dynamic, as it involves making, discussing and feeling the benefits of creativity, psychologically, physically and spiritually. Art became a tool for psychotherapeutic assessment and treatment.

Margaret Nauremburg and Edith Kramer led the field of art therapy in the United States, exploring aspects of symbolic speech (conceiving visual images as symbolic, like dreams) and sublimation (integrating conflicting feelings into visual forms). Nauremburg focuses on therapeutic effects of artmaking and conceives art as a form of communication. Kramer centers on the relationships between art therapists, clients, visual materials and theory. Kramer’s work theorizes sublimation or making the unconscious conscious and visible. Other prominent figures in art therapy include Elinor Ulman and Bernard Levy, who together established the first American art therapy journal, Bulletin of Art Therapy. In the 1930s, the Menninger Clinic in Houston, Texas, known as a premiere psychiatric healing center, began incorporating art therapy into their methods of treating their patients. In 1968, Mayra Levick started the first graduate programme at Hahnemann Medical College and one year later the American Art Therapy Association was formed. Malchiodi is currently the director of Trauma-Informed Practices and Expressive Arts Therapy Institute.

Art therapist Judith Rubin maintains that art therapy offers a release of tension and a freedom from the disciplines of traditional talk therapy. Its practices give visible form to traumatic and repressed thoughts and feelings and can synthesize a number stages in a lifespan. Integration is the goal of much psychotherapy and art therapy offers a means to envision such synthesis, particularly through collage. Malchiodi explains that collage is a popular medium for art therapy as it appeals to people who

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may not have art-making experience and may be intimidated by drawing and painting (See ATS, 92). Gioia Chilton and Victoria Scott articulate how collage is an embodied visual form that can integrate therapeutic discourse with ‘hands-on’ activities, for groups and individuals.\textsuperscript{21} Catherine Hyland Moon’s edited volume on healing through arts explores connections between art therapy and contemporary art, in materials, analysis and exhibition. The essays in Moon’s book focus on a variety of visual, digital, musical, site-specific, group and individual practices and consider the implications of such media in social, cultural and theoretical frames.\textsuperscript{22}

Art therapy practices enabled me to materialize emotion, purge guilt and reconnect with lost memories. Artmaking also became meditative, as I practiced mindfulness, or the acknowledgement of all the senses and sensual stimuli from the world around me. I directed more attention to the patterns of my emotions and behaviours. Becoming more self-aware enabled me to slowly release the need to control everything, as I felt more capable of anticipating and coping with my feelings. My art therapist Ilene said that she used to offer me less directive assignments, as compared with many of her clients, because I was more verbal than most and that my art had its own ways of evolving. Because I would often articulate my trauma verbally, she suggested a visual project to access a different area of my brain.

In art therapy, I drafted my swirl motif. During a winter break from teaching, art therapy images made visible the hope that craniosacral therapy could cure my unexplainably tense and painful knee. Connections between thoughts, emotions and physical distress arose in my sketchbook in forms of words and images. While I was lamenting anguish and frustration over my knee, Ilene suggested that I create a healing symbol. I chose a rose-coloured marker and drew a coiling design that I imagined spiralling outward from its centre. The rose spiral was healing for me because it represented movement and release from mental and corporeal contraction. I return to this image repeatedly in artmaking projects.

Circles and mandalas are forms specific to art therapy, as they have been associated with sacred forms and cosmology historically. Malchiodi explains: ‘mandalas format […] can have calming physiological effects on the body in terms of heart rate and body temperature’ (ATS, 127). I began to relate my spiral to a mandala image that would heal me both psychologically and corporeally. The mandala is specific to the ancestry of art therapy in the theories and practices of psychoanalyst Carl Jung. Jung relates the mandala shape with the universe and to layers of the psyche and believed that working with mandalas was healing and helped people achieve ‘individuation.’\textsuperscript{23} Furthermore, contentions between philosophies of and treatments for trauma could be recognized through making and interpreting a collage-like mandala image.\textsuperscript{24} Following Freud’s theories that a subject’s history and unconscious could inform on their actions, Jung theorized that the mandala image was protective and potentially transformative. Both psychoanalysts derived imagery from a subject’s life and dreams to analyse that subjects’ psychosis. Departing from Freud, Jung believed people could alter their unconscious neurosis, particularly through creative acts. In Active Imagination, he

\begin{flushendnotes}
  \textsuperscript{23} See Jung, 1959, 4 and 66.
  \textsuperscript{24} See Jung, 1959, 71-100.
\end{flushendnotes}
proposed that the images created and juxtaposed through active imagination, or through art therapy, materialized the unconscious and trauma. Jung also made art images and collage-like mandalas for himself.

In 2009, I made a homage collage to the dexterity of my hands. I located three ink drawings of my hands that I made before TBI and arranged them vertically. The top drawing is of my left hand drawn with crosshatching and surrounded by a flowing keychain; a durable chain or stretchy headband was the most practical for me when I drove a van. At the bottom there is a drawing of my right hand, encircled by a moulded ring with an attached spoon, exhibiting my childhood method of eating. In between these images one can see another drawing that I cannot place in time. I had drawn my hands holding a pen and writing: ‘my body is …’ The upper right-hand corner of the drawing is made up of a fragment of a self-portrait that I made as a child. In it I did not draw fingers and my doctor Ernest Johnson suggested that this detail indicated self-acceptance. I arranged these three drawings in a column resembling a vertical triptych on top of a piece of paper with a salmon coloured watercolour design and adhered the composition to a stretched canvas. This new autobiographical assemblage titled Collage with Ann Drove a Van; My Body Is; and Ann’s Spoon composes representations of my amputee hands and their actions.

Throughout work in art therapy, I produced numerous collages. They juxtapose, magazine clippings, watercolour paintings, cards and other remnants that my mother collected and kept for me throughout my time in San Francisco and Columbus. In 2010, I assembled a collage of found, drawn and painted imagery titled Art Therapy. On a square, 0.9 meter stretched canvas, I adhered seven sheets of standard size white paper. Six sheets are collages I made previously in a sketchbook related to the anatomy of knees and craniosacral therapy, sections of mail, printed personal photographs and other marks made with ink, marker and acrylic paint. Images of sushi, clothing, shoes, female icons, eyes, sleeping figures and fine art repeat throughout these collages that are placed around one central drawing of the rose spiral, my art therapy symbol of healing. The composition on canvas is meant to overwhelm the viewer with an abundance of visual details. Eye imagery draws viewers in and confronts them. Three additional pictures placed against the edges of the collages include a reproduction of Frida Kahlo, The Two Fridas (1939), a drawn spiral in a wine glass and metal-based forms of interlocking, circular entanglements. Art Therapy (2010) serves as a visual record of my art therapy practices and testament to my investigations of and with visual images.

Fig. 4: Art Therapy, mixed media on canvas, 60 x .60 cm, c. 2010
Fig. 5: *Self Portrait with Flowers*, acrylic on canvas, 35.5 x 28 cm, 2012

For another painting and art therapy example, in 2012, I had recurring feelings of anxiety and guilt. Not knowing what exactly to do, I looked at images that calmed me. I created a self-portrait based on one of my wedding photographs in a composition that emphasizes my eyes receiving and delivering the gaze and stare.26 I illustrate my vintage wedding hat in thick strokes of gloss acrylic paint and position the flowers strategically. Entitled *Self Portrait with Flowers*, this painting pays tribute to several of Frida Kahlo’s self-portraits that I have analysed elsewhere. Kahlo mediated drama and trauma through production of her art.27 The white flowers from my personal photograph are transformed into painted blood or passionate red. They make the work brighter and warmer and conceal the end of my nose and mouth. This detail could be interpreted as a symbol of ‘unspeakability’ but here they suggest visually the smell of roses (*UETNH*, 132).

Because the left side of my brain hit concrete in 2007, the right side of my body had much muscle tightness, or contraction. In the hospital my right arm was bent and held tightly at my side. I lost range of motion in my arms and back and my right knee was at full, unbent extension. Together, Abby (PT) and I practiced exercises and routines to retrain my muscles to turn on and off at the appropriate times or in technical terms neuromuscular re-education. Before this therapy my knee could only bend at five degrees and eventually reached about thirty degrees. I repeated bending my knee in various body positions and stretching to make my back muscles more symmetrical. I wore a painful splint following the accident that eventually straightened out my right arm. When my right arm was immobile, muscles weakened and caused my back to ‘wing’, meaning that the muscles that held my shoulder blade to my rib cage were weakened. Abby could put her fingers between the underside of my shoulder blade and my rib cage and asserted that this could have put me at risk for future shoulder injuries or pain. I achieved more symmetry with repetition.

Fig. 6: CRIPERCIZE, acrylic on canvas, 45 x 60 cm, 2015

These techniques inspire my artwork. To increase flexibility and endurance, I use a cornflower blue balance trainer on which I exercise with arm weights and perform yoga-inspired stretches. In a self-portrait painted with scarlet, tangerine, and canary hues, my body lies sideways on the trainer and projects my arms and legs into surrounding space. My face as well as my body are strategically abstracted. Below the figure is the term ‘CRIPERCIZE.’ ‘Crip’ is developing rapidly in disability studies, as a noun signifying nonconformity to binary oppositions, for examples cripple/normal, disabled/able-bodied and queer/heterosexual, and as a verb meaning to imbue disability narrative within texts, representations and social systems. Crip, as an adopted identity signifier designates pride. The title is a portmanteau word of ‘Crip’ and ‘cize’ that designates idiosyncratic styles of exercise. This painting signifies and encourages my ‘crip’ practices.

The history of my corporeal trauma particularly the saga of my knee is long and painful. I benefitted from crani osacral therapy. It did not loosen my knee but served as meditation and a subject for artwork. I embodied trauma through strenuous stretches, muscle contraction, emergency room visits, a bone infection and expensive prosthetic legs that caused my fully extended knee to increasingly bend and consequently not unbend at all. Limited mobility, corporeal pain and fear of falling convinced me to relinquish my prostheses. I have since then felt comfortable without prosthetic legs in public and private. I am more content socially in and still active with my amputee body.

Still life compositions hold additional unique significance for me in my academic and personal work. I have painted fruits and flowers metamorphosing into body parts and analysed corporeal images as still life compositions.29 In Colourful Cabbage, I represent my brain as a scarlet or purple cabbage with thick strokes of gesso and lively hues like honeysuckle and magenta. The painting poses the cabbage cut in half in an inside/outside composition to emphasize its textures and colours in an intricate design. On the sliced half the flowing white core suggests a moving figure or ghost. The title ‘Cabbage’ can be interpreted as a derogatory synonym for a mind and body in trauma.30 In the painting the cabbage is vibrant.

**Forgiving and Forgetting**

We think we tell stories, but stories often tell us, tell us to love or hate, to see or to be blind […] The task of learning to be free requires to hear them, to question them, to pause and hear silence, to name them, and then to become the storyteller.31

Suggested by Colourful Cabbage and other works analysed in this essay, the effects of the 2007 accident proved both damaging and regenerative. This accident caused pain, loss, trauma, revision and art. In contradistinction to memory loss, I cannot forget the accident as I will always embody it. I can forgive myself as there is no alternative offender. For me, forgiving means letting go of the desire to place blame, rather than sanctioning any harm. Resisting self-blame enables me to take advantage of my knowledge and experiences. Making art and writing about it play roles in my ability to process traumatic events and articulate varied sensations.

Rebecca Solnit’s quotation at the opening of this section echoes how letting go of or forgetting the past always enacts loss. Telling stories about her late mother, personified by the ripening, rotting and canning of apricots, Solnit illustrates that what we do with our pasts, in our actions, words and art forms, transforms history into fruitful media for the present. This aligns with Cathy Caruth’s argument that narrations of trauma can demand ‘a command to respond’ (UETNH, 132).

This essay foregrounds personal narrative about disability and trauma through the production and analysis of art. I have drawn scholarship from disability studies,

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trauma studies, critical theory, art history and art therapy to construct my visual narrative of concepts that may seem unimaginable. I cited statistics regarding TBI across the globe in my introduction. A significant number of people live with TBI effects, and not because they have overcome trauma. The experiences investigated and illustrated in this essay are evidence that representations of TBI and more broadly, trauma, can transform conceptualizations of the needs and rights of minds and bodies.

**Bibliography**


**Figures**

Fig. 1: Ann Millett-Gallant, *Re-Membering*, mixed media on canvas, 90 x 90 cm, 2008.
Fig. 2: *Ann’s Hands*, acrylic on canvas, 25 x 20 cm, 2008.
Fig. 3: Collage with *Ann Drove a Van; My Body Is*; and *Ann’s Spoon*, ink drawings and paper on canvas, 30 x 30 cm, c. 2010.
Fig. 4: *Art Therapy*, mixed media on canvas, 60 x .60 cm, c. 2010.
Fig. 5: *Self Portrait with Flowers*, acrylic on canvas, 35.5 x 28 cm, 2012.
Fig. 6: *CRIPERCIZE*, acrylic on canvas, 45 x 60 cm, 2015.
Fig. 7: *Colourful Cabbage*, mixed media on canvas, 30.5 x 30.5 cm, 2016.

**Transformări ale minții și ale corpului prin artele vizuale**

**Rezumat**

Acest eseu narează experiențele mele ca persoană amputată cu probleme congenitale și ca supraviețuitor al unei leziuni cerebrale traumatice, prin analiza operelor mele de artă. Prin intermediul istoriei artei și al terapiei prin artă, am reușit să ajung în mod conștient la medierea cathartică a pierderii corporalității mele. Articolul analizează exemple cheie din arta mea vizuală care ilustrează aspecte ale dizabilitățile mele, trauma prin care am trecut și transformările minții și ale corpului meu. În integralitatea sa, articolul menține ideea că trauma nu este un eveniment izolat, ci unul conștient, colectiv și un fenomen dinamic.
Borderline Knowing: (Re)Valuing Borderline Personality Disorder as (Counter) Knowledge

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Abstract

This article explores Borderline Personality Disorder (BPD) as an epistemic standpoint defiant of dominant Western knowledge frameworks, which are (supposedly) rational, objective and linear. I engage with feminist, critical psychiatry and Mad critiques of BPD as a medicalization of trauma and ameliorate these critiques by engaging BPD as both a psychiatric diagnosis and as a (non-pathological) response to traumatic experiences. I conceptualize the ‘borderline standpoint’ as a subversive epistemology and examine the capacity of queer-crip temporalities to meaningfully engage with the borderline standpoint, arguing that a framework of queer time is useful insofar as trauma (and borderline knowing) are necessarily nonlinear. Ultimately, I employ concepts of queer-crip time, including the works of Alison Kafer and Elizabeth Freeman, to open new avenues of engagement with the ‘ugly’ affect of borderline and to embark on a maddening epistemological project.

Keywords: Borderline Personality Disorder, temporality, subjugated knowledge, standpoint theory, trauma, feminist psychiatric disability theory, queer time, epistemology

A Maddening Epistemological Project

Borderline Personality Disorder (BPD) is a stigmatized diagnostic category frequently associated with experiences of early childhood trauma. A close engagement with BPD as a site of epistemic production (or counter-knowledge) raises urgent questions about the nature of Western epistemic imaginaries, the medicalization of femininity and trauma, and the processes by which ‘subjugated’ knowledges (in this case, feminized, traumatized, and ‘mad’ knowledges) are erased and devalued. In this article I open radically new avenues of engagement with BPD and embark on a maddening epistemological project. I address the questions I have raised and articulate a borderline standpoint through a lens of (trauma-informed) feminist psychiatric disability theory; I seek to diversify how we engage in/with epistemological politics, madness and trauma. Feminist psychiatric disability theory is a framework that harmonizes the material realities and medical implications of psychiatric diagnostic categories with the critical approaches of feminist disability studies, both recognizing the materiality of mental illness categories and contesting the epistemic violences and hierarchies which foster their construction and pathologization.¹ I position the ‘borderline’ as a standpoint defiant of dominant Western epistemic frameworks while simultaneously holding the

diagnosis of BPD with a degree of suspicion. To be clear, throughout this article I use ‘borderline’ as a noun reflective of the experience, identification with, or subjectivity of being/having borderline. I also use it as an adjective to describe aspects of being/having borderline, for example, borderline knowing or borderline feeling. I also use ‘borderline’ to refer to a person with borderline in an attempt to reclaim the borderline label.\(^2\) I use ‘BPD’ to refer to the psychiatric diagnosis of Borderline Personality Disorder, which can be disempowering and epistemically violent.\(^3\) By differentiating between ‘borderline’ and ‘BPD’ I hold space to critically engage with the politics of diagnostic categories while acknowledging that some (fellow) borderlines may find solace and validation in the process of diagnostic labelling.\(^4\) The relationship between BPD and borderline then, is one of contention, negotiation, and multiple possibilities. I ultimately argue that ‘borderline knowing’ exposes fundamental cracks in dominant (Western) modes of knowing and illuminates spaces of possibility for the deconstruction of harmful Western epistemes. I engage with feminist, critical psychiatric and Mad critiques of BPD as a medicalization of trauma and ameliorate these critiques by engaging BPD as both a psychiatric diagnosis and as a (non-pathological) response to traumatic experiences, employing a lens of feminist psychiatric disability theory to hold productive tension between the ‘construction’ of BPD, as well as the diagnoses’ potential to validate borderline knowers/knowing. I conceptualize the ‘borderline standpoint’ as a subversive epistemology which can productively expose and challenge the linear nature of Western knowing. This is not to ascribe totalizing epistemic responsibility to the borderline knower, but to think about how borderline knowing can be lovingly (and productively) encountered and re-valued; I consider this primarily in the context of ‘compassionate contextualization’ and nonlinear encounter facilitated through a lens of queer-crip time. This pragmatic consideration welds the theoretical and the material and offers an intervention into scholarship about BPD, psychiatric disability, and trauma.

**Borderline Knowing-as-Feeling**

A central tenet of my argument is that feelings are an important mode of borderline knowing. I conceptualize borderline feelings as an ‘abject affect’ which can be encountered (and contextualized) in a nonlinear fashion fostered through a lens of queer time. I define ‘abject affect’ as affect that is ugly, difficult, uncomfortable and inconvenient to encounter; for the borderline, it can appear as uncontrollable emotions, self-harming behaviours, or impulsive suicide attempts. By engaging a nonlinear contextualization of the borderline standpoint we can imbue the borderline knower with

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\(^2\) I acknowledge that disability activists have worked to contest the use of the disability condition to reflect the person living with that condition. In this article, I am using ‘borderline’ to refer to people with borderline, being a borderline myself (a person with borderline, a borderline subjectivity) and I am seeking to radically reclaim borderline from traditions of extreme stigma and epistemic invalidation. My use of the term is therefore contextual, intentional and political.

\(^3\) In the introduction to *Psychiatry Disrupted* Bonnie Burstow and Brenda LeFrançois conceptualize psychiatric diagnostic categories as forms of epistemological violence predicated on ‘pathologizing and “treating” everyday life’ [Brenda LeFrançois, Bonnie Burstow and Shaindl Diamond, *Psychiatry Disrupted: Theorizing Resistance and Crafting the (R)Evolution* (Montreal: McGill-Queen’s University Press, 2014), 4].

epistemic ‘authority’ and thus resist the devaluation of this particular standpoint by Western epistemic traditions which are oriented towards a linear, or to borrow from Elizabeth Freeman, chrononormative, progression, centralizing reason, rationality, sanity, and ‘objectivity’. The devaluation of borderline knowing is generally enacted within psychiatric and medical knowledges, which fit neatly within a Western paradigm of knowing, where ‘doctors and scientists are observers of the truth of [the mind and] the body, uniquely able to read, interpret, and understand’. I take up a lens of queer-crip time as useful insofar as trauma (and borderline knowing) are necessarily nonlinear. I return to this theoretical (re)orientation later in my article, suffice to say that I argue queer-crip time, which I understand as a nonlinear orientation to time marked by queerness and disability and defiant of Western chrononormative temporalities, is productive for highlighting the nonlinearity of trauma-informed borderline knowing, and can point to some productive means of revaluing borderline knowing. I conclude my article by thinking about how the borderline standpoint disrupts chrononormative, Western epistemic orientations. This engagement is predicated on the nonlinearity and willingness to engage with abjection offered by queer theory. To be clear, by ‘engagement’ I do not (and cannot) intend to offer ‘solutions’ to the epistemic dismissal of borderline knowing; rather, I offer strategic understandings and a more informed contextualization of the borderline standpoint at the intersection of feminist disability and trauma studies.

A note on positionality and epistemic orientation: I enter into this work as a queer borderline advocating for borderline knowing and for recognition of our lived experience and our uncontrollable emotions as valid forms of counter-knowledge – for lack of a better term, an ‘outsider within’; a borderline in the academy. Black feminist scholar Patricia Hill-Collins conceptualizes the ‘outsider within’ as a standpoint generated by Black feminist sociologists within the academy; it is a standpoint which generates creative tensions, which allows Black female scholars to draw on their lived experiences as Black women to see ‘differently’ and generate new knowledges. It is a site of knowledge production informed by lived experiences of marginality. While I do not conflate my experiences here with those outlined by Collins, the ‘outsider within’ provides a meaningful theoretical framework through which to ‘read’ my own experiences into this text. My borderline allows me to see and articulate the value of borderline knowledge and to advocate for a new engagement with BPD, as well as its abjection, as an epistemic paradigm in contrast to Western epistemic traditions which I link to dominant accounts of rationality and objectivity that carry social power and legitimacy; Sandra Harding’s work on epistemic politics and standpoint theory will tell us that all knowledge is socially situated and contingent on the position of the knower/speaker. As such, despite Western epistemic claims to ‘objectivity’, ‘in societies where scientific rationality and objectivity are claimed to be highly valued by dominant groups, marginalized peoples and those who listen attentively to them will point out that from the perspective of marginal lives, the dominant accounts are less than maximally


6 Alison Kafer, *Feminist, Queer, Crip* (Indianapolis: Indiana University, 2013), 34. Hereafter cited as *FQC*, with page numbers in the text.

objective’. I am operating under and with the assumption that Western epistemic ‘objectivity’, despite its dominant social position and capacity to invalidate ‘marginalized’ knowledge claims, is not only less than maximally objective, it is harmful.

**Borderline Personality Disorder (BPD): Conceptualizations and Critiques**

I have noted that a close engagement with BPD (as a psychiatric category) can expose questions about the harmful nature of Western modes of knowing, the medicalization of femininity and trauma and the subsequent erasure of subjugated knowledges. In order to facilitate my argument, I provide a general conceptualization of BPD as articulated in the DSM-5 and elucidate major feminist and antipsychiatric critiques of BPD as a ‘pathological’ schema. I explore these critiques of BPD while situating BPD in its roots of traumatic experience to make possible the ‘logic’ of borderline knowing and to facilitate a critical engagement with the diagnosis as it stands. BPD is the most commonly diagnosed personality disorder in North America, estimated to affect up to 6% of the population. BPD is generally characterized by ‘manipulativity, impulsivity, identity disturbances, and self-injurious acts’, and is frequently diagnosed in women-identified trauma survivors. Rebecca Lester articulates BPD as a collection of interpersonal and emotional traits, including ‘fears of abandonment, relationships where others are alternately idealized or demonized, an unstable sense of self, impulsivity, suicidal behavior, mood swings, feelings of emptiness, overwhelming anger, and stress-related paranoia or dissociative symptoms.’ This generalization encompasses the DSM-5’s conceptualization of BPD, outlined as a ‘pattern of instability’ that filters into the borderline’s affective states, interpersonal relationships and sense of self. The unstable affect and reactive mood of the borderline are what I aim to take up most closely in this article – these affective states lend easily to the invalidation of borderline knowing based on instability, unreliability, and abjection. It is important to note that I have referenced the diagnostic criteria of BPD for the DSM-IV; while changes to the DSM-5 have shifted how BPD is diagnosed and conceptualized in clinical practice, both the DSM-IV and DSM-5 stress the ‘core’ features of emotional and relational instability, impulsivity, self-harm and difficulty ‘controlling’ emotions. The emphasis placed on controlling (and failing to control) the frantic, inappropriate and

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9 The DSM-5 has undergone many changes in its conceptualization of Borderline Personality Disorder as a diagnostic category, when compared to the DSM-IV. A complete analysis of these changes is beyond the scope of the present article, yet it can be found here: www.psi.uba.ar/academica/carrerasdegrado/psicologia/sitios_catedras/practicas_profesionales/820_clinica_tr_personalidad_psicosis/material/dsm.pdf
unstable (read: ‘hysterical’) emotions of the borderline form the basis of feminist criticisms of BPD, as well as the main site of the borderline’s epistemic invalidation.

**Feminist Critiques OF BPD**

Feminist critiques of BPD tend to identify BPD as a harmful diagnostic category insofar as it constitutes a medicalization of femininity; BPD is an overwhelmingly gendered diagnosis irrefutably linked to trauma. 75% of people diagnosed with BPD are women, and 88% of these women have experienced abuse in their lifetimes (WM, 486). Statistically, borderlines have experienced particularly high rates of childhood sexual trauma. Given high rates of abuse and trauma survival among diagnosed borderlines, particularly childhood sexual abuse, it is relevant, if not troubling, to observe that BPD is diagnostically conceptualized without mention of or link to trauma. Unlike diagnoses of Post-Traumatic and Complex Post-Traumatic Stress Disorders, which centre the ‘aetiological importance of trauma’ in their conceptualizations, Claire Shaw and Gillian Proctor argue that the silencing of interpersonal trauma and violence in BPD both responsibilizes the individual in bearing the burden of their ‘illness’ and continues psychiatric traditions of ‘denial and distortion’ (WM, 486). Such traditions are exemplified in the implementation of false memory syndrome in the 1990s as a distorting mechanism used to invalidate psychiatric patients’ experiences of assault and abuse (WM, 486). Shaw and Proctor ultimately write that ‘the individualization inherent in the diagnosis of BPD maintains the general failure to understand that for many women the “symptoms” of BPD are a complex attempt to maintain personal survival and integrity in the face of past and current trauma’ (WM, 486). The erasure of trauma’s role in BPD is part of a longer tradition of obscuring gendered, racialized, and classed oppressions which cumulate on the bodies and minds of those rendered vulnerable and precarious. While BPD has been critiqued for its erasure of aetiological trauma, feminist and critical disability scholars have critiqued the diagnostic criteria of BPD for medicalizing traditionally ‘feminine’ attributes such as instability, dependency and emotionality (LB, 71). In addition, they have argued that the diagnosis of BPD constitutes an effort to pathologize the ways that women cope with past and present trauma and oppressions (WM, 483). Rather than medicalizing (and therefore dismissing) the borderline, symptoms such as fear of abandonment, emotional dysregulation and unstable interpersonal relationships are perhaps more productively interpreted as ‘adaptive reactions to early relational traumas… an attempt to ensure “some measure of mastery, control and alliance with others, in the face of trauma, helplessness and inner vulnerability”’ (WM, 486). Furthermore, these aspects of borderline knowing/feeling have the capacity to illuminate important lessons with regards to epistemic power, authority, and trauma.

I have shown that BPD has been critiqued as a disciplinary mechanism wielded to demarcate ‘acceptable’ norms of femininity; while emotionality and dependency are normatively ‘feminine’ traits, the unstable emotionality and desperate dependence of the borderline create a line of transgression which is pathologized. Shaw and Proctor argue that high rates of BPD diagnosis among women have emerged as a means to ‘indicate behaviours which are disapproved of, and specifically employed as a male term of abuse for “difficult” female behaviour’, similarly to the ways that allegations of witchcraft and hysteria have functioned in the past (WM, 485). This is not to say that all borderlines identify as women, but to particularize the gendered aspects of Western
epistemic power in creating hierarchies of rational/irrational, valid/invalid. Scholar Elaine Showalter writes that in contrast to the perceived ‘objectivity’ of Western science (and psychiatry in particular), women are ‘typically situated on the side of irrationality, silence, nature and the body, while men are situated on the side of reason, discourse, culture, and mind’. Of course, this binaric generalization is overly simplistic; however, Showalter’s positioning is helpful for conceptualizing and interrogating problematic dichotomies between intelligible/unintelligible, sane/mad, powerful/powerless that render some knowledges ‘valid’, while others are easily dismissed. I take up these dichotomies (informed by Western science, medicine and psychiatry) as rooted in power, which are necessarily gendered, raced, abled, and classed. It is worth noting here that I present these criticisms of BPD and psychiatric categories more generally, not to dismiss BPD as an affective and experiential phenomenon, but to illuminate the precarity and power dynamics of diagnostic categories which have the potential to ‘enable forms of regulatory control through which individuals may be constrained within prescribed forms of being deemed morally acceptable’ (LB, 72).

**Critical Psychiatric Critiques of BPD**

A critical psychiatric analysis of BPD acknowledges that the politics of psychiatric categorization are fraught with power and shift and expand over time and across spaces/places. These assertions have led critical psychiatric theorists to assert that illness categories, particularly those of mental illness, are ‘products of social discourse with little, if any, stable grounding’ (LB, 72). Jane Ussher’s work on women and madness, for example, has taken up women’s madness as a historically employed technique for regulating acceptable feminine behaviour and deportment. Ussher outlines antipsychiatric arguments, such as those of libertarian psychiatrist Thomas Szasz, who in the early 1960s conceived mental illness as a fictitious entity coined to validate the authority of the medical profession; Szasz contends that ‘behaviour is deemed mad because it breaks social rule’. As such, Szasz argues that medical authority, while applicable to physical illness, does not extend to the ‘mad’, whose illness is, indeed, a ‘falsely legitimated moral judgement’. Ussher outlines major tenets of antipsychiatric arguments which consider ‘madness’ to be a subjective label – one that is ‘arbitrary, founded on values, morals, and political allegiances – a medicalization of deviance in order to maintain social control’. The antipsychiatric arguments articulated by Ussher find resonance in the contemporary Mad movement, which takes up madness as an experience/valid positionality to be reclaimed from the violences of Western psychiatry. Here I clarify that Mad scholarship/activism and Antipsychiatry scholarship/activisms are not synonymous; while both operate within the same community of resistance, antipsychiatry is a fundamental opposition to psychiatry in all of its forms and operates towards an end goal of psychiatric abolition. Mad politics may include an antipsychiatric politic or praxis, however, the goal of mad politics is to reclaim the

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16 Ussher, 132.
17 Ussher, 134.
experience and subjectivity of madness, which may or may not include antipsychiatric activism/orientation. This is similar for those who operate in the critical psychiatry camp; being critical of psychiatry may or may not include antipsychiatric politics and praxis. Bonnie Burstow states that what ultimately unites this (broad) community is ‘some type of withering’ of psychiatry and a critical orientation toward psychiatric discipline and practice,\(^{18}\) whether this orientation and praxis includes psychiatric reform, psychiatric abolition, or the reclamation of the psychiatrist/mad self. While Antipsychiatry and Mad movements/scholarship are not necessarily interchangeable, it is worth noting that Richard Ingram is credited with coining the term Mad Studies in 2008 after determining Disability Studies’ inability to adequately and wholly reflect the experiences of psychiatristed people, while acknowledging the debt that Mad Studies and Mad activism owes to fields of Disability Studies.\(^{19}\) Mad Studies and Critical Disability Studies are intimately related and mutually informative fields of study and activism where both seek to ‘pursue this project of “transformative revaluation” […] such a pursuit must reflect the specificities of Mad experience and politics (and thus is not fully co-extensive with disability studies), just as it seeks to forge strategic coalitions with other peoples in struggle’.\(^{20}\) In the introduction to Searching for a Rose Garden Brenda LeFrançois offers the following conceptualization of Mad Studies:

Mad Studies centres the knowledges of those deemed mad, bolstered on the periphery by the important relationships, work and support of allies – or by those who comport themselves as mad-positive. This allows those of us deemed mad to formulate and advance our own understandings, theories, research, actions, practices and knowledge, each of which carries an inherently enhanced credibility because of direct experience… The Mad Studies project offers us a way forward in revealing or creating knowledges that do not contain the distortions and harmfulness proffered by a biomedical psychiatry that is so distant from our lived realities.\(^{21}\)

By exploring antipsychiatric arguments and Mad politics I aim to illuminate the precarious and violent construction of BPD as a mechanism of social control. I take up these antipsychiatric arguments, as well as feminist critiques of BPD, not necessarily as an advocacy of or alignment with their views but to reflexively comment on the social production of madness (and BPD more specifically). To be clear, I am highly critical of the diagnosis of BPD and hold that diagnostic categories more generally are epistemically unethical and violent. It is my assertion that BPD is a psychiatric construction embedded in mechanisms of power; however, I concede that borderline knowing is also a valid (and valuable) standpoint of knowledge (and emotion) production, and that some borderlines resonate with the diagnosis of BPD. Johnson’s feminist psychiatric disability theory, which dialogues with antipsychiatry and Mad arguments, is a complex theoretical framework which is capable of holding productive tension between the constructed and dangerous of BPD, as well as the ways in which diagnoses of BPD can reflect and validate the lived experiences of borderlines; I

\(^{18}\) LeFrançois, Burstow and Diamond, *Psychiatry Disrupted*, 50.

\(^{19}\) Richard Ingram, ‘Mapping “Mad Studies”: The Birth of an In/Discipline’, *Syracuse University Graduate Disability Studies Symposium* (2008).


therefore contend that the diagnosis of BPD, for some borderlines, can be both limiting and life-affirming.

**Borderline Subjectivities and Stigma**

I have argued that the label of BPD has the potential to dismiss, regulate, and control borderline subjects, and can be disempowering to the borderline knower/feeler. What are the impacts of this stigma on subjectivity formation, and how does this erasure impact the borderline standpoint I seek to develop? Here I explore the stigma attached to BPD and its material effects on borderline subjectivity formation and survival; these arguments are meant to support my contention that borderline is a subjectivity to be fiercely and radically reclaimed as a site of knowledge production. Where BPD is constituted by instability, emotional dysregulation, and inappropriate attachments, the figure of the borderline commonly appears in popular culture and dominant discourse as crazy and unstable; Johnson identifies the ‘borderline’ as ‘mired in the clinging, stalking, threatening abduction of the psycho girlfriend, a figure of absolute to-be-avoidedness […] the word “borderline” remains somehow too taboo, too undesirable, and perhaps too grotesquely female’ (*BR*, 253). The stigma associated with BPD carries into clinical practice – Lester notes that clinicians generally ‘despise’ working with patients with BPD, viewing them as needy, emotionally exhausting, hostile, and unstable, reporting one psychiatrist as commenting that ‘you look for the “meat grinder” sensation: if you are talking to a patient and it feels like your internal organs are being turned into hamburger meat, she’s probably borderline’ (*LB*, 70). Likewise, Nadine Nehls has examined the negative impacts of the borderline diagnosis on psychiatric patients who experienced dismissal of experience and lack of empathy from mental healthcare providers on the basis of their BPD diagnosis. Nehls argues that ‘while the controversy within professional circles centers on whether the borderline personality disorder diagnosis should exist and, if so, based on what criteria, those living with the illness contend that the diagnosis and its current criteria are not as problematic as the prejudice of providers’.22 The dismissive and violent ways that borderlines are regarded both in wider discourses and medical institutions constitutes an erasure of both borderline knowledge and borderline existence symptomatic of ‘rational’ Western epistemic paradigms.

Borderline feelings which easily splatter, that cling and manipulate, that cause harm to the self, constitute an ‘abject affect’. This abjection is mirrored in stigma and discrimination by clinical practice, rendering the borderline knower invalid and unintelligible. Borderline abjection also influences interpersonal and kinship relationships; it is common for borderlines to have patterns of unstable relationships and painful fallings-out, often informed by an inability to control powerful emotions. I contend that the abjection of the borderline does not render these affective knowledges useless or somehow less ‘valid’; rather, they encourage us to consider knowledge in different, more complex ways. Ann Cvetkovich offers a compelling argument for the merit of negative affect in her discussion of political depression; negative and positive affect are not so easily disentangled but are mutually informing. Cvetkovich states that ‘[b]inary divisions between positive and negative affects don’t do justice to the

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qualitative nuances of feeling that are only crudely captured by such designations.’ 23 In this reading, the negative affect that accompanies BPD is not invalid, but constituted of and through attempts to acquire safety and stability; the undiluted emotional responses and dysregulation that accompany borderline, while abject, can teach us something about trauma and subjegated knowing.

Feminist Psychiatric Disability Theory

As I have indicated, feminist psychiatric disability theory offers a means of holding productive tension between recognizing BPD as a psychiatric diagnostic category, which is potentially desirable, and holding this category with a degree of suspicion, remaining attuned to the gendered, raced and classed power dynamics which make such a diagnosis possible, both in terms of its dismissive potentiality (by medicine, including stigma by healthcare providers), as well as how systemic violence informs experiences of trauma which are linked to BPD. While I have noted that BPD as a psychiatric category can be limiting and damaging, illness categories can also provide ‘explanatory models through which people can narrate their experiences and make sense of their behaviors’ (LB, 72). This is the crux of feminist psychiatric disability theory, which recognizes the realities of borderline feelings (as a category of experience) while troubling the gendered, raced and classed power dynamics on which it stands. Here I emphasize that my goal is not solely to trouble BPD as a diagnostic category, but to reclaim and revalue the ‘borderline standpoint’ as a valid place of knowing/feeling without pathologizing or medicalizing the borderline knower. This reclamation will expose limitations of dominant modes of knowing with regards to emotional, visceral and embodied knowing, and open conditions of possibility for meaningful engagement with borderline knowing.

As a diagnosed borderline, I am critical of the diagnosis of BPD; however, I do not deny the realities of borderline tendencies and how they inform my interpersonal relationships, nor the power that a ‘recognized’ diagnosis carries in accessing treatment and therapy. I received my diagnosis at eighteen years old, after years of uncontrollable emotions, reckless behaviour, self-harm, suicide attempts, drug use, and subsequent (and repeated) hospitalizations. ‘Borderline’ spoke to me. It validated my experience. My illness was ‘real’. To have a label to articulate my tumultuous relationships, chronic feelings of emptiness, histories of self-harm and repeated suicide attempts provided a (perhaps not unproblematic) sense of legitimacy, where otherwise I felt lost and out-of-control. Lester writes that

harsh critiques of BPD make a great deal of sense. But they only tell part of the story. The diagnostic parameters of BPD are often deeply resonant with clients’ daily lived experiences. In addition to their regulatory propensities, BPD diagnostic criteria capture a cluster of dispositions, emotions, behaviors, and experiences that hang together in discernable patterns, under certain conditions, for certain people, in certain historical and cultural circumstances. (LB, 71)

In conducting this analysis and reflecting on my lived experience, I hold space for both the psychiatric diagnosis of BPD, as well as critical feminist engagement with it, to conceptualize BPD as a psychiatric experience informed by trauma as well as a ‘specific

constellation of feelings and coping mechanisms’ (BR, 253). I strategically associate this ‘constellation’ with a medical diagnosis to undertake a project aligned with feminist psychiatric disability theory, outlined by Merri Lisa Johnson as a body of work ‘comprised of scholarship that [critically] integrates medical knowledge about diagnostic categories with the anti-stigma stance of critical disability studies’ (BR, 253). By recognizing the validity of borderline symptoms and the aspects of BPD rooted in trauma, I articulate a borderline standpoint of knowing.

**Borderline Standpoint**

In this section, I use the term ‘borderline standpoint’ to refer to the particular (abject) knowledges generated by the borderline knower/feeler. This is not to universalize the borderline experience, but to take up the ‘borderline’ as a strategic site of counter-knowledge production and to illuminate spaces of possibility for the deconstruction of harmful Western epistemes. Sandra Harding’s standpoint theory exists in relation to dominant epistemic modalities. That is, in a hierarchized society, those ‘at the top’ organize the world around them; as such, knowledge of and by marginalized groups can offer a more complete picture of the workings of any given social world because the experiences and knowledges of marginalized selves render visible new knowledges, new problems, and new solutions. The borderline standpoint can attune us not only to gendered dynamics of power, but causal trauma, madness, and the richness of intense emotionality. Often, borderline knowing looks crazy. It materializes as ‘irrational and monstrous: self-cutting, mercurial emotions, inconstant attachment, hypersensitivity’ and impulsive suicide attempts (BR, 255). Under a dominant lens of Western knowing, where ‘valid’ knowledge is rational, objective, and reasonable, the stalker ex-girlfriend and desperate cutter have no claim to epistemic authority – Shaw and Proctor assert that BPD marks a deviance from the ‘rationality’ and ‘individuality’ valued under Western epistemes; the rational individual is arguably a hallmark of Western epistemic schemes (WM, 485). In contrast, the emotional, dependent and often feminized borderline subject is rendered unintelligible. This ‘abject affect’ of the borderline, which I have previously conceptualized as expressions of affect or emotion which are normatively conceived of as difficult, ugly, or uncomfortable, makes it easy to dismiss under Western epistemic imaginaries. The borderline standpoint is (often) occupied not only by women, but by women who have little to no control over extreme and unstable emotions. It is these uncontrollable emotions, informed by trauma, which form the basis of borderline knowing. I seek to carve out a place where the borderline’s knowledge can be held as valid, in spite, or perhaps because of, this abjection by ‘asserting BPD as the basis of a distinctive epistemology that constitutes a valuable form of counter-knowledge’ to dominant Western thought (BR, 255). What can borderline feelings teach us about epistemic power and trauma? From here, I explore how the borderline standpoint is undermined by the objective ‘god trick’ of Western epistemic imaginaries, and how an engagement with BPD and ‘ugly’ borderline affect through trauma-informed queer-crip temporalities can open up new avenues of engagement with borderline feelings.

In ‘Situated Knowledges’, Donna Haraway conceptualizes Western knowledge as a disembodied god trick that sees ‘everything from nowhere’; the supposed objectivity and rationality of powerful groups dominates at the expense of marginalized

24 Harding, 443.
bodies and communities which produce ‘biased’ or messy knowledges – knowledge that is embodied and informed by lived experience at the margins. I challenge the disembodied god trick of Western thought by forwarding the borderline standpoint as a particular form of subjugated knowledge rooted in trauma, affect and embodiment. In this assertion, I ground the borderline standpoint within gendered power dynamics that prioritize and define the sane and the rational. Haraway employs the term ‘subjugated knowledges’ to refer to sets of knowledge rendered unintelligible by the ‘god trick’ of Western objectivity. The uncontextualized borderline standpoint defies Western scripts of intelligibility, rendering it easy to dismiss and hard to hold. This dismissal is particularly salient in discourses surrounding medicine, ability, and sanity. Critical disability scholar Alison Kafer references Haraway’s ‘god trick’ when discussing the objectivity and authority of Western medicine, stating that ‘Within this framework, doctors and scientists are observers of the truth of [the mind and] the body, uniquely able to read, interpret, and understand’ (FQC, 60). Epistemic norms of Western medicine and psychiatry inform ‘the usual cultural undermining of epistemic authority that comes with the BPD diagnosis’, where borderline feelings, as ugly, unstable and embodied, fail to ‘count’ under the Western epistemological imaginary as valid and complete (BR, 255). Insofar as Western medicine and psychiatry constitute the dominant framework through which we can understand borderline knowing, it becomes necessary to develop a new point of departure, a new opening of engagement, with borderline knowing. In order to recognize the borderline standpoint as a ‘valid’ form of knowing and to trouble dominant epistemic hierarchies, I turn to Merri Lee Johnson and Robert McRuer’s work on cripistemologies, as well as queer (crip) conceptualizations of time and trauma.

Cripistemologies

‘Cripistemology’ is a framework developed by Merri Lee Johnson and Robert McRuer as a means of challenging the co-optation of ‘mainstream’ disability knowledges/epistemologies under neoliberal capitalism. Johnson and McRuer argue that the booming psychopharmaceutical industry operates as a co-opted knowing of disability which ‘compels’ targeted consumers to know about and from a space of impairment. This compulsion to know ‘from a space of impairment’ does not explode, deconstruct, or challenge dominant modes of knowing – it is rather an unproblematised co-optation of crip knowing into pre-existing structures of neoliberal capitalism. In opposition to this co-optation, or ‘pink-washing’ of disability rights and knowledges, cripistemologies can be regarded as a framework for ‘knowing and unknowing disability, making and unmaking disability epistemologies… and challenging subjects who confidently “know” about “disability”, as though it could be a thoroughly comprehended object of

26 Haraway, 581.
28 I hold that structures of ‘neoliberal capitalism’ follow a similar logic to structures of Medicine and Psychiatry; indeed, they are intimately connected by and with scripts of Western ‘objectivity’ and dominant Western knowing. We cannot separate disability-oppression and neoliberal ideologies; both are oriented towards a linear productivity.
knowledge.’ 29 Cripistemologies pose a fundamental challenge to dominant means of
‘knowing’ disability and radically ‘expands the focus from physical disability to the
sometimes-elusive crip subjectivities informed by psychological, emotional, and other
invisible or undocumented disabilities’. 30 I align my analysis within this
cripistemological framework because, while I seek to explore borderline knowing from
a place of trauma and disability, I simultaneously aim to deconstruct, collapse and
challenge dominant modes of knowing, rather than subsume the borderline standpoint
into hierarchized Western epistemes. Cripistemology is an undoing of epistemic
hierarchies which have infiltrated disability movements and knowledge; cripistemologies emphasize disability knowledge as a shifting and unstable
epistemological project that counters that ‘stable’ knowing of Western medicine (and
psychiatry). While ‘cripistemologies’ arises out of a highly specific context, it is a
useful concept for thinking through the destabilization of knowing, and how this
interacts with disability and madness at the site of borderline knowing. By expanding
conceptualizations of disability to include emotional and otherwise ‘elusive crip-
subjectivities’, such as those of the borderline, Johnson and McRuer provide a
conceptual framework through which to re-think borderline knowing as a crip-specific
episteme. Borderline epistemologies fit within this expansion, surely; the borderline
standpoint I have advocated for is a means of ‘maddening’ epistemologies and
encouraging the valuation of borderline-specific knowledge. Of course, I have noted
that this borderline specific knowledge, or the borderline standpoint, often looks crazy. I
would therefore like to offer a means of engaging with the borderline standpoint through
a lens of queer-crip time and trauma, particularly, investigating how notions of queer-
crip time can dialogue with the “abject affect” of borderline knowing.

New Engagements: Queer-Crip (Trauma) Time

How can notions of queer-crip time help us to engage with the abject borderline
standpoint? In this section I explain “queer time”, introduce a conceptualization of
“queer-crip time”, and discuss the relevance of queer-crip time for encountering the
borderline standpoint. I stated in my introduction that queer theory offers a lens of
nonlinear engagement, as well as a willingness to engage with the abject. Elizabeth
Freeman, in *Time Binds*, notes that ‘what makes queer theory queer as opposed to
simply deconstructionist is […] its insistence on risking a certain vulgar
referentiality’. 31 This willingness can help us to think through borderline knowing,
especially as it materializes as overwhelming – even undesirable – emotions. Freeman’s
work on chrononormativity is helpful for illuminating borderline feelings and
knowledges as they collapse and deny Western epistemic regimes. Freeman
conceptualizes chrononormativity as a mastery of time, a temporal organization of
bodies towards maximum productivity, belongingness, and collective attitudinal
dispositions, noting that ‘subjectivity emerges in part through mastering the cultural
norms of withholding, delay, surprise, pause, and knowing when to stop – through
mastery over certain forms of time’. 32 Queer time is most clearly articulated as an
orientation to time marked by queer failures to achieve the “natural” milestones of

29 McRuer and Johnson, 130.
30 McRuer and Johnson, 134.
31 Freeman, 11.
32 Freeman, 4.
heterosexual adulthood; particularly, heterosexual marriage and reproduction. Queer time is nonlinear in these respects, marking a deviation from the ‘natural’ course of heterosexual human development. Disability scholar Alison Kafer takes up time, particularly straight time, as ‘foundational in the production of normalcy; engaging in particular things at particular moments has become reified as the natural, common-sense course of human development’ (FQC, 35). The linear sequence of childhood, independent adulthood, marriage and reproduction is interrupted by both queerness and disability, where bodies move more slowly, or sideways, or backwards; these deviations constitute what we know as queer-crip time. Kafer argues that queer time has always been crip time, where ‘[q]ueer time is often defined through or in reference to illness and disability, suggesting that it is illness and disability that render time queer’ (FQC, 34). This is not to equate queerness and disability, nor is it to subsume queerness into disability. Rather, it is to emphasize that both queerness and disability are temporalities marked by difference and that the interrelations between queerness and disability as sites of temporal dislocation is intricate and mutually informative; it is for this reason that I use the hyphenated ‘queer-crip’ time. Kafer situates queer-crip time in relation not only to straight time, but curative time, a notion which refers to an orientation to time structured by compulsory able-bodiedness (or heterosexuality), where disabled people are often left ‘out of time’ until they are ‘cured’ (FQC, 28). We can conceptualize linear, curative temporalities as co-constituted with Western rationality; each assumes a superiority of knowing reinforced by the power and privilege to direct, redirect, and validate. These linear orientations to futurity leave little room for the ‘strange temporalities’ of mental illness, psychiatric disability, and trauma, where time is experienced as asynchronous – in flashbacks, dissociations, temporal stretches and quick bursts that blur memory (FQC, 36). As such, the borderline is a temporal outlier, failing to comply within the parameters of chrononormative and curative temporalities. Insofar as BPD is conceptualized as both a disability (psychiatric category) and as a borderline standpoint/subjectivity, the ‘reorientation to time’ offered by queer-crip temporalities generates a nonlinear lens through which to encounter the borderline standpoint. Of course, core aspects of borderline include impulsivity, uncontrollable emotions, and instability, pointing towards a general failure of mastery over both emotions and time. Bursting into tears or dissolving into panic at inopportune moments is not uncharacteristic of borderline expression and is symptomatic of the borderline standpoint’s ono-epistemic salience, insofar as it constitutes a disruption and a confrontation with normative, intelligible expression within dominant modes of knowledge and recognition. Borderline knowing, therefore, can be theorized as a creative disruption in the fabric of ‘rational’ Western knowing; a central site of borderline dismissal is its failure to comply with normative temporalities which structure and dictate ‘appropriate’ emotional expression.

This temporal reorientation scaffolds a non-linear framework through which to encounter the borderline standpoint, where the borderline standpoint is similarly framed by the strange temporalities of trauma and mental illness (FQC, 36). The explosive emotion of the borderline can be read as informed by past pain; the extreme fear of abandonment can be centred around a potentiality of future isolation, and the engagement in self-harm may be used to ground these overwhelming affects in a present moment. By understanding the ‘abject affect’ of borderline as a nonlinear phenomenon, we are offered a different point of entry into the epistemic significance of the borderline standpoint.
Spaces of Possibility

All of this is to say that the borderline is a subjectivity left ‘out of time’, and that this temporal dislocation renders borderline knowledge easily erased. As such, an engagement with borderline knowing/feeling must be contextualized and trauma-informed. Trauma, which I have argued can be strongly associated with BPD, is necessarily a nonlinear phenomenon, and its strange temporalities can include the anticipation of future triggers and flashbacks to past memory, all of which are grounded in the present (FQC, 39). The ‘abject affect’ of the borderline is similarly framed by these strange temporalities; we can enter into knowing with the borderline in a nonlinear fashion, according to the demands of trauma which (help) to constitute and inform borderline knowing. Visceral emotions tell a story. Fear of abandonment indicates something more complex than undesirable, uncomfortable, or ‘abject affect’. As previously noted, the complex expressions of borderline are better conceptualized not as irrational, but as adaptations to relational trauma, and as a means of maintaining a sense of control over the self and connection with others. Viewed in this light, borderline knowing is granted a degree of epistemic compassion. Conceptualizing queer-crip time as related to nonlinear ‘trauma time’ allows us to witness borderline emotionality in a non-linear way, and by doing so, engage in a ‘maddening’ of epistemic authority.33 These extreme reactions and borderline feelings, while abject, make sense and can be encountered lovingly given the right tools. By advocating for the validity of borderline knowing this article challenges epistemic traditions of power which invalidate feminine, traumatized, and mad ways of knowing, all of which surface in the borderline standpoint.

The ‘right tools’ I have advocated for are not easily named or materialized – I offer an opening through which to rethink and revalue borderline knowing, and not necessarily finite solutions. I have established that a nonlinear engagement with borderline knowing is conceptually useful insofar as it facilitates a destabilization of Western curative and chrononormative temporal-epistemic regimes. This nonlinear encounter can materialize as an attitude of ‘compassionate contextualization’; this ‘attitude’ emphasizes witnessing the borderline and valuing borderline knowledge, rather than treating or medicalizing the borderline. ‘Compassionate contextualization’ is a nod to queer-crip temporalities; it takes into account the nonlinear nature of borderline knowing. This can materialize as understanding that borderline emotions are not only about the present moment – they’re also about the past and future. In ‘Trauma Time’, Clementine Morrigan remarks that ‘[t]he queer temporalities of my traumatized mind are not a problem, a tragedy, or an unfortunate condition requiring a cure. Instead, they are a different way of being in the world, a creative, flexible, and nonlinear way of relating to time.’34 I advocate a similar logic of encounter with the borderline. Where the borderline standpoint is rendered a subjugated knowledge in relation to objective epistemologies and curative time, by encountering borderline through a lens that resists linear, curative temporalities – through compassionate contextualization – the borderline standpoint is given space to expand and to be witnessed in all of its abjection. Borderline illuminates the epistemic violence enacted on overwhelming emotions and

34 Morrigan, 56.
destabilizes hegemonic worldviews, calling for address through contextualization. This
is not to responsibilize the borderline to deconstruct Western epistemic hegemonies, nor
is it to absolve the borderline of epistemic accountability. It is rather to recognize that
witnessing and valuing the borderline is a fundamental challenge to Western epistemic
regimes which would rather have the borderline medicalized, erased and silenced. It is a
task fundamentally feminist, fundamentally radical and wholly necessary.

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Știința despre cauze-limită. (Re)valorizarea tulburării de personalitate borderline drept (contra)știință la ce se cunoaște despre borderline

Rezumat

Acest articol explorează tulburarea de personalitate borderline dintr-un punct de vedere epistemic care contrazice cadrele științei vestice care se presupune că ar fi rațională, obiectivă și lineară. Articolul abordează criticile feminism, psihiatria critică și criticile despre nebunie în legătură cu tulburarea de personalitate borderline atât ca diagnostic psihiatric cât și ca răspuns non-patologic la experiențe traumatizante. Conceptualizez punctul de vedere borderline ca epistemologie subversivă și examinez capacitatea temporalităților de tip queer-crip pentru a susține semnificativ punctul de vedere borderline, argumentând că un cadru precum timpul de tip queer este necesar, deoarece cunoștințele pe care le avem în prezent despre trauma și despre limită sunt în mod necesar nonlineare. În final, utilizez conceptele de timp queer-crip, abordate în operele lui Alison Kafer și ale lui Elizabeth Freeman, pentru a deschide noi modalități de abordare a afectului neplăcut al personalității borderline și pentru a mă angaja într-un nou proiect asupra nebuniei tratat din punct de vedere epistemologic.
Fictional Narratives Featuring Encounters between Disability Studies and Critical Trauma Studies in Films and in Literature
Reclamation of the Disabled Body: 
A Textual Analysis of Browning’s *Freaks* (1932) vs Modern Media’s Sideshow Generation

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Abstract

This article introduces Tod Browning’s 1932 film *Freaks*, in conversation with nineteenth century carnival and fair practices and further explains the creation and development of the freakshow. In tandem with theoretical work by authors such as Judith Butler, Rosemarie Garland-Thomson, Adrianna Cavarero and Lennard Davis, the article positions the freakshow within disability and trauma through the notions of ‘staring’, ‘normal’ and ‘horrorism’. Using two contemporary texts such as *American Horror Story: Freakshow* and the reality television series *Freakshow*, this article firstly introduces these texts thematically before analysing all three in conversation with one another as a means of further contextualizing the role of the freakshow in contemporary cultural products, then connecting these texts to the notion of violence and the use of disability as a tool for horror. The article concludes that although the freakshow has been dismantled in the literal sense, the obvious bodily difference that predicates it still remains present in today’s cultural sphere.

Keywords: trauma, disability, carnival, circus, freakshow, abjection, American Gothic, film, media, television

Freaks and the Marginalized Body

Tod Browning’s 1932 film *Freaks*, its reception, and later revival can be considered as one of the most fascinating case studies for freakshow culture, trauma and disability studies in cinema. Not only does the film draw attention to one of the most controversial sides of 19th century carnival culture in North America, but it has also become a reference point from which disability, trauma, film and media studies can further explore the phenomenon of the freakshow and its manifestations in media today. While Tod Browning’s film has influenced audiences and filmmakers for generations, the carnival, but most importantly the freakshow, has remained an integral part of American storytelling. Highlighting the marginalized bodies ‘corporeal vulnerability’¹ in society, societal preoccupation with the ‘grotesque body’ and the consequent othering of these marginalized bodies; filmmakers such as Browning have used the American gothic mode to highlight the thematic links connecting these texts to trauma and disability studies. By using Judith Butler’s term ‘corporeal vulnerability,’ I suggest the implied mortality, vulnerability and agency the human body experiences when exposed to the

gaze, touch and violence of another (VMP, 26). The body, or in the context of this article, the marginalized body therefore has public dimension, further placing it under risk.

In relation to Browning’s film, I will firstly use season four of the hit television series American Horror Story. Aptly titled Freakshow, the season depicts a fictional freakshow set in 1952 where the freaks must navigate external and internal threats to their community in a town in which they are clearly not welcome. The protagonists of the series confront both psychologically and physically violent spheres while mitigating past and present traumas they have endured due to their bodily differences. The series makes many allusions to Browning’s work while also highlighting many arguments about the autonomy of the disabled body that disability studies has commonly attempted to resolve in addition to also highlighting the economy of the traveling freakshow.2 I argue that the series reveals the politics behind the existence of freakshows as well as the treatment of the disabled body outside of the carnival space, as the body has an ‘invariably public dimension’ (VMP, 26). Additionally, the series reveals the financial implications attached to the decline of this carnival culture and its direct impact on the performers of the freakshow. My use of carnival in this context must not be confused for a circus, but instead a travelling form of entertainment popularized in America. Traced to the middle decades of the 19th century, the emergence of the carnival space in American culture can be attributed to an ‘urge within the US to redefine its national and cultural identities in tandem with the period’s burgeoning reform culture.’3 During this era the first American World Fairs began to emerge and with them so did a culture of exhibition and materialism in tandem with a strict focus on American cultural heritage (NCC, 21). Lastly, I will use Freakshow, a reality series set in one of the last remaining freakshows in America, in conversation with the previous texts. The series claims to ‘truthfully’ document the lives of the freakshow’s owners and performers as they navigate their lives in contemporary society. Documenting the freakshow performers attempts to re-claim the word ‘freak’ through organizing parades and their ‘say no to normal’ campaign, as well as their capitalization of difference through the sale of merchandise during events and their regular show hours. The series follows the day-to-day lives of the self-proclaimed freaks, in tandem with the non-disabled owners of the freakshow. Simultaneously focusing on the interpersonal relationships between the performers themselves and the owners, the series positions itself as a champion of an ‘alternative culture.’

By taking a multi-faceted approach, this article highlights the application of sideshow culture in modern media in order to further contextualize the trauma marginalized bodies face in contemporary culture. Firstly, I will present the social and economic history of the freakshow, the employment of disabled performers and the influence of Tod Browning’s Freaks (1932); then compare the film to Ryan Murphy’s American Horror Story: Freakshow (Season 4, 2014-2015) and AMC’s Freakshow (2013-). By using these three distinct texts, this article will then dissect the reasoning

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behind the recurring theme of sideshows and society’s obsession with the disabled body and how the distinct format of reality television can potentially afford performers a sense of control and autonomy not presented in other media. In doing so, the article highlights the traumatic re-contextualization of the sideshow in the 21st century, how this re-contextualization functions within mass media and also identifies how individuals who have been presented as ‘freaks’ for decades are now attempting to reclaim their bodies as autonomous in a traumatic and hostile terrain. I use these texts in conversation with one another as a means of revealing an autonomous self-therapization by marginalized groups.

**American World Fairs, Circuses and Freakshows**

The aforementioned World Fairs were exhibitionary spaces that were specifically inclusive for the white, cisgender and non-disabled citizens, providing racially coded entertainment, specific to the social and political reality of American life (NCC, 21). Since these fairs already encompassed the ethos of museums and funfairs, they soon paved the way for the emergence of circuses and freak shows, mainly functioning through the carnivalization of such spaces. Far removed from the European meaning of fair, the American fairs operated within an ‘inclusive political system for the nation’s white race, providing it with an entertainment zone that doubled as a site of educational and cultural insemination,’ reflecting white American theories regarding race and racial division (NCC, 21). It is important to note here that these stages were sanctioned and promoted by an array of federal, state and corporate interests with the purpose of presenting identities under the premise ‘of education, information, and instruction’ and predicated themselves upon a culture of ‘carnival delineations and carnivalized seeing’ that allowed for a consequent carnivalization of identity, race and otherness (NCC, 22).

This principle of a curated exhibition informed by the dynamics of earlier fairs was refocused by the 1890s (NCC, 24). As was the case in Chicago and other major cities at the time, ‘renowned circus proprietor P.T. Barnum was consulted by the fair’s designers Burnham and Bennett with regard to the architectural and entertainments planning,’ transforming the fairs into fairgrounds (NCC, 24). Creating a circus atmosphere, specific methodologies for the display of ethnic identities or of other ‘abnormalities’ were consequently incorporated from 1893 onwards (NCC, 24).

In opposition to the strict confines of the World Fairs, circus culture freely manipulated cultural codes and systems through a restriction of its transgressive possibility (NCC, 30). Combining the three-ring format with the nation’s sideshow culture, the circus became an alternative arena for interpreting reality, thus speaking to American culture in ‘accentuated tones’ (NCC, 31). Created in tandem with the emerging circuses, freakshows emerged as safe venues in which the audience could satisfy its obsession with fear and the curiosity of the unknown (NCC, 30). Bogdan defines the freakshow as ‘a formally organized exhibition of people with alleged and real, physical, mental or behavioral anomalies for amusement and profit.’

The operative term in this definition is the word ‘anomaly’, allowing for the body to be coded as ‘other,’ or to borrow from Judith Butler ‘a way of being for another or by virtue of another’ (VMP, 24). Attributed as the creative force behind both American

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circuses and freakshows, P.T. Barnum included horses, clowns and the exhibition of ‘human curiosities’ in his circus, ‘The Greatest Show on Earth’ (NCC, 31). After the destruction of his New York museum in 1868, where he exhibited ‘world-famous specimens’ of ‘freakish’ and ‘abnormal’ humans such as the Siamese Twins Chang and Eng, as well as Charles Stratton, known as Tom Thumb, Barnum took his oddities on the road (NCC, 31). In tandem with the display of individuals with varying disabilities, Barnum also displayed false spectacles such as ‘the mermaid’ and the famous ‘Zip, the What-Is-It?’ Zip was alternately identified as ‘an intelligent black man named William Henry Jackson who was born with a deformed skull . . . the size of a silver dollar and the shape of a cone’ or as the mentally retarded William Henry Johnson, born in 1840, a sufferer from microcephaly and exhibited in the Barnum circuses and at Coney Island between 1860 and 1926 and was often displayed as the missing link between humans and apes (F, 134).

These sensationalized representations of identity, in tandem with the emerging fields of phrenology and eugenics,5 capitalized on the potential primacy and criminality of the othered people of the time. Myths of cannibal tribes from Africa were frequently used in Barnum’s displays, when in fact the performers were simply citizens who were former slaves or individuals with disabilities (NCC, 33). As the freakshow is dependent on a spectacle of abnormality and exploitation, misrepresentation is then integral to the production of the freak in American culture. However, it is also important to note that exhibitions such as Barnum’s were ‘not simply seedy manifestations of American subcultural fascinations; at the time, his American Museum was a main tourist and visitor attraction’ (NCC, 33). While these spaces functioned as spaces of exclusion and the sensationalized narratives contributed to the mistreatment and misrepresentation of those with disabilities, the freakshow also functioned as a space where the performers themselves could market and profit from their own differences.

Regardless of the problematic nature of the freakshow itself, by employing techniques such as the ‘ten-in-one’6 and ‘dings’,7 the performers were able to capitalize on American society’s obsessions with the grotesque body by creating a spectacle, or as defined by the performers of the Coney Island Freakshow – a ‘theatre of guts’.8 Freakshows create an experience where the audiences’ ‘guts respond first’ and ‘afterwards their mind can reflect on what their eyes have seen’ (TG, 110) and played on the themes of ‘arousal, cancellation of skepticism and visceral empathy’ (TG, 113). By doing so, the freakshow was transformed into a lucrative showcase of the marginalized body, simultaneously providing a safe space for its performers’ resulting financial security. Some of these individuals have even become famous in their own right. Henry Johnson, or Zip, was noted to have colluded with his manager as a co-conspirator is quoted as saying ‘well, we fooled ‘em for a long time’.9 Similarly, Michael Wilson currently performs as a tattooed man at the Coney Island Freakshow as a part of a long-standing tradition in which individuals with multiple tattoos and facial

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6 A sideshow in which ten acts would perform for one low admissions price.
7 A low price, non-advertised sale of memorabilia during shows.
9 Mikita Brottman and David Brottman, Return of the Freakshow: Carnival (De)Formations in Contemporary Culture, Studies in Popular Culture 18.2 (1996): 89. Hereafter cited as RF, with page numbers in the text.
piercings were and are still exhibited. Otis Jordan, one of Michael’s co-workers, also known as Otis the Frog Boy, in turn capitalized on his small stature and his highly ossified bones that severely limit his mobility, has been performing since an early age at the Coney Island Freakshow as the ‘human cigarette factory’ in which he rolls and lights a cigarette with nothing but his mouth (TG, 114).

**Staring and the Politics of the Freakshow**

While the ability to capitalize on difference and the aggrandized expositions used to describe the performers elevated their status, the use of mockery and parodic staged events, simultaneously demeaned the performers while making the audience feel more at ease in the presence of the freaks themselves (RF, 90). The thrust of this mode was ‘to claim that the exhibit in the picture, in spite of his or her particular physical, mental or behavioral anomaly was an outstanding person’, going as far as labelling citizens as ‘above average’ through titles of royalty (CPD, 6). While anthropological information on the structure of the freakshow and the placement of the either ‘natural’ or ‘self-made’ freaks as privileged or not continues, it is often discussed that an alternative counterculture had formed within carnival culture (RF, 90). Often portrayed on screen as both private and privileged spaces, where the ‘normal’s’ are deemed unwelcome.

Despite the creation of an alternative carnival culture, the freakshow had become a space where the performers can celebrate their differences, consequently creating an even larger divide between the performers and the audience they perform for. Bogdan argues that the performers saw themselves as inherently superior and more worldly than the ‘humdrum’ audiences they performed for, going as far as using derogatory terms for those not within the culture (CPD, 7).

The feeling of mutual disgust fuelled by society’s obsession with the grotesque body only furthered the othering of the performers. As Bogdan further argues, it is ‘not simply, then, that there is a “discourse” of dehumanization that produces these effects, but rather that there is a limit to discourse that establishes the limits of human intelligibility’ (VMP, 26). Freakshows in their essence then have very little to do with the person whose deformity was exhibited. Instead this person’s physical abnormality became a starting point for the construction of difference (F, 267). These differences and the framing of the performers themselves as individuals with differences is what defined them as ‘freaks’ (F, 267). In tandem with the aggrandized mode of advertisement, such in the case of ‘armless wonders’, lead to fraudulent system of exploitation of both those with disabilities and their spectators (CPD, 9).

This, with the medicalization of ‘monstrosities’ and concepts such as eugenics linking physical anomalies with violence (CPD, 122), consolidated individuals with both inferred and actual disabilities as the perpetrators of violence within many different genres in film, television and literature. While the last decade of the 19th century was deemed the ‘era of eugenics,’ many medical professionals focused their attention on ‘describing, explaining, photographing, and controlling classes of people they thought were responsible for most social problems’ (CPD, 75). Labelled as ‘feebleminded’, these individuals were considered the root cause of an array of crimes

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10 Individuals, who by any means were ordinary in the sense that they accomplished the same tasks the non-disabled audiences could.

Through the association of disability with degeneracy, eugenicists sought out the ‘feebleminded’ in order to study them and control their reproduction, simultaneously popularizing theories about the dangers of such ‘feeblemindedness’ (CPD, 76). The individuals who were the object of study were often photographed and classified as scientific specimens, ‘mental defectives, carriers of particular diseases and conditions’ (CPD, 77-8). In her work on staring, Rosemarie Garland-Thomson introduces the association of visual observation as the source of truth in the scientific enterprise, as the ‘uneasy primacy of vision’. Exposure of the body to the ‘clinical gaze’ allowed the body to be interpreted, in this case, with a medical authority (SHWL, 29). Such an interpretation takes place as a rationalization that abstracts and simplifies the body through various societal structures, allowing for pre-existing patterns of embodiment to exist and erase human particularity. The prescription of average, through medicalization associates a certain normality with certain bodies, a notion of normal consequently shaping our own and societal expectations (SHWL, 30). If we take the notion of normality itself to be both descriptive and prescriptive and in the context of Lennard Davis’s work, enforced, then individuals who deviate from norms are marginalized and reduced. Notions of normalcy dictate the way in which we regulate ourselves, how we are expected to act, and how we are received based on our perceived level of normalcy, ‘[W]e are obligated to act, feel, look, and be normal – at any cost’ (SHWL, 31). The ‘abnormal’ body deviates from the norm, allowing ‘medical science’s influential preference for normality and prejudice against abnormality’ to render the abject human form ‘repugnant to us’ (SHWL, 30-31).

Following the rise of the ‘era of eugenics’, early cinema frequently depicted individuals with both ‘feigned and actual disabilities’ as ‘central to horror and gangster genres as well as to other types of films featuring murderers and other perpetrators of violence’ (CPD, 115). In his work on the representation of disabled bodies in early cinema, Bogdan discusses associations with the word ‘monster’, not exclusively referring to a strange and frightening creature, but in scientific terminology meaning an animal with ‘a congenital deformity,’ and the medical term used to define a ‘fetus or infant with a severe disability’ (CPD, 115). The implications of such language were commonly utilized in popular imagination, and the consequent overlap allowed for the ‘dangerous’ characters of early cinema to commit violent acts, rationalized through their ‘deformed, maimed and mentally impaired’ or disabled bodies, linking physical and mental differences with violent crime (CPD, 116). Dating back to short-films exhibited at dime museums, freakshows and fairs, the association of disability and violence, open plays on ‘age-old folk tales,’ and the era of eugenics. Therefore, early cinema frequently presented audiences with a disabled victim of violence who then turns to violence, irrational acts of violence, violence as a result of self-loathing or violence due to a propensity to sexual assault (CPD, 120-5). Commonly depicted by individuals

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13 Bogdan lists films such as: The Hunchback of Notre Dame (Universal Pictures, 1923); Dr. Jekyll and Mr. Hyde (Paramount Pictures, 1931), Phantom of the Opera (Universal Pictures, 1925); Frankenstein (Universal Pictures, 1931); The Body Snatchers (RKO Pictures, 1945); The House of Wax (Warner Brothers, 1933); The Pearl of Death (Universal Pictures, 1944); The Penalty (Goldwyn Pictures, 1920) and West of Zanzibar (MGM, 1928).
pretending to be disabled, the disabled body is either inherently violent or one that requires a sympathetic gaze (CPD, 120).

Hence, I argue that the depiction of the ‘freak’ as violent creates a doubly traumatic social sphere for these bodies. Literal violence is done onto a body by delineating it as abject; and the imagery of violence at the hand of the abject body consequently undoes social connections between ‘normal’ and abject bodies. As a result, a space of violent difference is created, which becomes evident in the ‘othering’ or ‘derealization’ of abject bodies, as those who are abject then by default have already suffered the inherent violence of the act of derealization. Butler attributes this act to a cyclical kind of cultural violence, attributing the negation of this violence to the ‘inexhaustibility of its object’ (VMP, 33).

Stuck in a seemingly infinite loop between voyeurism and a gaze unable to prescribe a normative understanding, the abject body must mitigate the socio-political sphere in its own unique manner. According to Butler, as each of us can be considered to be politically constituted, ‘politically in part by virtue of the social vulnerability […],’ the notions of loss and vulnerability are intertwined with our ‘socially constituted bodies,’ ‘at risk of violence by virtue of that exposure (VMP, 20). This notion of exposure can be seen through what Garland-Thomson calls ‘uncivil attention’; the awareness that is afforded the abject body therefore demands a type of ‘attention,’ as it disrupts expectation (SHWL, 37). The consequent social illegibility of the disabled body is what causes a discomfort in the non-disabled, it is not the disability itself that then creates a discomfort in the spectator, but the inability to read the disabled body as routine in the nature of social relations (SHWL, 38).

The placement of the body as abject can be further explained through Adriana Cavarero’s work in trauma studies that looks at the way in which trauma is instilled in the audience/viewer through horror. Citing Perseus, Cavarero notes the ‘affinity’ between horror and vision, one that exists between a ‘scene that is unbearable to look at and the repugnance it arouses’.14 Unlike what occurs in the body in the face of terror, horror operates as a statis, one that occurs when the ontological singularity of the body is threatened by violence. This implies that horror is less reactive to the active threat of death than it is to the ‘instinctive disgust for a violence,’ one that ‘aims to destroy the uniqueness of the body,’ a reminder of the body’s ‘constitutive vulnerability’ (HNCV, 8). When faced with such vulnerability at the scene of horror, the body is placed in its singularity, an exposure of oneself to the other, an act of seeing or gazing then must take place for this singularity to be realized. It is through this process of realization that the individual is confronted with a visual difference, one that as an individual we are aware we do not possess but are not immune to. If indeed the ‘face-to-face’ aspect of horror cannot be avoided, a shared repugnance occurs when we are faced with the disabled body. The disabled body therefore becomes repugnant to the singularity of everybody, acting as a mirror (HNCV, 15-16). The very corporeality of this constitutive vulnerability acknowledges that through singularity we define ourselves as vulnerable as we cannot definitively argue that our bodies will never be regarded as such. As spectators of images, or in the case of the freakshow, bodies on display, what we witness does not necessarily signify material identification with suffering. We gaze

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upon a body that we are now aware is different than our own, but the gaze is not one of empathy, instead one of voyeurism.

**Staring at the Freak Staring Back at You**

Garland-Thomson defines staring as an act that sets in motion an interpersonal relationship between a starer and a staree, a visual engagement that holds consequences in the circuit of communication and meaning making (*SHWL*, 3). Staring at the abjected body allows us to challenge our own visual norms and shifting who we are into focus ‘by staring at who we think we are not’ (*SHWL*, 8). However, as culture regulates human behaviour overall, then visual behaviour, such as the urge to stare, is also associated with cultural history. Within this frame, Garland-Thomson classifies the act of staring into four parts. Firstly, a disturbance in the visual status quo draws us into a ‘staring relationship’; secondly, the history of staring is specific to its culture, therefore shaping its meaning and practice, establishing a social relationship between the starer and staree; lastly serving as a conduit of knowledge for the unknown that was incomprehensible at first glance (*SHWL*, 13-5).

The visual sorting process is what allots the act of staring, even dictating the way one looks, with attention or without, stigmatizing the ways in which we stare (*SHWL*, 40). This form of nonverbal behaviour is then used to enforce a social hierarchy privileging bodies visually coded as ‘normal’. According to Garland-Thomson, when a person in an authoritative position stare s ‘staring functions as a form of domination, marking the staree as the exotic, outlaw, alien, or other’ (*SHWL*, 43). Separating the starer and the staree as legitimate and outside respectively, Garland attributes the colonizing gaze to collective social staring rituals such as World Fairs and Expositions, museums, freak shows, drag shows and the pages of National Geographic’, fixing individuals within respective systems (*SHWL*, 43).

Staring similarly functions as a means of stigma assignment. If we predominantly consider the ‘proto-ordinary’ body as the authentic body, then forms of stigmatized distinctiveness that occur in comparison to the ‘seen body’ define any embodiment outside of the norm as abject (*SHWL*, 45). As those with abjected bodies cannot exist as inconspicuous, they are by default discriminated against, since to ‘be a stareable sight is unseemly, then, in part because it outs the starer for inappropriate looking’ (*SHWL*, 46). Abjected bodies confront our visual landscape and therefore not only threaten our perceived notion of expected body but confront our understanding of our own embodiment, as the vulnerability of becoming a staree is a threat to our own conception of self.

Changing the scale of the ordinary or a visible lack or replacement to the body codes the body as ‘visually novel’ (*SHWL*, 162). This approach explains further the aggrandized mode in which freakshow performers were presented, as ‘armless wonders’, such as Charles Tripp and Anna Leake Thompson who performed with their toes rather than simply display themselves, presenting their bodies as a novelty to behold (*SHWL*, 133). While the display of the disabled body for amusement dates back centuries, ‘freaks’ ‘were profitable performers in the developing commercial economy of the last several centuries,’ and functioned as public displays of novelty (*SHWL*, 164).

The body of a freak could merit staring as these bodies were commonly abjected and freakshows capitalized on this by exaggerating the unusual body, a prominent example of this being the display of those with gigantism next to an individual with
dwarfism (SHWL, 162). As the unusual structure of the body can ‘overwhelm the realities of the actual people,’ their bodies often shape their stories, blurring the disabled or ‘unusually shaped’ body into monsters, inviting us to ‘remap fantastic stories’ about the people we are staring at (SHWL, 167). In her example regarding Robert Wadlow, the tallest man in recorded history, Garland-Thomson argues that while a medical condition had given Wadlow his size, the act of staring had made him into a Giant (SHWL, 168). Upon his death, Wadlow was buried in a concrete bunker in order to protect his remains, as these unusual bodies can be the recipient of stares even after death. His family took control over how his story was told (SHWL, 168).

The stare then does not only control how the individuals’ story is structured but how the story itself takes shape. Altering our gaze then has the ability to significantly alter the way disability stories are told. Although the use of the freakshow in various forms of media have been suspect at best, Tod Browning’s *Freaks* should be considered as one of the first attempts of a departure from standard disability narratives. The films unique nature standing as a reference for the narrative re-working of not only the freakshow and the carnival space, but also a narrative re-adjustment of the depiction of the disabled performers who call these spaces home.

The First: *Freaks*

Tod Browning’s *Freaks* counters the normalization of the display of the disabled body, attempting to use the ‘aggrandized mode’ as a means of creating a space of visual empathy. Juxtaposing the then upcoming medium of film with a ‘residual form that threatened to drag film back to its unglamorous beginning,’ Browning bases the film on an explicit formal and thematic link between the two media. Instead of following the overall freakshow aesthetic, Browning uses the film medium as a means of identification between the characters and the audience.

By utilizing the camera’s ability to alter perception through the usage of angles, Browning creates a world in which the audience is forced to identify with the performers on their level, on their terms, thus evoking sympathy. This more sensitive viewing can be seen as an attempt to also decouple disability from freakishness (SC, 64). By placing the viewer as the implicit example of normality, Browning attempts to blur the lines of difference between the disabled performer and the non-disabled viewer by depicting their day-to-day lives as un-exceptional (SC, 69). However, it is evident from the film’s negative reception that although Browning attempts to normalize the performers of the freakshow, the distinction between them and their ‘normal’ counterparts remains all too shocking. Not only did the film’s negative reception effectively ruin Browning’s career, leading him to become a recluse and renounce his career, but the contempt the actors faced during filming also indicated how the initial reception of the film mirrored sentiments on disabled bodies at the time. Adams not only cites asking the cast to eat outside at an assigned table, but also an incident involving F. Scott Fitzgerald sharing a table with conjoined twins Daisy and Violet Hilton (SC, 60-1). The fact that the siblings discussed about what the other wanted to

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eat became too much for the author who ran outside to vomit (SC, 60-1). Not only does it seem that this combination of high and low brow entertainment became too much for those on set, but the film grew as a stand-in for the freakshow itself.

Loosely based on a short story ‘Spurs’ by Tod Robbins, the film takes place behind the scenes of a travelling circus. Hans (Harry Earles), a man with dwarfism falls in love with a trapeze artist named Cleopatra (Olga Baclanova). However, Cleopatra plots to marry and poison Hans, inherit his money and run off with the circus strongman Hercules (Henry Victor). During a carnivalesque wedding feast celebrating the happy couple, Cleopatra refers to the performers as ‘filthy, slimy freaks’ when they attempt to chant their acceptance of her, singing and dancing ‘one of us.’ After Hans falls ill, his fellow freaks learn of her elaborate scheme. Following the circus code of justice, ‘offend one and you offend them all,’ the ‘freaks’ plot their revenge on the blissfully ignorant lovers. The film ends with the performers murdering Hercules and transforming Cleopatra into the ‘chicken woman,’ maiming her and covering her in feathers. Eventually Hans and Freida are re-united after Hans retires to a mansion to nurse his broken heart.

Inherently hybrid in form, the film utilizes authentic sideshow jargon, as well as the fact that ‘freaks from sideshows all over America played principle roles and the setting and props were actual circus material handled by circus people.’ (SC, 65) Similarly, the stage and screen identities of the performers are blurred as each character goes by the same name they use in their live performances, resulting in the film to function more as a re-production of the sideshow transformation of bodily difference into freakish spectacle (SC, 67). Browning also frequently plays with size, building sets to scale, filming from his actor’s height as well as perspective and coupling his actors in groups that are seen as un-moved by the presence of these bodies.

This highlighted difference in ‘normalcy’, coupled with the violence the performers enact on Cleopatra and the Strong Man, are what arguably draw the audience away from the sympathetic intentions of the film. This fear of our potential to become marginalized like the performers, so easily objectified by the audience, connotes the very real possibility of a warped ‘downwards mobility’ for the non-disabled audience. In the words of Butler, ‘[o]ne speaks, and one speaks for another, to another, and yet there is no way to collapse the distinction between the Other and oneself’ (VMP, 25). In the end, we all have the potential to become freaks.

Using his film as a platform for societal commentary instead of a pathologizing of the performers, ‘Browning accomplishes this goal by using dialogue and mise-en-scene to take the characters literally and figuratively off of the freakshow display platform, building a paradigm of reception into the narrative itself’ (SC, 72). Linking violence to the gaze during the final scenes of the film, Browning inadvertently comments on the act of staring as the primal activity that produces the freak in the first place. As the camera lingers on Cleopatra’s new form, the monstrosity of the actions taken at the hand of the freaks is not necessarily what frightens us. It is the level of identification we feel with the perpetrators of the crime, much like the mirror in the act of staring, ‘the surfaces of the disabled body are not radically Other but reflect back the convolutions of our own tortured interiority’ (SC, 83). In this sense, I argue that the film’s ending provides a potent societal critique as opposed to a simple reading of an ableist horror narrative.
American Horror Story: Freakshow

Years after the release and even the re-release of *Freaks*, we can see clear parallels between the film and Ryan Murphy’s *American Horror Story: Freakshow (AHSF)*. Both texts provide insight into how the performers of freakshows are not inherently violent due to their differences but are in many ways coerced into violent acts as a means of protecting themselves from society. The trauma enacted onto the freaks is met with a violent re-action, resulting in a cycle of violence based on difference.\(^\text{16}\) The violence seen throughout the series is only enacted by the members of the freakshow in terms of self-defence while the true instigators of violence are those outside of the freakshow community. The series therefore aligns itself with *Freaks* but presents a messy moral universe fuelled by bodily difference. Throughout the season, the show deals with the internal and external threats this community of ‘freaks’ face in 1950s America. An important side-note, however, is that the series is complacent in casting non-disabled actors as disabled, having their disability on screen be performative rather than informative as with the case of *Freaks* and *Freakshow*.*\(^\text{17}\)

The season begins with the ‘discovery’ of conjoined twins Bette and Dot (Sarah Paulson) who, due to their unique form, become the object of disgust in their community. Simultaneously, the performers must also deal with the external threats they face from the community upon their arrival and are even threatened by the police (*AHSF*). Soon Meep (Ben Woolf), also known as ‘the wild thing,’ is found murdered in front of the freakshow after being taken into custody for a crime he did not commit. He proves unable to survive the justice system that is meant to protect every individual. Although Meep’s disability is not explicitly addressed in the series, his small stature, inability to speak, his assumed mental disability and disfigured head make him particularly vulnerable in the confines of a 1950s small town jail.

The second episode of the series becomes pivotal in defining the line between the performers and the audience as soon Dandy (Finn Wittrock), a representative of the era’s rich and elite, attempts to proclaim himself as a self-made freak and tries to join the ranks of the company, eventually becoming the villain of the series (*AHSF*). Similarly, during the third episode a new external threat to the community is introduced, as a local conman begins his attack on the company, attempting to sell their bodies to oddity museums for profit. The show proceeds somewhat peacefully until we are given insight into the lives of the non-disabled performers. Penny (Grace Gummer), originally a candy striper at the hospital where Elsa (Jessica Lange), the troop’s leader, found Bette and Dot, is kidnapped by Elsa and forced to stay with the company. It is revealed in Episode 7 that Penny has begun a relationship with one of the performers and when she attempts to leave her normative world behind, her father mutilates her, tattooing her face with scales, giving her a lizard tongue and shaving off her hair, in essence making

\[^{16}\text{An example of this can be seen in Frankenstein’s monster. The creature is not inherently violet but is forced into committing violent acts as a means of protecting himself from societal backlash.}\]

\[^{17}\text{The debate surrounding the representation of disabled individuals by non-disabled actors is an area of contentious debate. In her work on cultural representations of disability in television, Elvira Psaila discusses this notion under the term ‘crip-drag.’ One end of the debate argues that these representations are just as offensive as black face, and denies disabled actors the ability to represent themselves on screen. See Elvira Psaila, ‘Culture, Disability and Television’, *Considering Disability Journal* 1.1-2 (2015); [https://cdjournal.scholasticahq.com/article/831-culture-disability-television](https://cdjournal.scholasticahq.com/article/831-culture-disability-television) [accessed 19 July 2018].}\]
her truly ‘one of them.’ In a reversal of form, instead of violence enacted on a person refusing to accept the freakshow performers, we see violent outer paternal force. Penny’s father uses physical disfigurement as punishment for wanting to be a part of and accepting a community of ‘Others,’ placing the violence in the film and the horror, much like with the conman hungry for body parts, in the hands of the non-disabled townspeople.

During Episode 8, the company covers Penny’s father in tar and feathers, transforming him into a ‘chicken’ man, while during one of the final episodes of the season the con-man responsible for much of the company’s deaths is murdered underneath a wagon and is fashioned into the male counterpart of Cleopatra’s final form. During the final moments of the episode, Elsa explicitly references *Freaks* stating that retribution for these interlopers’ crimes comes in the form of becoming one of them (*AHSF*). Although the aforementioned episodes directly associate themselves with the film, it can be said that Episode 10 is the one in which social commentary on the societal stance of the disfigured body is most underlined. Pepper (Naomi Grossman), a character also present in Season 3, is sent to live with her sister upon news of the company’s imminent separation. It is soon revealed that Pepper, who has microcephaly, is framed for a crime her sister committed and as punishment is sent to an asylum. The episode clearly speaks to the institutionalization of those with ‘deformities’ and also speaks to the abuse of disabled persons in the hands of the non-disabled members of society. The series goes a step further than *Freaks* and explicitly implicates upper class non-disabled citizens in crimes committed against the disabled performers. In this context – and throughout the series – although the freaks commit similar crimes, the audience is aligned for the freaks, rooting for them as opposed to villainizing them.

### The Contemporary *Freakshow*

In stark contrast to Ryan Murphy’s television show, AMC’s reality show *Freakshow* places the audience in modern-day Venice beach while ‘truthfully’ depicting the lives of its performers. Similar to *Freaks*, the series uses actors who were part of freakshows during filming. Although the reasoning behind their use and the fact that the actors in *Freakshow* are social actors, i.e. acting for a documentary series as opposed to a film, the experience of their performances and their testimonies become all the more compelling and allow for an authenticity in understanding disability that is not present in *A.H.S: Freakshow*. Throughout the series’ two seasons, the employees of the freakshow navigate their day-to-day lives in tandem with their placement in contemporary society. One of the main recurring themes of the show is the concept of the self-made freak. During both seasons, the non-disabled Asia, the daughter of the freakshow’s owner, explores her identity and place within the freakshow and ultimately identify as a ‘self-made’ freak by becoming a contortionist and performing other ‘death-defying’ stunts, eventually becoming one of the show’s headliners (*FN*). Although contortion or performing stunts does not classify an individual as a freak, Asia takes

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18 A condition that effects the patient’s ability to learn, communicate and develop due to the irregular formation of the skull.

pride in aligning herself with her fellow performers, often advocating for them in tense situations. As opposed to witnessing any adverse reaction from her parents, Asia is encouraged to explore her identity as a performer, after all her act is one of skill but does not display an overt physical ‘abnormality’. While Asia attempts to align herself with her disabled counterparts, her choice highlights the reversal of norms that take place in the freakshow space. While being a freak is the norm in this space, being non-disabled places the ‘self-made’ freaks either as frauds or as ‘unremarkable’ a theme congruent in the three aforementioned works.

In tandem with Asia’s transformation, Creature, another self-made freak and title holder of ‘the man with the most facial piercings,’ attempt to reconcile his family life with his life at the freakshow (FN). Creature faces blatant discrimination as his appearance inhibits him from finding a new apartment, his looks often frightening potential roommates and landlords (FN). During one of the final episodes of the season, Creature reconciles with his estranged wife and gains acceptance from her and their daughter, who still proclaims that he is scary (FN). Creature’s wife is unable to understand and accept his choice to make himself into a freak. Tattooed men and women who commonly operated outside of the confines of societal norms and wanted to capitalize on their difference, chose to modify their bodies into ‘freakish’ forms.20

Another performer faced with the reconciliation of his status as self-made freak is Morgue, a fellow headliner who-usually performs dangerous and sometimes consciously grotesque stunts. Morgue has chosen his stage name and persona based on his interest in Goth culture and argues that this allows him to express his individuality as a counterexample to the societal norm. In this sense, an observable trend of seeking refuge from societal norms seems to be taking place in freakshows, where disenfranchised individuals who do not necessarily have ‘extraordinary’ bodies commit to a different form of embodying difference as a means of asylum.

A second recurring theme in the show is the reclamation and reconciliation of the performers’ status as ‘freak.’ During the first season, the show’s smallest performers stage a wedding that is an exact replica of the famous freakshow personality Tom Thumb’s wedding, imitating the publicity event originally orchestrated by P.T. Barnum (See CPD, 15). By appropriating their past freakshow counterparts, the couple both acknowledge past performers’ legacies while also transforming their special day into a public spectacle (FN). In similar fashion to the re-created wedding, the company takes a trip to Gibsonton, Florida, a city that once served as a safe communal space for performers during the heyday of the famous Florida Freakshow. The sixth episode of the second season however, centres around a guest performer, the son of the famous ‘Lobster Boy’ and his reconciliation with the freakshow culture

One of the clearest examples of reclamation however comes in the first season, as the company decides to ban the word ‘normal’. The show and its performers then travel through Venice beach selling memorabilia during a large and elaborate parade (FN). Their campaign is especially powerful in an increasingly ‘diverse’ sphere as they highlight the hypocritical nature of contemporary society. If in fact ‘diversity is the new normality’21, then progress made for the sake of diversity has commonly excluded disability. In this context, disability is then filtered through a normative window that


either allows for an optimistic agenda that is carefully arranged in a manner that doesn’t offend viewers. The disabled body is fixed and confined to a medical paradigm, the choice to be a self-made freak may exist but the choice to be disabled does not exist. In a social sphere that perpetuates ableism the work done by the Venice Beach Freakshow, is in line with Browning’s humble intentions. Departing from the notion of disability as abnormal, the performers, freaks and ‘self-made’ freaks alike, stand together in opposition to the notion of normal. Refusing the umbrella of diversity, the members of the Freakshow simply wish to exist, without terms that define them as either or.

**Contemporary Freakshows**

Although the idea of presenting marginalized individuals for profit seems rather unacceptable in modern day society, Brottman and Brottman argue that due to our ongoing obsession with the grotesque body, the freakshow has simply re-appropriated itself within a modern context such as television shows, talk shows and other sensational media. They also argue that disability for profit is still very much a part of our modern media content (RF, 90). The implication of their argument is that although the display of bodily difference may no longer be seen as acceptable, as newer methodologies of exploiting the disabled body have emerged to take the freakshows place. Brottman and Brottman explicitly reference television talk shows as perpetuators of a fragmentary approach in situating the body in postmodern culture (RF, 95). By aiming to place the body as a mode of defining and exploring difference, these programmes play on the basic principle of the freakshow and the resulting exhibition of the disabled body for profit, blurring the notions of voyeurism and the gaze further. In this light, it is easier to identify the forces which these media outlets operate by. By remaining under the guise of ‘informative’ talk shows, news segments and even tabloids consciously exploit physical and even emotional differences. I argue further that this placement of the self in the unknown implies that one is not exempt from the ‘particular vulnerability’ as in any given moment, one’s body may be considered outside of the norm and labelled as ‘freak’. The body that is stared at is vulnerable by default as it rests upon its intelligibility to the other, placing the body at risk of exposure.

The notion of intelligibility then finally brings in the question of the reclamation of the autonomous body. If the performers on AMC’s *Freakshow* are truly able to reclaim their status as ‘freaks’, then shouldn’t they be able to continue their lives free of gaze and objectification or is this not possible due to the status they still hold within media texts today? The unlikely answer comes from comedian Lee Ridley, self-named Lost Voice Guy. Ridley has cerebral palsy and has not been able to speak for 37 years. During this time, however, his nuanced sense of humour translates over the computerized voice and his sarcastic T-shirts. Ridley took *Britain’s Got Talent* by storm with his performances, eventually winning the 2018 competition. During his first appearance he refers to himself as lost voice guy for ‘obvious reasons’, pointing at his computer. His work self-reflexively both attacks ableist notions of disability and the emotionality attached to disability throughout his time on *Britain’s Got Talent*. During

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22 Davis, 8.
23 See for a compilation of all three performances: https://www.youtube.com/watch?v=wyTC3tRBo4s [accessed 30 September 2018].
his final appearance, Ridley addresses the issue of disability and staring. When asked why he put himself in such a position, he argues that he is simply seeking the agency of determining how his ‘extraordinary’ body is looked at and coded, his success, moving him to the elevated position of artist.

Disability studies has in some ways provided an answer to these questions through the work of disability performance artists, although critical trauma studies has taken a different approach focusing more so on disability issues surrounding disfigurement rather than the reception of the disabled body itself. What differentiates these individuals from the performers in the freakshows is that the former, unable to live their day-to-day lives without scrutiny, are attempting to reclaim their autonomy by confronting society rather than seeking reclamation and understanding while simultaneously appeasing society’s need to look. Eisenhauer states that the act of looking transforms individuals into property, and that in order for reclamation to occur, these artists must critically appropriate sideshow culture in a way that subverts the gaze back to the audience. By confronting the audience-directly with what sets them apart, these artists have begun to re-gain their bodies’ autonomous status. Although it is evident that the difference between the non-disabled and disabled body will perpetually fascinate audiences, it is important to recognize the damage that this causes for the individuals in search of reclamation and, for lack of a better word, ‘normalcy.’

Although visual activism and individuals such as Ridley, have begun to normalize our visual sphere with what I suggest are ‘extraordinary’ bodies (following Garland-Thomson), modern medicine, media, and even charitable institutions continue to exploit this antagonism. With a historical precedent of monsters and freakshows of all kinds and a human propensity for staring, will we eventually move beyond a staged encounter with the disabled body and allow starees full reclamation? Although I do not think it is possible to answer this question just yet, the intersection between trauma and disability has become clearer. While the era of the freakshows could be marked as clearly traumatic spheres, the post-modern freakshow remains equally traumatic. Although labelled and presented differently, the intelligible gaze and the unintelligible body remain at odds, and as long as there is an antagonism present, there remains a means to exploit this antagonism.

Bibliography


25 Eisenhauer, 13.
Recuperarea corpului cu dizabilități. O analiză textuală a filmului lui Browning *Freaks* (1932) și a versiunii de mâna a doua din mass-media modernă

Rezumat

‘It’s a Pity and a Sin’:
Images of Disability, Trauma and Subverted Power in Disney’s Beauty and the Beast

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Abstract

This article explores parallels between society’s treatment of those with disabilities and the characters in Disney’s 1991 and 2017 versions of Beauty and the Beast. By comparing Gabrielle de Villeneuve’s text with the films, I will highlight where they deviate from the text in order to connect with a disability stereotype. With a focus on the perceived connection between moral character and physical appearance, my article will analyse how the character of The Beast perpetuates the idea that only those with moral deficiencies become disabled. Employing Wolf Wolfensberger’s classifications of deviancy and disability, such as the eternal child, the subhuman organism and others, the article seeks to prove that Disney continues to promote pejorative images of the disabled body. Using trauma theory, I will illustrate how the curse of the Beast is a source of trauma. Lastly, this article analyses Foucault’s principle of subject and object, focusing on how the most recent film versions of Beauty and the Beast posits able-bodied characters as subjects over the disabled ones.

Keywords: Beauty, Beast, Disney, disability, trauma, Wolfensberger

Stepping Into the Disney Cannon

Disney’s Beauty and the Beast features a heroine unlike her counterparts.1 Belle has no witches offering poison apples, or princes touting glass slippers. In the last stanza of the song ‘Belle,’ the townspeople belt out, ‘It’s a pity and a sin/She doesn’t quite fit in.’ While Belle’s nonconformance to traditional gender roles has made her the target of gossip, the line ‘it’s a pity, it’s a sin […] doesn’t quite fit in’ is more aptly applied to Disney’s portrayal of the Beast. The Beast is an outlier on the spectrum of Disney heroes: he is neither the adventurous hero that we have come to expect from Disney, nor is he a true villain. Regardless, Disney happily deviates from the character that Gabrielle de Villeneuve presents, and packages him as a lesson by associating the Beast’s outward appearance with morality. Mirroring the line ‘it’s a pity, it’s a sin,’ Disney uses the Beast to showcase antiquated stereotypes of the disabled body. By pigeonholing the Beast into these stereotypes that centre heavily on objectification and passivity, Disney bestows Belle with the ability to become a more active heroine than her predecessors.

First, I explore how Disney departs from Villeneuve’s original text to create a clear connection between the prince’s beastly appearance and the moral model of

1 Beauty and the Beast, dir. Bill Condon (Burbank, CA: Walt Disney Pictures, 2017), DVD.
disability. Second, I analyse how Disney forces characters into pejorative stereotypes based on Wolf Wolfensberger’s classifications of the disabled body. In order to illustrate Wolfensberger’s concepts, I solicit Derrida’s deconstructionist strategy which holds that while society has created a power structure that always preferences one type of person over the other that binary opposition has the ability to become fluid and posit the less valued person over the other, making society anxious. Additionally, using foundational tenants of trauma theory, I examine how embodiment of a disability can affect both the individual and those around him. Furthermore, I enlist Foucault’s ideas of subjectification and objectification to explore how the perception of the physically disabled person in film is constantly in the role of an object, rather than a subject that has the ability to act.

Wolfensberger’s Categories of Disability in the 21st Century

Significant strides have been made in Disability Studies since the publication of Wolfensberger’s article, ‘The Concept of Deviancy in Human Management’ in 1972. Nonetheless, the classifications of the disabled body have adapted to 21st century life. To demonstrate the timelessness of Wolfensberger’s categories, I refer to the 2005 case of Terri Schiavo, an American woman at the heart of the ‘right to die’ debate. Secondly, I apply the work of Ian Matthews, who analysed how the 2011 Winterbourne View Hospital scandal in the United Kingdom, fits into Wolfensberger’s classifications.

The first role that Wolfensberger highlights is that of sub-human organism. Here, society intentionally disassociates humanness from the individual, classifying him as either animal or object. For example, Terri Schiavo, a woman in a ‘persistent vegetative state’ was objectified by warring political ideologies on the issue of end-of-life care. As a ‘diseased organism’, those with disabilities are defined by the medical model of disability as society seeks to understand, even cure, the limitations of the body. After Florida courts ruled that Schiavo’s feeding tube be removed, the governor ordered healthcare providers to reinsert it. As an ‘object of pity,’ a person with a disability is viewed as being in need of care and sympathy. In the case of Schiavo, her situation did elicit compassion, with then-president George W. Bush commenting, ‘Those who live at the mercy of others deserve our special care and

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3 Though Wolfensberger’s classifications apply exclusively to those with intellectual disabilities, I use them in a broader context.
Along with the category of pity is the label of ‘holy innocent’ – one who is considered to be totally innocent or ‘incapable of sin’ (**NLU**, 1357). Although Schiavo was incapacitated, her case attracted the attention of the Vatican, which argued for continuation of life support. **10** Schiavo’s situation could make her an ‘object of dread’ because the legal battles surrounding her case presented a reality that few wanted to consider. **11**

Contrastingly, Wolfensberger presents the ‘menace,’ one who poses a threat to societal norms and must be monitored. The staff at Winterbourne viewed their charges as ones who would upset order, and were, therefore, constantly beaten into submission. (**NLU**, 1361) The label of ‘eternal child’, another of Wolfensberger’s category, confines a person with a disability to the societal status of a child, regardless of age (**CDHM** 29). Matthews considers the patients of Winterbourne to be eternal children because they did not have the ability to understand the abuses that were occurring (**NLU**, 1361). It is likely that the Winterbourne patients comprehended the abuse, but had no power to stop it, as they were dependent upon those caregivers for basic functions. The role of ‘object of ridicule’ places the individual as a source of humour for others (**CDHM** 28). For those patients at Winterbourne, they became amusement for the staff that harmed them (**NLU**, 1362). Matthews’ work proves that while Wolfensberger’s categorizations may be dated, they are still, unfortunately, applicable to the modern age.

**Moral Model of Disability**

The moral model of disability argues a connection between a person’s behaviour and development of a disability. **12** While the moral model is widely eschewed by practitioners today, previous Western cultures held fast to the Puritan edict. **13** Nonconformity to Christian ideals, thus displeasing a righteous God, was a logical explanation for physical deviance and illness. An excerpt taken from the diary of Puritan minister, Cotton Mather, shows a perceived connection between ill-health and a vengeful God. Mather, suffering from a headache, correlates the condition to his ‘horrible Filthiness, Unthankfulness, and Unfruitfulness,’ while soliciting a cure for his impairment by ‘imploring pardon, thro’ the Blood of Jesus’. **14** Beyond the common illnesses of the time, bearing a child with a visible defect or disability served as a tangible harbinger of personal wrongdoing. As Nielsen explains, ‘disability was a material reality for many European colonists, but it also served as a potent metaphor and symbol’. **15** Women who had birthed children with abnormalities were viewed as liable for the conditions of their children. Some mothers were accused of entering into a

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**Notes:**


11 Caplan.


liaison with Satan.\textsuperscript{16} Wolfensberger notes that a child with a disability could be seen as an ‘object of dread’ because he represented God’s displeasure, alienating him from community inclusion (\textit{CDHM}, 26). Disney’s \textit{Hunchback of Notre Dame} features villainous Frollo who promulgates the moral model by terming Quasimodo an ‘unholy demon’ that should be drowned and ‘sent back to hell’ due to his physicality.\textsuperscript{17} \textit{Beauty and the Beast: An Enchanted Christmas} shows the enchantress placing a ‘curse upon [the Prince’s] house and all within it,’ even though the servants have not encouraged the Prince’s actions.\textsuperscript{18} Despite the fact that society has largely distanced itself from equating a moral shortcoming with disability, Disney has built a cinematic enterprise around this antiquated model.

\section*{Moral Model and the Individual}

In Disney’s universe, following the moral model of disability is logical. By correlating good moral character with an attractive outward appearance, and corruption with a scary exterior, dialogue does not need to be spent on explanations. Children quickly understand the implication that those who are unattractive are considered to be villainous and children should not emulate that behaviour.\textsuperscript{19} Whether directly stated or not, Disney is teaching lessons about good and evil as tied to bodily image.\textsuperscript{20} The Disney logic is simple: if a character is attractive, he or she plays a heroic role, while those who are not are relegated to the status of villain.\textsuperscript{21} In many cases, Disney villains are also punished for their evil deeds by changes to their outward appearances. \textit{Tangled} snatches away Gothel’s motivation of immorality and reduces her to dust.\textsuperscript{22} In a quest to become ‘the fairest of them all’ the witch in \textit{Snow White} dies, not as a beautiful queen, but as a fearful hag.\textsuperscript{23}. While the moral model of disability is viewed as antediluvian, it still remains heavily prevalent in the above cinematic examples. Henry Giroux explains that ‘the Disney Company is not ignorant of history, it reinvents it as a pedagogical and political tool to secure its own interests, authority and power’.\textsuperscript{24} On Disney’s didactic watch, even the most feared historical villain can be redeemed and turned into a hero if it the transformation teaches young viewers a lesson. In Disney’s \textit{Blackbeard’s Ghost}, the infamous pirate, Edward ‘Blackbeard’ Teach, is crafted as a bumbling, yet lovable,

\textsuperscript{16} Barnes, 21.
\textsuperscript{17} \textit{The Hunchback of Notre Dame}, dirs. Gary Trousdale and Kirk Wise, 1996. (Burbank, CA: Walt Disney Pictures, 1997), DVD.
\textsuperscript{18} \textit{Beauty and the Beast: The Enchanted Christmas}, dir. Andrew Knight, 1997 (Burbank, CA: Walt Disney Pictures, 1997), DVD.
\textsuperscript{21} Bazzini et al., 2097.
\textsuperscript{22} \textit{Tangled}, dirs. Nathan Greno and Byron Howard, 2010 (Burbank, CA: Walt Disney Pictures, 2011), DVD.
\textsuperscript{23} \textit{Snow White}, Dirs. William Cottrell, David Hand, Wilfred Jackson, Larry Morey, Perce Pearce, Ben Sharpsteen, 1937 (Burbank, CA: Walt Disney Pictures, 2009), DVD.
\textsuperscript{24} Henry Giroux, ‘Memory and Pedagogy in the ‘Wonderful World of Disney’: Beyond the Politics of Innocence’, in \textit{From Mouse to Mermaid: The Politics of Film, Gender, and Culture}, eds Elizabeth Bell, Lynda Haas, and Laura Sells (Bloomington, IN: Indiana University Press, 1995), 46.
character who saves his modern-day descendants from financial ruin.\textsuperscript{25} While creating a correlation between morals and appearance could cause confusion for young viewers, Disney seems to look the other way.

In both the animated and live-action versions of \textit{Beauty and the Beast}, the Prince is transformed due to his pride and vanity. Both opening scenes show the Prince heartlessly turning away a beggar asking for shelter, even after being warned: ‘not to be deceived by appearances.’ Villeneuve’s plotline, however, puts forth an adolescent prince who gently refuses the marriage proposal of an aging fairy instead of a socialite obsessed with appearances. By straying from the text and relying on flawed logic that associates appearance and morality, Disney reinforces a stereotype that is hard to undo. Schwartz, Lutfiyya, and Hansen explain that negative perceptions of a person based on a single characteristic can lead to the diminishment of a person’s worth in the eyes of those that heed normative culture.\textsuperscript{26} The idea of homogeny creates a divisive, and flawed, mindset – one is either accepted or part of the other. For example, the work of Robinson, Callister, Magoffin and Moore showed that elderly characters in Disney films were often classified by viewers as being ‘senile’ ‘sad’ ‘helpless’ and ‘object[s] of ridicule,’ which reinforces the concept that they are not meant to be viewed positively.\textsuperscript{27} By equating the Beast’s transformation with a lack of decorum, there is a similar risk of creating a larger divide between the non-disabled and disabled populations.

\textbf{Disney’s Absconded Morals and Mothers}

Parental fault is at the heart of the moral model, as well as some of Disney’s most beloved cinematic tales. Several films center on a king or queen having displeased a deity or other supernatural creature. Like in Puritanism, a child is often the crux upon which retribution is focused. In Disney’s \textit{Hercules}, an envious Hades, god of the underworld, conspires to turn Zeus’ son mortal so that he can overthrow his brother without interference.\textsuperscript{28} In \textit{Sleeping Beauty}, Aurora faces the prospect of death at the prick of spindle because her royal parents refuse to welcome Maleficent to the infant’s Christening.\textsuperscript{29} Interestingly, Disney creates conflict where none existed before. In the legend of Hercules, Hades had no desire to overthrow his brother, as the two were bestowed their respective kingdoms by chance instead of Hades being banished to the underworld by his brother, as the Disney film suggests.\textsuperscript{30} However, in Villeneuve’s \textit{Beauty and the Beast}, it is the vanity of the mother, not the Prince turned Beast, which incites the anger of the aged fairy. When the Prince rejects the fairy’s marriage proposal, the Queen brings up appearances, saying, ‘Deign to contemplate without prejudice, the object this glass presents to you, and let it reply for me’ (\textit{SBB}, 59). In this

\textsuperscript{25} \textit{Blackbeard’s Ghost}, dir. Norman Tokar, 1968 (Burbank, CA: Walt Disney Pictures, 2002), DVD.


\textsuperscript{28} \textit{Hercules}, dirs. Ron Clement and John Musker, 1997 (Burbank, CA: Walt Disney Pictures, 1999), DVD.

\textsuperscript{29} \textit{Sleeping Beauty}, dir. Clyde Geronimi, 1959 (Burbank, CA: Walt Disney Pictures, 2008), DVD.

\textsuperscript{30} William F. Hanson, \textit{Handbook of Classical Mythology} (Santa Barbara: ABC-CLIO, 2004), 179-180.
version, the Prince plays a minor role in his transformation, but, due to the words of his mother, he is left to suffer the consequences.

Given Disney’s propensity for parental-based conflict, the vanishing mother seems contradictory. In the 2017 version of Beauty and the Beast, the mother is removed from the storyline by death, thereby leaving the prince to be raised by a vice-ridden father. The mother’s death has a deconstruction-like effect which leaves him vulnerable and open to other parental influences without any counterbalance. Lynda Haas notes that ‘the mother/woman is the mirror into which men look to find their […] identity [while] she has no identity of her own’. Mrs. Potts, the teapot, informs Belle that the Prince’s moral character was affected by his ‘cruel’ father who ‘twisted [the Prince] up to be just like him.’ Judith Herman points out in her book, Trauma and Recovery, that a child’s sense of safety is rooted in a ‘caretaker’s benign use of power’. Perhaps the Prince emulated his father’s uncaring demeanour in order to cope with the change in lifestyle. The addition of an unkind father lines up with the moral model of disability, but Disney rejects the idea of the son paying for the sins of the parent. By having the Prince transformed by his own selfish comportment, the Beast can at least earn internal redemption in an act of selflessness. In the latter half of the film, the Beast releases Belle from her incarceration in order to allow her to save her father – which will also seal the Beast’s fate. As Belle rides from the castle, the Beast laments in the song Evermore that ‘I was the one who had it all/ I was the master of my fate/ I never needed anybody in my life/ I learned the truth too late.’ Disney takes the opportunity to teach a lesson fit for a hero: think of others first and yourself last. The first line of Evermore alludes to previous selfishness and arrogance. The last line shows acceptance of responsibility, personal growth, and the importance of doing the right thing. Disney’s deletion of the mother and slight mention of the father deviates from the moral model but realigns when the servants are punished for the Beast’s actions.

Community Retribution and the Eternal Child

Part of the moral model inflicts punishment for an individual’s conduct upon the community. Beauty and the Beast emphasizes this feature through backstory of the Prince’s childhood. The Beast is not apologetic for his role in robbing his staff of human form, but this may be because he does not hold himself responsible. The concept of the eternal child places a person in a societal holding pattern of childhood. Despite actual age, a person who is classified as an eternal child is excused from the expectations of adulthood, including the need to be held accountable for his tenue (CDHM, 29). An example of the traditional use of the eternal child stereotype is seen through Dopey, the dwarf in Snow White who does not speak and is looked after by the other dwarves. An eternal child stereotype is also put in place by the environment in

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31 Lynda Haas, ‘86 The Mother: Murder, Matricide, and Good Mothers’, in From Mouse to Mermaid: The Politics of Film, Gender, and Culture, eds Elizabeth Bell, Lynda Haas and Laura Sells (Bloomington, IN: Indiana University Press, 1995), 196.
32 Haas, 196.
33 Judith Herman, Trauma and Recovery: The Aftermath of Violence – from Domestic Abuse to Political Terror (New York: Basic Books, 1997), 52. Hereafter cited as TRAV, followed by page numbers in the text.
34 Dan Stevens, Evermore (Burbank, CA: Walt Disney Records, 2017); available at https://www.youtube.com/watch?v=diLa-gpHRKc, emphasis added [accessed 30 September 2018].
35 Schwartz et al., 183-5.
which the Beast functions. The staff adapt themselves to the needs of the Beast, even shouldering the blame for his deeds, rather than forcing him to change his demeanour. Mrs. Potts’ statement of ‘We’ve made our bed’ and implying that her status as a teapot is directly tied to the fact that she allowed the Prince-turned-Beast to be raised without morals, is curious. Mrs. Potts’ comment is reminiscent of someone who was too traumatized to stop the abuse of a child (TRAV, 83). Even when Belle, unbeknownst of the opportunity she has to break the curse, offers to help, Mrs. Potts dismisses the idea, saying that it is ‘nothing for you to worry about, dear.’ Even though they had no parental right to interfere in the upbringing of the Prince, Disney reinforces the eternal child stereotype and moral model by holding the community accountable for his ways. The Beast is excused from culpability, and even in the days before the curse becomes permanent, the Beast has still to learn the lesson for which the curse was bestowed. While the Beast’s insolent manner is disappointing, it is what the film industry has applied to disabled characters in order to keep able-bodied characters, like Belle, or even the servants, in control. Perhaps interacting with his anthropomorphised household staff is too much of a traumatic reminder of the Prince’s role in ruining the human lives of the staff, which is why he isolates himself and resorts to childish acts. Similar to the 1991 version, the live-action Beauty and the Beast features a Beast who is chided when he roars, has to be told to show empathy, taught basic social skills, and has to be educated on how to eat like a human, even though the Beast is in his early twenties. All of the aforementioned tasks are led by others who are acting on behalf of the Beast because he is unable to do them on his own. Marilyn Dahl comments on the contrast between the disabled and non-disabled heroes asserting the following: ‘[t]he images [of people with disabilities in film] equate disability with childlike behaviour and an infantile condition, a minor role, while the healthy, normal star has the spotlight, status and prestige’. In the previously-mentioned scenes, the servants seem to be raising a sulky child more than breaking a time-sensitive curse. Indeed, it is only until the very end of the 2017 version of Beauty and the Beast that the re-transformed adult Prince seems to acknowledge the human existence of the staff that he has belittled and shouted at throughout the film. Suddenly, upon transformation, the childish doings disappear and the Prince is returned to the status of a perfect gentleman who embraces his staff warmly, without any apology. However, after the transformation from Beast to Prince, the Prince no longer has to keep his staff at a distance. The previous comportments displayed by the Prince seem to be excused by the eternal child stereotype and forgotten about because the adult, and able-bodied, Prince has returned.

In Disney’s universe, the Beast seems to deserve his curse due to his earlier antics but his textual counterpart is quite the opposite. Villeneuve’s version portrays a Beast that is still physically alarming, but chivalrous and generous to Beauty. From the beginning of the tale, there is no connection between a lack of moral character and appearance. This Beast is polite, providing Beauty with everything that she needs upon her arrival, even gifting Beauty’s father with enough riches to be removed from poverty.

38 Jeffords, 168.
Even when Beauty continuously rejects his proposal of marriage, the Beast is described as being ‘quiet’ and ‘docile,’ a high contrast to the Disney Beast who *eventually* learns how to be a gentleman (*SBB*, 27). In Villeneuve’s text, the Beast is a character that acts with maturity, respect, and foresight, shunning child-like actions that Disney uses. The attitude that the Beast demonstrates in both cinematic versions illustrates a desperate attempt to regain power and normalcy by physical and emotional intimidation, even though able-bodied Belle is the only one who can truly restore order.

**A Subhuman, But Powerless, Beast**

Disney and Villeneuve differ in the way that they choose to physically portray the Beast. Villeneuve describes ‘a horrible beast’ with a ‘terrific voice’ and a ‘kind of trunk, resembling an elephant’s’ (*SBB*, 13). The conglomeration of animals making up the Beast describes him as physically intimidating, setting him apart from any human characteristic. In the textual scene in which the Beast seeks recompense for the stolen rose, his imposing, animalistic qualities are juxtaposed by the timid and sincere nature of Beauty’s father. The Beast demands that the father die for his crime or persuade one of the daughters to take their father’s place as implied victim. The unfeeling nature and unnecessary cruelty of the Beast further alienates him from being classified as human. Even Beauty’s father questions the humanity of the demanded solution, saying, “could I be so inhuman as to save my own life at the expense of one of my children’s?” (*SBB*, 14). Again, the concerned nature of the father compared with the detached nature of the Beast is important. It is from these ‘inhuman’ requests that the Beast draws his power. The Beast’s temper is ignited by human addressment, when Beauty’s father pleads with him by saying, “my lord […] Have mercy on me” (*SBB*, 13). Replying the Beast roars, “I am not my Lord; I am the Beast, and thou shalt not escape the death thou deservest” (*SBB*, 13). In rejecting human qualities, Villeneuve’s beast places himself in direct comparison to Wolfensberger’s classification of the disabled body as a subhuman organism. The subhuman organism is defined as a person without fully human characteristics, or a person whom society views as being illogical, unintellectual, unfeeling, and animalistic (*CDHM*, 23-4). By instilling fear and rejecting any human similarity, the Beast becomes a menace, an object of dread, and a sub-human organism that forces Beauty to arrive on the castle doorstep.

The interactions between the Beast and Beauty’s father can be compared to the medical and social models of disability. Villeneuve’s words describe a body that is beyond normative limits and must be cured in order to be a part of society.³⁹ Beauty’s father’s remark about the Beast’s inhumaness, highlights that the Beast’s behaviour, as well as his body, are not standard. The very appearance of the Beast creates instability for an able-bodied character because it is a reminder that ability is not permanent (*DT*, 60). For the Beast, Beauty’s father represents the social model as he symbolizes norms of an inaccessible culture (*DT*, 25). As he would not be accepted into a wider community in his current state, the Beast must adapt to the isolated world in which he lives. In order to escape the visage of the Beast, the man must sacrifice his daughter, which means nothing changes. The body of the Beast is not altered by its interaction

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with the man, but the larger society does not have to adapt in order to accommodate the Beast.

The balance of power in Villeneuve’s text places the Beast as the wielder of power and Beauty as the object that is sacrificed to appease the Beast’s temper. When the father returns to the familial home, he gifts Beauty the rose, but declares, “there is what thou hast demanded of me, but thou wilt pay dearly for it” (SBB, 17). In this statement, Beauty has very little power, as he names her as the one who will pay the debt that is owed to the Beast. The Beast, again, takes the role of subject through physical presence. The power that the Beast displays, though, is a façade. In the ending, the transformed Prince reveals that in punishing Beauty’s father for stealing the rose, he did not have autonomy. Alternatively, the Beast was acted upon by yet another fairy who sought to help him undo the curse by luring Beauty to the castle. The Beast/Prince explains his actions to Beauty saying, “I executed exactly the fairy’s commands” (SBB, 64). In the text version, the Beast has no desire to be a fear-inducing creature, nor does he lack sympathy – he is, simply, the object of a supernatural being. The fact that the Beast/Prince has no authority over his actions leads to conflicting emotions. In being complicit with the fairy’s plan, the Prince is subjected to the trauma of ‘total surrender’ and must ‘violate [his] own moral principles and betray […] basic human attachments’ (TRAV, 83). Revealing himself to have been an object who was required to create a persona of rage and indifference, the Beast/Prince cannot be held responsible for his previous lack of decorum. Disney, however, deletes the ubiquitous fairy from the storyline and creates a Beast who is less sub-human in appearance but more so in moral character.

Disney reduces the physical ferocity and sub-human appearance of the Beast by removing the elephant trunk and creating a body that is similar to a lion than a collection of different animals. Furthermore, the Beast is imbued with human qualities and characteristics, which, Villeneuve’s Beast lacks. The humanization of the Beast may have been done to lessen potential trauma on audience members, as Walt Disney was known to ‘overlook [the] more horrific aspects’ of a story. The revulsion, and subsequent humanization, of the Beast’s disabled body arises from the fact that it is visibly unnatural and different from the body of the non-disabled viewer. While the non-disabled audience finds the disabled body ‘exotic’ because it is something rare and interesting, that same audience is afraid of the body because having a functioning mind in a deformed body creates what James Elkins terms ‘visual desperation.’ The audience does not know how to categorize the disabled body as either a subject or object, and this places the audience in a state of cognitive dissonance. The Beast also represents the fallible nature of the human body and symbolizes the fact ability and disability exist cyclically, creating trauma for those audience members who currently have normative bodies (DT, 60). Therefore, in order to enjoy gazing upon the disabled body, but have a sanitized version of it, the film industry accommodates the non-disabled viewer by providing a buffer between the reality of the disability and what the

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42 Elkins, 220.
audience can cope with seeing. The cinematic version of the Beast walks upright, wears clothing, and still has the capacity to feel emotion. The Beast is certainly not the last animal to be anthropomorphized at the hand of Disney, as *Brave* features a queen-turned-bear who still wears her crown and tries to cover her nakedness with quilts, despite being covered with fur. The humanization of these characters shares a common goal: to make the character relatable and less animalistic. The cinematic Beast is not restricted in the actions that he can utilize to pursue Belle’s affections, as Villeneuve’s Beast is, but chooses to act more animalistic than he looks. Disney’s Beast refuses to treat either Belle or her father with decency, even though there is nothing stated in *this* curse that says he cannot. In both Disney versions of *Beauty and the Beast*, the outward appearance of the Beast is meant to match the internal character. The Beast descends furiously upon Belle when she discovers her father, shivering, in the tower.

Though the Beast is aware of what is necessary to break the curse, he seems to embrace the sub-human characteristics that Wolfensberger describes by trying to defy his reality and ignore the logic that the rest of the castle sees – that Belle could break the curse. Henry Tiebout notes that defiance allows one to live ‘unperturbed.’ Perhaps the Beast has lived so long in isolation that he believes he does not need to be human again, or he is unwilling to realize that he needs Belle in order to be human. The Beast is engaging in what trauma theorists’ term ‘learned helplessness.’ The Beast has become so accustomed to his current situation that he considers escape from it to be futile. The solution to learned helplessness is for someone else to remove the traumatized party from the environment (*BWWRD*, 54-5). However, even as Belle unknowingly attempts to remove the Beast from his animal-like stasis by presenting herself as a solution to her father’s imprisonment, the Beast seems unaware of what Belle’s presence could mean. Indeed, in the 1991 version, the Beast roars, ‘There’s nothing you can do, he is my prisoner.’ While Villeneuve’s Beast’s motives are calculated in order to bring Beauty to him, Disney’s Beast remains indifferent to her presence.

Belle takes her father’s place, and by doing so, she is able to gain a small amount of power because she chooses her fate instead of being the ‘doomed […] prey’ that Villeneuve’s version dictates (*SBB*, 64). The transformation from Beauty to Belle shows an addition of spunk and independence that the original character lacked. Moving Belle into a subject position was a timely choice. The culture of late 20th century America demanded that Disney rebrand the female role as one who takes action instead of waiting to be rescued. The title character in *Mulan*, for example, boldly passes as a male to keep her father from conscription. *Frozen* deviates from the traditional Disney narrative of the helpless woman by having Anna sacrifice herself for her sister.

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Davis showcases the shift from damsels in distress to heroines, stating, ‘[u]nlike the earlier films, in which the heroine’s honour was depicted and proven simply through goodness and acquiescence, the heroines of Disney’s animated films […] show their integrity through their action rather than through their inaction’. Putting her father’s needs before her own comfort solidifies Belle as the hero of the story and presents the lesson that the Beast himself needs to learn.

Belle’s agency in the tower is brief, but it is in the tower scene that Belle validates the Beast’s status as a sub-human organism and is to be feared. In the 1991 film, it is only after agreeing to take her father’s place, that Belle asks the Beast to ‘step into the light,’ and when he does so, Belle recoils, placing her hand over her mouth. Emma Watson’s Belle is made more formidable by seeing the Beast’s visage before she decides to become the prisoner, but her reaction is still one of horror. Belle’s reaction relieves any guilt that the non-disabled audience may harbour over their own reaction to the physicality of the Beast because Belle’s initial reaction conveys that same shock. Martin Norden states in his book *The Cinema of Isolation*, that ‘Movie makers photograph and edit works to reflect the able-bodied point of view.’ Belle’s response to the physical appearance of the Beast reinforces that he is dangerous and to be feared by the majority, which is exactly the attitude that the sub-human stereotype promotes. Upon seeing the Beast, Belle shrinks back, instinctively trying to become less noticeable, which might be interpreted as an act of disassociation. The body’s reaction to trauma is to engage the ‘fight or flight’ system, which asks the individual to choose between running from the perceived danger or fighting it. As Belle cannot flee the castle without sacrificing her father, she must remain in the situation. Along with their heroine, the audience may experience the initial desire to escape the Beast, which could manifest in looking away from the screen or covering of eyes. However, as Belle represents the majority of the audience, her ability to remain in the situation and fight her natural instinct, extends to the audience. Belle’s presence in those first interactions with the Beast not only allows the viewer to create a clear binary between the heroine and the other, but also allows the audience to regulate their own sense of fear through Belle’s response.

Like the Beast, people with disabilities have, historically, been focal points of societal fear. Negative images of the disabled body have created the idea that, if left unchecked, the disabled body could upset the hegemony created by society. The representation of the disabled body as monstrous has been portrayed in film, leaving able-bodied audiences concerned about the possibility of carnival, as seen in the 1932 film *Freaks*. Belle’s presence stabilizes the able/disabled binary that has been created. Wolfensberger acknowledges that subhuman organisms often required ‘supervision’ from another, presumably able-bodied, individual (*CDHM*, 24). As it is Belle who must fall in love with the Beast and see past his outward appearance, this reassures the audience that the Beast cannot be restored to a subject position without the permission

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50 Davis, 171.
53 Inna Arnaudova and Muriel Hagenaars, ‘Lights… Action: Comparison of Trauma Films for Use in the Trauma Film Paradigm’, *Behavior Research and Therapy* 93 (2017): 74.
54 *Freaks* is a 1932 film that chronicles the lives of disabled and deformed circus performers who maim a non-disabled woman because she is the only one of them who is not disabled.
of the non-disabled character. Additionally, the Beast’s animalistic tendencies are
lessened by Belle’s tutelage and presence. The idea of seeing someone who has been
deemed an ‘other’ overcome obstacles is part of what makes disability, and trauma, in
the cinema so popular. Audiences may be curious about the disabled body, but they are
not comfortable with the idea that it could easily become the subject rather than the
object. In a scene specific to the 2017 edition of Beauty and the Beast, the Beast
presents Belle with a book that would take them anywhere she wants to go, but states
that ‘the world has no place for a creature like me’. The reminder that this, now gentle,
character is perceived as something to be feared inspires yet another emotion in the
audience member – pity.

Object of Pity

The role of the disabled body is typically categorized into two moulds—monstrous or
helpless. In order to subvert the fear that the disabled person might wield a sort of
unchecked power over the non-disabled person, the disabled person is relegated to the
status of a helpless creature. The film industry, as Martin Norden cites, has placed
people with disabilities into two categories, the ‘demonic cripple,’ which is
disconcerting to the non-disabled public, and the ‘charity cripple’, who soothes the
audience into feeling that this character is not a threat. The classifying of the disabled
character as more of a weakling than a monster can be done by appealing to Biblical
images of the disabled man begging for alms. Here, the disabled man is voided of any
violence, or even dignity, and is forced to act as a sweet, humble and grateful recipient
of the charity of others – contributing greatly to the film industry’s promotion of Tiny
Tim as the tottering champion of the disability-themed film, instead of the leering,
deformed monster. Wolfensberger adds that while society is more accepting of the
disabled body as an object of pity, it is often a role that is ‘devoid of respect’ (CDHM,
26). In Villeneuve’s version of Beauty and the Beast, the character that subdues the
Beast into an object role, and calms the audience, is the Unknown. The Unknown, the
Prince trapped within the Beast, is presented as a parallel character and is only exposed
to Beauty through her dreams. The Unknown is everything that the Beast is not –
handsome, sensitive, articulate, heroic – and Beauty immediately falls in love with him.
Beauty expresses love to The Unknown while feeling gratitude and obligation toward
the Beast. The Unknown is representative of the non-disabled fear of the ‘other’ and the
need to relegate the disabled body to a place of submission, but it is also the Unknown
that furthers Beauty’s pity for the Beast. When The Unknown jealously tries to kill the
Beast in order to be sure of Beauty’s affection, the Beast remains passive and ‘offer[s]
his neck to the blow with [...] submission and calmness’ (SBB, 34). In offering his neck,
the Beast is an object that has no power and it is Beauty who must intercede on his
behalf, crying, ‘Harm not my benefactor or else kill me [...] I owe everything to the
Beast’ (SBB, 34). Beauty’s utterances about the Beast do not equal love, they reflect
pity. Villeneuve makes it clear that Beauty is sacrificing her own happiness to ensure
the safety of the Beast, even though she does not care for him romantically. In addition
to showing gratitude toward the Beast, Beauty also makes herself into a martyr figure
by putting duty before true love. Beauty is aware that the Beast loves her, as he

55 Norden, 11.
56 Cited in Norden, 11.
57 Barnes, 22-3.
proposes to her each night after supper, but each night, she refuses. Beauty’s father capitalizes on his daughter’s sense of pity and obligation toward the Beast. ‘I advise thee not to refuse him [when the offer of marriage approaches again]’, Beauty’s father suggests (SBB, 39). Beauty’s father rationalizes that Beauty should consent to the marriage rather than wait for true love or beauty because he realizes that the Beast will treat his daughter with kindness – something that could not always be guaranteed at the time. Beauty, again, in the literary version is an object whose future is decided by men. Out of pity and obligation, Beauty agrees to a marriage that will leave her economically secure, but not truly happy.

Pity for the Beast is something that Disney readily provides through the character of Belle. After the Beast saves her from a pack of wolves, Belle takes weaponised pity on him. The heroic actions that the Beast displays in rescuing Belle place him in a position of power, but he must embrace his animalistic qualities in order to do so. In the 1991 version of Beauty and the Beast, the expressions on the face of the Beast and that of the leader of the wolf pack are incredibly similar – both bare teeth and showcase a menacing snarl. The Beast even stands protectively, on all fours, in front of Belle, as if to claim ownership. Before Belle is able to flee, the Beast is attacked. The Beast, previously intimidating, becomes helpless. The audience is eased by the idea that the animalistic, disabled body cannot affect society because it cannot function effectively without someone to care for it. The body becomes an object because it is deprived of dignity. Without the ability to fight or run, the Beast is vulnerable and engages in dissociative behaviour by crying out to Belle (BWWRD, 50). Belle covers the Beast with her shawl and takes him to the castle. Belle chooses to take care of the Beast because he is weak and, at this point, harmless. Again, Belle has control in the situation and it is the Beast who is at her mercy. As Charles Riley puts it, ‘[p]roducers, directors, and writers package disability in such a way as to safely ensure that the audience feels nobly uplifted, even ethically superior for “supporting” what is in effect a blatantly over sweetened version of life with a disability.’ By placing the able-bodied Belle in a role of subject and the Beast in the role of object that needs assistance, the non-disabled audience, who identifies with Belle, feels vindicated. The heroic status of the disabled man is gained through his ability to inspire, but the audience is still uncomfortable with the disabled character acting as the sole hero of the film. Therefore, to assuage the audience’s fears of a deformed or disabled body taking a position of cinematic power, a non-disabled character with more power and prestige than the disabled character is provided in order to assure the audience that the limping disabled hero will not become too powerful throughout the film and upset the able/disabled binary. The resonating takeaway from the wolf attack scene in Beauty and the Beast is not that the Beast saved Belle from the wolves, but that she saves him. The Beast is not the only male character in Disney history to owe his life to a female character, though. John Smith, from Pocahontas, is saved from bludgeoning by the daughter of the chief. The Little Mermaid shows Ariel rescuing Prince Eric from the depths of the sea. However, in both of the previously mentioned films, the heroines save the men out of affection. Belle saves the Beast out of a sense of duty and charity.

58 Riley, 71.
59 Pocahontas, dirs. Mike Gabriel and Eric Goldberg, 1995 (Burbank, CA: Walt Disney Pictures, 2002), DVD.
60 The Little Mermaid, dirs. Ron Clements and John Musker, 1989 (Burbank, CA: Walt Disney Pictures, 1999), DVD.
Fools and Foils

The theme of Beauty and the Beast is the idea of selflessness and the ability to see past appearances. Disney, unable to promote the Beast as a villain, creates a foil for the Beast that shows the embodiment of unchecked vanity. Gaston’s appearance in the story of Beauty and the Beast adds a physical parallel to the Beast. Perhaps Gaston is a reminder of what the Prince-turned-Beast might have become – if not for the curse. Gaston continuously uses others for his own gain, often bolstering his own ego at the expense of others who have considerably less status in society. Wolfensberger notes that, historically, disabled people were relegated to roles of ridicule and were not to be taken seriously – such as jesters or ‘village idiots’ (CDHM, 28). Gaston takes advantage of those who should be the focus of the town’s compassion. From trying to get Belle’s father committed to an asylum to making fun of the town beggar, Gaston has no qualms about making other people the object of his ridicule. However bigoted his character may be, Gaston seems to be the voice for the majority of society. No one steps in to correct his uncouth demeanour – not even Agatha, who, in the 2017 version of Beauty and the Beast, is the enchantress in disguise.

Gaston’s presence reinforces the Beast’s status as the other and highlights the fact that the Beast will never truly belong as a subject in society, at least in his current physical state. The showdown between Gaston and the Beast may be symbolic of the Beast confronting his own trauma. As Gaston displays some of the same qualities as the Prince before his transformation, Gaston represents the journey that the Beast has taken. By choosing to engage Gaston physically, he proves that he is willing to re-engage with his own trauma, and thus, reclaim his pre-transformation identity (TRAV, 196-7). It is only by restraining his animalistic tendencies of violence and embracing a more humanistic level of compassion toward Gaston that the audience sees the progress that the Beast has made. Instead of displaying additional animalistic qualities and seeking revenge as a way to assert power, the Beast attains subjecthood by displaying mercy. By offering Gaston a chance to escape with his life, the Beast is able to transcend being an object of ridicule to become a subject who has begun to heal from his own trauma.

Even though Gaston is a Disney addition, his mannerisms may have roots in the behaviour of the Prince who appears to Beauty in her dreams. The Unknown is continually at odds with his animalistic counterpart. The Unknown derides the Beast, and proclaims that he would rather kill him so as to be assured of Beauty’s affection. Even though the Beast and the Unknown are one in the same, the Unknown’s commentary on the Beast is concerning. Countering Beauty’s devotion to the Beast, the Unknown scathes, “Of what use is he to the world? Will any one be a loser by the destruction of a being who appears on earth to be horror of all nature?” (SBB, 37) In naming the Beast a ‘horror of all nature,’ (SBB, 37) the Unknown seeks to separate himself from the Beast and behaves more as an able-bodied captor who degrades and ‘destroys the victim’s sense of autonomy’ (TRAV, 77). Upon seeing Beauty’s affection for the Beast, the Unknown seems to experience a crisis, rationalizing that if the Beast ‘wins’ Beauty, the human part of the Prince will be forgotten. The Unknown’s attitude toward the Beast is troubling as the Prince and the Beast are both victims of the same curse. Perhaps the Unknown craves reassurance that he will not lose his identity to the Beast, as he lost his physical being. Similar to a survivor of trauma who ‘needs clear and explicit assurances that she will not be abandoned once again,’ the Unknown sees...
the Beast as the cause, not the cure, of his isolation. Herman writes that survivors of trauma ‘fear separation from one another more than they fear death,’ but the Unknown does not seem to realize that by advocating for the death of the Beast, he is advocating for his own death (TRAV, 62). The Unknown is overly-willing to kill the beast in Beauty’s dreams, similar to the rallying cry that the animated version of Gaston uses to inspire the townspeople to attack the castle: ‘Kill the Beast.’

**Happily Ever After?**

Happy endings are expected in Disney films, but Villenueve’s version does not give the empowering ending that the audience might expect. In the text, Beauty is allowed to visit her father, but is warned that if she does not return, the Beast will die. Beauty neglects her obligation, delaying her departure, and is held accountable for the Beast’s near-death state. In a dream, the Beast ‘reproach[s] her with being the cause of his death and having repaid his affection with the blackest ingratitude’ (SBB, 43). The text highlights Beauty’s inaction as the cause of the Beast’s suffering, which allows her subject status, but casts her as more a villain than a heroine. Knowing that Disney cannot have ambiguity in establishing who is good and bad, Belle is presented as the heroine, the saviour and the love interest, all in one scene.

No sooner has the Beast accepted his identity than he is transformed back into the Prince. Surprisingly, the Prince does not overly seem alarmed or elated to find himself human. There is no confusion or trauma on the part of the Prince. Survivors of trauma assert that, after recovery, they feel as if they are ‘refugees’ acclimatizing to a new world (TRAV, 196). For the Prince, he is entering a new culture, as he must adjust to life as a royal, after being a beast for more than a decade. However, Disney does not show a readjustment period. Despite the fact that trust is the foundation of recovery work, Disney does not display the Prince establishing true a bond with Belle (BWWRD, 260). In the ending banquet scene, the Prince is surrounded by people, without any sign of trauma or discomfort, though it would be expected after spending years in almost total isolation and with little social interaction (TRAV, 91). Perry and Szalavitz note that recovery from a traumatic experience demands time and establishment of a daily pattern – something that is absent from both films (BWWRD, 275). While Judith Herman decrees that there is ‘no single […] magic bullet’ that one can use to recover from trauma, Disney seems to have found it (TRAV, 156). Disney skips the recovery period of a traumatic experience because aftereffects of trauma don’t make for immediate resolution. The happy ending in *Beauty and the Beast* is the restoration of the Beast to subjechood, but that title is only given once he is fully healed.

In terms of disability representation, a happy ending is essential to the film because it creates a *Deus ex machina* of sorts; the happy ending allows the audience to find an easy way out of the film without coming face to face with the reality of a disability. Having found someone who loves him just the way that he is, the Beast is readily transformed into a handsome prince, allowing him to be a hero once more. The happy ending has to come directly after the disabled character has overcome his disability, because the audience does not want to contemplate the fact that the disabled character may not be rewarded for all of his hard work. The audience demands these light, heart-warming and inspiring stories to such an extent that there has become, as

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Riley, 25.
Riley interjects, a ‘basic “overcoming” recipe of normalcy, injury, and recovery’. Once the character has proven that he has the ability to be courageous, he deserves a reward that must culminate in a ‘happy ending’. In the end, the Beast disappears, and the Disney cannon is rewarded with one more non-disabled prince.

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62 Riley, 25.

`E mare păcat` 
*Imagini inversate ale dizabilității, traumei și ale puterii în producția Disney Frumoasa și Bestia*

Acest articol explorează câteva paralele dintre modul în care societatea tratează persoanele cu dizabilități și personajele din cele două versiuni ale producției Disney intitulate *Beauty and the Beast* (Frumoasa și Bestia), respectiv versiunea din 1991 și cea din 2017. Comparând textul lui Gabrielle de Villeneuve cu filmele, evidențiez că unde filmele se abat de la text pentru a se conecta cu stereotipul dizabilității. Accentuând conexiunea percepută dintre caracterul moral al unui personaj și înfățișarea sa fizică, articolul analizează cum personajul Bestia perpetuează ideea că persoanele cu deficiențe morale au câștigat o dizabilitate fizică. Prin intermediul clasificărilor deviației și ale dizabilității ale lui Wolf Wolfensberger, ca de exemplu copilul etern, organismul subuman, etc., articolul încerca să dovedească faptul că Disney continuă să promoveze imagini peiorative ale corpului cu dizabilități. Ilustrez prin teoria traumei cum blestemul asupra Bestiei este sursa traumei. În cele din urmă, articolul analizează principiul subiect/obiect al lui Foucault, concentrându-se asupra modului în care cea mai recentă versiune a filmului *Frumoasa și Bestia* poziționează persoanele fără deficiențe fizice ca subiecți ai persoanelor cu dizabilități.
Setting the Stage for Bridging Disability and Trauma Studies: Reclaiming Narrative in *Amy and the Orphans*

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Abstract

Disability studies and critical trauma studies are both deeply concerned with the social construction of meaning and identity. However, these disciplines often remain mutually disengaged, inadvertently overlooking shared mechanisms of oppression that foster stigma. This article explores the novel depiction of disability and trauma in the play *Amy and the Orphans* by Lindsey Ferrentino. Amy, a character with Down Syndrome, challenges disability stereotypes by exercising autonomy; she is not solely defined by her disability or her experiences of abuse. The theatrical narrative is one of both disability and trauma, encouraging a nuanced reflection on the origins of stigma and revealing how theatre can be used as a tool of resistance to reclaim agency through performances that challenge conventional ‘disability’ stereotypes.

Keywords: disability, trauma, representation, performance, narrative, intersectionality, *Amy and the Orphans*, Lindsey Ferrentino

The fields of critical trauma studies and disability studies rarely engage with each other, despite similar concerns with overlapping personal experience/ narrative.1 Disability studies and critical trauma studies are both deeply concerned with representation and social constructions of meaning and identity. However, these disciplines abstain from contributing to each other,2 therefore perpetuating a cultural narrative that overlooks the shared mechanisms of oppression as articulated in narratives representing stigma.

Their isolated theoretical models can be enhanced through an interdisciplinary approach, thus creating an intersectional lens whereby the social justice component of the field of disability studies is bridged with the strengths of trauma-based theories that address issues of pain, denial, and loss.

This article explores how the depiction of Amy, a character with Down Syndrome, challenges stereotypes about both disability and trauma in Lindsey Ferrentino’s *Amy and the Orphans*.3 Amy exerts agency, she refuses to be reduced and defined by her disability or her experiences of abuse. This theatrical representation highlights the need for an interdisciplinary theoretical model that reveals how ‘trauma’

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and ‘disability’ are often interrelated as a result of social and political conditions. *Amy and the Orphans* exemplifies how the stage can be used to depict a nuanced narrative that reclaims ‘the gaze’ and engages the audience in critical, reflective process whereby the meaning of stigmatised groups can be rearticulated.

**Defining Disability and Trauma through a Disciplinary Lens**

The main theoretical model in trauma studies is often criticised for failing to address political or structural factors that shape the individual’s subjective experience and contribute to cultural trauma (*TWD*, 567). Trauma models often pathologize the individual, as their experience is understood in terms of symptoms and therefore treated in a medicalised fashion. Thus, these models exclude a social analysis that allows one to connect personal experience to that of a collective. Scholarship has been criticised for positing models that overstate social factors, limiting analysis and muting voices that bring attention to bodily pain or wounds that intersect with their lived experience as a person with a disability (*ITTCTS*, 7).

Disability studies is a well-established discipline mainly centred around embodied differences as a result of social structures and not from a physical impairment (*DII*, 584). The social model is the main conceptual foundation for disability studies scholars, who emphasise the distinction between ‘impairment’ and ‘disability’. The social model of disability asserts the following reconceptualization that redefines the traditional definition and perception of disability: the physical or mental feature qualifying the individual as ‘disabled’ is a result of social attitudes and social institutions, the organization of the physical environment perpetuates the lack of access and participation of persons with disability and discrimination against persons with disability reflect social norms and values that position them as ‘less valuable’ than abled individuals, thus denying them equal rights and treatment.

Morrison and Casper, along with David Goodley, Gabel and Peters, Alison Kafer and Tom Shakespeare and others, have criticised the predominant view of conceptualising disability strictly through a social constructionist lens, for it excludes experiences that imply pain originating or associated with one’s impairment (*EAD*, 299). There is an overall avoidance of tying suffering to the body due to the potential for

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regressing back to the medical model; however, ignoring these experiences restricts the collective narrative. Furthermore, impairment itself is also a social construction (EAD, 300 and DIJ, 586). To shift the perspective on suffering can acknowledge how physical bodies are the products of their social context, thus providing a theoretical framework that no longer denies the corporeality of disability (EAD, 300-301). This shifting perspective reveals how visible and invisible wounds that may originate from trauma are marked by socio-political environments and oppression.

Additionally, overstating the origins of limitations in social structures may invalidate others’ experiences related to their corporeality, such as pain or wounds, which are meaningful to one’s narrative. Kafer argues that the acknowledgment of loss, grief or trauma is essential to critical theories of disability, for the denial or rejection of seeing disability as tragedy, or as traumatic can be restricting to the progression of the social justice movement as a whole (UD, 7). To entirely ignore the ways trauma coexists with disability can be as problematic as ableist arguments that view disability as consistently being a tragic misfortune. I argue that a multidisciplinary, pluralistic approach is vital to enrich both the fields of trauma and disability studies. The theoretical foundation of traditional disability studies is rooted in the medical and social model, yet such theoretical paradigms are often reductionist, failing to provide a comprehensive lens to study one’s experience living with a disability. The adoption of an interdisciplinary approach would strengthen and enrich the scholarship of disability studies as well as the encounters of tangential academic fields — offering deeper insight, expanding the definition of disability and therefore increasing inclusivity.

Critical trauma studies originated from the larger discipline of trauma studies, which was influenced by medicalised models from psychiatry and psychology that pathologise trauma and the way it impacts individuals (ITTCTS, 5). The contribution of critical trauma studies is to contextualising the relationship between culture and the individual through adopting interdisciplinary approaches that address head-on social and political aspects of analysis of trauma (ITTCTS, 9). The theoretical models rooted in critical trauma studies continue to echo conventional medicalised discourses, limiting the analysis to symptomology or an individual’s experience, often expressed through metaphor (TWD, 567).

In her work, Screening the Body, Lisa Cartwright traces the way science has used cinema as a technological tool in discerning ‘healthy’ from ‘nonhealthy’ bodies in order to validate and affirm previous forms of medical knowledge.9 Cartwright provides additional historical context by providing a deeper understanding of Foucault’s concepts of the ‘clinical’ and ‘medical gaze’.10 Foucault introduced the idea of ‘the gaze’ in his 1973 The Birth of the Clinic: An Archaeology of Medical Perception. Overall, the ‘gaze’ is associated with the power of seeing, particularly with respect to the use of medical knowledge as an oppressive force to control and regulate bodies. ‘The gaze’ utilizes medical discourse to separate out ‘deviant’ bodies through the medicalisation of human experience and the exercise of power.11 The ‘clinical gaze’ refers to the process by which by his/her doctor no longer views an individual as a whole person, but rather sees them as their disease or condition (or disability, ‘product’ of their trauma). In contrast,

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9 Lisa Cartwright, Screening the Body: Tracing Medicine’s Visual Culture (Minneapolis: University of Minnesota Press, 2006), 1-16.
11 Foucault, 89 and 168.
the ‘medical gaze’ characterises the individual’s experience of feeling dehumanized as a result of being an object of analysis rooted in medical knowledge informed by optical instruments.

Generally speaking, the field of trauma studies is primarily informed by psychoanalytical theories and therefore employs medicalised language, as the theoretical foundation is rooted in the discipline of psychology and psychiatry.12 The main critique of the primary theories within trauma studies is that they rely too heavily on medical discourse and therefore perpetuate ‘otherness’ and stigma (TWD, 576), mainly through viewing disability and trauma through the lens of a ‘medical gaze’. The ‘gaze’ fosters a power dynamic that positions the ‘clinician’ as possessing power in the form of knowledge of one’s body or access to treatment and, therefore, that individual becomes submissive to or compliant with the clinicians to regain agency.13 Consequently, the patient-doctor relationship is inherently structured such that a person with a disability or a person seeking treatment after a trauma does not have equal power to that who she or he is relying upon as their primary source of care or support, thus presenting the potential for abuse of power.

Despite the critique of the field of trauma studies, scholars have also claimed that the emergence of this discipline has contributed to the rise in published autobiographical accounts of the lives of previously unheard voices (TWD, 571 and 577; IDTA, 90). The autobiographical narratives are then placed within a theoretical framework that validates one’s experience of physical pain and suffering as well as acknowledging the role of social stigma. Although conceptualisation of trauma may provide validation to one’s personal experience of suffering, this also positions trauma outside a socio-political context, which conflicts with the primary aims of disability studies (DII, 585; TWD, 569). However, the recent shift to critical trauma studies has begun to draw attention to the relationships between social and political forces and trauma, which reinforce oppression among marginalized groups (ITTCTS, 9).

Critical trauma studies differs from traditional trauma studies, shifting away from a restrictive, psychoanalytical paradigm to a pluralistic approach that positions trauma within a larger social, political and economic context, which dialogically shapes the meaning and practices inherent in traumatic experiences.14 By synthesizing conceptual models that address trauma studies’ ‘political inadequacy’ (TWD, 577), this addresses the fear that inclusion of trauma would undermine the overall aim of challenging powerful forces that perpetuate inequality (social, political and economic institutions).

**Trauma/Disability Narratives**

Cathy Caruth defines trauma as the psychological and physical response to an ‘unexpected or overwhelming violent event or events’, whereby one has yet to process the experience fully.15 Ruth Leys discusses trauma regarding its effects on memory,

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13 Foucault, 146.


since it produces a subject with an ‘incapacity to retrieve the past, or to speak truth about it’. To discuss trauma in relation to capacity is to define it as a disability, since ‘disability’ represents the social ramifications surrounding an individual’s mental or physical impairment (DII, 591). Situating mental disability with trauma not only warrants fusing theoretical models of trauma and disability, but calls for collective solidarity among those who have experienced either/or, as well as both/and. Thus, this intersectional approach draws attention to nuanced narratives and experiences of disability integral to traumatic experience.

Comparable to the ‘supercrip’ accounts of individuals that take form in the narrative of ‘survivors to thrivers’, medicalised discourse in trauma studies is problematic for emphasising a ‘cure’ or ‘fix’. Such rhetoric is reductionist as it pathologizes traumatic experiences, which may result in the individual feeling as if one is ‘broken’ or ‘diseased’. Like persons with a disability, those who have gone through a trauma may feel pressured to serve as ‘inspiration porn’ for the public. Some trauma-recovery narrative entail being strong enough to transform their pain so that they become a hero to themselves and others. Sehgal’s piece, ‘The Forced Heroism of the “Survivor”’, published in New York Times Magazine further explored the disconcerting nature of framing individuals who have experienced acts of violence or other forms of trauma, as heroic or inspirational. She poignantly states:

It’s ‘looking-glass shame’ all over again — that terror of facing your vulnerability — a treasonous thought in a society that is desperately optimistic and addicted to recovery narratives… And so, the pendulum swings from one extreme to another: from casting rape as insurmountable pain to casting the survivor as possessing superhuman strength. (FHS, 13)

20 Parul Sehgal, “The Forced Heroism of the “Survivor””, The New York Times (3 May 2016): 13; available at https://www.nytimes.com/2016/05/08/magazine/the-forced-heroism-of-the-survivor.html [accessed 30 March 2018], hereafter cited as FHS, with page numbers in the text. Regarding Wagatwe Wanjuki, a sexual-violence activist and author, who published an article on transforming the survivor of trauma into a hero, she states: ‘[y]ou’re best known for enduring the worst experiences of your life.’ Similar to arguments made among disability scholars and activists, trauma survivors do not want to be defined by one trait, the trauma, nor do they made to be a one-dimensional character consumed for the public’s inspiration of the day. For Sehgal, ‘[t]rauma is a visible wound — suffering we can see — but it is also suffering made public, calcified into identity and, inevitably, simplified […] Those who have faced sexual violence are so commonly sentimentalized or stigmatized, cast as uniquely heroic or uniquely broken. Everything can be projected upon them, it seems — everything but the powers and vulnerabilities of ordinary personhood.’
21 See for instance, Edward St. Aubyn’s Patrick Melrose’s novels, Hanya Yanagihara’s A Little Life and Raymond M. Douglas’s memoir On Being Raped for resistance to this survivor-victim dichotomy.
The narrative of victim-to-survivor-to-thriver is beyond semantics, it is an ideological shift. The rise of medical discourses in the context of trauma and ‘treatment of trauma’ shifts how one classifies one’s experiences and seeks guidance or care following exposure to a traumatic event.

The push to identify as a survivor or ‘thriver’ (instead of victim) is comparable to Barbara Ehrenreich’s discussion on the problematic discourse surrounding ‘victims of cancer’ in her book *Bright-sided: How Positive Thinking Is Undermining America*, in which she argues that America’s obsession with positive thinking has constructed an unhealthy survivorship narrative based upon and perpetuating certain expectations for individuals. As such, this narrative is one whereby the value of individual survivors is based on whether they participate in certain or expected acts (e.g. receive chemotherapy, go to therapy, require or reject trigger warnings, attempt to ‘correct’ an impairment). This in turn suggests that certain individuals are more deserving or trying harder more than others to ‘survive’, and thus should be honoured for their dedication and strength. Whereas those who do not live up to one’s expectation or resist mainstream treatment are seen as deserving of the consequences, whether in the form of social stigma or physical suffering.

Dana Bolger, a director of a sexual violence education training school in New York City, expressed a similar frustration, referring to the prevalent trauma narrative as ‘[c]ompulsory survivorship’ that ‘depoliticizes’ society’s understanding of the consequences and impact of violence (*FHS*, 13). ‘Compulsory survivorship’, and the restrictive binary script in which trauma is often placed, further individualizes and isolates the individual. As a result, individuals enduring the aftermath of the trauma feel responsible for having survived unlike the others and for their healing ‘while comfortably erasing the systems and structures that make surviving hard, harder for some than for others’ (*FHS*, 13). Prior to the late 1960s, it was not common for there to be public discussion or even a consideration of certain events as traumatic (e.g. war, physical violence, sexual assault, psychological abuse). These tended to be disregarded or seen as insignificant events in a person’s life. War veterans, holocaust survivors, feminist scholars and activists contributed to shifting the public’s perception of the consequences of enduring a traumatic experience. Furthermore, the recognition of one’s trauma was common among groups. As such, the shared experienced was often coupled with advocating for a social-political cause. For instance, ‘rap groups’ popular among members of the Vietnam Veterans Against the War, frequently gathered to share the psychological disturbances they experienced after returning to the United States after combat in Vietnam. They then advocated for a revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM). In 1980, the veterans shared their stories before members of the American Psychological Association as a form of activism to

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24 Judith Lewis Herman, *Trauma and Recovery: From Domestic Abuse to Political Terror* (London: Pandora, 2001), 19.
ensure that the newest DSM included post-traumatic stress disorder as a billable code, as means of receiving relief from their suffering.27

Comparably, during the same time, feminist scholars and activists advocated and raised awareness of the traumatic experiences common among women such as rape and domestic violence.28 Many campaigns brought attention to the ways in which individuals were adversely impacted by such traumas as childhood sexual abuse, psychological abuse or other forms of abuse.29 The overall sentiment that the ‘personal is the political’ reflects the initial approach to trauma survivors including veterans, holocaust survivors, and women at risk or who have had a history of sexual or physical trauma.30 Although contemporary advocacy groups and resources for trauma ‘survivors’ may also have a socio-political aspect to their organization, there has been a rise in the medicalisation of trauma and abuse and thus the process of healing is most often highly individualized and depoliticised (CVRW, 88-92).31 Again, this is reflected in the individualized routinized treatment for trauma such as one-on-one therapy and the tendency of the media to construct heroic survivors, creating a hierarchy of legitimate and illegitimate ‘survivors’ of trauma (FHS, 13; CVRW, 88).32

Moreover, a central critique of trauma studies is that it depoliticises trauma (TWD, 577), and the public perception of trauma has shifted to reflect an individualized healing process, whereby treatment may entail being isolated from others who have endured trauma. Therefore, it becomes increasingly difficult to identify social factors contributing to one’s experience, which is problematic considering the trauma may be a result of war or gender-based violence – a systemic problem in need of a collective, public response or efforts to remedy (TWD, 577; CVRW, 86).

Critical trauma studies emphasise that pathologizing trauma or promoting such models has the potential to perpetuate mass violence against marginalised groups around the world, as this conceptual framework overlooks critical macro-level factors that would provide insight necessary to develop social or political interventions to prevent future systemic acts of abuse. Margaret Price suggests that if we are to understand trauma in terms of disability, or recognise the intersection, we must then call for a conceptualisation outside the medical model of disability; this reconceptualization will lead to reclaiming power from the medical community that fundamentally pathologizes suffering.33 Cvetkovich34 and Kafer (UD, 4) aim to re-conceptualise trauma and, in turn, redefine disability. Kafer argues for a political/relational model within the field of disability studies, further supporting the critique that the predominant framework is problematic because it fails to recognise the physical pain and struggle of those who have different ways of being and experiencing (UD, 3) the world, whether that be due to a trauma directly or indirectly to an individual’s impairment. Advocating

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27 Scott, 300-2.
28 Herman, 19.
29 Davis, 79.
30 Herman, 246
31 See also McKinney, 270.
32 See also Jennifer M. Gómez, Jenn K. Lewis, Laura K. Noll, Alec M. Smidt, and Pamela J. Birrell, ‘Shifting the Focus: Nonpathologizing Approaches to Healing from Betrayal Trauma through an Emphasis on Relational Care’, Journal of Trauma and Dissociation 17.2 (2016): 168.
33 Margaret Price, Mad at School: Rhetorics of Mental Disability and Academic Life (Ann Arbor: The University of Michigan Press, 2001), 33-7; Carter.
an integrative theoretical model brings to the surface more narratives that reveal how accidental, isolated traumatic experiences are the minority. In fact, the majority of traumatic events are the result of institutional forces of oppression in the form of racism, sexism, ableism and homophobia.\textsuperscript{35}

**Depiction of Disability and Trauma in the Arts**

**Representation of Disability**

What can the representation of disability in the media tell us about societal beliefs and values concerning persons with disability? Portrayals of disabled persons have changed over time, both reflecting and influencing society’s understanding of disability. Societal beliefs and values concerning persons with disability have been heavily influenced by medical insights and knowledge of the body.\textsuperscript{36} Research has shown that the representation of disability continues to be a narrative shaped by the ‘medical gaze’.

Though nearly 20\% of the US population report having a disability, only 2\% of fictional film and television characters have a disability. A Ruderman Foundation study found that among the small percentage of characters that do have a disability, 95\% of the roles are given to non-disabled individuals.\textsuperscript{37} Further, much of the media formats are inaccessible for persons with disability, thus preventing them from participating in the production and viewership of material. Therefore, it is critical that actors with disabilities continue to fight for self-representation.

Traditionally, film, television and theatre have depicted disabled persons in a negative light by positioning the disabled character as either an object of ‘cultural fascination’ or a ‘charity case’.\textsuperscript{38} Persons with disability are rarely the protagonist, and the narratives lead the spectator to identify with the non-disabled character, reducing disabled characters to ‘objects of spectacle’ (\textit{CI}, 22). Arthur Campbell Jr, a disability rights activist with cerebral palsy, states that ‘[m]ost filmmakers want to make us either some sympathetic poor little character that no one could have mature normal relations with or some kind of monster who has to be kept away and watch for the safety of society or themselves’ (\textit{CI}, 24). To reduce the disabled individual on film to mere spectacle or to construct him or her as the ‘Other’ is reflective of society’s understanding of disability.

Hunt’s study conducted in 1991 identified the ten primary media stereotypes used to portray disabled people as: pathetic, mysterious, sinister, supercrip (overcoming all ‘impairments’ to be like able-bodied individuals), clown, a prop, self-destructive, 35 Samantha C. Holmes, Vanessa C. Facemire, and Alexis M. DaFonseca, ‘Expanding Criterion A for Posttraumatic Stress Disorder: Considering the Deleterious Impact of Oppression’, \textit{Traumatology} 22.4 (2016): 314-21; Carter.
36 Cartwright, 4.
asexual, a burden, and unable to participate in daily life/as a death sentence. All of these tropes are present in the cult-classic film *Freaks*, one of the first films to cast people with disabilities as opposed to non-disabled individuals acting as persons with disability. Though it may have cast people with disability, the plot plays on exploitative stereotypes. Many disability rights’ activists critique this film, arguing it to be the ‘pornography of disability’, given that the plot centres around circus performers with disabilities that become unrestrained monsters seeking to destroy their non-disabled peers.

Current mass media depictions do not portray people ‘living with’ disability but rather convey disabled persons as ‘overcoming’ their disability. As mentioned above, this is the ‘supercrip’ narrative. This type of narrative sends a message that living with a disability is so horrific and devoid of value, that one must go to any length to heroically ‘overcome’ the disability. Furthermore, conventional narratives position characters with disability as ‘the Other’ or merely helpless or confined without the help of an ‘able-bodied’ individual (CI, 22). This discourse represents ability as a binary, with ‘disabled’ individuals reliant on others to fulfil their human potential, unable to reach their dreams without the assistance of ‘able-bodied’ individuals. Disabled people lack agency in such representations, even when the author’s intention may be to demonstrate a survival story with a disabled individual at the centre.

Regarding the portrayal of developmental disabilities, adults with Down syndrome typically get cast in roles for Public Service Announcements advocating for a disability or raising money, perpetuating the ‘pity’ and ‘charity’ stigma. Studies show that when the media uses negative, ableist language, this fosters a negative self-image for people with the disability as it impacts the use of such terminology in society.

Concerning casting, *Born This Way*, a reality-based US television series, cast multiple adults with Down syndrome. The show depicts a variety of issues and illustrates the diversity within a group stereotyped as being all the same. The show constructs a multi-dimensional narrative, whereby the individual(s) are independent, sexual, and face challenges that resonate with the majority of able-bodied viewers. However, this is just one media portrayal among many, and the major networks

44 Levine.
continue to portray the vast majority of persons with disability as ‘charity cases’ at one end or ‘supercrips’ at the other.48

Among theatrical performances, themes reflect the construction of disability through the medical model, which views disability as a deviation or as a marked but otherwise able body (DCP, 15). The medical discourse is prevalent in early depictions of disability in theatre as far back as 400 years ago.49 For instance, in William Shakespeare’s The Tragedy of Richard the III, the protagonist Richard III is described as ‘deform’d, unfinish’d’ (1.1.20) and, more directly, ‘elvish-mark’d’ (1.3.228).50 Richard III’s narrative is not a display or powerlessness, but rather a claim to power.51 The character illuminates the transformation of the disability narrative throughout time; during the Renaissance, when the play was written, disability was conceived of as a result of one’s moral character, thereby becoming intertwined with the medicalized/medical model of disability.52 As such, this informed modern representations, framing disability as a disease in need of modern medicine’s ‘cure’.

In the majority of mainstream theatrical performances of disability, these characters are isolated, infantilised, and pitied. Furthermore, a person with disability rarely appears on stage alone; a doctor or a caregiver frequently accompanies them as it understood that s/he is incapable to care for or speak for themselves. In this regard, in this article I argue that the play Amy and the Orphans does not entirely depart from this prevailing plot, reflecting that disability is still often understood as a pathology in need of medical treatment or a cure. The fact that the main character, Amy, has Down syndrome is a central plot piece. However, unlike other representations of disability, especially those set in the pre-modern era (WIBMB, 150), disability today is not always seen as a death sentence, and her disability does not define Amy, as she exhibits far more qualities than any other character on-stage.53 Later I consider the ways that the play reinforces certain stereotypes while challenging others, especially in relation to the intersection of disability and trauma narratives.

Representations of Trauma/Narrative

According to predominant theoretical models of trauma, a traumatic experience is a severe psychological disturbance often unable to be fully processed in one’s memory, therefore posing a difficulty for the integration of a cohesive autobiographical narrative. Freud’s study of trauma profoundly influenced the pathologization of trauma, thus isolating individuals who endured or exhibited any ‘symptoms’ or change in behaviour after a specific event.

48 Hunt.
51 Schaap Williams.
53 Unlike many mainstream theatrical performance and narratives surrounding disability, Amy does not exhibit self-pity. Further, Amy is not defined by her disability or her trauma. Finally, Ferrentino appears to intentionally further develop Amy’s character more than her siblings’ to challenge the audience’s preconceptions of disability.
As a formal discipline, trauma studies is heavily informed by psychoanalytic theories and is criticized for pathologizing human experience, best exemplified by the relatively recent development of trauma-related diagnoses such as post-traumatic stress disorder (PTSD). 54

Media scholar Suzanne Little argues that there is an ‘obsession’ with the real, seen for instance, in the depiction of trauma that is often in the form of a testimonial, using words to describe the trauma or visual imagery in the form of documentaries concerning torture, abuse, and war. 55 This is illustrated within the arts through written testimony, cinematic style to emulate flashbacks, fragmented memories through non-linear narratives and character-driven plots repeat scenes of the traumatic events as a means to communicate a desire to ‘recover and reprocess’ 56 through repetition.

The arts often use the audience’s memory or previous knowledge of history to affirm the witness role that is needed to establish meaning and shape the trauma narrative. 57 Among theatrical representation of trauma, ‘the real’ relies even more so on the audience’s ‘gaze’ 58 and ‘collective memory’ of a shared historical past (ITTCRS, 6-7). 59

Within the sphere of theatrical representation, the audience rarely see a character experience trauma, but instead meets the character before or during the aftermath of a traumatising event. The award-winning off-Broadway show Indecent which follows a predominantly Jewish theatre group as they find venues in which to perform a controversial play in Europe, never depicts actual death or violence, despite taking place during the Holocaust during the Second World War. 60 The group has the opportunity to perform in New York City just before the horrors of the Second World War begin in Europe.

Indecent is a portrayal of intimacy, the building of relationships, and the protection of the stigmatized Jewish identity amidst the terror and trauma of the Second World War. Director Vogel’s juxtaposition of the past and the present weaves poetry and beauty into a nuanced and honest depiction of what it may have been like to try to survive the trauma of wartime, specifically when the war is waged against one’s personal identity. Thus, the theatrical performances explored Jewish, political and queer identity through an intersectional lens, since expressing terror and trauma necessitates such a theoretical frame to capture the nuanced experience. Such an intersectional approach uses theatre as a site to reclaim power through a narrative that re-politicises trauma to build solidarity through shared experience (DCP, 4). 61

The opening scene exemplifies finding unity and agency through the collective trauma, which is depicted as a stream of ashes falls from the sleeves of the actors’ jackets, while beautiful music plays. In the background in Yiddish and English, the

56 Little, 46.
58 Fahy, xiii.
60 Paula Vogel, Indecent (Guthrie Theatre, New York, January 2018).
61 See also Sofer, 119.
audience reads ‘through the ashes we rise.’ Given that the play opens with this scene, this specific depiction of trauma is both foreshadowing and a haunting memory associated with the lives lost during the Holocaust. Throughout the production, there is minimal dialogue about the increasing horrors the Jewish community was facing in that historical moment; death and physical violence are not portrayed. Instead, the characters repeatedly rise, allowing the ashes to depict this cultural trauma. The ashes serve as ‘as tantalizing proof of “real” experience’ of a trauma many audience members know of only indirectly. As with Amy and the Orphans, this theatrical performance becomes a space for the ‘historical recovery’ of systemic abuse and violence against those deemed ‘less than’ human.62

Turning the Gaze: Intersecting Trauma and Disability

This article explores the theatrical representation of the disability narrative of the play’s main character Amy, a woman with Down syndrome, who is shaped by both disability and trauma. The Off-Broadway show, Amy and the Orphans is one of the few that casts a lead actor with Down syndrome.63 Amy was placed in the State-run facility Willowbrook in Staten Island, New York, where she endured many traumas. Her sense of autonomy, despite her past and her disability, challenges conventional stereotypes of persons with disability.

Furthermore, the abuse she was subjected to reveals ways in which disability and trauma interconnect through institutionalised violence against marginalized groups. As such, this theatrical performance depicts a narrative of disability and trauma that necessitates an intersectional theoretical approach, encouraging an exchange between the two disciplines of ‘disability’ and ‘critical trauma studies’.

Amy and The Orphans

Written by Lindsey Ferrentino and directed by Scott Ellis, the play Amy and the Orphans premiered at Roundabout Theatre in early 2018. The show continues to gain media attention due to the lead role being played by Jamie Brewer, who has Down syndrome.64 Her male understudy is Edward Barbanell, who also has Down syndrome.

Amy’s narrative is inspired by the real-life experience of the playwright’s aunt, illustrating how traumatic experience intersects with disability off-stage. Ferrentino describes her aunt as ‘not of a high-functioning level, not because of Down syndrome, but because she was abused her whole life’.65 Like Amy, Ferrentino’s aunt resided in Willowbrook in Staten Island, New York.

Amy is a film-loving, middle-aged adult who must spend a few days with her distant siblings as they take a road trip from Queens, NY to Long Island, NY to bury

63 Lindsey Ferrentino, Amy and The Orphans (Roundabout Theatre, New York, February 2, 2018).
64 Brewer’s casting in the lead role increased attention to the play, as she has a strong fan following from being the first model with Down Syndrome to appear on the runway at New York Fashion Week. She was also a favourite character on the US television series, American Horror Story.
their father. Amy refuses to be defined by her disability, while her two ‘able-bodied’ and ‘neuro-typical’ siblings continuously and foolishly undermine Amy’s self-agency out of guilt.66

The Role of Theatre in Shifting the Gaze

Theatrical performances have the potential to provide a space for the audience to engage in reflexivity about assumptions and meaning associated with disability (DCP, 11). Amy’s performance challenges the conventional stereotype of people with disability through self-assertion and expression of understanding beyond the expectations of the other characters (and most audience members). Performing is a form of representation that allows for marginalized groups to reclaim power and control; meanings of disability can then be re-articulated (DCP, 9). The ‘gaze’ is shifted onto the audience, altering their perspectives of disability. Since the performer has Down syndrome, rather than being a non-disabled person, the audience is made increasingly aware of their cultural assumptions of bodily difference (DCP, 12). There is profound potential to evoke social and political change through theatrical visibility among stigmatized individuals. Theatre performances offer a space for the audience to engage in an interplay and exchange of meaning. Amy’s assertion of self-agency, coupled with the complexity of her life experiences of being abused due to her disability, exemplifies how narratives can shift ‘the gaze’ on to the audience, altering their perspectives of disability.

Another way the play has used their platform to raise awareness concerning disability issues is through the presence of Spread the Word to End the Word, an organization that campaigns against the word ‘retard’ at each performance. Viewers were asked to sign a large board that was in the lobby pledging not use the word ‘retard’, considering its negative and belittling connotation. Signing the petition is another aspect of the overall experience of attending a viewing of Amy and the Orphans that contributed to reshaping the meaning of disability.67

The campaign engaged the audience members, providing an opportunity to educate and shift their perceptions of disability before and after the play. Since 2009, millions have signed similar petition banners, pledging to end the use the of the R-word (retarded), in support of Intellectual Developmental Disability (IDD) communities throughout the world. People with Down syndrome are classified as having an IDD, which is the reason that Spread the Word to End the Word had requested to be present for each theatrical performance of Amy and the Orphans.

Similar to the multiple people-first, disability rights organizations that came before, Spread the Word to End the Word advocates on behalf of people with IDD, emphasizing inclusion and reducing stigma. The word being used to describe any

66 The siblings find out the institution Amy was placed in was shut down due to inhumane acts.
67 In 2010 Rosa’s Law was signed into United States law by President Barack Obama, requiring that the terms ‘mental retardation’ and ‘mentally retarded’ be prohibited from any federal record. Such terms were to be replaced with ‘intellectual disability’. Rosa’s Law was a success families and people with IDD have been fighting to obtain since the late 1970’s. This law is a testament to the dedication of activists and families as advocates and active participants in the IDD-rights movement. See Charles Edmund Degeneffe and Jaciolo Terciano, ‘Rosa’s Law and the Language of Disability: Implications for Rehabilitation Counseling’, Rehabilitation Research, Policy and Education 25 (2011): 167.
population identified with IDD must be replaced to ensure ‘respect, dignity, acceptance and inclusion’ for all.  

The production of *Amy and the Orphans*, as well as the community of fans that seeks to involve audience members in advocacy on behalf of people with IDD, can be further contextualised by Snyder and Mitchell’s cultural model of disability. This model is useful for it extends beyond the social model, integrating the importance of arts and culture as ‘a political act of renaming that designates disability as a site of resistance and a source of cultural agency.’  

Snyder and Mitchell posit an interdisciplinary theoretical model, integrating concepts from cultural studies and disability studies. Similarly, this paper seeks to provide support for the use of pluralistic approaches to bring insight to ‘cultural locations of disability’, commonly referred to as the ‘sites of violence, restriction, confinement, and absence of liberty for people with disabilities’. 

Throughout the play, Amy refers to her home in Staten Island, despite living in a group home in Queens for the last 15 years. An aide who is required to accompany Amy during the trip to their father’s funeral reveals to the unknowing siblings that Amy was moved to Willowbrook as a small child. The audience then realises the opening scene of the two parents arguing was about moving Amy from their home to an institution described to them as a beautiful college campus, fully staffed to care for their young daughter with special needs.

In reality, Willowbrook State School was a state-supported hospital and school for people with mental retardation, which was located in Staten Island, New York (*WIBMB*, 41-52). There was an investigative study conducted in the 1960s due to suspicion of unethical and abusive treatment of the inmates. Some of the horrors found were overcrowding, insufficient sanitary facilities, and physical and sexual abuse by the staff. During the 1970s, more abuses were revealed, and new human rights legislation forced the institution to close in 1984 (*WIBMB*, 41-52).

The aide explains to the siblings that Amy is highly functional and many of her limitations are a result of the trauma she endured and have very little to do directly with Down syndrome. The audience initially are likely to attribute Amy’s behaviours (e.g., eating fast) or physical marks of the body (e.g., dentures, ‘deformed’ leg) to Down syndrome, however, in light of the information about the abuse she endured at Willowbrook, this conceptualisation of her disability is challenged.

For example, Amy does not eat quickly as a result of her intellectual disability. In fact, it is a survival habit she learned from life at Willowbrook. Her food would be taken away if she did not eat quickly enough; and she did not know the next time she would eat at all. Another example of the consequence of institutionalised abuse attributed to Amy having Down syndrome is that her legs are disproportional because at Willowbrook she was left outside during a winter blizzard, which resulted in the flesh on her legs deteriorating from frostbite. Also, she has dentures because she was fed dog
food for a year. Again, her physical state is the result of the wounds and trauma embedded within the system in place to ‘care’ for her.

When it is disclosed to the siblings that Amy was severely abused at Willowbrook, she is talked about as though she is not there. However, she can hear everything with her headphones on, and in response to her sister asking if she remembers the abuse, she reasserts her identification with her traumatic past by restating that Staten Island is her home. She follows this statement, as she frequently does, by boasting to her siblings about her current new boyfriend and job at the movie theatre. Amy does not exhibit shame of her traumatic past or hide any grief from the current loss. She continues to assert agency over the life she has built for herself throughout the years.

Theatre provides a space for the audience to re-examine their cultural assumptions concerning disability. As a result of the presence of an alternative narrative that challenges conventional stereotype, the gaze is turned back to the audience in a non-threatening manner. Accordingly, the audience begins to question their misconceptions and role in perpetuating the stigma and discrimination of marginalised and stigmatised groups.

**Depicting Autonomy**

Full of guilt, the day after the siblings find out about Amy enduring so many traumas at Willowbrook, they ignorantly invite her to live with one of them, as if they are doing her a favour. As a result of this, Amy storms out and attempts to cross the highway, screaming out why they would even think to take her away from her friends, boyfriend, and job. It is in this scene that the audience begins to understand that ‘the orphans’ in the title refers to how she was never part of the family in the same way as her siblings. Her life was the consequence not of being born with particular chromosomes, but the result of an agreement made by her parents, long before she had a voice of her own. Luckily, that voice was not taken away from her at Willowbrook.

Amy’s character is multidimensional, capturing the complexity and nuance needed to challenge prevailing, negative notions of disability that often position the individual as weak or dehumanized. The performance includes a disability narrative that challenges the stereotype of one-dimensional ‘charity case’ or ‘super-crip’ characters; the character displays vulnerability, strength and, most of all, resilience. The aide treats Amy as an equal.

However, the two siblings treat Amy as extremely fragile, almost like an infant. Each time they approach her to inform of her vital information, it appears not only that Amy already knows, but it is the siblings who seemingly need extra care. There are several humorous scenes of the siblings being flustered over how much Amy knows and remains unfazed, whereas the siblings cannot manage their emotions.

Amy is the only sibling of the family that displays the ability to accept and grieve the loss of their parents. She does not overcome any obstacles but rather lives through them. Amy’s character is multidimensional, exhibiting the need for increased attention to the intersection between ‘critical trauma studies and ‘disability studies’ to establish a stronger theoretical frame. An interdisciplinary approach is critical to enriching our understanding of how trauma becomes intertwined with a disability, as a result of institutional abuse.
The need to reshape one’s understanding of disability is felt most in scenes where Amy reclaiming and justifying her life choices is juxtaposed with scenes of her parents fighting over whether to have Amy live at a facility. Amy’s voice becomes stronger as she illustrates that a person with disabilities can both acknowledge the trauma, grief, and loss associated with a disability, without compromising one's political voice in resistance to stigma or self-worth. Amy's radical, total acceptance that fosters her overall ability to exercise self-agency, despite others ignorance, illustrating how empowerment can fostered not hindered by the intersection of trauma and disability.

Using the narrative in the play *Amy and the Orphans*, this article sought to deconstruct the narratives and symbolic boundaries that create trauma and disability as separate categories. The deconstruction of these categories can redirect the focus to the connection between disability and trauma, revealing how the lived experience is at risk of oppression and social control through medicalization of the human condition. In doing so, the analysis of representation shifts the perspective to enable identification of what social forces determine the meaning and hierarchy of trauma, explicitly revealing the importance of visibility of a marked body in determining disability. Traumatized bodies are understood as disabled, also broadening the definition to be more inclusive of unseen disabilities that are the result of structural forms of violence (e.g., war, poverty, abuse). However, these ‘disabilities’ are often not visible. In Amy’s case, her traumas are visible on her physical person as well, as in her use of dentures.

An analysis of this production reveals how ‘trauma’ and ‘disability’ are often interrelated as a result of social and political conditions, providing deeper insight into how these categories are experienced. The stage offers a platform to rearticulate meanings of stigmatized groups and promote social change. The theatre serves as a space to challenge stereotypes, through presenting an alternative representation. It also allows for the reclamation of ‘the gaze’ by providing a space for the audience to engage in a critical, reflective process on the construction of meaning and social factors that foster stigmatization of certain groups.

The show closes with Amy performing a monologue. She stands alone onstage, reciting movie quotes. The last few quotes remind the audience of the discrimination and abuse that individuals living with a disability continue to face, not because of the disability itself, but because of stigma which significantly impacts one’s sense of self-worth. She recites the following:

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I’m a human being, goddamnit.
MY LIFE HAS VALUE.
You don’t understand.
I coulda been a contender.
I coulda been somebody.
I coulda been somebody.
I coulda been somebody.
I coulda been somebody.
Go ahead.
Make.
My.
Day.72
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The lines she quotes beg the question – what would life be like without the stigma and abuse associated with disability? A few years back, the question may have been –

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72 Ferrentino.
what would life have been like without disability? But Amy’s story is told from her perspective and thus her performance is a reclamation of agency in the representation narrative, one that reveals the intersection between disability, trauma, and stigma without the loss of personal or political aspects of identity.

**Closing Thoughts as the Curtain Closes**

Until now, critical trauma studies and disability studies have remained largely mutually exclusive and disengaged from one another, despite both fields’ examination of similar populations through different theoretical frames (TWD, 577; DII, 584). An analysis of the theatrical representation of the disability and trauma narrative in *Amy and the Orphans* illustrates that disability and trauma not only coexist but often intertwine. The portrayal of the integration of disability and trauma in the theatrical representation warrants a fusion of theories rooted in disability and trauma studies. An intersectional, interdisciplinary approach broadens the scope of understanding the oppressive forces contributing to systemic abuse and, therefore, advancing disability rights and social justice movements.

This article sought to deconstruct the symbolic boundaries that create trauma and disability as separate categories. By challenging the separation of disability and trauma, the analysis shifts the perspective to enable identification of what social forces are at play that determine the meaning and hierarchy of trauma, explicitly revealing the importance of visibility of a marked body in determining the value and labelling of disability. Understanding narratives of traumatised bodies as also disabled is instrumental in increasing solidarity and strengthening collective identities.

**Bibliography**


Pregătirea scenei pentru întâlnirea dintre studii ale dizabilității și studii ale traumei. Revalorificarea narațiunii din *Amy and the Orphans*

Rezumat

Studiile dizabilității și studiile critice despre traumă sunt ambele angajate profund în construcția socială a înțelesului și a identității. Însă, aceste discipline rămân adesea în afara unui dialog, neglijând-și reciproc modul în care abordează mecanisme pe care le folosesc în mod comun pentru a analiza oprestiunea care produce stigmatizarea. Acest articol explorează o posibilă nouă descriere a dizabilității și a traumei în piesa de teatru *Amy and the Orphans* scrisă de Lindsey Ferrentino. Amy, un personaj care suferă de sindrom Down, revendică stereotipiile studiilor dizabilităților prin exercitarea unei autonomii, definindu-se nu doar prin dizabilitatea sa, ci și prin experiența sa trăită în urma unor abuzuri. Narațiunea teatrală este atât una a dizabilității cât și una a traumei, încurajând o reflecție nuanțată asupra originii stigmatizării și revelând faptul că teatrul poate fi folosit ca mijloc de rezistență care revendică mijlocirea acestuia prin intermediul spectacolului și care provoacă stereotipiile convenționale despre „dizabilitate”.
To Leap First Down into the Trench:  
*Tristram Shandy*’s Critique of the Wounds of War  

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Abstract

While scholars have mined Laurence Sterne’s *Tristram Shandy* to understand the form and development of the novel as a literary genre, a central narrative element that has garnered significant scholarly attention is Tristram’s troubled Uncle Toby – a veteran of the Nine Years War who bears a mysterious wound in the groin and who is obsessed with understanding war through the construction and use of miniature battle re-enactments. By recognizing Uncle Toby as a central character of *Tristram Shandy* and by contextualizing the novel as war literature, this essay demonstrates that Uncle Toby’s struggles to express his ambiguous trauma suffered as a soldier become a critical commentary on the social structures and circumstances that lead to the experiences of wounded veterans. Situating *Tristram Shandy* in the context of war literature, this article reveals how Toby’s character plays on Enlightenment conceptions of honour and valour as motivators for soldiers. Furthermore, the article argues that applying the theory of Moral Injury (long present but largely unnamed in war literature), rather than the tempting diagnosis of Post-Traumatic Stress Disorder (PTSD), allows for a more holistic understanding of Toby’s critical commentary.

Keywords: moral injury, wounds, soldiers, British army, veterans, *The Life and Opinions of Tristram Shandy*

Uncle Toby’s Wound: Physical, Psychological or Spiritual?

Laurence Sterne’s *The Life and Opinions of Tristram Shandy* is populated by disabled characters: Tristram has his own traumatic birth injury (a crushed nose), caused by Dr. Slop’s forceps during delivery and he also bears a disfigurement from a complication of his circumcision. Corporal Trim carries a debilitating battlefield injury to his knee. Uncle Toby’s war wound in his groin is a central motif throughout the novel. While Tristram makes explicit the nature of his birth injury, and Corporal Trim’s knee injury is also described in straightforward terms, the reader gains little insight into the nature and extent of Uncle Toby’s disability from the novel’s beginning chapters to its closing, despite continual references to his ambiguous wound at every quintessential Shandian digression and narrative turn.

The bodily, psychological and spiritual recovery from war is no side plot of *Tristram Shandy*. Uncle Toby, who is a veteran of the Nine Years’ War and who is obsessed with staging elaborate miniature military events with his companion Trim in order to make sense of the ambiguous wound that he received at the famous Siege of Namur becomes a recurring focus within the apparently erratic form of the novel. Most of Toby’s interjections and many of Tristram’s digressions deal with war, contributing
substantially to the humorous tone of the novel as the reader gradually begins to anticipate them and comes to understand the familial politics and patterns of the eccentric Shandy men. Yet, however humorous the effect of the Shandy men’s obsessions and eccentricities, the reoccurring interjection of war stories into the philosophical discussions of the Shandy men creates a reading experience that is mostly about the topic of war. Practically all subjects that Tristram, William, Dr. Slop or Yourik broach are brought back to wounds, bullets and the methods, moral questions, or beauty of warfare by either Toby or Trim. Toby’s character and his family’s response to his obsession satirize 18th century Britain’s obsession with the narrative of war and its supporting intellectual infrastructure of honour, valour and glory by revealing the moral tension and disappointment of a disabled veteran and his attempts to make sense of his experiences.

While scholars have tended to ‘mine’ *Tristram Shandy* ‘for perspective on the genre of the novel as a whole, and the development of “realism” as the novel’s new defining feature,’ Tristram Shandy’s continuous emphasis on Uncle Toby and Trim’s traumatic military experiences have recently received increasing scholarly attention as central thematic material of *Tristram Shandy*. In his exploration of Toby’s miniature battle scenarios as a cultural precursor to historical re-enactment as a performative genre, Simon During rejects the tempting impetus to apply the diagnosis of Post-Traumatic Stress Disorder (PTSD) to Toby’s troubled condition and ambiguous, multifaceted wound. During instead asserts that Toby’s practice works to satirize larger contradictions of the time: those between ‘Protestant nationalism and European cosmopolitanism, chastity versus libertinage, social participation versus retirement, marriage (for men) versus bachelordom, professionalism versus classical ruling-class *otium*, and the contradictions attached to the notion of modern chivalry at the point at which it is just beginning to underpin the gentlemanly ideal.’ During argues that Toby’s re-enactments engage more broadly with these contradictions, largely dismissing the commentary that Toby’s re-enactments offer on the loss and confusion of personal trauma.

In contrast, in a disability-sensitive reading of *Tristram Shandy*, Anna Sagal positions Toby as ‘a disabled veteran suffering from what modern psychology would term post-traumatic stress’ while at the same time she acknowledges Toby’s character as serving comic and other functions within the novel. Sagal applies trauma theory and the concept of PTSD, arguing that Toby’s practice is necessitated by the central contradiction, or ‘unbridgeable gap’ between the experience of pain and the ability to express the pain in language. One valuable contribution of Sagal’s reading is that it refutes those critics who have tended to see Toby’s re-enactments as ‘nostalgia for days gone by’ and, instead, accepts his Hobby-Horse (the staging of elaborate miniature battles which will be discussed later in this article) as the serious artistic communication of a disabled veteran. However, my criticism of the application of the term PTSD is

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4 Sagal, 111.
5 Sagal, 128.
that it does not thoroughly address the ambivalence of his wound, nor does it take into account what Toby philosophizes about the meaning of his own role as a soldier and the function of his Hobby-Horse.

Sterne wrote in a philosophical context of Enlightenment dualisms, where human existence was being parsed out and divided into body and mind. As Ala Alryyes puts it, dualistic thinking popular during the Enlightenment divorced "what passes in our minds" from our living human bodies.6 In describing Toby’s character and practice, Tristram declares: ‘Vain science! thou assists us in no case of this kind ‒ and thou puzzlest us in every one.’7 Alryyes is critical of the application of psychological terms like ‘trauma, repetition, and compulsion’ to understand Toby’s condition and character, arguing that doing so ‘short-changes the poetics of the novel and glosses over how Sterne’s representation puns on the changing nature of the soul and its science, psychology.’8 With this in mind, I suggest that a reading of Toby’s re-enactments and romantic encounter with the widow Wadman that is more grounded in Tristram’s commentary on Toby's character and Toby’s own commentary about war allows for Toby’s wound to be of the kind that cannot be encompassed by a clinical definition.

In my application of the theory of moral injury, I present Toby’s wound as not merely psychological or physical, both or either, but as a spiritual injury. Toby’s ambiguous wound comments on the contradictory nature and spiritual condition of his world. Furthermore, Toby’s Hobby-Horse works as an artistic ritual practice that represents and allows him to attempt to make sense of the inconsistencies of war from the perspective of a combat veteran. Toby’s primary struggle is to communicate to his family, post-war and back home in the English countryside, the nature and meaning of his injury and war experience. To this end, he turns to eccentric manipulation of miniature war architecture and obsessive study of military terminology. With Uncle Toby’s narrative, artistic expression and ambiguous wound, Sterne articulates several contradictory aspects of warfare and British soldiering during the 18th century and the moral uneasiness between the genial values of English domestic life and the brutality of its emerging warfare state. Uncle Toby must make sense of his physical traumatic experience as much as he does of his experience of being a soldier and the instrument of warfare in the context of the long 18th century.

Toby’s concerns about the techniques, bodily experience and moral implications of war are exemplary and by no means isolated. Uncle Toby’s obsessive descriptions of battles and sieges, as well as his philosophical justifications for and heavy-hearted reflections on the effects of war echo treatises on war published during the mid to late eighteenth century. Given that warfare is a defining context for this novel and a central cultural and technological characteristic of the eighteenth century, Toby becomes not an eccentric character with a strange, personal Hobby-Horse, but, as Alryyes argues, ‘a representative man,’ where Uncle Toby’s ‘war-mindedness only echoes the war-mindedness of European culture and knowledge in the long eighteenth century, where history cannot be separated from accounts of perpetual state wars and where science is intermingled with war science.’9 In the same way that Toby’s technological obsession

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8 Alryyes, 1119.
9 Alryyes, 1100.
with war is exemplary rather than eccentric, his pondering of the moral implications of war is exemplary.

**Uncle Toby as the Morally Injured: The Paradox of Soldiering in the 18th Century**

Tristram continually paints his Uncle Toby as having a gentle nature, but couples this gentle nature with Toby’s fetishistic obsession with the movements, objects and physical characteristics of sieges as elaborately staged violence. Bullets follow trajectories, launched out of firearms in order to kill or wound. And fortifications exist as implements for armies and individual agents to mangle bodies and take lives. His obsession with the implements and actions of war designed to do harm to human bodies complicates his consistent ethic of avoiding unnecessary or unjust harm. Tristram tells us that one incident of Toby revealing his nature left such an impression on him that it is the origin of Tristram’s own attitude of general benevolence. Tristram tells us that Toby is surely a man of courage, but ‘he was of a peaceful, placid nature,’ to the extent that he ‘scarce had a heart to retaliate upon a fly’ (*TS*, 100). In this remembered incident at the dinner table from Tristram’s childhood, Toby is harassed by a buzzing, overgrown fly, and Toby’s response is ‘I’ll not hurt thee...I’ll not hurt a hair of they head’ and ‘go poor Devil, get thee gone, why should I hurt thee? – This world surely is wide enough to hold both thee and me’ (*TS*, 100). Toby does not try to justify hurting such an insignificant, mindless animal; he sees no need to. Killing this fly would be meaningless and purposeless. This haphazard incident distils Toby’s entire character for Tristram. He includes it in his narrative as illustrative of Toby’s true nature. Yet, Toby is sent to such a bloodbath (the Nine Years’ War) based largely on expansionist ideologies and rivalries between European dynasties.

Uncle Toby’s contradictions become indicative not of Sterne painting the character of an isolated eccentric but of contradictory views surrounding soldiers and the British Army during the long 18th century. Toby both holds to the ideals of honour and of individual responsibility and is attracted to the destruction, pain and senselessness of the near-global warfare of the 18th century. Toby is so full of honour that he will even take the high road in not hurting an annoying fly, but, as a soldier, he loves war. This paradox reflects civilian tensions surrounding soldiers of the 18th century, where soldiers were simultaneously celebrated as symbols of national pride and honour and treated with suspicion and contempt as brutish, hyper-masculinized lovers of violence.10 Uncle Toby’s status as both excessively emotionally affected, polite and compassionate (honourable) and obsessed by the instruments of war echo the famous conception of soldiers being both the ‘scum of the earth’ and ‘fine fellows.’11

Joshua Daniel, a scholar in ethics and religion, outlines the basic premises of the concept of moral injury, which exists most often in conversations about veterans: ‘The basic idea is that, in combat, soldiers harm their own moral capacities by committing or participating in acts that they understand to be morally repugnant,’ noting that although the term is relatively new, the concept certainly is not. He explains,

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11 Linch and McCormack, 2.
In other words, ‘moral injury’ names a phenomenon that the fallout of recent wars has forced in front of us, but which itself is a perennial feature of moral life: all moral agents are vulnerable to committing or participating in acts they affirm to be morally repugnant. If this is true, then we can expect the history of moral thought to include discussions of moral injury, even as the term itself remains unused.\footnote{Joshua Daniel, ‘Moral Injury and Recovery in the Shadow of the American Civil War: Roycean Insights and Womanist Corrections’, \textit{American Journal of Theology and Philosophy} 2 (2016): 151.}

Daniel notes that much of the discussion on moral injury has been in defining it as distinguishable from ‘psychological and psychiatric diagnoses.’\footnote{Daniel, 154.} Contrasting moral injury and PTSD, he explains that both soldiers and the communities that created a set of conditions in which they were sent to war are affected by such a wound, since individuals were asked to/required to participate ‘in acts that they understand to be morally repugnant’ and they fail to re-enter the larger civilian community after returning home. And, importantly for Uncle Toby, ‘moral injury is a violation of one’s own moral agreement with one’s own inner moral world.’\footnote{Daniel, 154.}

The moral difficulties faced by British soldiers of the 18th century, although not named as ‘moral injury,’ lie directly under the surface of war writings published contemporaneously with \textit{Tristram Shandy}. The intellectual and cultural infrastructure of the Enlightenment tied abstract concepts such as honour and valour to the actions of the soldier, although Soldiers were also subject to scrutiny by civilians.\footnote{Linch and McCormack, 1.} One artefact revealing the intellectual infrastructure of Enlightenment England that justified the morality of war which contextualized the publication of \textit{Tristram Shandy} is \textit{Essay on the Art of War}, published in London in 1761.\footnote{A. Millar, \textit{Essay on the Art of War: In which the General Principles of All the Operations of War in the Field are Fully Explained: The Whole Collected from the Opinions of the Best Authors} (London: A. Millar, 1861).} The collection compiles short chapters on many of Uncle Toby’s favourite military subjects, targeted in the paratext towards young officers and those new to service:\footnote{Millar, vii.} defences, passages and (of course) sieges.

While this work anthologizes essays on such technical aspects of war, the first order of business is to discuss the moral implications of warfare. The starting chapters include sections on honour, valour and the moral questions of warfare, revealing a contradiction similar to the one that Toby laments. While honour is defined in terms of universally-admired actions with undiluted intentions, the reality of war – that it is the agent for direct harm on other human beings, as well as indirect harm on families and communities by proxy – is not a hidden subject but treated upfront. While soldiers with valour act as agents of necessity and do not hurt those who are considered unable to fight back (children, women, old men, etc.), \textit{Essay on the Art of War} notes ample contemporary violations of this code of honour: ‘The Civil Wars of England, Germany, France, Savoy, the Netherlands, the Conquests of the Spaniards in America, present us at every instant with Monsters, whom a Man of Honour ought to abhor. We cannot read without Horror the Wars of Hungary in the last Century. What Inhumanities have we not seen committed in our own? In Bavaria in the late War? In Pomerania in the present?’\footnote{Millar, 4.} The ideals of valour and honour are just that – ideals, which give way in the midst of war and are quite evidently not upheld by all agents of war to begin with.

The preliminary section titled simply ‘Of War’ reveals the essential
characteristic of war, that it is about killing and injuring fellow humans on the field of battle. The text quickly turns to a justification for war, which is portrayed as both utterly unnatural and entirely necessary: ‘[w]ar, considered in its Effects, is of all human Actions the most terrible and the last natural: To pillage, burn, plunder, abandon all to the Fury of Arms, to strike, kill, massacre Men, our Fellow Creatures, who never did us Harm, what Madness? what Fury? But, however unnatural, however horrible, War is often a necessary Evil, which cannot be avoided.’

The central content of war (injuring and killing) ‘slips from view,’ and the goal of one body being sent to battle to damage another body is quickly glossed by the intellectual infrastructure of ‘necessity’ and through language that places emphasis on collective action rather than individual action. War, the author explains, is not the action of individuals killing other individuals, but the ‘action of armies’ maintained by sovereigns, with the goal of defending national values, resources and religions. This chapter moves quickly between seeing individual soldiers as agents of war and monarchs and political figures as the actors controlling warfare. Like Uncle Toby, Essay on the Art of War acknowledges this essential contradiction – that war is enacted for good, but begets ill – at the forefront of its treatment on war. Uncle Toby celebrates and physically re-enacts war at the same time that he mourns the loss, fear and physical and psychological harm that it begets.

Tristram Shandy exemplifies a similar tension between war as a collective action and war as an action of individual soldiers. When Tristram begins a new book to explain Toby’s Hobby-Horse, he talks in broad historical terms about the Siege of Namur. He reminds the reader, ‘In case he has read the history of King William’s wars,’ that its actors are ‘the English’ and ‘the Dutch,’ and its settings ‘the gate of St. Nicolas’ or ‘the demi-bastion of St. Roch’ (TS, 70). The actors are, for the most part, kings, nations and leaders of armies, spread out and moving on maps in sterile, broad strokes. A single army becomes ‘a single gigantic weapon.’ This type of abstractive style that veils the existence of the individual human body has long been an idiomatic element of war writing, where war’s actors morph into ‘a mythology of giants lumbering across rivers and stalking through forests.’ In contrast, the individual soldier’s relationship to war, as well as the essence and ambiguity of moral injury, are suggested in Uncle Toby’s eloquent ‘Apologetical Oration’ in which he explains his reasons for wishing the war to go on longer and relates those reasons to his Hobby-Horse. The oration is framed as describing his reasons for regretting the peace that was achieved with the signing of the Treaty of Utrecht. In this speech, war begets the beauty of narrative – of the Iliad and the sentiment and painful beauty created through the context of war. Here, Toby reveals an irresolvable contradiction. War, in all its misery and destruction, begets beauty. Without the long and nonsensical siege of Troy, readers cannot mourn for Hector, which, to him, is beautiful. For Toby, this belief (or acceptance of such an obvious yet troublesome truth) is to be hidden and revealed only to kin, whose loyalty prevents initial rejection or categorization of this belief as ‘evil’ or ‘bad.’ Toby recognizes that his simultaneous attraction to and recognition of the ill of war is nonsensical. Similar to the conception of soldiers as both the agents of justice and scapegoats for powerful

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18 Millar, 6.
20 Scarry, 6.
21 Scarry, 8.
22 Scarry, 8.
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oppressors, Toby’s is a contradiction that cannot be resolved.

Toby identifies the traditionally-ascribed meaning of warfare as he continues his oration: an individual soldier is honourable and brave, and the underlying myth is that individuals fight ‘from public spirit and a thirst of glory’ (TS, 415). Soldiers ‘march bravely on with drums and trumpets, and colours flying about his ears’ (TS, 415). From here, his oration takes a sharp turn into melancholia. The illusion of this grandeur of war that he has described is shattered by experience, where excitement morphs into terror and where knowledge of glory is not worth the price that has been paid to gain it. Toby’s sharp caveat to his attraction to war is as poignant an encapsulation of the moral disappointment and individual experience of war as any: ‘—‘Tis one thing, I say, brother Shandy, to do this, ’or to reflect on the honour of warfare and the bravery of the soldier, ‘—and ‘tis another thing to reflect on the miseries of war;—to view the desolations of whole countries, and consider the intolerable fatigues and hardships which the soldier himself, the instrument who works them, is forced (for sixpence a day, if he can get it) to undergo’ (TS, 416). And, significantly, the ‘instrument’ acting in this scenario is neither a bullet, nor a king, or a country, or the designers and builders of fortifications – but the average foot soldier. In the end, he is the one who operates the rifle or cannon and marches to his own death. He is ‘forced to undergo’ these circumstances that he himself works, becoming both the subject and object of war.

Ascribing a different meaning to this irresolvable contradiction, Toby positions individual soldiers as ministers of necessity. War is certainly an unnatural activity, because (quoting Yorick), ‘so soft and gentle a creature, born to love, to mercy, and kindness, as man is, was not shaped for this.’ (TS, 416) Yet, war is a necessity enacted by those individuals who are ‘quiet and harmless people, with their swords in their hands, to keep the ambitious and the turbulent within bounds.’ (TS, 416) Soldiers come together at specific times and places to do what they need to do for their larger communities: a form of ministry, that is, performing ‘An act of ministration, a task or service; a function, role, or office.’

Toby understands his Hobby-Horse as representative of the necessity and beauty of war. He ends his oration with a justification not for the continuation of war – but by relating the rationale for his Hobby-Horse, saying ‘And heaven is my witness, brother Shandy, that the pleasure I have taken in these things,—and that infinite delight, in particular, which has attended my sieges in my bowling-green, has arose within me, and I hope in the corporal too, from the consciousness we both had, that in carrying them on, we were answering the great ends of our creation’ (TS, 416). He sees his military re-enactments as a part of the ‘great end of our creation,’ as answering a call to ministry, or the call to take on and carry this role of the soldier as literal role-play and, in turn, use it as a means of healing.

Toby explores the role of a soldier through his Hobby-Horse, which becomes for him a spiritual practice, where spirituality is a ‘a search for meaning and significance by contemplation and reflection on the totality of human experiences in relation to the whole world which is experienced and also to the life which is lived and may mature as that search proceeds.’ Even though the practice began as a way for Toby to revisit a

23 Linch and McCormack, 1.
24 The Oxford English Dictionary provides several useful definitions of this word, which is most obviously linked to religious offices, but also connotes agency and instrumentality, where an actor functions to fulfill a role that has been established by an agent beyond themselves.
moment in his own past, it is important to note that Toby’s Hobby-Horse develops into
a means to organize and represent warfare and the history of a soldier and his role more
generally. PTSD-centred theories about the role that the Hobby-Horse plays have
difficulty encompassing its evolving nature over the course of the novel. Accepting
Toby’s loss as ambivalent and contradictory and taking Toby’s understanding of his
practice into consideration enables a more seamless, evolutionary understanding of
Toby and Trim’s later practice of ‘re-enactment’ of events that are, for them, currently
ongoing. Toby’s oration suggests that it is not only about revisiting their own traumatic
experiences of war, but also about making sense of, representing and experimenting
with the larger geopolitical and technological world and their place in it.

Hobby-Horses (the Shandian vocabulary term Tristram introduces early in the
novel to describe and theorize about leisure activities) work in a mysterious way to
reflect the nature of their riders. In his explanation on how Hobby-Horses function,
Tristram sees the relationship between body and soul as an imperfect but usable
metaphor. The language of Hobby-Horses is markedly physical, if not sexual, where
‘the heated parts of the rider, which come immediately into contact with the back of the
HOBBY-HORSE. –By long journies and much friction, it so happens that the body of the
rider is at length fill’d as full of HOBBY-HORSICAL matter as it can hold’ (TS, 67).
While there is a clear distinction created between the rider (a man) and the inanimate
object or idea (the Hobby-Horse), the relationship between the two entities (rider and
Hobby-Horse) is blurred to the point that distinguishing between action and reaction is
impossible.

In anthropologist Mark Auslander’s study of African American re-enactment of
past traumatic community events (slave auction and lynching re-enactments), he
demonstrates a similar collapse of the conventional distinction between subject and
object, where actors taking on ‘roles’ through their interaction with objects allowed
participants to establish the mere simulacrum of the event as real.26 Toby and Trim’s
constructions in the bowling-green may also be described as simulacrums, where the
essential elements needed to understand the situations (battles) in question are present
and symbolically manipulated. Yet, these simulacrums are functional for Uncle Toby.
They fulfil their purpose, despite their evident strangeness. And, as Tristram explains,
‘In good truth, my uncle Toby mounted him with so much pleasure, and he carried my
uncle Toby so well, —that he troubled his head very little with what the world either
said or thought about it’ (TS, 68). Toby’s Hobby-Horse serves him well as a leisure
activity: it allows him to have fun, while also serving a significant cognitive and
emotional function.

Alex Solomon situates Toby’s re-enactments as not only illuminating Toby’s
suffering, but also evoking a replacement of ‘first-person narrative realism’ that, ‘for
Toby and for writers and readers of novels, obviates the burden of situating local facts
within larger events.’27 But the ‘facts’ that Toby is trying to represent go beyond the
nature and origin of his own wound and seem to extend toward a broader understanding
of what Toby suggests in his Apologetical Oration. As I have noted above, in that
speech, as transcribed by his brother Walter, he presents the role of the soldier as
ministerial and necessary and his practice on the bowling-green stems from this
understanding. In ‘carrying on’ these military engagements as mimesis, he has ritualized

26 Mark Auslander, ‘Touching the Past: Materializing Time in Traumatic “Living History”
27 Solomon, 269-70.
military conflict and the role of the soldier in the context of his domestic world: the garden.

Certainly, the origin of the Hobby-Horse is to bring Uncle Toby relief from his ambiguous wound; in fact, this seems to be the only thing that is able to do so. However, Trim and Toby’s practice seems to evolve far beyond the initial need to relieve the psychological pain surrounding the inability to communicate about his wound and into a mimesis of another kind, which comments on the larger world of the characters. As Stuart Sherman notes, Toby and Trim’s practice on the bowling-green is foreshadowed by Tristram’s commentary, where he warns that the ‘Search of Truth’ is endless (TS, 112). And like Tristram, Toby ‘quickly becomes busied and dizzied with infinitudes,’ where ‘the shift from words to maps is only the first step in a carefully elaborated sequence.’ While Tristram turns to his narrative, for Toby, ‘the micro-reconstruction of a defining autobiographical moment now long past – gradually metamorphoses into something very different,’ which eventually leads to re-enactments of not the past conflicts of the Nine Years’ War, but ‘battles currently passing and to come.’ While the reader initially is introduced to Toby as a convalescing physically disabled veteran, it quickly becomes evident that his mysterious wound extends far beyond the physical.

These re-enactments of contemporary events rely on information gained not only from study of military tactics, implements and the principles of motion, but also on information sourced from the texts that civilians would read about the country’s ongoing military engagements and ‘by the accounts my uncle Toby received from the daily papers, – they went on, during the whole siege, step by step with the allies’ (TS, 401). Their practice becomes a way not only to (re)gain access to the past, but also to represent the present. More specifically, to represent the motions, movements, and physical characteristics of these events, transposed into a distinctly domestic setting, or ‘betwixt two rows of his cabbages and his cauliflowers’ (TS, 401).

In the quest to bring order and meaning to the ambiguity and pain of Toby’s wound and experience, these re-enactments take on distinct ritualistic aspects. As Ronald Grimes explains, ‘[w]hether conserving or transforming, rituals model actions into paradigms that wrap ideas and values in a blanket of feeling and multisensory experience.’ Grimes asserts that this occurs through artistic activity, or, ‘the process of imaginative world-making. Whether performative, plastic, literary, visual, or digital, art transforms what is into what it might be.’ Like any functional Hobby-Horse, these rituals work through imagination, to make real what is not, which is, as Auslander notes, a process through which simulations and ritualistic objects allow for a ‘return to the prelinguistic domain of “the real” which is normally closed to us as adults.’

After Trim initially and humbly suggests that they improve their mimesis by going ‘into the country,’ where he would ‘work under your Honour’s directions like a horse and make fortifications for you something like a tansy,’ Toby responds with childlike, pure enthusiasm for the idea (TS, 86). He agrees to the plan, with a ‘blush as red as scarlet as Trim went on;—but it was not a blush of guilt,—of modesty,—or of

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28 Sagal, 112.
30 Grimes, 315.
31 Grimes, 315.
32 Auslander, 163.
anger,—it was a blush of joy' (TS, 86). Although Trim takes on a distinct secondary role in the relationship that is represented by Sterne as almost mentorship-like, Toby and Trim are of the same mind on this matter. Toby is pleased that his servant appreciates what he is trying to do through these ritualized performances; his specific suggestion to improve the re-enactments here demonstrates that Trim understands their larger goal as artistic representation of warfare.

Trim does not even have to finish the explanation of his suggestions for how to improve the re-enactments before Toby interjects with approval. Toby responds to Trim’s suggestion by cutting him off with ‘thou hast said enough,’ meaning that he is sure that they are of one mind about what the improvements will bring to the Hobby-Horse. Trim continues with the explanation that they can ‘begin the campaign…on the very day that his Majesty and the Allies take the field and demolish ‘em town by town’ (TS, 86-7). Toby cuts him off with the command to ‘Say no more’ and an assurance that he understands full well what this means. While this exchange may suggest a kind of annoyance at Trim’s characteristic talkative presentation of these possible details for the improvement of the Hobby-Horse, it reveals Toby’s overwhelming joy at the thought of these possibilities in the country bowling-green. They go out into a place set apart for these ritualistic endeavours to perform their spiritual work of understanding warfare as ‘answering the great ends of our creation,’ but also for the pure joy gained from doing so.33

Interestingly, Grimes notes that rituals very often beg outsiders to wonder and inquire about the meaning, purpose and motivation behind them. For instance, Sagal even theorizes that Toby’s ritualistic pipe-smoking has a specific, identifiable and even reasonable purpose: it serves as a method of ‘avoidance of confrontation or stressful situations,’ where ‘[t]he recourse to his “social pipe”, too, becomes a method of avoiding conflict and a way of communicating certain emotions through the manipulation of objects – a companion behaviour to his hobby-horse.’34 Yet, as Grimes also comments, answers from practitioners of rituals, when approached by inquirers, are typically along the lines of ‘Because we enjoy it….Because we feel better.’35 While several scholars are now tending to characterize Toby’s condition as akin to post-traumatic stress disorder and his Hobby-Horse as a ritualization of trauma rather than a nostalgic, masculine return to Toby’s glory days as a soldier,36 Uncle Toby and Trim’s re-enactments also serve an obvious comic function in the novel in the context of the near-constant, global warfare involving the British army during the eighteenth century. During this time, soldiers and veterans appeared frequently in literature and developed as both sentimental and comic stock characters to be ridiculed or pitied.37 If Toby and Trim’s re-enactments work as an exaggerated, comical representation of British veterans, they only further demonstrate the tensions surrounding soldiers and the

33 In this way, the Hobby-Horse serves as a kind of fetish in its Enlightenment context—religion—through which non-Western religions which collapsed the traditional distinction between subject and object (the fetish object) were seen as irrational and primitive (McCallum, 109).
34 Sagal, 118.
35 Grimes, 229.
36 In addition to Sagal’s disability-focused reading of Tristram Shandy, Fiona Reid in Broken Men: Shell Shock, Treatment and Recovery in Britain 1914-30 (London and New York: Continuum: 2010) also points to Tristram Shandy as offering an important and serious literary representation of the “old soldier” and suggests his condition is representative of what came to be called ‘neurosis’ or ‘shell shock.’
inability of civilians to understand the needs of disabled serviceman.

Toby and Trim’s imaginative world-making resembles ritual, but also play. In their private world of the garden, Toby and Trim arrange objects and implements, physically interacting with them in a way that allows them to ‘lose themselves’ in the work. In this way, the pain of the injury is relieved. They intently plan for, design and build their fortifications and other features to accomplish their end. They engage in specific, technical processes, such as taking ‘the profile of the place, with its works, to determine the depths and slopes of the ditches, –the talus of the glacis, and the precise height of the several banquets, parapets’ (TS, 400). Toby puts ‘the corporal to work’ yet the work is immensely enjoyable, so much that ‘sweetly went it on’ (TS, 400). Tristram even provides readers a clue into why this work was so enjoyable and these are as simple and wholesome as bodily interaction with the soil and the kind conversations and shared history between the two men. The work, which evidently spans from dawn to dusk, ‘left LABOUR little else but the ceremony of the name’ (TS, 400).

Scholars of historical re-enactment and leisure studies often refer to this experience of rapture as ‘authenticity,’ which occurs with bodily and psychological investment in an activity. In this way, rituals operate as play, where participants are simultaneously keenly aware that what they are experiencing is, in fact, not real and yet, through interaction with objects, they allow the objects to act on them in such a way that they have an emotional response that is ‘real’ or ‘authentic.’ As Auslander explains, the conception of physical objects as emotionally powerful is ‘what structural anthropologists have long termed structural operators, allowing for dynamic exchange between the present and the past, and between the living and the dead.’ It is such an experience of authenticity that is valuable to Toby as a method of ministry to his ambivalent wound.

In short, it is no small incident that Tristram’s guiding metaphor for the concept of Hobby-Horses involves a child’s toy. Quite obviously, imagination and play are central to the practice of Toby and Trim. Helene Molgen, in *The Trauma of Gender: A Feminist Theory of the English Novel*, positions the Hobby-Horse as a method of resolving the Shandian ‘inherited impotence and lack.’

All the hobby-horsical activities of the men-Toby’s war games, Walter’s theories, Tristram’s autobiography, Yorick’s wit, Trim’s inventions – are forms of play which help the self to assimilate instead of accommodating to the undeniable otherness of the real world. They are transitional practices, in D. W. Winnicott’s sense, which allow inner and outer realities to be maintained as separate yet interrelated.

Molgen’s reading of the Hobby-Horse as play incorporates fetishism to describe its function, but relies on a more traditional (male-centered or lack-centered) arrangement.

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40 Auslander, 162.
42 Molgen, 58.
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of the essential tenets of fetishism, where ‘An imitation horse’s head mounted on a stick
that fits between its rider’s legs, the Hobby-Horse enables children’s mimicry of
power...A fetish object, the Hobby-Horse disguises and discloses the fear if not the
actuality of castration.’ 43 However, Molgen’s ordering of the subject-object relationship
centres around characters manipulating the objects, not the blurred type of relationship
between Hobby-Horse and rider that Tristram establishes and is reflected in Toby’s
practice.
In her discussion of the functionality of fetishism, Ellen McCallum notes that
such a blurring of the subject and object relationship was taken as a sign of irrationality
during the Enlightenment. 44 McCallum asserts that ‘fetishism inappropriately bridges
the gap between subjects and objects by disregarding the injunction that relations to
objects should be rational and unclouded by emotion while only relations to subjects
can be passionate or loving.’ 45 As such, it works to critique the concept of ‘reason,’
because it ‘contaminates knowledge with belief, dispassion with desire, defiling
philosophy’s epistemological ideals...more than a deviant form of desire ‒ it is a deviant
form of knowledge.’ 46 Despite his family’s negative reaction to his re-enactments,
which are framed as a departure from ‘cool reason and fair discretion’ (TS, 83), they
function to bring relief to Toby. The Hobby-Horse, Tristram tells us, is (almost) sexual,
since ‘Never did lover post down to a belov’d mistress with more heat and expectation,
than my uncle Toby did, to enjoy this self-same thing in private’ (TS, 88). In an effort to
make sense of and minister to his multi-faceted disabilities, Toby turns away from
reason and to the realm of ritual and artistic expression through his Hobby-Horse.
Certainly, such a function (blurring the lines between subject and object, or producing
an alternative form of knowledge through imaginative, child-like ‘play’) is the means
through which Toby finds relief, even though he cannot resolve the contradiction of his
beliefs and experiences, but only minister to them, memorialize them and ritualize them.

The Pain of Misunderstanding
One key element of moral injury is the struggle of the soldier to be understood by those
who were safe at home when the circumstances for the injury occurred. Toby’s
philosophy-minded brother Walter (who, we learn early on in novel, was safe in London
while Toby was away at war) echoes, or warps, elements of the Apologetical Oration
near the close of the novel, where he opines: ‘—The act of killing and destroying a
man...is glorious—and the weapons by which we do it are honourable⸺We march with
them upon our shoulders⸺We strut with them by our sides⸺We gild them⸺We carve
them⸺We in-lay them⸺We enrich them⸺Nay, if it be but a scoundrel cannon, we cast
an ornament upon the breach of It.—’ (TS, 587) These comical lines suggest that Walter
is trying to understand what his brother has been telling him, but he cannot quite do so.
He repeatedly fails to understand or even demonstrate respect for his brother’s HobbyHorse throughout the novel. 47 Walter has the right characters and agents ‒ the foot
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Molgen, 59.
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McCallum, 109.
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McCallum, 109.
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Tristram continually reminds his readers that the bizarre nature of the Hobby-Horse is a kind of
embarrassment or contention between his uncle and father: ‘My father, as you have observed, had no
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soldiers and firearms of Toby’s own orations — but the wrong arrangements of ideas. Walter fails to grasp the essential ambivalence that Toby is grappling with and his psychological need to make sense of his experience as a soldier.

It is clear that Walter does not quite understand what Toby is trying to explain about his Hobby-Horse. As Daniel notes in his discussion of Moral Injury and womanist strategies for societal recovery from such injuries: ‘some evil can only be endured, not triumphed over, and so demands a ministerial form of response. Moral injury is such an evil.’ Whatever this evil that makes war a ‘necessity’ to be executed by soldiers cannot be eliminated, only ministered to. Toby’s Hobby-Horse is a continual practice that allows him to endure and bring relief to his injuries, not cure or eliminate them. Toby’s physical disability is certainly ambivalent; and the nature of his psychological disability is equally hard to put into words. However, what is clear is that there is a significant lack of communication and understanding between Toby and Walter and also a marked ambivalence on Toby’s part about how he feels about warfare and the role of a soldier within his larger world and within the larger narrative of war.

Tristram’s plans to write what readers anticipate as early as the third volume (his Uncle Toby’s amours) finally culminate in the last two volumes, which relate, in a fairly straightforward manner, Uncle Toby’s short courtship with the widow who lives next door to his estate. From the opening chapters that slowly piece together Toby’s character and experience, his long convalescence as a wounded veteran, the origins of his hobby of creating miniature battles in his backyard garden and Tristram’s continuous hints that the amours of Toby and the widow Wadman will be the best part of the novel prime the reader to pay special attention to the ambiguity of Toby’s wound.

The purposeful ambiguity of Toby’s wound to the groin draws continual attention to the cause of his disability. His mission throughout the novel is to represent and communicate the exact geographical location where he received the wound and spatially and mathematically understand the circumstances that led to it. But the larger circumstances that led to his wound and possible disability take place at the intersection of his identity as an honourable soldier of the British Army and the development of the art of war in the long 18th century. The doubt and contradiction surrounding Uncle Toby’s wound are the subject of the last two chapters of the novel centring around Toby’s amours with the widow Wadman, which Tristram labels as the kind of chef-d’oeuvre of his narrative several chapters before presenting it to his readers and critics.

The widow Wadman’s attraction to Toby as a soldier and as a potential marriage partner comically mimics the phenomenon of ‘Scarlet Fever,’ or the preference of British women for military men. Aside from the attraction of women to the stunning scarlet uniforms of British soldiers, military activity in a domestic setting brought excitement to 18th century women’s otherwise quiet lives. As Carter notes,

Having large numbers of men quartered throughout the nation, who hosted and attended balls in their glittering ball-uniforms, engaged in mock battles, strode about the parade ground or marched through the streets with the boom of the military drum literally reverberating through the bodies of spectators, all brought novelty, diversion, gossip, spectacle and the possibility of a romantic adventure or flirtatious fantasy into women’s
great esteem for my uncle Toby’s obby-horse; he thought it the most ridiculous horse that ever gentleman mounted’ (TS, 189).

48 Daniel, 152.
49 Louise Carter, ‘Female Enthusiasm for Men in Uniform, 1780-1815’ in Britain’s Soldiers: Rethinking War and Society, 1715-1815 (Lancaster: Liverpool University Press, 2014): 156.
Women were portrayed as appreciating and seeking out military drills as sexualized spectacles and were also seen as willing participants and instigators of sexual liaisons with visiting soldiers rather than simply being seduced by more sexually experienced soldiers. Thus, the widow Wadman’s amorous attack and attraction to observing Toby and Trim’s miniature military enactments in the garden comically mimic ‘scarlet fever.’ Tristram observes that the widow is pleased that she ‘could observe my uncle Toby’s motions, and was mistress likewise of his councils of war’ (TS, 501-2). The widow and her servant Bridget plot to increase communication and encounters between themselves and the two soldiers.

In addition to satirizing the phenomenon of ‘scarlet fever,’ Toby’s much-anticipated amours with the widow Wadman draw further attention to the ambiguity of Uncle Toby’s wound and the multi-faceted experiences of a disabled veteran of the British army. The reader is left to wonder to what extent his disability is manifest physically and to what extent it is manifest as psychological. The widow seems more concerned with Toby’s physical disability than his psychological disability or moral recovery from his experience of war, even though these less ‘visible’ disabilities have a greater impact on Toby’s actions throughout the novel, as manifest in his obsession with reconstructing and representing the narrative of war. Uncle Toby’s status as a potential mate for the widow Wadman is complicated not only by the question of his physical disability, but also his psychological disability and subsequent obsession with making sense of his war experiences.

The story of Toby’s amours with the widow Wadman are obscene in the most basic sense; the words on the page prompt the reader to continually imagine the character’s genitals and picture both whole and disabled penises, as the widow Wadman does. The widow Wadman’s obsessive quest to uncover the extent of damage done to Toby’s groin and the nature of the injury is ultimately disappointed. Her servant, Bridget, finds out from Col. Trim that the wound is not as severe as it was rumoured to be: ‘—Upon my honour, said the corporal, laying his hand upon his heart and blushing, as he spoke, with honest resentment—‘tis a story, Mrs. Bridget, as false as hell’ (TS, 581). As Toby begins to fall in love with the widow, citing her great care and ‘tender inquiries after my sufferings’ (TS, 584), Trim must dutifully inform Uncle Toby that the widow has been inquiring about the place on his body where the wound is located, rather than the place on the ground, or the exact geographical location at the Siege of Namur where the damage was done and where his experience of war culminated in a bodily wound. After Trim informs Toby that the widow’s interest stems only from her curiosity about his sexual ability, the joke is ultimately on the widow, because Toby no longer wants to marry her after discovering her obsession with his genitals.

Toby’s revelation that the widow Wadman is not interested in his story so much as his sexual function comes as a shock to him, and he is left speechless. His response is a long, quiet whistle, and the gentle placement of his pipe near the fireplace, ‘as if it had been spun from the unravelings of a spider’s web—’ (TS, 585). The pain born of this communicative failure between Toby and the widow Wadman adds to the theme of failed communication that has characterized Toby’s relationship with his brother William throughout the novel. Toby’s confusion is not only in the widow Wadman’s

50 Carter, 161.
51 Carter, 167-8.
sex-obsessed, fetishizing of Toby’s military masculinity and status as a potential marriage partner, but also that he entrusted her with his war narrative that he treats as the definitive moment of his life, yet she did not grasp its importance. What he wanted to communicate about himself is rejected by her in lieu of seeking information about his physical condition. Toby has been trying to make sense of his experience of war for years and through various means throughout the novel and finally he believes he has secured a confidant — a woman — and hopes to share this experience with her, however fractured and hard to understand it is. But the widow Wadman is not genuinely interested in his narrative at all; her concerns are merely domestic and contractual and also resonate with contemporary disability studies conversations about the perception of disabled men as impotent, unsuitable as sexual partners.\textsuperscript{52} His psychological disability and the reason behind his obsession with the narrative of war remain hidden for the widow Wadman. For her, the disability that is concerning is physical in nature and can be overtly identified as posing a problem, or not, for a potential marriage. The widow Wadman’s blunt approach to Toby’s disability as being merely physical in nature undermines the multifaceted, hidden nature of Toby’s disability and further critiques the tendency of civilians to misunderstand the needs and experiences of combat veterans.

Ultimately, while Trim informs the widow Wadman that Toby’s physical disability is not so severe as she and Bridget had feared and would not be a hindrance to his technical sexual performance, it is clear that the damage to Toby’s moral and psychological life is still smarting. While the extent of his physical disability is the central concern for the widow Wadman, Toby’s intense need and inability to understand and communicate the circumstances of his wound and the definitive traumatic moment in which he received it ultimately affect his sexual and marital statuses more significantly than his physical wound. In short, Toby’s amours with the widow Wadman reveal how holistically tied Toby’s physical and psychological disabilities are. Although communicating how and where he received his groin injury at the Siege of Namur is the external motivator for Toby’s intensive communications with the widow Wadman, given the context of Toby’s artistic and philosophical exploration of war throughout \textit{Tristram Shandy}, his need to communicate with her exposes his continued debilitating moral and psychological condition.

\textbf{Uncle Toby’s Wounds and The Soldier’s Tale}

Uncle Toby’s physical wound and moral injury combat the spirit of science that made its way into 18\textsuperscript{th} century views on warfare as well as its techniques.\textsuperscript{53} Many scholars have pointed to Toby’s un-linguistic or pre-linguistic turn as a methodology to understand his experiences. In contrast to published technical, hypothetical, theoretical and geometrical approaches to war that Toby refers to while recovering from his wound, Toby and especially Trim, turn more prominently to trying to dissect war as a narrative. Toby and Trim verbally tell their war stories as much as they physically and spatially try to represent their experiences. Toby’s Apologetical Oration, in particular, accentuates the attraction to war in terms of story and epic, representing a turn away from science and precision and into the realm of the qualitative, of art and human


expression. The Apologetical Oration stands out as one of the most straightforward sections of the novel, although his view on war is notoriously ambiguous and almost entirely avoids technical language and instead turns to literary references about war. Toby reveals the appeal of war as adventure and narrative and also the subsequent sorrow or even anti-climax reached when real knowledge of war is gained. This paradox is a recurring theme in war literature and this is the issue at the heart of Toby’s pain and confusion about his experiences.

While scholars have pointed to a number of contradictions that are evoked and emphasized both by the form that Tristram’s narrative takes and by Toby’s hobby, Solomon centralizes ‘the fraught mediation between event and representation,’ meaning that the problem of language is what Toby and Tristram ultimately share, making Toby’s Hobby-Horse akin to the narrative form used by Sterne. Furthermore, both Toby and Tristram try to place and understand the individual in their context and history. Perhaps this is why Tristram writes a book about himself that is really about his family and why Toby attempts to understand his wound through the larger structures and implements of war.

Certainly, ‘the history of a soldier’s wound beguiles the pain of it’ (TS, 69). Telling the story of his wound brings relief to Uncle Toby only to the extent that his story is understood and taken seriously by those to whom he tells his story. Tristram Shandy continually forces the reader to doubt the nature of Toby’s wound--and if there really was a loss at all. As Sagal explains, ‘the reader can neither know nor acknowledge Toby’s pain... the exact nature of Toby’s injury remains a much speculated-about mystery: an ambiguity that only points to Sterne’s deliberate embodiment of Toby’s disability as traumatic and life-altering.’ However, given that warfare is such a defining context for this novel and a central cultural and technological characteristic of the eighteenth century, Toby becomes not an eccentric character with a strange, personal Hobby-Horse, but, as also Alryyes argues, ‘a representative man.’ Toby’s world is one where the soldier bears much of the weight of the injury and the knowledge of the ‘truth’ about warfare, but a lack of understanding of the nature and extent of its wounds is clearly shared by all.

Bibliography


55 Solomon, 273.
56 Sagal, 118.
57 Alryyes, 1110.

**A sări înaintea tuturor în tranșee.**

**Critica din romanul Tristram Shandy referitoare la rănile provocate de război**

**Rezumat**

Romanul lui Laurence Sterne, Tristram Shandy, a fost abordat de majoritatea criticilor literari în încercarea de a înțelege dezvoltarea romanului ca gen literar, însă un element central al naraționii lui Sterne care a reprezentat un punct de atracție pentru cercetători a fost și personajul
controversat, Unchiul Toby – veteran al Războiului de Nouă Ani care are o rană misterioasă în zona inghinală și care e obsedat de înțelegerea războiului prin construirea și utilizarea unor miniaturi pentru a reconstitui scene de război. Admitând faptul că Unchiul Toby este un personaj central în Tristram Shandy și punând romanul în contextul literaturii de război, acest articol demonstrează că străduința Unchiului Toby de a-și exprima trauma sa de veteran de război, greu de definit, devine un comentariu critic asupra structurilor sociale și a circumstanțelor care au provocat experiențele traumatice ale veteranilor răniți. Situând Tristram Shandy în contextul literaturii de război, articolul revelează cum personajul Toby folosește conceptele de onoare și de valoare din Iluminism ca motivații ale soldaților. Mai mult, articolul argumentează că aplicarea teoriei rănii morale (atât de prezentă, dar în mare parte nenumită în literatura de război) în defavoarea aplicării diagnosticului de sindrom post-traumatic ne permite să înțelegem mai bine comentariul critic al Unchiului Toby.
Biographic Accounts at the Intersection between
Disability Studies and Critical Trauma Studies
Narrating Disability, Trauma and Pain: The Doing and Undoing of the Self in Language

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Abstract

This article analyses themes from Christina Crosby’s disability memoir *A Body, Undone: Living On after Great Pain* through the philosophical works of Judith Butler. Both Crosby and Butler propose complementary ideas on corporeal vulnerability, the precariousness of life, relationality and interdependence. Crosby’s memoir provides a critique of dominant disability discourses that affect the social formation and reception of disability narratives, such as narratives that unilaterally characterize disabled subjects as strong, resilient and autonomous while bracketing the traumatic dimension of disability out of the narrative. Crosby’s book is discussed as a rich disability memoir that, while it firmly presents an account of living on, accounts for debilitating physical pain, the traumatic aspect of disability and the intense grief for lost bodily functions, abilities and life possibilities. Reflecting also on the socio-political character of disability narratives, the article considers how and why certain narratives can function critically and motivate a critical analysis of contemporary representations of disabled people. Approaching philosophically Crosby’s memoir through Butler’s work enables a wide-ranging consideration of topics found in the memoir such as the therapeutic nature of writing, narrative identity and its difficulties, the relations between disability studies and trauma theory, the political import of the personal and the ethico-political significance of interdependence.

Keywords: Christina Crosby, disability, grief, interdependence, Judith Butler, narrative, pain, self, trauma

Narrating Disability as Trauma

‘Trauma shatters one’s most fundamental assumptions about the world, including beliefs about our ability to control what happens to us’,\(^1\) writes Susan Brison in her philosophically-rich autobiographical work on trauma. ‘Physical pain is not only itself resistant to language but also actively destroys language, deconstructing it into the pre-language of cries and groans. To hear those cries is to witness the shattering of language’,\(^2\) emphasizes Elaine Scarry in her book on physical pain. ‘Spinal cord injury has undone my body, bewildering me and thwarting my understanding’,\(^3\) Christina Crosby, *A Body, Undone: Living On after Great Pain* (New York: New York University Press, 2016), 20. Hereafter, any in-text page numbers in brackets refer to this book.

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Crosby unambiguously highlights in her disability memoir. These three works – on sexual trauma, physical pain and disability brought about by spinal cord injury respectively – all highlight a common theme, namely, that such experiences are perceived as a shattering on various levels: of the body, of the psyche and of language. Moreover, they all resort to the same medium – language – to try to account for this shattering while acknowledging the inherent difficulties, both structural and personal, involved in doing so. Through accounting for these experiences, the implicit hope – although not always a celebratory hope – is that one restores a sense of self after the body has been breached, its solidity compromised, its intimacy violated and its dignity infringed. This interplay between, on the one hand, the shattering that trauma brings with it and, on the other hand, the use of language to connect the broken pieces in the aftermath of dissolution is captured in the titles of Scarry’s, Brison’s and Crosby’s works.

This article focuses on Crosby’s disability memoir, particularly her emphasis and bold portrayal of living with chronic neurological pain. Crosby’s memoir will be analysed as functioning as a counter-narrative of sorts, that is, a narrative that exposes, problematizes and sometimes subverts dominant discourses and narratives of disability. This subversion is not just of dominant discourses about disabled people that circulate in society, but also subversion of dominant strands of thinking and speaking by people with disabilities themselves and within disability studies in general, emphasizing that discourses of disability employed by disabled individuals themselves are open to critical scrutiny as much as discourses that disempower and marginalize persons with disabilities.

By this latter point, I am referring, for example, to how discourses of vulnerability are sometimes considered as debilitating and disempowering people with disabilities by representing them as dependent, instead of independent and autonomous. I am referring also to how rigid interpretations of the social model of disability – the model of disability that identifies the barriers enforced by social structures and organization, rather than individual impairments, as the cause of disability – have failed to account deeply for experiences of pain and loss brought about by physical impairments. Lastly, I also refer to how some disability stories tend toward the overarching narrative structure of success, achievement, if not of a fantastical normalcy, conforming to ‘the public demand for a story of healing and renewal, suffering and redemption.’ Such narrative expectations, some of which are at odds with each other, proceed at the expense of disavowing the traumatic dimension that can accompany, for example, acquired physical impairment. Crosby’s *A Body. Undone* deviates from such narratives by presenting a rich disability memoir that, while firmly putting forward an account of “living on”, attempts to account for the *debilitating pain*, the *traumatic aspect of disability* and the *intense grief* for lost bodily functions, abilities and life possibilities.

It must be emphasized that in no way is it being implied that there are easy and clear criteria through which to judge narratives, or that it is anyone’s business to judge disability narratives as critical, subversive, or otherwise: it is not a desirable and useful

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exercise and I do not feel entitled to do that. What this essay hopes to achieve, at best, is to show how Crosby’s disability narrative sheds critical light on some of the intricate ways in which power functions to hinder, structure and regulate particular narrative expressions of disability.

Writing the Self, Writing Disability

‘Disability demands a story’, writes Michael Bérubé. Ample important work has been done, and continues to be done, on disability and narratives, capturing different interests in how stories about disability and self-narratives by disabled individuals are told. A significant strand of this work focuses on cultural representations of disability, for example, in films, literature and popular culture, to study how disability is portrayed and, in doing so, reveal assumptions, prejudices and societal inclinations on disability. Another strand of scholarship on disability narratives aims to counter problematic portrayals of disability by presenting first-person accounts of what it is really like to live with disability and to manifest the variety of forms and experiences that disability signifies, in contrast with attempts to transform disability into a homogeneous thing that means the same thing always and everywhere. Such work also creates spaces where disabled individuals can explore different identities than the ones that arise out of social interpellations and labelling. It also includes life writing and reflections on disability life writing that do not only present a narrative or memoir of a person with disability, but also enable critical philosophical reflections on notions such as embodiment, rationality, gender and identity and contribute to the disability movement by reflecting on socio-political aspects of disability such as rights, access and policy. Situated in this latter strand, this article engages with Crosby’s A Body, Undone, analysing the narrative she provides, as well as how she reflects on disability life writing itself, with a particular focus on notions of pain, grief and trauma. Such an engagement also serves to identify how Crosby’s language and manner of writing are positioned in relation to, and sometimes in tension with, discourses about disability as well as discourses employed by persons with disability and, more generally, in disability studies.

The various strands of scholarship on disability and narrative cited above all highlight the centrality of language to communication and the generation of meaning.

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Indeed, language is the tool that bridges us with other people and what is within us with what is outside of us. ‘How can I know what you’re thinking if you don’t tell me?’, one might say in frustration at being unable to read someone else’s feelings. Yet, language is just a tool, not the tool we have to communicate. We all know of experiences that precede or exceed language, or experiences in which language is insufficient or breaks down because of its inability to capture “the moment”. Even in matters of research, linguistic articulations of research protagonists have been invoked against the so-called cold and hard scientific facts in such a way that narrative analysis or qualitative research are seen as more immediate gateways to people’s lives and their experiences. However, it can be argued that even this shift from quantitative data to narratives is a privileging of sorts that assumes various things, among them that people can articulate essential truths about themselves through language and that these experiential truths can be linguistically captured in the first place. Narrative privileging can also come dangerously close to an ableist position of assuming that narrative capabilities are intrinsic and essential to humanity, to the extent that whoever does not satisfy these requirements of narrativity falls short of the normative category of being human.

Moreover, narratives obtain meaning and significance through a social sphere. No matter how private the use of language might be, meaning is not privately generated. Even when it comes to ascribing meaning to private events, one must resort – one is condemned to resort – to a public medium: language. Thus, it is important to highlight that although first-person narratives are and should continue to be treated as important gateways to people’s lives, they are not the be-all and end-all of critical inquiry. A certain wariness surrounds narratives: what is being included in the narrative and what gets left behind, wittingly or not, behind the veil of narrativity? Moreover, not all narratives are treated equally; like language, they have a social existence: they are born, composed and circulate in a social sphere. And in language – in discourse – resides power.

When considering narratives in general and, for the purposes of this article, self-narratives in particular, one must be attuned to the socio-political and cultural forces – or what could be called power relations – that are necessarily operating upon them, giving meaning to narratives, facilitating their understanding and regulating their dissemination. Here, I follow Michel Foucault’s understanding of power: ‘it incites, it induces, it seduces, it makes easier or more difficult; it releases or contrives, makes more probable or less; in the extreme, it constrains or forbids absolutely.’ Adopting and adapting Foucault’s model of analysing power to the study of disability self-narratives, this article raises questions such as: What narratives of disability does power incite, induce, seduce? What narratives of disability does power make easier or more difficult to produce? Which are the more probable narratives of disability and why are certain narratives dissuaded, discouraged or kept in check? Is there a danger that resides in some narratives that makes them subject to control and neutralization by power?

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Narrating Disability, Trauma and Pain: The Doing and Undoing of the Self in Language

Crosby’s narrative is functioning on multiple registers: on a basic level, it is a memoir detailing her life from the point of view of her acquired disability; it is also a reflection on pain, grief and trauma in relation to the experience of disability and a contribution to the politics of disability through its engagement with core notions in disability studies such as the disability movement, activism and the social model of disability. It is also a critical work of thought on disability that draws upon and incorporates insights from philosophical works on embodiment, affectivity and gender. The rest of the article elaborates on these different registers in which Crosby’s work intervenes, specifically by using the work of Judith Butler, a gesture justified not only because it is rich in conceptual resources – vulnerability, dependency, relationality – that lend themselves to interpreting and further illuminating Crosby’s work, but especially because in order to frame her narrative, Crosby clearly relies upon, uses and directly cites Butler’s *Precarious Life* and *Giving an Account of Oneself* (see 209).

Reading Crosby through Butler

Giving an Account of Oneself

Crosby’s memoir opens with the facts about the impairment:

On October 1, 2003, I caught a branch in the spokes of the front wheel of my bicycle, and hurtled toward the pavement. My chin took the full force of the blow, which smashed my face and broke the fifth and sixth cervical vertebrae in my neck. The broken bone scraped my spinal cord, and in an instant I was paralyzed. There’s no knowing right away exactly what impairments will result from a spinal cord injury, but as the days passed, it became clear that I had lost the use not only of my leg muscles, but also the muscles of my torso, arms, and hands, and that the loss of muscle compromised my body’s circulatory systems. I also lost control of my bladder and bowels. [...] Lying in the intensive care unit of Hartford hospital, I knew very little about the present and nothing about the future. I only knew that I had been grievously injured, and was lost in space. Not until I reached the rehab hospital a month after the accident could I begin to put into words a body that seemed beyond the reach of language. (3; emphasis added)

What becomes immediately clear is that this accident is experienced as an undoing; not just of a body (as the memoir title suggests) but also of language, the self and the self-narrative. Yet, it is to language and narrative that Crosby resorts in an attempt to weave her life threads, think and live through her disability: ‘I started writing this book to

14 Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (New York: Verso, 2004). Hereafter cited as PL, with page numbers in the text; Judith Butler, *Giving an Account of Oneself* (New York: Fordham University Press, 2005). Butler also provides an endorsement of *A Body, Undone*: ‘*A Body, Undone* is a memoir about surviving in the midst of community, reflecting on loss, the interminable nature of grief and on the meaning of living on. Christina Crosby is a writer whose intellectually expansive reflection is simply awe-inspiring. With prose that can only be described as burning with lucidity and precision, she takes us through the aftermath of the accident and the gradual understanding of its implications for her physical and psychic life. An extraordinary and luminous book.’ Moreover, it is presumably her who is acknowledged at the end of the book (as ‘Judy Butler’) in a list of ‘[e]arly readers of the manuscript, each of whom helped me see more clearly what the book was and what it might be, and thereby encouraged me to keep writing.’ (204). Incidentally, the relationship between the two can be traced back to at least the early 1990s when Crosby contributed a chapter to a 1992 volume co-edited by Butler. See Christina Crosby, ‘Dealing with Differences’, in *Feminists Theorize the Political*, eds Judith Butler and Joan W. Scott (New York: Routledge, 1992), 130-43.
create something from an otherwise confounded life. Only through writing have I arrived at the life I now lead, the body I now am." (12)

From the very beginning of her narrative, Crosby makes it clear that her narrative draws on and is inspired by Butler’s work, particularly her ideas on precariousness and interdependence. In the opening pages, Crosby puts forward her guiding theme in what might be called Butlerian terminology:

I know for sure that we are much more profoundly interdependent creatures than we often care to think, and I know imperatively that we need a calculus that can value caring labor far differently than we do today. Life is precarious, a fact that has been borne in on me by my injury, recovery, and continuing dependence on others for survival and well-being. (4, emphasis added to show references to PL)15

In the opening chapter, Crosby also introduces the thematic that guides the memoir and the sentiment that will go on to conclude it, that is, the deep reach of relationality, the precariousness of life and the inarguable dimension of the dependency that sustains and supports life. This facet of life is especially foregrounded, argue Butler and Crosby, when the body is violated and/or when one suffers loss. In the aftermath of the accident that injured her, while knowing that she ‘can’t resolve the intractable difficulties of disabling incapacity’ (189), Crosby endeavours to write about it, to account for it: ‘How can I give an account of myself after “catastrophic injury”? ’ (18). Crosby echoes Butler’s terminology and ideas in the following excerpt, at the end of which she provides a reference to Giving an Account of Oneself:

Because of my condition, I’ve been pondering the reality that everybody has/is a body. Your body emerges through the perception of others as different from yourself, at a touchable distance, and selfhood is not self-contained. What you want, who you are, how you feel are all brought into being over time and in relation to others, and those thoughts and feelings are repeatedly inscribed, creating powerful circuits that organize a sense of embodied self. Such is human interdependency that my self-regard depends on your regard for me. I need and want a more fully livable life, which turns importantly, if not exclusively, on this play of recognition. (18-19)

The form of self-narration, or autobiographical writing, presented in Crosby’s book does not simply reflect back a stable and coherent subjectivity (an ‘interiority’) through writing. Rather, she captures the various performative (and dialogical) dimensions of self-narration. The self emerges through the writing itself.16 Thus, Crosby’s self-narration entails an eccentric and eclectic mix of confessional discourse (revealing her inner thoughts and feelings), medical truths (the facts about her injury), academic discourse (the texts she draws upon and cites) as well as hints of self-creation. The memoir does not represent a fixed truth about Crosby; rather, the truth is constituted through self-narration, whereby this is a precarious process haunted by incomprehensible realities, unaccountable facets, demands for recognition and a future-oriented concern with a self-creative becoming otherwise: ‘Now I need you to know from the inside, as it were, how it feels to be so radically changed. If I can show you, perhaps I’ll be able to see, too. The intricacies of bodymind interactions defy certainties

15 At the end of these sentences is a reference to Butler’s PL.
and confound representation, but I see no other way to go on – how else will I understand? How will you?’ (20-1; emphasis added).

This autopoetic dimension of self-narration is particularly revealing of relationality since the moment of self-creation is not a solitary or individualistic endeavour; in fact, Crosby concedes that ‘I need you’ in order for her to ‘be able to see’. The notion of an actual or implied listener is a crucial one here and reflects a recurring concern in trauma theory. Susan Brison, for example, too emphasizes this notion:

[T]he trauma survivor must find empathic listeners in order to carry on. [...] In this book I explore the performative aspect of speech in testimonies of trauma: how saying something about the memory does something to it. The communicative act of bearing witness to traumatic events not only transforms traumatic memories into narratives that can then be integrated into the survivor’s sense of self and view of the world, but it also re-integrates the survivor into a community, re-establishing bonds of trust and faith in others.  

Crosby notes that although her own relational self-narration is part of her attempt to live on, affirm her existence and relations, there are different narrative forms at play in her book. Aside from a call for recognition and self-restoration, there is also an implicit “darker” or traumatic narrative operating which Crosby repeatedly refers to as horror:

Whenever you offer an account of yourself to others, you labor to present yourself as coherent and worthy of recognition and attention, as I am doing right now. Yet because my sense of a coherent self has been so deeply affronted, I’ve also been thinking about stories that are devoted more to affect than to reason, and because the accident and its aftermath were so horrific, horror stories suddenly make sense to me in a way they didn’t before. Such stories gather affective intensity as their narratives develop. (19; emphasis added)

This characterization captures how the self-narrative, which essentially revolves around the corporeal damage, is shaped by intense affective states, particularly pain – both physical and psychical – and grief.

Grief, Vulnerability and the Body

In her lecture entitled ‘Loss is Inseparable from What Remains’, Crosby emphasizes that her disability is a constant reminder to her of all that she has lost physically, affectively, professionally and socially: ‘[a]ll too often I’m reminded of what I’ve lost, and confronted with what I must endure to go on each day. [...] It’s true that I cried many times, every day, when I was in the hospital. I cried for all that I had lost. A body, and a way of life that I loved, destroyed.’ (LIIFWR, emphasis added)

A body and a way of life.

The body as a site of loss: Butler remarks how bodily existence is a perpetual sign and reminder of vulnerability. The body is both the site of agency but it is also that which exposes the individual to others and to potential injury: ‘[l]ives are by definition precarious: they can be expunged at will or by accident.’ The body is the site of illness, violence and debilitation. The body is also a social site – it marks the subject as ‘attached to others, at risk of losing those attachments, exposed to others, [and] at risk of

violence by virtue of that exposure’ (*PL*, 20). Thus, although typically associated with one’s private realm, the body as a social phenomenon has a public dimension: ‘my body is and is not mine. Given over from the start to the world of others, it bears their imprint, is formed within the crucible of social life’ (*PL*, 26). In this sociality we inhabit, ‘we are, from the start and by virtue of being a bodily being, already given over, beyond ourselves, implicated in lives that are not our own’ (*PL*, 28). Crosby almost literally echoes this portrayal of corporeal vulnerability and relationality when she writes about her relationship with her partner Janet: ‘Our lives are intertwined, and my life is not mine alone, but shared with her’ (200).

Butler argues that the grief that follows the loss of a beloved heightens one’s awareness of the extent to which one is constituted through one’s relations, claiming that the loss of a significant other cannot be understood as the termination of a chosen relation between two clearly distinct agents. Rather, the subject is constituted through the attachment one has to another in such a way that when one loses another, one also loses a part of oneself: ‘Who “am” I, without you? When we lose some of these ties by which we are constituted, we do not know who we are or what to do. On one level, I think I have lost “you” only to discover that “I” have gone missing as well. At another level, perhaps what I have lost “in” you, that for which I have no ready vocabulary, is a relationality.’ (*PL*, 22) This formulation of the experience of grief is echoed by Brison, who, in her account of the aftermath of trauma, reflects on the interplay between the feeling of losing a beloved and the feeling of losing one’s sense of self due to trauma:

The loss of a trauma survivor’s former self is typically described by analogy to the loss of a beloved other. And yet, in grieving for another, one often says, ‘It’s as though a part of myself has died.’ It is not clear whether this circular comparison is a case of language failing us or, on the contrary, its revealing a deep truth about selfhood and connectedness.19

**Pain**

Crosby’s account continually emphasizes how, since her accident, her body became a crucible of impossible pain that makes her embodied existence unbearable at times. She also evokes past memories of when her body reminded her of possible pleasures: the body as the site of desire and their perpetually unquenchable nature. However, in the present, her desire remains unquenchable because of her ‘profoundly compromised strength and tactile perception.’ (119) ‘Exposing sentiments that are often taboo in disability memoir’, 20 in her account Crosby writes:

The idea of fucking still makes me happy […]. For me, fucking is so changed from what it was that, try as I may, I cannot reconcile myself to my losses. How can I settle for a life with deadened sensation that decrees I’ll never again have an orgasm? [… ] How I miss the way sex used to feel! How I miss feeling my entire body – every molecule, every atom, every subatomic particle, every Higgs boson – moved by desire! (118-9)

Perhaps taboo too – at least among those who challenge to the pervasive connotation of disabled lives with lives unworthy of living – are sentiments of a death wish expressed by persons with disability, sentiments which Crosby voices: ‘[i]n the months after the

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20 Adams.
accident, as I lay in my hospital bed unmoving and in a firestorm of neurological pain, I sometimes – many times – wished I had died at the instant my chin struck the pavement. Had it not been for Janet, my dear lover, this wish would, I believe, have gathered darkness around it to become an active desire for death.’ (7) Rather than desire and life, Crosby concedes that what move her body now are the contortions and jolts of pain, as can be seen from the evocation of such an episode of pain:

I awoke at night on fire, my skin crisping from the soles of my feet, up my legs and back, tight around my abdomen right up to just under my rib cage, and down my arms onto my hands. I was burning the way you burn when shocked with static electricity, but the shock was infinitely multiplied and running thickly, continuously under my skin. This ferocious buzzing was let loose on me by scrambled nerves that will never ever fully recover, neurological pain that could outline my body by thickly fizzing my skin, as it did that night, or more deeply penetrate my extremities, as was sometimes the case. What a horror, to finally and viscerally understand how profoundly I was hurt! (27)

For Crosby, this dimension of her disability is unsharable and uncommunicable; not only is it impossible to convey its intensity to others, but she also cannot incorporate and surmount the breakdown brought about by pain: ‘[p]hysical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned.’

Echoing and directly citing Scarry’s characterization of pain as fundamentally unsharable due to the way in which it breaks down language, Crosby writes: ‘[p]ain brings with it a dour companion, loneliness. I feel an unassuageable loneliness, because I will never be able to adequately describe the pain I suffer, nor can anyone accompany me into the realm of pain. […] Crying, and screaming, and raging against pain are the sign of language undone.’ (31) Crosby discloses how her partner contests this loneliness of pain and insists that although she cannot herself actually feel the pain Crosby is feeling, she is still affected by the pain and she is pained to see her suffering while knowing that her desire to remove her pain is impossible. Nonetheless, Crosby reiterates that, ultimately, even if it is communicable, the pain she feels is a hindrance to relationality. While pain can serve as a common ground for communication – since everyone knows what pain is like – Crosby chooses not to disclose her pain whenever possible, as doing so, at best, is futile, and, at worst, damages her ties to others:

I don’t talk much about the pain to anybody other than my therapist, who is not my lover, or my friend, or a member of my family, or my colleague. To her I will complain bitterly, but not to others. I won’t complain about the pain because such plaints become corrosive, and would eat at the ties that bind me to others. It’s not that I’m bravely suffering in silence, but rather that I know there’s something to be done. (34)

Apart from the effects of disability on her sex life and the shattering pain, Crosby discusses how her disabled body precludes her from a way of life of certain social pleasures. She recounts how being a wheel-chair user marginalizes her from the heart of parties and social events, in contrast with her way of life prior to the accident. She writes:

There I stayed. The living room was loud and crowded with people. The rooms beyond — and the food and drink — were utterly inaccessible to me. [...] Increasingly free laughter and talk came from the crowded rooms, and, sitting there, stuck just inside the front door, the party felt largely inaccessible to me, despite my ramps. I left after about an hour and went home sober and sad. (181)

Crosby’s account agrees with foundational work in disability studies that maintains that it is of utmost importance to critically theorize the disablement brought about by social barriers; after all, disability studies as an academic discipline owes its roots to the disability rights movement which grew as a reaction to the unilateral equating of disability with the assumption that disability is purely a medical and welfare issue rather than being also a demand for rights and recognition. While these historical circumstances should be acknowledged, one must also take heed of the other side of Crosby’s argument in this regard, which is that alongside the emphasis on social disablement, it is as important for disability studies to think of the facets of disability, at least of acquired physical disability, as a trauma, a pain, a loss. These facets are not always in seamless complementarity with certain strands of thinking in a disability studies, as the next section shows.

The Politics of Narrating Disability

Crosby’s book links the themes of grief, corporeal vulnerability and relationality with broader socio-political considerations and situates her narrative in relation to tendencies of thought and discourses within disability studies. Crosby, a professor of literature, ascribes a therapeutic role to words in her attempt to restore and rebuild her self-narrative: ‘I started writing this book to create something from an otherwise confounded life. Only through writing have I arrived at the life I now lead, the body I now am. I’ve done this work in language, because my profession is the study of literature. It’s what I have and what I know.’ (12) Here, a small but significant point needs to be made: given her academic background, Crosby’s narrative is not just any disability narrative — it is the narrative of an educated white person with superior linguistic abilities, attuned and sensitive to the rich potentials of language and with a great mastery over words. Thus, when considering disability narratives, it is important to ask ‘who is narrating?’, since not everyone has access to the same narrative capabilities. Indeed, Crosby herself notes that experiences of disability differ according to the socio-political and class status of the individual and that in this regard she was quite privileged:

Moreover, when approaching disability narratives, one must be attuned to the discourses at play. Work in disability studies has shown that there are narratives of

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disability, or rather, about disability that are terribly hegemonic, for example narratives that describe disabled individuals as ‘inspirational’; ‘angelic’ or, contrastingly, as ‘burdensome’. Crosby describes the discourse at play in which her own story was reported in a hegemonic way in the press: her spinal cord injury was perceived as a tragedy which, however, was transformed ‘into a testament of human resilience and a triumph of the will.’ (LIIFWR) A fundraising event (reported in a newspaper article with the headline of ‘Massaging Away Tragedy’) was organized by Crosby’s massage therapist and her friends to help her buy a minivan she needed.

Besides the grave faults of these narrative arcs, which include the infantilization, objectification and marginalization of disabled individuals, one could also focus on narratives which might not immediately strike us as evidently hegemonic, including narratives from within disability studies itself which could possibly be functioning in a disempowering way. Crosby argues that a critical approach to pain and disability ‘should ironize any happy idea that disability leads to profound insight or higher understanding, despite the narrative arc that organizes so many stories about living with an incapacitated bodymind. That arc carries the troubled subject through painful trials to livable accommodations and lessons learned, and all too often sounds the note triumphant’; Crosby’s response to this dominant “progressivist” narrative is simple: ‘Don’t believe it.’ (116) Elements of this dominant narrative coincide with a celebrated model of disability in disability studies and activism: the social model of disability. As Crosby describes it:

Scholars have convincingly argued that disability is not a personal attribute of crippled bodies or minds, but a social phenomenon that bars the full participation in public life of persons so impaired. Impassable barriers and narrowly conceived measurements of ability make it hard to acknowledge and address nonnormative bodyminds. [...] Disability is created by building codes and education policy, subway elevators that don’t work and school buses that don’t arrive, and all the marginalization, exploitation, demeaning acts, and active exclusions that deny full access and equality to “the disabled.” (6-7; emphasis added)

Crosby approvingly cites the social model of disability, as well as the affirmative side of the social model that resulted in ‘disability-positive’ movements such as neurodiversity, crip pride and deaf culture. According to this affirmative self-identification, rather than disabling, ‘neuro-atypical[ity] endows some with enviable abilities of memory,’ deafness is regarded ‘as a fully elaborated culture, not a disability, [and] Crip Pride turns the table on the disabling world, and orients non-normative bodyminds to a future of our own making’ (LIIFWR). Crosby supports all of this, both philosophically and politically.

Yet she suggests that such models foreclose something: namely, they preclude possibilities of expressions of disability that may not fit in smoothly with the main tenets of these models: ‘[t]he social model of disablement is just that, a social model. The emphasis on pride that contravenes pity makes discussing chronic pain difficult, and forecloses what is for me, the necessarily interminable work of mourning the loss of

24 S. E. Smith, ‘Disabled Children Aren’t Burdens – or Angels’, This Ain’t Livin’; available at meloukhia.net/2014/09/disabled_children_arent_burdens_-_or_angels [accessed 19 June 2018].
Crosby is definitely not arguing that we should resort to models that treat disability solely as debilitating; rather, she is shifting our attention to what may be left out from the social and affirmative models, pointing out that not surprisingly there is ‘so little writing in disability studies [that] concentrates on pain or mourning’ (LIIFWR). Such affective states place emphasis on what is lost because of disability or impairments, thus going against basic premises of the social model. For Crosby, ‘[t]o focus on intractable pain, then, or grief at the loss of able-bodiedness […] may be thought to play into a pathologizing narrative that would return disability to “misshapen” bodies and “abnormal” minds’ (7). Her account emphasizes that while the social model has had crucial historical and socio-political efficacy, it is not – and it cannot pretend to be – an exhaustive and totalizing model of disability. It leaves a lot unaccounted for, especially matters of pain and mourning, and facets of her relationship with her partner: ‘[t]hat I mourn my lost body and the world of delights Janet and I elaborated together, is hardly speakable in the critical discourse of disability’ (LIIFWR).

Crosby identifies the ways in which certain disability narratives are excluded and argues that presenting her self-narrative in the way she does is not only a personal need, but is also an attempt to resist certain tendencies within disability studies itself that may function in a normalizing way: ‘[d]espite their strategic elision in disability studies or transcendence in happy stories in the popular press about trauma overcome, bodily pain and grief persist, to be accounted for as best one can. This book is my contribution to that record’ (7). Thus, the memoir can be seen as a response to what she perceives as spaces within disability studies itself and among disabled individuals themselves that serve to hinder rather than facilitate and encourage the expression of the diverse facets of disability, notably the facet of grief, loss and trauma that some disabled individuals feel the need to express. Besides their utility for individuals, such expressions may also function to widen the sphere of disability which can be narrated. Hindering this space of narrating can function to censor and preclude disabled individuals from narrating in their preferred mode aspects of their lives which they deem to be crucial, or to do so at the risk of possible rebuke. Crosby recounts one such episode of rebuke: ‘[w]hen I presented some of this work to a study group, one guy in a wheelchair more or less told me to “man up” and get on with my life’ (7).

Notwithstanding the gender misidentification and the various problems associated with the toxic masculinity implied in ‘man up’, this remark can be seen as indicative of a wider problematic in disability studies that was identified by, among


27 For other models of disability, see Jan Grue, Disability and Discourse Analysis (Surrey: Ashgate, 2015).

28 A Body, Undone contains various references to and analyses of gender in relation to disability, including episodes where she is misidentified: ‘I’m now misrecognized as a man more often than ever before, almost every time I go out’ (60). Incidentally, even Crosby’s remarks on gender can be read in light of Butler’s work on gender performativity.
others, Susan Wendell with the image of the ‘healthy disabled’ that is perpetuated at the expense of relegating and silencing concerns raised by individuals who suffer from chronic debilitating pain.29 Criticisms of the harms resulting from the excessive medicalization of disability – criticisms that Crosby confesses ‘I now understand better’ (6) – have inadvertently circumscribed the narratable realm of disability. According to Wendell, ‘[b]ecause disability activists have worked hard to resist medicalization and promote the social model of disability, activists sometimes feel pressured to downplay the realities of fluctuating impairment or ill health.’30 Thus, refusing to acknowledge and account for vulnerability ‘may perpetuate our culture’s devaluing of dependency and inflating of the value of self-sufficiency’. Disability studies must move away from masculinist theorizing by presenting a more inclusive approach to disability that ‘does not exaggerate the value of strength and independence.’31 Crosby’s work is a step in this direction by continually highlighting the value of care work and the virtues of interdependency throughout her memoir, especially in a chapter specifically dedicated to her care worker, Donna, and the concerns raised by how much care work is undervalued, both emotionally and financially. Crosby narrates how she is extremely dependent on the care of her carer, a duty which her carer executes with love. However, Crosby importantly views this work from a political lens and connects it with broader social inequalities with which it is uneasily entangled. On the one hand, Crosby rightly highlights how an ethic of care fosters an intimate relationality: ‘I love her [Donna], and she loves me, for a decade of intimate care has created an intimate bond’ (37). On the other hand, Crosby also points out that this intimate bond has brought her in proximity to the struggles that care workers face with debts, bad housing, long working hours knowing that being unwell or having a bad day at work may mean not being able to have enough money to last the month, the tiresome work of exertion involved in handling people requiring assistance to move, to stand and to satisfy their basic needs: ‘I know in a way that I never could have learned otherwise than through such an intimate relationship how bitterly, sometimes desperately, hard it is to be working poor’ (37). Care work entails ironic inequalities in that, aside from working under continually stressful and terrible work conditions, the carers can end up injured themselves and not be able to tend to their needs, or depend on someone to care for them. These realities

highlight that the work of care is, ultimately, work and should be treated as labor. Thus, while recognizing that ‘money cannot begin to measure the value of her [Donna’s] work’ (43). Through her narrative, Crosby reflects on the virtues and affects of care, but importantly connects the work of care to the broader socio-political realities in which it is situated. To do so, Crosby writes, is ‘to link my dependency to a broader vision of caring labor and reproductive work. It is to see the political in the personal and the personal in the political’ (42; emphasis added).

Acknowledging Trauma, Living on Interdependently

Crosby’s narrative functions as a possible counter-narrative of disability; “counter” not in the sense of going absolutely against other narratives of disability, as if these occupy a homogeneous and fixed pigeonhole. Her account serves to widen that which is understood as disability, both narratively and affectively, especially with close regard to the dimensions of grief and trauma. However, the narrative is not a unilateral tragic story of despair. After all, the memoir, which is subtitled ‘living on after great pain’, does resort to a notion of living on. It is living on, but it is living on after great pain, or rather living with or despite the pain. Crosby’s account tries to account – impossibly – for various shatterings: the shattering of her spinal cord, the shattering nature of pain and the shattering of language that this brings with it.

Yet it does not stop there. Although A Body, Undone is not a celebratory narrative, its hope lies in the moving account it gives of human interdependence, announced in the opening chapter: ‘I know for sure that we are much more profoundly interdependent creatures than we often care to think’ (4). The memoir then concludes with the same insight; in the true spirit of really recognising the power of interdependence, Crosby’s book ends with a 5-page long acknowledgements section literally showing how her life is intertwined with other lives: ‘[p]aralysis and pain have impressed on me something that I knew before breaking my neck, but understand now with vivid clarity – the simple and profound fact of human interdependence’ (203). This is not meant as a sombre concession but as a celebration of dependency: ‘I have no wish to embarrass you or mortify myself, but I do believe that living in extremis can clarify what is often obscure, in this case the fragility of our beautiful bodies and the dependencies of all human beings’ (10). Dependency, rather than a fact to be eschewed, is understood as a life-affirming reality. In this thought too, Crosby is echoing Butler’s recognition that exposure implied by vulnerability and dependency, at times unwanted if not potentially traumatizing, is nonetheless key to life and to living on after great pain: ‘Let’s face it. We’re undone by each other. And if we’re not, we’re missing something’ (PL, 23). Crosby’s book is a serious celebration of interdependence, acknowledging her dependence on her partner, her career, her friends and peers. In response to discourses that privilege autonomy and independence while presenting dependence as a negative thing to be eschewed, Crosby mobilizes a counter-discourse of dependency and care that aims to stop pitting dependence and independence against each other and instead attempts to redefine the category of the human in terms of a continuum of dependencies.

Throughout A Body, Undone, Crosby often describes her disability as ‘horror’. In a chapter toward the end, titled ‘The Horror! The Horror!’ (184-97), whose title echoes the end of Joseph Conrad’s Heart of Darkness, pain and disability are discussed in relation to realist literature, particularly Eliot’s Middlemarch, which Crosby asked to be read to her while in hospital. Crosby argues that in realist literature, the world is
'comprehensible, and rationally ordered [...] unlike] the neurological storm of spinal cord injury' (187). That is why she confesses that she understands why disability memoirists wittingly or unwittingly resort to the realist narrative arc in their writing in an attempt to reclaim some form of narrative coherence in their life and self-understanding. Crosby admits that even if she herself may have resorted to such realist and stabilizing narrative conventions in her own memoir, she considers her story of profound neurological damage as more akin to a horror story, ‘a literary genre governed not by rational exposition but rather by affective intensification and bewilderment’ (189). Interestingly, Adriana Cavarero also concludes her book Horrorism with an appendix titled ‘The Horror! The Horror! Rereading Conrad’. Besides their choice of titles, Cavarero and Crosby can be compared on how they both read horror in relation to vulnerability, particularly in tandem with Butler’s elaboration of the notion of corporeal vulnerability. Cavarero’s work on horror, although rooted in a discussion of contemporary violence, terrorism and mutilated bodies in particular, highlights how the truly horrific is that which strikes the human in its corporeal vulnerability, in that part of one’s self which exposes one to care and affectionate touching on one hand and, equally, to violence and harm on the other. This could be said to link disability, horror and trauma in Crosby’s book as well as theoretically.

Crosby insists that it is amid this horror, amid this possibly traumatic ‘constitutive vulnerability’, and not by disavowing it, that she can find the capacity to live on. She admits that the grief she feels is gray – ‘[l]ife no longer feels radiant’ (12) – and that she cannot relish in mundane enjoyments any more since she is immersed in grief. Nonetheless, she wants to hold on to the grief insofar as she can vicariously experience these pleasures through her past self and through recollection: ‘I don’t want to forget how those pleasures felt in my body’ (12); ‘I may be perverse, but I’m terrified of what I’ll lose in making my peace with what I’ve lost’ (197). Crosby thus continually highlights the rich meanings that grief continues to have in her life; indeed, that she can only live on through grief, not as something she must overcome but as hope that guides her onward: ‘I am certain about one thing – whatever chance I have at a good life, in all senses of that phrase, depends on my openness to the undoing wrought by spinal cord injury, because there is no return to an earlier life’ (20). This ‘openness’ is not just past-oriented: ‘I am no longer what I once was – yet come to think of it, neither are you. All of us who live on are not what we were, but are becoming, always becoming ‘ (201-2). Thus, the grief mobilises a future-oriented commitment to living on and becoming otherwise.

**Bibliography**


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33 Cavarero, 20.

Narrarea dizabilității, traumei și a durerii. Facerea și desfacerea sinelui prin limbaj

Rezumat

care, în timp ce prezintă o narățiune a supraviețuirii, încearcă să nareze durerea fizică debilitatingă, acel aspect traumatic al dizabilității și durerea intensă provocată de pierderea funcțiilor vitale ale corpului, ale abilităților fizice și ale posibilității de a trăi o viață normală. Reflectând și asupra caracterului socio-politic al narațiunilor despre dizabilitate, articolul ia în considerație cum și de ce anumite narațiuni pot funcționa critic și motiva o analiză critică a reprezentării contemporane a persoanelor cu dizabilități. Abordarea filosofică a jurnalului lui Crosby prin opera lui Butler ne permite să facem analizăm în profunzime subiecte regăsite în jurnal, respectiv natura terapeutică a scriiturii, identitatea narativă și dificultățile sale, relațiile dintre studii asupra dizabilității și teoriei traumei, intruziunea politicului asupra personalului și semnificația etico-politică a interdependenței.
Invincible yet Vulnerable: Race, Disability and Trauma in South Africa after Oscar Pistorius

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Abstract

When the global sporting icon, Paralympian and Olympian Oscar Pistorius was accused of killing his girlfriend, Reeva Steenkamp on the morning of Valentine’s Day in 2013, one of his many defences was, simply put, that his disability made him do it. An expert witness for the defence made the connection between disability and violence that suggested that disabled people are particularly prone to ‘over-react’ as it were because they feel especially vulnerable. This defence provides the link between the two extremes claimed by Pistorius’s public persona, that of invincibility and vulnerability – extreme physical ability epitomized by sterling sporting prowess and fear of victimisation because of his physical limitation. The formula proposed by this defence is that extreme vulnerability results in extreme aggression. Here I want to analyse what this claim suggests about prevailing social attitudes toward disability and disabled people, particularly in post-apartheid South Africa – or more accurately in post-TRC (Truth and Reconciliation Commission) South Africa. In this article I propose that the corrosive legacy of TRC created rich ground for white victimization and popularised the medical model of trauma.

Keywords: Social Media, Disability, Trauma, Truth and Reconciliation, supercrip, inspiration porn

When Oscar Pistorius, a South African world-renowned athlete, and double-amputee who gained world fame for competing in both the Paralympic and Olympic Games from 2004 to 2012 was reported to have murdered his girlfriend on Valentine’s Day in 2013, jokes about his disability proliferated in social media. It was as if a valve had been released on the pressure cooker of social revulsion against disabled people and social media users felt free to break social taboos around stigmatizing disabled people. The proffered excuse for this opprobrium was that Pistorius had earned ridicule through his actions and that he was mocked for what he had done rather than as a disabled person, even though much of the scorn focused on his disability.1 By the time he was on trial, some of the jokes had become defining features of the social media discourses around him, and there were websites, Facebook pages and twitter accounts dedicated to mocking him as a disabled athlete who had conned everyone or at least misrepresented himself.2 Of course, the scorn heaped on Oscar Pistorius has become standard in the wake of OJ Simpson and many athletes and celebrities who have fallen from grace and

1 Twitter jokes about Pistorius ‘not having a leg to stand on’, and tasteless puns about Pistorius being totally ‘legless’ when he shot his girlfriend were shared over and over again on various social networking platforms.

2 The hashtags #pistorius, #OscarPistorius and #Oscar were buzzing with jokes and puns about legs like this one https://twitter.com/YoniHaz/status/302089805523722240 [accessed 20 September 2018].
have become the butt of jokes, particularly because they had been previously elevated. What stands out in the Pistorius case is that the flippancy with which social media users discussed disability broke social taboos around maligning disabled people and in the process pulled a curtain on the festering social resentments about persistent inequalities in post-apartheid South Africa.

In mocking Pistorius, many social media users vented their frustrations about white privilege, class inequalities, gender violence and the exceptionalism of disabled people (particularly the access enjoyed by white disabled people). The fact that much of this venting focused on the body relates to how disabled people are framed culturally, particularly as dependent and lacking. Pistorius had sought to distance himself from these perceptions by cultivating the image of a supercrip, a disabled person who is able to accomplish ‘superhuman’ feats, and is therefore able to ‘heroically overcome’ his disability. When Pistorius was eventually tried for murder, his defence claims also fuelled the social opprobrium toward disabled people that had come to characterise the discussion of Pistorius on social media. Pistorius legal counsel advanced three lines of defence: that of rampant (black) crime and lawlessness, masculinity/(white) male chivalry and lastly, disability as trauma. In fact, this defence is neatly summarised in the affidavit he swore at his bail application a few days after the shooting wherein he stated that when he heard a sound in the bathroom, ‘terror rushed through him’ and that:

It filled me with horror and fear of an intruder or intruders being inside the toilet. I thought he or they must have entered through the unprotected window. As I did not have my prosthetic legs on and felt extremely vulnerable, I knew I had to protect Reeva and myself. I believed that when the intruder/s came out of the toilet we would be in grave danger. I felt trapped as my bedroom door was locked and I have limited mobility on my stumps.

Given South African history and politics, the prevailing perception, especially from the media, was that the imagined intruder in this statement is black, but in order to ensure that his fear of black criminality in well-secured environment does not appear irrational, in this statement Pistorius inserts disability as an exacerbating factor, that makes him feel extremely vulnerable. And lastly, Pistorius makes sure to paint himself as Reeva’s protector. While these defence claims have been variously discussed and challenged by the prosecution, scholars, social media users and other social commentators, not many

3 As I will make clear, the supercrip, as articulated by disability studies scholars such as Eli Clare, Robert McRuer and Michael Berube among others, serves to subject disabled people to different standards and does nothing to challenge ableism, and in Pistorius’s case, his cultivation of the supercrip image obscured the intersections of disability with race, class and sexuality.
have linked all three in order to explicate what the Pistorius defence strategy reveals about South Africa after apartheid, in particular South African society after the Truth and Reconciliation Commission (TRC). Not many scholars and social commentators have looked at how race, gender, sexuality and class intersect with disability to fuel discourses around Pistorius and his murder trial.

Those who mocked and disparaged Pistorius as a disabled person were able to do so because they couched their statements in familiar parlance and stereotypes about sexism, racism or white privilege. Take, for instance, the much-retweeted sexist ribaldry that ‘surely Oscar Pistorius can’t be the first bloke to wake up legless on Valentine’s Day and shoot a load into his girlfriend thinking she was somebody else.’ Superficially, this joke paints Pistorius as a regular, albeit insensitive, guy who did what most drunk young, heterosexual males do, and yet its punchline is that Pistorius is not drunk (legless) but really has no legs, and did not have sex (shoot a load) with his girlfriend but has literally shot her. Such tasteless humour circulated precisely because everyday ableism, like sexism, and trivialization of gender violence, goes unremarked. But beyond tasteless tweets and Facebook posts, much of the commentary around the Pistorius saga seemed to struggle with the diversity within disability. It was lost to most commentators that disability as a social identity is fluid and porous. As Mark Sherry makes clear, ‘disability is always sexed, gendered, racialized, ethnicized and classed experience’ and, as he continues, ‘every response to disability operates within a framework of multilayered and complex patterns of inequality and identities.’ This means that there is difference within disability in terms how differently impaired people identify and also in terms of their differing social locations. Without inputting diversity and difference within disability, one can only focus on how Pistorius is ridiculed for being disabled and miss other ways that this lampooning taps into social anxieties about other bodies that defy what is considered normal.

Thus, whereas there have been numerous disquisitions on how the trial shaped perceptions around disability in South Africa and internationally, and analyses of the racial politics of the trial and what it says about the post-apartheid state, or how the trial taps into social constructions of gender, class and racial inequalities, very few have sought to link all these together and look how the trial dealt with interlocking oppressions, even cursorily. I propose looking at the trial as part of the afterlives of the South African Truth and Reconciliation Commission, because doing so will link the trial, including public discussions of the trial and the media personality of Oscar Pistorius before and during the trial, to pervasive narratives of violence that followed

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the TRC and how such narratives are inextricably tied to social inequalities. Here I want
to suggest that the discursive space created by the trial, including events leading up to it,
was shaped by popular understanding of the legacy of the TRC. An analysis of media
commentary, social media conversations and scholarly examination of the trial and
Oscar Pistorius the public person will provide the basis for this discussion. I analyse
these using the ‘afterlives’ to refer the way that the TRC processes and the history it
produced often leach away from the public domain, while its narrative styles, modes,
and rituals, and practices continue to shape the present.

The TRC is an important nodule in the timeline of South African history because
it was a process that was designed to put distance between the brutal apartheid past,
characterised by racial inequality and violence and the (envisioned) new non-racial
South Africa that is now a constitutional democracy. As the Chairman of the TRC,
Archbishop Tutu made it clear in his foreword to the TRC Report, the commission
sought to expose the brutalities of the past in order to foster a new culture of human
rights.9 As such, the TRC sought to expose apartheid history in its brutality, its gross
human rights violations and perpetrators of such violations, to create conditions for both
victims and perpetrators to tell the truth in order to provide ‘as complete a picture as
possible of the causes, nature and extent of the gross violations of human rights which
were committed’10 during a particularly brutal phase of apartheid spanning 34 years
from 1960 to the dawn of democracy in 1994. Framed as an open process that prized the
truth above all – those who sought amnesty had to tell the whole truth pertaining to their
actions, demonstrate the political nature of their actions and prove its proportionality in
order to be granted amnesty – and encouraging individuals from all sectors of society to
come forward with their stories, the commission was meant to be an inclusive airing of
past grievances in order to heal and reconcile. A process that accepted four kinds of
truth – social/shared, healing/narrative, personal and forensic truth – the TRC obviously
understood that past inequalities meant that not everyone, in fact, many of the country’s
racialized and poor, did not have access to official bureaucracy and therefore were cut
off from representation; many would not have been able to produce official records or
forensic evidence, the commission resolved to hear personal and narrative truth.

Here, I would suggest that the commission, as ceremonial event that normalized
particular forms of public speaking, brought into South African consciousness and
jurisprudence ways of self-representation that favoured spectacular affective modes
such as loud crying or wailing, atavistic public reactions such as fainting and vomiting
in public formal forums. Most importantly though the TRC concretised a clinical,
western understanding of trauma. Although the commission and organizations assisting
the commission understood that trauma could be collectively experienced, they
advanced a medical model that framed trauma as a personal experience that individuals
needed to heal from. The TRC further imbued victimhood with morality such that those
who had suffered had the power to not only forgive but to reconcile with perpetrators
and assist in reintegrating them to society. Such framing of victimhood became
particularly problematic when the Commission turned to white pain and it is the
corrosive legacy of white victimhood that I identify as the afterlife of TRC whose traces
were evident in the Oscar Pistorius trial; this article will focus on the wounded white
privilege that characterised the Pistorius trial and what it portends for disability
discourses in an unequal society like South Africa.

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10 Promotion of National Unity and Reconciliation Act 34 of 1995.
While the scope of this essay cannot accommodate a thorough analysis of the representational modes of the TRC or how they influenced South African jurisprudence, nor can it accommodate an exhaustive analysis of social media discourses surrounding the Pistorius trial, I investigate the way that the TRC shaped, even standardised, the way that violence can be publicly recounted. The article looks at echoes and traces of the TRC in the way that wrongdoing, popular understanding of trauma and its relation to violence and framing of social identities were individualised. It demonstrates how the pre-murder trial Oscar Pistorius relied on hegemonic, heterosexual, white masculinity to structure his public personae, the peri-and post-murder trial Oscar Pistorius drew on his disability to eschew the same registers that had fed his image as a highly paid elite athlete. In what follows I track how, to paraphrase Eli Clare, public discourses about Oscar Pistorius reached into gender, wrapped around class, strained against heterosexuality, collapsed on race and folded into disability, as all discussion pivoted on one human body.11

The Race to Normate: Oscar Pistorius and Ableist Masculinity

In contrast to social media that was saturated with puns about legs and cheap humour about Pistorius’s disability, none of the traditional media commentators mentioned his disability as an important factor in the case. In fact, before the commencement of his trial for the murder of his girlfriend, very little was said to link Pistorius’s disability to his crime. Leslie Schwartz suggests that superficially the focus on race, crime and gender violence and not on disability in the public discussions of Oscar Pistorius may be evidence of the success of mainstreaming, that ‘Pistorius had become such a mainstream icon that his impairment seem irrelevant.’12 But, when one digs deeper, according to Swartz, the issues relate to intersectionality, specifically the failure to chart ways that disability, gender, race and class work with and against each other. However, even if superficial, the mainstreaming of Oscar Pistorius is still important, because his public personae embraced a hyper-masculinity that subscribed to able-bodied heterosexuality. In this hegemony, as critical disability studies scholars drawing upon a range of disciplines and theoretical standpoints have amply demonstrated, the social and cultural constructions of disability as abnormality in turn produce institutions and architecture that treat disability as an alien condition that requires special accommodation.14 Pistorius’s public image embraced the construction of disability as abnormality in turn produce institutions and architecture that treat disability as an alien condition that requires special accommodation.

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11 Eli Clare’s oft-cited dictum that “gender reaches into disability, disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race ... everything finally piling into a single human body” pinpoints the intersectionality that attends all identities but also posits disability as difference within difference. Eli Clare, Exile and Pride: Disability, Queerness and Liberation (Durham and London: Duke University Press, 2015), 143.


13 I am using able-bodied here to refer to the cultural representation that Pistorius subscribed to in his public image, which as I demonstrate frames disability as a choice rather than a socially constructed reality, so my intention in using this word is to highlight its meaning for Oscar Pistorius: while ‘able-bodied’ is cultural construction, his public image bought into it as a reality, especially through his comments about disability.

deviance or difference that one can, with admirable fortitude of course, overcome. He did not reject these social constructions of disability but reinforced them when he pushed his own story of overcoming and transcendence. In his various retelling of his life-story, Pistorius emphasised his own persistence and drive, rather than social support or identitarian solidarity. His narrative of overcoming and assimilating depoliticizes disability and instead portrays physical impairment as personal tragedy that gifted and driven individuals can overcome. His personal story makes light of his class, race, gender and sexuality. While many individuals are positively recalled as having supported and helped him throughout his life: for instance, his extended wealthy family provided financial support for him to attend the best school in the country, which were equipped with the best sporting facilities, he had coaches who recognized and nurtured his talents, all of which are social structures that his life narrative treats as individual blessings.15

When Pistorius is extracted from the cultural and social conditions that facilitated his success; for instance, when he is depicted as the ‘ultimate meritocrat’ in a ‘nation obsessed with disadvantage’16 as Alex Perry claims, the social barriers that prevent many disabled people from living full lives, let alone exceptional ones like Pistorius, are depoliticized. This is the narrative of the supercrip that Pistorius embraced, that of someone who excels at many physical pursuits, more so than the ‘abled’ people, so much that he exhorts or motivates or inspires others to do the same. It was this image that was celebrated by those who covered Pistorius before the murder. Nearly all commentators focused on his super-ability, how he ‘defied the odds’ ‘never let his physical impairments limit him’ and his own oft repeated claim that ‘You’re not disabled by your disabilities but abled by your abilities’ also emphasised individual prowess over social redress.17 As a supercrip, Pistorius fell into the ‘inspiration porn’ trap that many scholars identify,18 where disabled people either performing amazing or mundane tasks are held up as examples for other disabled people to follow and as reminders to the normates that life could be worse. This is the so-called inspiration porn that is criticized for objectifying, devaluing and individualizing disabled people. As Eli Clare wryly observes that the inspiring supercrip narrative serves to reinforce the superiority of nondisabled people and does nothing to change the conditions that make the lives of disabled people challenging. Media writing about Pistorius before the murder exalted his ability to ‘transcend’ his disability and to inspire others to ‘overcome’ their challenges. When he sought to compete with nondisabled athletes in

16 Perry, 181.
17 Before the murder trial, Pistorius was to feature in the ‘It Gets Better Campaign’ meant to encourage gay youth and against bullying, and in various message he punted the message that anything can be ‘overcome’. Granted, as the late activist and comedian Stella Young remarked: ‘Most journalists seem utterly incapable of writing or talking about a person with a disability without using phrases like “overcoming disability”, “brave”, “suffers from”, “defying the odds”, “wheelchair bound” or, my personal favourite, “inspirational”. (Stella Young, ‘We’re Not Here for Your Inspiration.’ ABC; available at http://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006. 2012 [accessed 10 September 2018].
18 See Young. Jan Grue also makes the point that inspiration porn fetishes disability and ‘focuses on impairement, and specifies disability as biophysically caused and symbolically distinct’ (‘The Problem with Inspiration Porn: A Tentative Definition and a Provisional Critique’, *Disability and Society* 31.6 (2016): 838-49).
the Olympic Games, he stretched the supercrip narrative even further to the discourses of ‘too abled’, superhuman and therefore ‘freakish’ as Eli Clare would put.19

The late disability activist and educator Stella Young has argued that images of ‘inspiring’ disabled people ignore the social construction of disability, because as she puts it, ‘[b]y far the most disabling thing in my life is the physical environment,’20 and, most importantly, these exhortations to view what disabled people do as inspiring ignore other associated oppressions faced by people with disability. Young observes: ‘[t]here’s the one pictured here. It’s of a little girl running on a set of prosthetic legs alongside Oscar Pistorius, also using similar prostheses. Those legs, for the record, cost upwards of $20,000 and are completely out of reach for most people with disabilities.’21 When Pistorius cultivates this image of disability as inspiration, he is extracted from South African society where the majority of the population would not have the kind of access that he has. Wendy Chrisman has tried to recover inspiration for disability studies, urging scholars not to discard the concept that people with disabilities can be inspired by the work that they and others do22 and there is plenty of evidence that for many Paralympic athletes Pistorius was as inspiration. For example, Sabelo Radebe, his 4x100 m relay teammate for the London Paralympics credits Pistorius for improving his performance.23 However, whereas such examples are important, they do not translate to political solidarity with other disabled athletes, since among other disabled athletes, Pistorius stood out precisely because unlike many black, disabled, and poor people, he enjoyed wealth and access that facilitated his rise to the top. Class and race added extra fuel to his sporting ambitions, and historically, apartheid provided support and access for white people with disabilities, a fact that is reflected in the over-representation of white athletes in the Paralympics.24

When disability is objectified and individualised in order to highlight the individual’s ability to transcend limitations, Stella Young adds, other people living with disabilities are shamed, hence the tag ‘your excuse is invalid.’25 As a super-crip, Pistorius was not just projected as a super-athlete, and a humble nice guy to boot, but as an almost mythical alpha male, who bought and sold tigers, loved guns, fast cars and women. In fact, a year before the tragic killing, the New York Times Magazine wrote an acclamatory article titled ‘The Fast Life of Oscar Pistorius’ about his super-ableism that included references to his love of guns, extreme sports and his boundless energy.26 The picture of Oscar Pistorius that emerges from this article is of a young carefree athlete who is living what is a ‘normal’ professional athlete’s life of privilege and access that exceeds that of elite disabled athletes. As disability activist Eddie Ndopu remarked, ‘Oscar’s stardom as a professional athlete stemmed from his capacity to “overcome” the

20 Young.
21 Young.
23 See Carlin.
25 Young.
26 Sokolove. And as an aside, the article also hinted at his love of women: ‘Pistorius had recently broken off a relationship with his long-time girlfriend, though another young woman was visiting when we got there.’
“tragedy” of a “broken body” by outperforming what Robert McRuer calls “a compulsory ablebodiedness” and in so doing, re-entrenching it in the able normative imagination as a benchmark of personhood.’

The pre-murder portrayals of Pistorius perform what Judith Butler terms, in ‘Critically Queer’ an approximation of the norm. In approximating ableism, rather than challenging debilitating stereotypes about disabled people, or questioning normative hegemony, Pistorius re-inscribed normalcy at the heart of hegemonic ableism. As many disability studies scholars have highlighted, in fact, disability studies theories, in particular crip theory, hew close to queer theories in regarding approximation with suspicion as a reiteration of hegemonic identities. Thus, when Pistorius built his public career on rejecting the limitations of his physical impairments, in fact on transcending disability, he was not subverting ‘compulsory ablebodiedness’, but rather reaffirming the portrayal of disability as a flaw or deviance that needs to be fixed or at least transformed through medicalisation. When Pistorius went further than competing in disabled athletics and sought inclusion in the Olympic Games, he was not rejecting the exclusion of athletes with disabled or ab/normal bodies, rather he was facilitating his own passing; and, according to Swartz and Watermeyer, he was reinforcing ‘the neo-liberal pecking order of capital accumulation and the economy of power.’ However, Swartz and Watermeyer go on to suggest that Pistorius was seeking to destabilize this pecking order, threatening to ‘move successfully from one discursive meaning system, where he may be seen to belong, to another.’ And by so doing ‘shaking the very foundations of the attribution system which maintains the separation as meaningful.’ However, I argue the contrary, that by seeking inclusion into the ‘abled’ category, Pistorius was succumbing to the power of the system, making the case that he was exceptional enough for its rules to admit his inclusion. His was an approximation of the heteronormative ableist norm. His hyper masculine image, ‘the bullet in the chamber ads’, was framed as compensation for whatever shortcomings he might be perceived to have. Pistorius did nothing to challenge the image of disability as pain and trauma, he claimed to have surmounted both. It is not coincidental that magazine articles referred to how his stumps would bleed after practice or races, to emphasize the price of admission, which was, in his case, the pain he had to endure in order to accomplish his goals. He therefore was not seeking to subvert or rejig social orders but seeking a higher place in the social hierarchization of bodies that is inherent in professional sports.


29 Michael Berube, Robert McRuer, Eli Clare are among the leading Crip theorists who have drawn parallels between Crip and Queer theories.


32 Swartz and Watermeyer, 188.

33 Of course, De Oca points out that ‘the athlete who heroically emerges from physical and mental trauma is a repeating metaphor or trope of masculinity in sport films’. See Jeffrey Montez de Oca, ‘Paradox of Privilege: Sport, Masculinities, and the Commodified Body’, in eds David L Andrews, Ben Carrington, A Companion to Sport (Oxford: Blackwell Publishing 2013), 153.
Many anecdotes illustrate Pistorius’s disavowal rather than denial of his impairment; in various articles he refers to an incident where his mother instructs his older brother to put on his shoes, and him (Oscar) to put on his leg and get in the car. Another equally illustrative anecdote appears in the biography Oscar Pistorius: Chase Your Shadow, where Pistorius and his mother are interviewed by the headmaster at Pretoria Boys High and the headmaster expresses concern about whether Pistorius will cope at the school. His mother reportedly responded: ‘But please don’t worry. There’s no problem at all. He’s absolutely normal.’ In both these anecdotes, Pistorius is taught to at once acknowledge and ignore his physical impairment. Rosemarie Garland-Thomson refers to the differentiation between felt and ascribed identities and suggests that one becomes disabled when one’s disability is recognized and accommodated. As Garland-Thomson explains, ‘[s]imply put, one’s felt identity is how one experiences oneself as an embodied, perceiving, conscious subject at the center of one’s own world. One’s ascribed identity is the subject position other people project upon one or understand one to occupy.’ It is only at his trial that Pistorius seeks accommodations as it were, where he wants to merge his felt identity with his ascribed identity as a disabled person.

For pre-Murder Oscar Pistorius, subscribing to the supercrip image was not necessarily noteworthy or even contradictory because for elite athletes, frequently framed as role models, there is an expectation of ‘extraordinariness’ and for disabled athletes, according to Jan Grue ‘[t]he ideal Paralympic athlete is so impaired that ordinary achievement looks inspirational, but not so impaired as to be incapable of truly inspirational, extraordinary accomplishment’. It’s not the performance of unimaginable feats for the ‘ordinary’ folk, or excelling at something that few excel at, it’s doing so within limits; it’s the visible limitations that are rendered ‘meaningless’ even as all signification depends on them, To put it in other words, there is a reason why in what Stella Young calls ‘inspirational porn’, as mentioned earlier, the disability is always prominently displayed, whether it’s stumps or the wheelchair next to extraordinary feats, either physically sculpted bodies on wheelchairs or mountain climbers with no hands, the ‘inspiration’ of the message imagines someone with arms or not on a wheelchair, someone who just does not have the right attitude, because they have no real impediments. Oscar Pistorius wanted to move beyond the fetishistic focus on his impairments, rather he sought to ‘normalize’ and then transcend as if he were normal. I emphasize this because his public image depended on the oft repeated stories of how he had never been accommodated, how his prosthetic legs were as different as a pair of shoes, so that, as mentioned earlier, his mother can tell his brother to put on his shoes and Pistorius to put on his legs, both acts being the same. A big part of his case against the IAAF, when he wanted to compete with ‘abled athletes’, was that he gained no advantage from his carbon fibre prosthetics.

If, as Robert McRuer suggests, ‘compulsory able-bodiedness functions by covering over, with the appearance of choice, a system in which there actually is no

34 See, for instance Sokolove and Carlin.
35 Carlin, 48.
37 Grue, 843.
choice’, then Oscar Pistorius constructed an image of someone who chose to be abled; his entire public personae hammered home the idea of disability as choice and accommodations as unnecessary luxuries for the self-indulgent. This glossed over class and race experiences of many of South Africa’s disabled, who could not have access to schools, sports facilities and therapies that most whites, regardless of class, had. Pistorius was able to subscribe to the disability as choice notion through what McRuer describes as the ‘well-nigh universal valuation of flexibility’ which he articulates as the hegemonic social order’s ability to expand and contract to accommodate and exclude depending on circumstances. The notion of able-bodiedness can expand to include Pistorius when he checks many other boxes in the social order and complies with capitalist imperatives to instrumentalize his body. He becomes a particularly useful symbol for what Michal Ran-Rubin calls the liberal citizen subject, a subject who ‘is the liberal, labouring subject of modernity: in other words, the autonomous rights-bearing subject who exhibits the qualities and capacities – such as rationality, free will, and intellect – deemed necessary to ensure formal equality; who produces and consumes for the nation-state; who possess an equal moral weight in comparison to all other subjects and can therefore be held responsible for his or her own actions.’ So the heteronormative able-bodied hegemony can be flexible enough to accommodate Pistorius even with his visible impairments if he more than compensates in other aspects, particular where he reiterates individual choice where many expect social support. It makes sense therefore that many commentators ignored the social construction of Pistorius as a disabled person and focused instead on his actions as a white wealthy, heterosexual male because, difference, in disability scholarship struggles to encompass other alterities. What are we to make of Lisa Vetten’s comment that:

Disabled men and women often struggle with their sense of masculinity or femininity because they are to some degree dependent. I have seen examples of them placing particular pride on physical attractiveness. Maybe he struggles with that. The guns and sports cars gave an impression that he was over-compensating so as to be seen as ‘normal’?

Such generalizations simplify what is a complex interlocking of race, ethnicity and class; they pretend that disability cuts across all these categories seamlessly. For millions of South Africans guns and sports cars do not connote normal, and for even more there are many differing cultural interpretations of what constitutes disability so much that ‘attractiveness’ is an insignificant factor. The question of dependence also has so much to do with one’s social location that it is hardly generalizable.

Whose Trauma Is It Anyway? White Victimhood after the TRC

In the previous sections, I have been referring mainly to pre-trial Oscar Pistorius to track the many contradictory claims that he relied on to either carve out an important

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38 McRuer, 8.
39 McRuer, 7.
41 Lisa Vetten, quoted in Alex Duval Smith ‘South Africa’s macho society, where attacks on women are the norm’ The Guardian, 17 February 2013, via www.theguardian.co.uk [accessed 30 September 2018].
cultural space for himself or to avoid consequences for his actions. Such differentiations refer only to the claims made by Pistorius, his legal counsel or his publicity machine, and not to the actual person, because this article engages with Oscar Pistorius’s public personae and how that figure has moved through various phases in public discourse. There is also Oscar Pistorius as the subject before the law, what Michal Ran Rubin calls the legal-liberal abstract subject with abstract rights. This Pistorius was a construction of his legal team and it is his claims about trauma, vulnerability and rights that I will endeavour to link to the wider social discourses of white vulnerability in South Africa.

Part of Pistorius’ defence in his trial was that he feared crime and had shot through the door because he thought there was an intruder lurking in his bathroom. In his bail application, he filed an affidavit that emphasised this defence and sought to paint himself as shocked and traumatised by the death of his girlfriend because he had not intended to murder her. This fear though, as Alex Perry was quick to point out, has a troubling history in South Africa. Crime writer Margie Orford calls it the South African version of the ‘black peril’, which she goes on to describe as ‘perhaps the most atavistic of white South African fears.’ Thus, even before the trial commenced, Orford was able to predict that the trial would be haunted by the phantom black body of this peril:

So the trial will revolve around Pistorius’ intention: essentially, the psychology of a man who claims to have been driven by fear to shoot before asking any questions. This claim inserts a third body into an all too familiar narrative of domestic violence. This imaginary body, of the paranoid imaginings of suburban South Africa, has lurked like a bogeyman at the periphery of this story for the past year. It is the threatening body, nameless and faceless, of an armed and dangerous black intruder.

This imaginary black intruder was meant to resonate with the South African middle class that was struggling against rampant crime and lawlessness; and was, therefore, not a racial imagining. Yet, this fear of the black intruder, particularly in its use in the Pistorius trial, was linked to various popular perceptions of white victimization, particularly the white victimization after the advent of the democratic dispensation. It is this victimization that Pistorius’s father, Henke Pistorius, appealed to when he blamed the ANC government for Steenkamp’s shooting, claiming that the government failed to protect white people.

A few days after the shooting, Pistorius swore an affidavit in his bail application which was to be the basis of his defence. At his trial, he expanded on claims made in

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42 Rubin, 247.
45 Orford.
this affidavit where he paints himself as someone who did not harbour racial prejudices and who had friendly interactions with black neighbours, security guards and other black workers. He interspersed his testimony with anecdotes that highlighted the high level of crime he always faced in a way that was supposed to set up his later claims of generalized anxiety disorder. Throughout his testimony and from cross-examination, this was clearly his defence strategy. Pistorius sought to paint a picture of violent lawlessness that threatened all lives, especially in middle class suburban areas, and a corrupt police force that was wholly incapable of dealing with criminals. As Orford claims above about the phantom (yet ubiquitous) armed and dangerous black male intruder at the heart of these fears, this hallucination legitimizes all manner of violence against the black poor. So, in his claims about the imaginary intruder, Pistorius was linking together many cultural stereotypes about social relations in post-apartheid South Africa. The first is that white people are targets for violent crime, a claim which is popular despite statistics showing that white people are 8.9 times less likely to suffer violent crime than black people. Second, perhaps most glaringly evident in the so-called family murders of the late 1990s, that white women and children deserve protection from this menace at all costs – a claim that has been used to explain all manner of violence against white women and children. Third, that white fortunes drastically changed for the worse after 1994, which again justifies all manner of transgressive acts by white people, especially socially prominent ones. All three stereotypes that paint a picture of white people under siege in South Africa are undergirded by popular understanding of trauma and its effects, which I want to suggest, is linked to the way the TRC framed trauma in its proceedings, and how the media also popularised that framing.

Early on in the TRC’s life, there was concern that white people were not visible at the public hearings, specifically the victims’ hearings into human rights violations and this gave the impression of black victimization and white apathy or worse, white-sanctioned violence. As former commissioner, Pumla Gobodo-Madikizela explains:

> Public hearings had been in session for two months throughout all the regions and white people were simply not visible at the hearings… The first step was to figure out how to engage white people with the process, to find something that they [sic] could make them identify with the work we were doing. Now, army conscription is one thing in apartheid history that affected all white families. So we approached a woman whose son had been killed in ‘action’ and asked her if she could tell her story before the TRC.

In hindsight (perhaps at the time it was not so obvious) such assertions raise racially charged questions: why it was important to have ‘white visibility’ at the hearings, or why would a process designed to counter the effects of a system that had been labelled a crime against humanity, a system that unashamedly advanced and protected white hegemony, need white people to identify with it? Of course, at the time, the commission took its ‘reconciliation’ mandate seriously, and part of that mandate, at least in the commissioner’s interpretations of it, meant white and black/coloured/Indian people coming together. But how far did this reconciliation go when there is white fear

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48 Some of Pistorius’s claims in his trial can be viewed on YouTube, the trial transcript is not publicly available.
49 This makes statistical sense considering that white people make 8.9% of the population
that still trembles at imaginary black danger nearly 20 years after the TRC held its last victim’s hearing?

During its run, the Commission relied on the western medical notion of trauma to bring everyone together, and there were oft repeated references to wounds of the past that needed to be exposed to healing light. The past was framed as a trauma that everyone needed to recover from, both perpetrators and victims. One of the ways of bringing people together was around the notion of trauma as harming everyone in similarly debilitating ways. For the TRC, apartheid had been a traumatic experience for many people, black witnesses testifying at the commission were describing ‘traumatic events’, and many displays of emotion were characteristic of relating traumatic experiences. Radio broadcasts of the Commission’s proceedings were preceded and followed by contact details of the Trauma Centres for counselling where listeners could seek help if they needed it. The Commission itself made extensive use of trauma counselling centres and employed various counselling specialists. These popular framings of trauma ignored culturally specific ways of thinking about suffering and healing. Furthermore, even in cases where specific brutalities were inflicted on communities, the collective aspect of the suffering was reframed as individual trauma by the TRC. As many critics have subsequently pointed out, the Commission individualised both the perpetration of human rights violations against groups of people, and the suffering of human rights violations in its preferred binary of victims and perpetrators. When used to interpolate a recalcitrant white minority into a national project, trauma is depoliticized and diluted to variety of harms and individuals. And trauma as popular psycho-legal concept that is portrayed as a pathology relating to a set of events risks medicalisation, which in turn negates its social and cultural significance.

The TRC’s medicalization of the experiences of apartheid brutality created a framework where everyone could claim to have been harmed by apartheid and could therefore seek reconciliation over the trauma of apartheid. For the TRC, this meant recognition of white trauma in the hope of reassuring the white public that it was not a witch hunt meant to villainize the white populace, but rather a forum to air grievances about the brutality of apartheid. Thus, as Commissioner Gobodo-Madikizela states, the conscription hearings could foreground white suffering; where white families were lied to by their government and young white men were pressed to serve an abusive government and were in the process maimed or killed.

51 Mahmood Mamdani has written extensively about how the Commission was not just caught up in apartheid legality but in focusing too much on individual perpetrator and victims ignored bystanders and beneficiaries. Mark Sanders also criticizes the Commission for focusing on ‘extraordinary violence’ in a way that ignores everyday violence of apartheid against communities.

52 For instance, the term PTSD was bandied about in much of the TRC writing of the time, Commissioner Wendy Orr wrote about her work under the title ‘PTSD and the Truth and Reconciliation’, Continuing Medical Education Journal 16 (1998): 142-3. A clinical psychologist writing about the ‘trauma of testifying at the TRC’ wrote that ‘[p]eople who testify or give statements to the TRC are survivors of horrific traumas and violence, and many of these people are coping well with the stresses which they have endured. …. Counselling provides an opportunity to understand and work through the symptoms of their trauma’ (See Trudy de Ridder, ‘The Trauma of Testifying: Deponents’ Difficult Healing Process’, Track Two, 6.3-4 (December 1997), 2).

53 These were hearings held at the urging of Commissioners Pumla Gobodo-Madikizela and Wendy Orr to hear about the experiences of young white males who were conscripted to join involuntary service to apartheid security forces for two years after completing high school. See Wendy Orr, From Biko to
When victims like Mrs McGregor appeared before the commission, the TRC was radically configured as a space for harmed, traumatised individuals who were victimised by a vicious (apparently faceless) system. That is because Mrs McGregor testified about losing her son, Wallace McGregor, when he was conscripted in 1986, and her testimony was anchored in the belief that the apartheid government lied to her about what her son was doing and how he died. She was disturbed by the fact that she had never been allowed to see her son’s body when he was brought home for burial. Her TRC appearance received extensive media coverage, and outpouring of responses in the media, creating space for white victimization. The public outpouring also allowed the commissioners to pontificate about the shared grief of mothers who lost their sons and the public at large to externalize human rights violations as ‘apartheid’s war’ that left victims on all sides. To put it another way, while before the McGregor moment, white apathy was described as a ‘problem’ requiring a solution, and not a statistical reality, or a reflection of how apartheid operated, after McGregor, pop psychology explained white apathy as a symptom of suffering. The commission imagined a wounded white public that needed a channel to voice its collective pain and the image of the grieving mother, willing to embrace the other (much was made of the black women who embraced Mrs. McGregor) served to draw in the apathetic white audience.

This attention to white victimhood, especially through conscription, allowed social discourse of ‘white genocide’. For instance, the cultural legend of bossies, literally ‘bushes’, a colloquial reference to PTSD symptoms exhibited by those returning from conscription was immortalised in Paul Slabolepszy’s play *Saturday Night at the Palace*. The vulnerability of white males also featured in the works of Mark Behr, Michiel Steyn to mention a few. So, Pistorius’s claim of special vulnerability has a history and context, he becomes a poster child for ‘unspoken’ (while loudly trumpeted) white pain. Thus, just as the TRC, a process that was meant to heal the wounds of apartheid, presumably a system that harmed black South Africans ended up attending to white pain (even if for a while) through conscription hearings, the Oscar Pistorius trial turned away from the dead white woman and the black male phantom she was purportedly imagined to be, and focused on white male trauma of exclusion. As Jacqueline Rose puts it:

> To save his skin, Oscar Pistorius ventriloquised a woman, or was led by his legal team to do so. He took her place. Behind what might be seen as a moment of unanticipated and welcome gender confusion – since gender confusion is always, or nearly always, to be welcomed – we might also, or rather, see a man going to the furthest lengths he can go, including sacrificing the image of himself as a man, to make absolutely sure that no one hears the voice of a woman crying out in fear for her life.  

It is this ventriloquism that disability studies needs to address in order to be useful in a South African context where apartheid history and the TRC has always marginalized black pain. The medical model of trauma allows whiteness to ventriloquize and

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54 Orr, 18.

55 Michiel Heyns’ *Children’s Day* (2009), Mark Behr’s *The Smell of Apples* (1997), Rachel Zadok’s *Gem Squash Tokoloshe* (2006) are all novels that deal with white children who suffer apartheid related traumas, and whose childhood is marred by apartheid cruelty.

56 Rose, 10.
eventually displace black pain. Trauma as a medical concept that defines a particular experience of dealing with painful experience appealed to the Oscar Pistorius defence team because it explained his actions and absolved him of culpability. As a disabled white male with a history of marginalization and victimisation as a white person, he suffers both individual trauma as a person with disability and collective trauma suffered by other wealthy white people whose wealth makes them the target of crime. Support of Pistorius, the white interest groups like Afriforum and other media, sought to tie his actions to persistent white fears of falling victim to black crime or being dispossessed by the new dispensation. It is in this context that Pistorius’s father could blame the ANC government for his son’s actions, as he emphasised that ‘crime against white South Africans was a huge problem.’

While some of those who defended Pistorius bought into this whiteness under siege in South Africa portrayal, Pistorius’s defence also laid claim to individual trauma. This defence focused on Pistorius’s body as the primary site of trauma, during his trial and sentencing he ‘embodied’ his defence claims, retching and crying when emotional testimony was heard, and walking on his stumps in lieu of testifying during the sentencing phase, after the state had successfully appealed his earlier conviction. During the trial he claimed that his disability made him particularly vulnerable to crime and that his disability would make imprisonment exceptionally cruel and unusual as prison lacked proper accommodations for his physical impairments. For someone whose entire public persona was based on his careful management of his body to the extent of transcending his disability, it was particularly jarring that much of the reportage on his trial focused on his ‘broken-ness’: he was a broken man, broke down during his testimony, and so on. Ironically, the defence tallied in a macabre way with earlier claims of disability as a matter of attitude. Essentially, the claim that Pistorius had generalised anxiety disorder which made him prone to violence at the slightest provocation, placed disposition at the heart of disability. Such representations resonate with pernicious stereotypes of ‘disability as the most traumatic experience on earth’.

Where before Pistorius was acclaimed for transcending his disability, he was now pathologized for having been taught to repress his disability and ignore its effects on his life. Where before he had objectified himself as an inspiration, he now became a pitiful spectacle. At issue here is that Pistorius is right about the vulnerability of disabled people and the prohibitive built environment that does very little to protect them and correctional services that was not built to accommodate people with disabilities. However, he could have done so without constructing disability as a trauma. His counsel would have done better to point out how ableism constructs disability as lack, deviance and difference, and could have raised trauma with regards to ableist prejudice. When Pistorius claimed disability as trauma in his defence, he effectively valorised the self above social context and historical conditions. On the one hand, many commentators sought to cast Pistorius as a stand-in for many white South Africans who are terrified of crime and many also referred to his purported crime as a symptom of

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South Africa’s violent culture.\textsuperscript{59} And while his defence tapped into these generalizations, by claiming a unique pathology that results from his disability and how he was raised to view it, Pistorius was at once incorporating and rejecting these generalizations; simultaneously claiming to be part of a community that was exceptionally vulnerable to victimization and yet an individual who suffered from anxiety due to being raised to repress his disability.

**The Unfinished Story of History and Trauma**

Trauma as a cultural concept (for instance in trauma studies theories), may at first appear to be a useful way to think about reconciliation, and it may appear that the TRC could have framed trauma as a a useful concept for reconciliation, as Cathy Caruth, envisaged that ‘trauma may provide the very link between cultures’.\textsuperscript{60} However, it is the western understanding of trauma that frames it as that link, because if trauma is about grappling with the unspeakable, then we need to understand the mutability of the unspeakable, that is, we need to accept that what is unspeakable in one context is not universally so. Trauma is therefore not a universal experience and pain as a cultural concept necessitates a cultural response. As Stef Craps has usefully pointed out, by mapping ‘the Euro-American concept of trauma and recovery onto the apartheid-colonial situation [the TRC] was subject to the same problems and limitations faced by trauma theory.’\textsuperscript{61} For Craps, one of those limitations is that trauma theory individualizes suffering and therefore depoliticizes it. He writes: ‘[s]urvivors are pathologized as victims without political agency, sufferers from an “illness” that can be “cured” within existing structures of institutionalized psychiatry.’\textsuperscript{62} Hence, the western model of trauma does not account for pain and suffering in different cultural contexts. I am thinking here of culture as learned behaviour and therefore the way that we are taught what events are worth committing to memory, how to think about the past and even how to feel about certain events. In this sense, traumas must inherently be defined through difference. The way that Pistorius became the ‘inspiring’ hero was through denial of difference and marginalization of raced and gendered experience of disability. Hidden in this image is the racialized access that Pistorius enjoyed as a disabled white male. In the image of Pistorius as an inspiration, many were supposed to learn about transcending the historical legacies of apartheid even if no resources were made available to do so. In the previously cited *New York Times Magazine* article for instance,\textsuperscript{63} Pistorius takes the journalist on a site visit to Khayelitsha, a township outside Cape Town, and impresses upon him that the prevailing inequality and black poverty cannot be ignored. And yet the resulting article does precisely that, rather than offer any account of this ‘site’ and its history, Khayelitsha and its poor are mere props in the story about Oscar Pistorius’s social consciousness, humility and disposition. Oscar Pistorius


\textsuperscript{60} Cathy Caruth, *Unclaimed Experience: Trauma Narrative and History* (Baltimore: Johns Hopkins University Press, 2010), 11.


\textsuperscript{62} Craps, 56.

\textsuperscript{63} Sokolove.
the villain however, the man who lived in fear of being victimised by black criminals, gives us the self in history. A white self that emerged in the TRC hearings, the victimised white male of the conscription hearings, whose wounds were ‘equally’ worthy to be licked by the TRC. In holding the conscription hearings solely to hear young white males’ experience of apartheid, the Commission advanced the idea that there was pain on both sides, as if there were two sides. By creating a forum for white pain the Commission truckled to apartheid racial imaginary of different races that needed to figure out a way of co-existing. Had the TRC been attuned to the different cultures under apartheid, and how difference meant separate and unequal, it could have reconfigured trauma in a way that is conscious of its historical context. Similarly, Pistorius’s claims of victimization and vulnerability, as unconvincing as they were for many who watched the trial, call attention to the ways that disability as a social construction needs to be sensitive to each context. As a star athlete Pistorius’s popularity relied on denial of the social limitations faced by many disabled people in South Africa, and in his trial he produced these self-same social limitations to defend his actions.

Bibliography


**Invincible, dar vulnerabil: problematicile rasei, ale dizabilității și ale trauimei în Africa de Sud după procesul lui Oscar Pistorius**

Atunci când personajul devenit iconic la nivel global, câștigătorul la Paralimpice, Oscar Pistorius a fost acuzat de uciderea prietenei sale, Reeva Steenkamp în dimineața zilei de Sfântul Valentin din 2013, una dintre multiplele apărări ale sale s-a bazat pe faptul că dizabilitatea sa fizică l-a făcut să ucidă. Un martor expert din partea apărării sale a făcut conexiunea dintre dizabilitate și violență și a sugerat că oamenii cu dizabilități au tendința naturală să exagereze deoarece se simt foarte vulnerabili. Această apărare prevede legătura dintre cele două extreme ale persoanei publice ale lui Pistorius, aceea a invincibilității și aceea a vulnerabilității – o abilitate fizică extremă definită prin modul în care a bravat fizic ca sportiv și teama de a deveni o victimă din cauza limitării fizice. Formula propusă de avocații apărării este aceea a vulnerabilității extreme care rezultă în agresiune extremă. Acest articol încercă să analizeze
ceea ce se sugerează prin această revendicare a dizabilității în legătură cu atitudinile sociale privind dizabilitatea și persoanele cu dizabilități, în mod particular în Africa de Sud din perioada post-apartheid – sau mai precis în perioada de după înființarea și funcționarea Comisiei pentru adevăr și reconciliere (Truth and Reconciliation Commission). Articolul sugerează că legalitatea fragilă a acestei comisii a creat un teren fertil pentru victimizarea albilor și a popularizat un model medical al traumei.
The Double Consciousness and Disability Dilemma: Trauma and the African American Veteran

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Abstract

Daniel Morrison and Monica Casper contend that disability studies and its cultural locations have been remarkably silent on matters of the traumatic origins of many disabilities, on the ongoing relationship between shocking events, their abrupt and chronic impact, and experiences of disability. This article explores how critical disability studies must intersect with critical trauma studies to address how the African American Vietnam war veterans who, traumatized and disabled by war and conflict, are further marginalized by societal constraints of race, class and gender. This essay focus on an understanding of W.E.B. DuBois’s ideology of double-consciousness, critical race theory and cultural studies and how they can emphasize the intersection of war injury and disability with a tremendous regard for the lived racial, class and socio-economic oppressions that contributed to what military service and disabilities of the African American Vietnam veteran reveal about masculine identity.

Keywords: double consciousness, critical trauma studies, critical disability studies, Vietnam War, African American veteran, post-traumatic stress disorder, Veterans Administration

In 1945, Harold Wilke, a journalist for the *Baltimore Afro American* newspaper, provided a socio-political commentary on both the pity and fear that the nation exhibited toward veterans with disabilities by stating:

> When you greet your wounded friend or relative for the first time, use your intelligence and imagination. Greet him as your friend, who was away and has now returned. Letting horror spread over your features and get in your voice because of his crutches or empty sleeves or sightless eyes will make him realize that you think of him, not as a personality, but as a cripple. Greet the Man, not the wound.¹

At the turn of the twentieth century, W.E.B. DuBois coined the term ‘double-consciousness’ describing a world which yields the African American no true self-consciousness, but only lets him see himself through the revelation of the other world. It is a peculiar sensation, this double consciousness, this sense of always looking at oneself through the eyes of others. ² For African Americans who served in the Vietnam War, this double consciousness also emphasizes the encounter between race, disability and trauma, in which, as Stephen Knadler discusses, one may re-imagine questions

about freedom, access, mobility, rights and citizenship. For some veterans, their return home after war and their readjustment to civilian life was coupled with living with debilitating illnesses and injuries that were further complicated by the Veterans Administration’s disability rating system. Identity for a Vietnam war veteran, although fragmented and fractured, had to be re-constructed despite their disabilities and marginalization and is rarely discussed within disability studies. To expand on these concepts, if the body itself is a link between the categories of ‘disability’ and ‘trauma,’ then what is the link between disability, trauma and war, especially for those war veterans whose lived experiences have been marked by racial injustices and systematic prejudices? This essay will reference DuBois’s ideology of double consciousness, intersectionality, cultural studies and critical race theory to further explore of how critical disability studies and critical trauma studies are applicable to the lives, experiences and identity formation of the African American combat veteran who served in the Vietnam War.

Biographical Case Study: My Father’s Story

The biographical case study, for this essay, is the African American combat veteran, specifically who served in the Vietnam War. It is not my contention that this population is worthy of study more than other populations. My contention is to illustrate that the relationship between trauma, war and disability is essential to understanding identity formation. I have witnessed and provided care for my father’s disabled life from wounds, both seen and unseen, that contributed to an expansive understanding of DuBois’ ideology of double-consciousness and how it can emphasize the intersection of war injury and disability with a tremendous regard for the lived racial, class and socio-economic oppressions that not only awaited my father’s return home from war but also contributed to what his service and disabilities reveal about his masculine identity.

My father, Louis Raynor, was drafted into the U.S. Army at the age of eighteen in 1966 and served a 365-day tour of duty in Vietnam (1967-1968) with the 3rd Squad/5th Cavalry, 9th Infantry Division (Black Knights) during the Tet Offensive. As an African American man serving in the military, he was historically perceived as a cowardly and servile soldier merely because of his race. My father never imagined himself maturing into a disabled veteran at the age of forty-three with an identity based on a myriad of social constructions. As a combat veteran, which service-connected injury or illness rendered my father ‘disabled’? Was it the tank explosion that caused temporary blindness and an eye injury; was it the migraine headaches that began to manifest while he was still in a combat zone; was it the diabetes that he was diagnosed with at the end of his tour of duty that lead to peripheral neuropathy resulting in his use of a motorized chair for mobility; was it the hypertension, stomach tumors or post-traumatic stress disorder (PTSD) from his service; or was it finally the diagnosis of multiple myeloma blood cancer from exposure to Agent Orange that requires chemotherapy for the rest of his life, and according the Veterans Administration (VA), comes with an automatic death benefit for my mother? During my father’s tour-of-duty, he began to keep a daily diary. It was within these pages that Raynor documented combat stressors, illnesses and injuries that later became service-connected disabilities.

When Raynor started writing in his small, leather-bond burgundy diary measuring 5.5” x 4” which was compact enough for him to keep in either his footlocker or inside his uniform wrapped in plastic to protect it from rain when he was out in the field, he did not know that it would be later used as evidence to prove his service and assist in acquiring his disability ratings. In the diary, Raynor immediately redefined himself as a soldier by writing on the inside cover of the diary all of his essential and physical information. Inside the front cover of the diary, he wrote his name, rank, unit, date of departure for Vietnam, body measurements, home address, telephone number as well as the name of his girlfriend who was later to become his wife and my mother. The body measurements such as height, weight, etc. reflected a part of the physical exam given to soldiers during their official induction into the military. Including that information at the beginning of his diary helped defy the stereotypes and prove his readiness for military service and combat while also leaving a trace behind in case this was the only evidence that he participated in the war. The organization of his diary would be extremely important for medical documentation but also for verifying when he experienced the traumatic stressors of being in a combat zone.

The first page of the Raynor diary began on January 1. He recorded the events of each day on that same exact date. On the first page of the diary (January 1), he scribbled a note to turn to September 24. Since his tour of duty began September 24, 1967, the diary began in the middle and read according to the days of his tour from September 24, 1967 to September 23, 1968. The diary chronicled the dates of his tour of duty from September to December and it continued from January to September. Instead of counting the days of his tour in chronological order, from Day 1 to Day 365, Raynor did a backwards countdown, indicating his first day in Vietnam as Day 365 and to his last day as Day 1. The very first entry in the diary was September 24, 1967, which was the day he was supposed to leave for Vietnam but because of delays at the airport, he marked September 26, 1967 as Day 365, indicating the day he actually left home for a 12-month tour of duty in Vietnam. As Raynor’s tour was ending, he wrote the last few days as multiple entries on the same page. He continued to count down until Day 1, September 24, 1968, which was the only blank page in his diary. On several pages in the back of the diary, he wrote the names and addresses of family and friends. On the inside back cover of the diary, there were tiny, monthly calendars for the years 1967 through 1972, where he marked the days of his time in Vietnam. Raynor creatively ordered the passing of time with the diary’s unique organization.4

On January 31, 1968 (240 days until the end of his tour), Raynor wrote: ‘I got paid today and went out on a recovery mission. First, we went to Swan-lock and pulled a P.C. pack then left and went to Apple (Red-Oak). It happened again. I stayed overnight with no sleeping gear or extra clothes. I went to the medic for some headache medicine. I have been having headaches since I’ve been here.’ In a span of just three days, starting May 3, 1968 (146 days until the end of his tour), Raynor continued: in his diary about several injuries and enemy kills. His confession went on: ‘I haven’t gotten any sleep yet. I got paid. I took an engine to B-Troop’s location and returned for my tools. C-Troop had lost fourteen men and 20 injured. 186 VC dead so far today. I pulled guard all night. C-Troop killed 6 VC and two G.I.s were injured. It was hot and about 105 degrees today. B-Troop was hit and a couple of G. Is were injured.’ Raynor wrote,

The gas exploded in my face. I was burned. I went to the 18 serge (hospital). I was treated then I returned to my location.’ On July 8, 1968 (80 days until the end of his tour), he wrote, ‘Today was a sorta wait to see what happened. My ankle and knee began to hurt so I stopped at the medic to have it checked. He said it came from working in the sand all day and standing.’ On August 2, 1968 (55 days until the end of his tour), Raynor continued, ‘I was sent to B-Troop to work on the VTR and a new tank B18. And that all I did was work on the VTR because I did not accomplish nothing only a headache. I repaired the tank and when I was done I returned back to my location and tried to rest’. By the end of his tour of duty, he returned home as a war veteran and immediately started seeking medical attention for ongoing migraine headaches and various other complications, including the trauma from combat exposure. Even later in his tour, he continued to document his condition. His writings indicated how soon into his tour his medical issues began and how they continued throughout his service in country. Multiple hospital stays and often unexplained illnesses marked his homecoming.

In 1992, when my father was only forty-three years old, according to the language used by the doctors, he was totally disabled and unable to work, but according to VA regulations and the disability rating system, he was only 10% disabled for debilitating migraine headaches. My father went from being a hard-working husband and father of five to a man who was no longer able to work and provide for his family. At that time, he went from making close to $550 per week as a long-distance truck driver and mechanic to only $91 a month. As my father’s health continued to decline, even after he was no longer able to work, he was further diagnosed with more illnesses that were ultimately service-connected. We, as a family, attended various appeal hearings locally in Winston-Salem, North Carolina and then even in Washington, D.C. As Gender and Women’s Studies scholar Leslie Reagan contends, women, and sometimes the children, also helped Vietnam veterans to submit claims to the VA and to voice their complaints as part of their masculine responsibility for their family’s welfare. As women fought on behalf of Vietnam veterans, they spoke their own gendered language of maternalism, wifehood, health and sacrifice on behalf of their suffering families.6 Encountering VA administrators and judges in Washington, D.C. who were not invested or interested in hearing his case, after merely ten minutes into the procedures, the judge rendered yet another denial of increased disability rating without looking at any evidence of documentation provided. That day, my father was the only veteran who showed up to petition his case. To better illustrate my father’s story, a few distinctions will be made between the medical model and the social model of disability studies with points of intersections with critical trauma studies. This intersectionality is further emphasized by critical race theory, cultural studies and gender and masculinity studies and how varying factors can affect veterans’ disability policies as well as their ability to seek political action and social change.

5 Raynor.
Veteran’s Disability Policies

According to the VA, a service-connected disability is a disability, disease, or injury incurred or aggravated during active military service. The amount of basic benefit paid depends on how disabled the veteran is determined to be. The VA makes a determination about the severity of the veteran’s disability based on the evidence he submits as part of his claim, or that VA obtains from his military records. VA rates disability from 0% to 100% in 10% increments (i.e. 10%, 20%, 30% etc.). Certain circumstances may warrant receiving additional amounts. These include if the veteran has very severe disabilities or loss of limb(s); the veteran has a spouse, child(ren), or dependent parent(s); and/or he has a seriously disabled spouse. If the VA finds that a veteran has multiple disabilities, the disability ratings are not additive, meaning that if a veteran has one disability rated 60% and a second disability rated 20%, the combined rating is not 80%. This is because subsequent disability ratings are applied to an already disabled veteran, so the 20% disability is applied to a veteran who is already 60% disabled. The disabilities are first arranged in the exact order of their severity, beginning with the greatest disability and then combined with a ratings table that involves intersecting, combining and calculating the subsequent disabilities to nearest degree divisible by 10. The VA calculates the total service-connected disability rating by combining evaluations of each disability rather than adding the individual ratings together. Disabilities that were due to military service but not considered disabling are assigned as 0%.

As a part of the veteran’s disability application, the veteran must submit all relevant evidence in their possession and/or provide information sufficient to enable the VA to obtain all relevant evidence not in their possession, such evidence may include the following as part of the application: discharge or separation papers (DD214 or equivalent); service treatment records; and medical evidence (doctor and hospital reports). The application will then go through either fully developed claims or standard claims process, which could take up to a year or longer. The VA will also assist in obtaining relevant records, providing medical exams and obtaining medical opinions. When the VA makes a determination that a compensation award is to be paid based on a claim, an effective date is also assigned. The effective date determines when benefits are payable. Effective dates can vary based on the type of benefit and the circumstances of the claim, which are deemed either direct service-connection or presumptive service-connection. Other regulations that are often not talked about or shared include: the veteran must attend the VA hospital or clinic closest to their residence (even if that facilitate does not provide the best care); and the veteran should attend all scheduled doctor’s appointments and pick up all prescribed medications. Failing to do any of these may also affect the disability application.

Historian Robert F. Jefferson contends that the history of the development of service-related disability policies in the twentieth century often reflected nonclinical evaluative practices couched in cultural and racial values. For example, Veterans Bureau physicians and administrators defined disability with reference to medical characteristics they thought innate to each race and that distinguished racial groups of veterans from one another. To further emphasize how this practice was employed,

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7 Veterans Administration, U.S. Department of Veterans Affairs; Compensation; available at https://www.benefits.va.gov/compensation/rates-index.asp#howcal [accessed 3 June 2018].
medical authorities considered African American soldiers to be biologically prone to upper respiratory and venereal disease, to possess below average intelligence, more liable to succumb to the emotional strain of warfare and combat, and readily predisposed to malingering. Since they utilized these nonclinical assessments, doctors would often reduce or deny the disability claims of African American veterans, attributing their injuries to experiences that had taken place prior to their entrance into military service. By rejecting the claims of disabled African American GIs, VA physicians were not only questioning the image that their military service signified, but also challenging African American veterans’ claims to access and rights. For example, in the progress notes of my father’s medical records, the attending physicians used descriptive language such as ‘pleasant African American gentlemen,’ ‘well-appearing,’ and ‘appropriately interactive’ to describe the person who was seeking treatment. This type of language, while may be standard practice for physicians creates a very specific stigma for the veteran. As K. Walter Hickel states: ‘Veterans Bureau administrators and physicians defined disability with reference to medical characteristics they thought innate to each race and that distinguished racial groups of veterans from one another.’ Understanding these policies and how they can be complicated by race, class, gender, environmental and cultural factors provides an underlying premise of why disability studies, as Tobin Siebers insist, should include trauma within its definition of disability and that trauma studies accept disability as a key concept and allow a conception of wounds as disability representations just as they are considered in disability studies. Maurice Stevens also adds that what and who we have come to know as the disabled is produced by and within norms of ability, while what and who we have come to know as the traumatized is produced by and within discursive and institutional conventions of the traumatic.

Understanding Disability, Trauma, Race and Identity

The medical model of disability studies, according to Justin Anthony Hegel and Samuel Hodge, is based on an individual and/or a medical phenomenon that results in limited functioning that is seen and understood as a deficiency. The disability is considered to be a result of the impairment of the body and/or mind and how they function. In this model, the disability can also be caused by disease, injury or health conditions; therefore, the disability becomes the defining characteristic of the person. In this model, treatment for the disability is to eradicate what causes it or fix the impairment. In the case of disabled war veterans whose disabilities may be a result of wounding during combat or trauma, this model does not seem to include war injuries that can neither be fixed or eradicated. This disconnection leads to the social model of disability studies which contends that society actually imposes disability on individuals with

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impairments. In this model, according to Dan Goodley, the concepts of disability and impairment are viewed separately. Impairment is considered an abnormality of the body such as a malfunction of a limb; whereas, a disability is viewed as a disadvantage or restriction of activity caused by a society organization that does not take into consideration those who have disabilities and are excluded from community life. In other words, the social model suggests that it is society that limits a person’s abilities not one’s bodily functions. This is an important intersection for disability and trauma studies because the social model suggests solutions should be directed at society and not the individual. This is very significant for veterans disabled by war injury or trauma because improvements for their lives must be through social and political change and action rather than expecting changes in their physical bodies. However, the social model has its disadvantages. It neither addresses an impairment as an observable attribute of a person that is an essential aspect of their lived experience nor does it account for differences between individuals with disabilities.13 This essay is designed to expand the conversation of the social model to include war and trauma. These intersectionalities will create a space to discuss how different forms of oppression or oppressive social, cultural, economic, and environmental conditions further affect a war veteran’s abilities to function when institutionalized discrimination has been a part of his lived experiences. This connects directly to how war veterans are systematically declared disabled by varying factors within the VA system.

According to The Center on Human Policy, Law, and Disability Studies, disability studies generally refers to the examination of disability as a social, cultural, and political phenomenon and focuses on how disability is defined and represented in society, which is in contrast to clinical, medical, or therapeutic perspectives on disability. Because it makes a distinction between impairment and the disabling barriers constructed by society. It is perceived that once people with disabilities are recognized to be an oppressed group that has to fight for its rights, access, mobility and freedoms, it is easier to contextualize and frame disability as we do ‘race’ and examine it through comparisons to the African-American civil rights movement. Within this context, it sets the premise to further expand this examination to include trauma studies and critical race theory in light of how African American soldiers were viewed historically and how this created a framework for the way in which not only their military service but also their disabilities would be clouded with prejudices and stereotypes.14

The editorial scholars of ‘Critical Disability Studies (1990s to Present)’, Allen Brizee, J. Case Tompkins, Libby Chernouski, Elizabeth Boyle and Sebastian Williams, discuss how it is important to understand disability as part of one’s identity, much like race, class, gender, sexuality, and nationality.15 Because of its concern with the body and embodiment, disability studies also intersect with other critical schools like critical race theory and trauma studies. The racialization of disability pertains to have ‘disability

has always been racialized and how race has been conceived as disability’.

Since at least the 19th century, race and disability have been intertwined and linked to ideologies of evolutionary hierarchy. Attributions of disability were often used to justify the institution of slavery and deny basic rights to African Americans have had concomitant negative consequences, such as denial of benefits.

As Daniel Morrison and Monica Casper believe that disability studies have erased the moment(s) of trauma in service to a social constructionist framework. Trauma theorist Cathy Caruth further defines trauma as:

An overwhelming experience of a sudden or catastrophic event in which the response to the event occurs in the often delayed, uncontrolled repetitive appearance of hallucination and other intrusive phenomena. The experience of the soldier faced with sudden and massive death around him, for example, who suffers this sight in a numbed state, only to relive it later in a repeated nightmare, is a central and recurring image of trauma.

Women’s and Gender Studies scholar Leigh Gilmore claims that trauma, that comes from the Greek τραύμα, meaning ‘wound’, refers to the self-altering, even self-shattering experience of violence, injury, and harm or as a wound of the soul- a spiritual or mental injury that is linked to memory. Trauma, in this sense, not only injures the body, but it also wounds the memory.

In disability studies, Morrison and Casper argue that trauma is not understood metaphorically, but rather practically and politically. They draw a distinction in their work between trauma as a marker and critical trauma studies as a reflexive analytical perspective. Such a distinction is similar to that drawn between disability as an indicator and the critical focus of disability studies. To further emphasize this, the significant part of critical trauma studies is the tensions between everyday occurrences and the extreme, between individual identity and collective experience, between history and the present, between experience and representation, between facts and memory, and between the ‘clinical’ and the ‘cultural’. Trauma is therefore interrogated to determine its own capacity for political and cultural work. Thus, while both trauma studies and disability studies focus on the body and its harms, each field has its own premises, goals and limitations. Peering at disability through a trauma studies lens would, on the surface, seem to amplify precisely those embodied disruptions that disability scholars often seek to minimize or contextualize.

Did the war take the identity of the African American Vietnam veteran? Did the trauma of war, as Leigh Gilmore suggests, wound his soul?

Did fighting in a war for civil liberties for others diminish his own fight for civil rights at home? Did being viewed and treated as a second-class citizen further burden his identity once home from the war? A more detailed profile of the African American soldier might help provide some insight and answers to these aforementioned questions.

The African American Soldier

Historically speaking, the African American soldier was stereotyped as ‘child-like, careless, shiftless, irresponsible, secretive, superstitious, more likely to be guilty of moral turpitude, comic, emotionally unstable, musically inclined, with good rhythm - if fed, loyal and compliant - lacking in physical courage and psychological characteristics which make him inherently inferior.’ White officers who commanded Black troops in World War I made these remarks in a War College report of 1936.22 These stereotypical images have distorted the perception and expectations of all African American servicemen. The New Yorker writer, Peter Baker, shares that when World War I started, it was questioned whether African Americans should fight for a country that was denying them rights to full citizenship. 380,000 African American men heeded W.E.B. DuBois’s call to enlist in a segregated Army in hopes of improving the conditions for African Americans at home. However, they were still confronted with how their service might undercut the racial hierarchy of the nation. Despite this, 1.3 million African Americans enlisted during World War II.23 As Todd C. Shaw discusses even after emancipation from slavery, African Americans were still denied meaningful citizenship rights by the ‘veil’ of race and racism though they contributed what DuBois calls the ‘gifts’ of their souls. Thus, American racism imposed an identity dilemma upon African Americans and affected their expressions of patriotism.24

To better understand the racial demographics of the Vietnam War and how that impacted the exposure to injuries and combat trauma, the VFW Magazine and the Public Information Office published a statistical profile. 88.4% of the men who actually served in Vietnam were Caucasian; 10.6% (275,000) were black; 1% belonged to other races. 86.3% of the men who died in Vietnam were Caucasian (includes Hispanics); 12.5% (7,241) were African American; 1.2% belonged to other races. 86.8% of the men who were killed as a result of hostile action were Caucasian; 12.1% (5,711) were African American; 1.1% belonged to other races. 14.6% (1,530) of non-combat deaths were among blacks. 34% of African Americans who enlisted volunteered for the combat arms. Overall, African Americans suffered 12.5% of the deaths in Vietnam at a time when the percentage of African Americans of military age was 13.5% of the total population.25 As shown in ‘Vietnam War Casualties by Race, Ethnicity and Origin,’ the combination of our selective service policies, testing of both drafted and volunteers, the need for skilled enlisted men in many areas of the armed forces, all conspired to assign

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African Americans in greater numbers to the combat units of the Army and Marine Corps. Early in the war during 1965 and 1966, when African Americans made up about 11.0% of the Vietnam force, African American casualties soared to over 20% of the total. After African American leaders protested and President Johnson ordered that African American participation should be cut back in the combat units, the African American casualty rate was cut to 11.5% by 1969. As further discussed by Encyclopedia of the Vietnam War: A Political, Social, and Military History, African Americans often did supply a disproportionate number of combat troops and represented almost one-fourth of the Army's killed in action. In 1968, African Americans, who made up roughly 12% of Army and Marine total strengths, frequently contributed half the men in front-line combat units, especially in rifle squads and fire teams. Under heavy criticism, Army and Marine commanders worked to lessen African American casualties after 1966, and by the end of the conflict, African American combat deaths amounted to approximately 12%—more in line with national population figures.

By the time the last American troops pulled out in 1973, according to Brende and Parson, nearly 2.8 million soldiers had been deployed to Vietnam. Nearly 100,000 American soldiers left Vietnam with physical disabilities with approximately 800,000 war veterans suffering from varying degrees of post-traumatic stress disorder, disorders that are significantly intrusive enough to rob their lives of fulfillment and meaning. Estimates place the casualties of American troops at close to 58,000 which includes over 10,000 lost to accidents and/or disease and the number of the wounded is well over 300,000. Sociologist Terri Kovach discusses that nearly a third of the hundreds of thousands of heavy combat veterans from the Vietnam War suffered from severe PTSD. Vietnam Veterans were particularly vulnerable to stress symptoms because of the length of the war, deployment patterns, guerilla tactics, the perceived lack of purpose, and the increasing unpopularity of the war, often resulting in veterans being treated with contempt. Some elements of the homecoming experience are more likely than others to predict PTSD. David Johnson and other scholars discuss how the negative personal interaction, resentment, and shame within the first few months of homecoming were also associated with the PTSD. Other predictors of PTSD followed by combat exposure, pre-military factors, and postmilitary stress, even though some of the homecoming stress may have been compounded by PTSD symptoms that were already present in the returning veteran.

Health economist Emilia Simeonova adds that the large and persistent differences in health outcomes between African Americans and whites have sometimes been attributed to differences in the quality of the facilities in which they receive care based on access, socio-economic patient population, the level of segregation in health care facilities and disparities in minority health care. Researchers in

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The Double Consciousness and Disability Dilemma: Trauma and the African American Veteran

psychology have examined combat veterans in relation to identity formation, quality of life, and resilience. Military Times writer, Carl Prine discusses how African Americans suffered higher rates of post-traumatic stress disorder and other mental health problems than other races, mostly because they were more likely to experience combat because they served in ground units. African Americans were also more likely to have been exposed to the Agent Orange dioxin while serving in Vietnam which was ultimately linked to such conditions as cancer and heart disease. Don Wilkins adds that it was not until 1991 that Congress passed the Agent Orange Act that gave the Department of Veterans Affairs the power to declare certain health conditions as ‘presumptive’ to dioxin exposure.

James Westheider contends that while combat duties created significant stressors for soldiers and PTSD is a serious disorder that affects veterans of all races, it often affects African American veterans most frequently, with one study reporting that nearly 40 percent of all African American veterans showed symptoms of stress disorder, compared to about one in five whites. Brende and Parson further define PTSD (historically known as shell shock or combat stress) as the development of characteristic symptoms following a psychologically traumatic event that is generally outside the range of usual human experience. The characteristic symptoms involve re-experiencing the traumatic, numbing of responsiveness, reduced involvement with the external world, symptoms of depression and anxiety, increased irritability associated with unpredictable explosions of aggressive behavior, hyper-alertness or exaggerated startle response, sleep disturbances, recurring nightmares, guilt about surviving when others have not, guilt about behavior required for survival, memory impairment, trouble concentrating, avoidance of activities that arouse recollection of the traumatic event, and/or feelings of detachment or estrangement from other people.

According to Todd Shaw, approximately sixty-two years after DuBois first wrote about double consciousness, his demands of Black political, economic, and social equality were fulfilled by the 1964 Civil Rights Act and 1965 Voting Rights Act. But now more than fifty years after those reforms and more than forty years since the end of the Vietnam War, there has been significant change in the specific manifestations that race and racism have assumed since the days of strict Jim Crow segregation. For African American Vietnam Veterans, their experiences and identities, since their homecomings, as disabled veterans, clash with racial structures that underlie the DuBois notion of the veil of race and emphasize other forms of unequal double-ness that they have encountered in the healthcare system. To further expand on what Leslie Reagan believes, the field of disabilities should not only focus on the damage done to bodies in

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war and the reaction to, treatment of and debate about veteran bodies in post-war years but also on the catastrophic and traumatic efforts that rendered the bodies such damage.\(^\text{37}\) Alan Foley adds to the discussion that often disability studies view disability in terms of culture and identity and/or as a label and a social construct while also using different language to refer to the people at the center of inquiry in this discourse.\(^\text{38}\)

**Expanding the Discussion: Critical Trauma Studies and Critical Disability Studies**

Vietnam veterans must continue to name their service, reference other veterans and emphasize their patriotism and willingness to serve, their masculine identity is firmly displayed based on their own morals. Despite systematic racial disparities in healthcare, the African American Vietnam veterans have also been able to fight and secure the health services and disabilities payments they sought and earned through their service and honor and quite honestly, that they were owed.\(^\text{39}\) As an African American soldier fighting in Vietnam during the Civil Rights Movement, his identity was already conflicted by societal pressures, so my father’s wartime diary emphasized the inevitable destruction war has on the lives of those who fought it. If, as Morrison and Casper argue, critical trauma studies and critical disability studies might usefully engage one another on a level in which we understand the notion that traumatic events may cause disability and that disabilities are often perceived as traumatic, then what might the social structure become for African American Vietnam veterans and how might we expand the discussion beyond just TBI (traumatic brain injury) and PTSD to offer additional insight into war, suffering, politics of diagnosis and/or lived experiences. Disability is a socially constructed definition imposed on people who may or may not agree to this characterization, and a disabled person is used to draw attention to the centrality of disability in individual identity. In fact, many races, classes, ethnicities, and other parts of identity have been classified as or associated with disabilities in the past. Thus, intersectionality affords crucial insights about the racialization of disability, compelling us to focus on both the power of assigning categories to individuals and on the authority of those categories to have social and material consequences and to refocus attention on the physical acts of disabling—the signal moments of bodily breach and psychic tear—feels dangerous.\(^\text{40}\) This speaks directly to the essential need for political action and social change so imposed labels and definitions do not further marginalize war veterans beyond the trauma of war.

Since the Veterans Administration requires evidence of service and medical records as a part of the disability application, my father was able to use not only the medical reports that began during his service and beyond but also the diary that he kept during his tour-of-duty. His writings not only helped him define himself as a young African American man and soldier, but it also marked moments of stress and injury. American Studies scholar Simon Wendt contends that a crucial affirmation of African


\(^{40}\) Morrison and Casper.
American manhood is often connected to violence, whether it is by armed resistance, the physical necessity to confront racist attackers, the ability to protect one’s family, especially the women, from insult or attack, or the ability to disprove and defy racist stereotypes while not acknowledging the actual shaming that racism inflicts, which some of these aspects became a part of my father’s journey through the VA system. At the age of 71, my father’s service-connected illnesses and injuries include chloracne, migraines, hypertension, diabetes mellitus type 2 with neurological manifestations and peripheral circulatory disorders; peripheral neuropathy, moderate nonpoliferative diabetic retinopathy, diabetic macular edema, prostate cancer, elevated prostate specific antigen (PSA), malignant stomach tumor, colonic polyps, hyperlipidemia, bone marrow metastasis, acquired onychodystrophy/onycholysis, diastolic heart failure, restrictive lung disease, spinal stenosis in cervical region, anemia due to unknown mechanism, benign essential hypertension, personal history of exposure to Agent Orange, multiple myeloma and PTSD. He is prescribed at least twenty-three (23) medications. With each disability, the severity must be re-evaluated so the compensation, based on the VA’s combined rating scale, reflects the accuracy of having multiple service-connected disabilities. Now, his identity is defined by a social construct devised by the VA based on rating scales, percentages, denials and approvals. In 2003, after eleven years of fighting the bureaucracy of the VA system, writing several letters to our local representatives and Congressmen, my father, with his combined disabilities, finally received a high enough percentage on the disability rating scale to be declared total and permanently disabled. His personnel struggle for social change within the VA system lasted for over a decade. This battle burdened by his multiple disabilities that can neither be eradicated nor fixed, as the medical model of disability studies suggests, speaks directly to the need to expand both the medical and social model of disability studies. This expansion should include critical trauma studies and take into consideration that the traumatic events of war can cause war injuries and disabilities and those disabilities may, in turn, create a traumatic lived experience for a veteran living in a society that has historically marginalized his very existence. The scope of critical trauma studies should include the notion of the social construction of disability; thereby, emphasizing how trauma can be created or even exacerbated by a disabling society.

Bibliography


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Dubla conștiință și dilema dizabilității. Trauma și veteranul afro-american

Rezumat

Daniel Morrison și Monica Casper susțin că studiile despre dizabilitate și localizările lor culturale au fost remarcabil de tăcute în a face publice aspecte ale multor dizabilități cu origini traumatice. Studiile despre dizabilitate au păstrat tăcerea și în ceea ce privește relația continuă dintre evenimente șocante, impactul lor abrupt și cronic și nu au comunicat experiențe ale dizabilității. Acest articol explorează întâlnirea care ar trebui să aibă loc între studiile critice despre dizabilitate și studiile critice despre trauma pentru a explora modul în care veteranii de război de origine afro-americană, care au trăit trauma războiului și conflictului și au devenit persoane cu dizabilități sunt în continuare marginalizate de constrângeri sociale și etnice. Acest articol susține ideologia dublei conștiințe a sociologului și istoricului W.E.B. DuBois, a teoriei critice rasiale și a studiilor culturale care reflectează asupra modului în care acestea au subliniat intersecțiile dintre ndările provocate de război și dizabilitate, cu un mare impact asupra opresiunii rasiale, de clasă și socio-economice trăite de veterani, studii care au contribuit la ceea ce serviciul militar și dizabilitățile veteranului afro-american relevă despre identitatea masculină.
Review Articles
Reading Disability in Literature and in Film:
A Review of
and

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Abstract

This is a review-article of two major studies in disability studies, one edited collection, The Problem Body: Projecting Disability on Film, edited by Sally Chivers and Nicole Markotić and one authored volume, Aesthetic Nervousness: Disability and the Crisis of Representation by Ato Quayson.

Keywords: disability, film, literature, Sally Chivers, Nicole Markotić, Ato Quayson

In their book Narrative Prosthesis, David Mitchell and Sharon Snyder describe an encounter with a Japanese literature scholar who was interested in representations of disability in American literature. Mitchell and Snyder asked him about representations in Japanese literature and, they write, ‘he honestly replied that he had never encountered any.’1 It was only after reflecting on the matter that he remembered the work of Kenzaburo Oë. Mitchell and Snyder add that ‘[t]his “surprise” about the pervasive nature of disabled images in national literatures catches even the most knowledgeable scholars unaware’.2 A similar story is recounted by Ato Quayson in Aesthetic Nervousness,3 one of the two books being reviewed here. His father’s limp and his grandfather’s blindness and post-traumatic stress disorder led him to having an interest in disability. However, he states that he started researching representations of disability when he was teaching at the University of Cambridge in the 1990s, after one of his students asked him why almost all the texts he had assigned the class had disabled characters in them. ‘Her question came as a complete surprise to me, for the simple reason that I had not noticed the disabled characters myself’, he writes (AN, xii). Surprise was a response that I myself experienced in 2014 when I was preparing lectures for a course on ‘Disability and Culture’ which I teach at the University of Malta. I naively thought that I could draw up two lists, one of

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2 Mitchell and Snyder, 51.
3 Hereafter cited as AN, with page numbers in the text.
novels and one of films that featured disabled characters. It did not take me long to realize there were simply too many of them to come up with exhaustive lists, and so I settled for indicative ones instead, and ones which, however much I continue to add to, will always remain indicative.

What is it that renders disabled characters ever-present and yet almost-invisible in narratives? *Aesthetic Nervousness* and *The Problem Body*[^4] are among the books that help us arrive at some answers to this question, through the concepts that they present and develop, and through the analysis of specific novels, plays, and films. In this review, I mostly discuss the former – the concepts – and present a summary of the chapters in the two books that focus on specific authors (in *Aesthetic Nervousness*) and films (in *The Problem Body*). First though, it is important to consider what each volume means by the term ‘disability’.

While Chivers and Markotić’s *The Problem Body* focuses, as the title suggests, on projections of the disabled body, the films considered by the various authors who have contributed to this edited collection present a wide variety of impairments and medical conditions, especially prosthetic limbs, phantom limbs, blindness, developmental disability, terminal illness and mobility impairments. Quayson’s range is even wider as it takes in different types of physical impairments and ailments, incurable diseases and chronic conditions, disfigurement, cognitive impairment and autism. The approach used by many authors, including those of the two books being reviewed, is to analyse a select number of narratives – literary texts – and the connection between disability and Robben Island in the case of Quayson’s book, and films in the case of Chivers and Markotić’s edited collection.

Trauma is also referred to by Quayson and by several of the authors in *The Problem Body*. In a chapter on trauma art in *Disability Aesthetics*, Tobin Siebers calls for the inclusion of trauma as a subject for consideration in disability studies, and vice versa. This step, he argues, enables a study of physical and psychological traumas from a disability studies perspective, and for trauma studies to consider how disability can be conceptualized. More importantly, he says, considering trauma and disability together helps us recognise ‘the fragility as well as the violence of human existence.’[^5] As mentioned in the introduction to this volume, the need to consider trauma in disability studies is also discussed by Alison Kafer,[^6] and is also the position taken by Daniel Morrison and Monica Caspar in their call for disability studies not to ignore the wounds, pain and trauma that are important aspects of the lives of many disabled people.[^7] Within this context, and in line with the social relational model, disability is here being taken to refer to the interaction between the person who has an impairment (including physical or mental illness) and the material and attitudinal barriers that they encounter in society.[^8]

[^4]: Hereafter cited as *PB*, with page numbers in the text.
Trauma has a dual meaning in the way Siebers uses it in relation to visual art. He refers to art that depicts and represents trauma, as well as the potentially traumatizing effect that these depictions can arouse in the viewer. Kafer also discusses this latter meaning. Likewise, in their contribution to *The Problem Body*, Snyder and Mitchell refer to trauma for the film viewer at the sight of the disabled body, either because of the way it looks or because it is perceived as a ‘threat toward the integrity of the able body’ (Snyder and Mitchell in *PB*, 181). The potentially traumatic effects of representations of disability are contiguous with the negative associations of disability and the assumptions that are generally made that life with a disability is necessarily a life of suffering and one not worth living.9 The authors of the two books being reviewed address these assumptions and associations in their discussions of the selected texts and films, in the conceptual frameworks within which they operate and in the title of the books themselves.

*Aesthetic Nervousness* and *Problem Body* present different yet related conceptual frameworks within which to study the representation of disability in literature and in film. Quayson bases his concept of aesthetic nervousness on the tensions that he identifies at three levels: between disabled and non-disabled characters in literary texts; between plots, motifs, perspectives and the representation of disability; and between the reader and the text. The nervousness, Quayson argues, arises because disabled characters and the representation of disability are located in ‘a universe of apparent normativity both within the literary text and outside it’ (*AE*, 20). How perceptions regarding normativity affect disabled people has been extensively explored in disability studies, most notably by Rosemary Garland-Thomson and Lennard Davis whose work about the normate and normalcy respectively Quayson refers to.10 What emerges from these various discussions is the point that having an impaired mind or body is not considered to fall within the normal range of human experiences but is deemed to be abnormal and therefore the binary opposite of normal. But this binary is not as simple as it may at first appear. According to the United Nations, 10% of the global population have a disability, making it the world’s largest minority.11 More to the point, it is a minority which those of us who do not have a disability can easily become a part of as a result of injury or ill-health. Manifestations of disability in literature thus bring to the fore what Quayson calls ‘dialectical interplay’ (*AE*, 21), which arises from the encounter between the preconceptions about disability that the reader brings with them to the text and the reminder presented by disabled characters that disability is after all an integral part of the human condition. As Davis, Mitchell and Snyder and also Quayson argue, disability in literature is very often used as a symbol, as a stand-in for social or narratological disruption. However, its symbolic nature cannot be divorced from the reality of living with disability. It is from this dual role of disability that tension, and nervousness, arise.

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9 One forceful rebuttal of this idea comes from Ben Mattlin, who has spinal muscular atrophy, a degenerative disease, in ‘A Disabled Life is a Life Worth Living’, *New York Times* 5 October 2016; available at https://www.nytimes.com/2016/10/05/opinion/a-disabled-life-is-a-life-worth-living.html [accessed 28 October 2018].


11 United Nations Enable, Fact Sheet on Persons with Disabilities. (undated); available at http://www.un.org/disabilities/documents/toolaction/pwdfs.pdf [accessed 20 October 2018]. It should be pointed out that, although women are not in a minority in terms of numbers, they are very much in a minority in terms of social equality.
It is significant that Quayson chooses to discuss the interaction between the representation of disability in literary texts and the readers of those texts in terms of ‘tension’ and ‘nervousness’. Both terms connote negativity, which is of course reflective of the misconceptions about disability discussed above. Likewise, Chivers and Markotić use a negative term for the title of their book. In order to explain their use of the term ‘problem body’, Chivers and Markotić turn to Louis Althusser and Michel Foucault12 who emphasized the importance of taking context into account when analyzing a concept or phenomenon, with Althusser taking a Marxist approach to studying production relationships, and Foucault analyzing power structures. Problematizing disability therefore involves considering the ideological structures within which it has evolved as a concept, and how this evolution has been determined by power relations, especially between those who have a disability and those who do not, with the latter mostly determining the meanings that disability ought to be given.

Furthermore, Chivers and Markotić remark that, with the term ‘problem body’, they ‘evoke a status that is both discursive and material’ (PB, 9). Disability is at once a lived reality for those living with impairments or ill health, and a social construct. The editors state that the discursive and the material, the social construction and the lived reality of disability are binary opposites, but are presented in their volume as complementary to each other, ‘so that disability can be understood as both physical and social’ (PB, 11). These points bring us back to Quayson’s aesthetic nervousness, for it is also with reference to the tension between these two aspects of disability that the films included in Chivers and Markotić’s collection are discussed. Since it is film that the various contributors to their book focus on, the discussion is on the projection of disability. Chivers and Markotić point out the different connotations of this term – theirs is a project to examine the ways disability is projected in film, a medium that physically projects images onto a screen and also relays figurative projections, in this case of the disabled body. Analyses, such as the ones offered by Quayson and by Chivers and Markotić and their contributors, thus serve to disrupt assumptions about disability that often go unquestioned and to consider the role of disabled characters in ways other than ones that simply conform to preconceived notions of disability. They address ‘the moral panic that has historically obtained in social encounters between disabled and nondisabled people and that often gets refracted within literary discourse to become normalized and unquestioned’ (AN, 33-4).

In both books, we also encounter a framework within which analyses of the representation of disability in literature and in film can be undertaken. Quayson provides a typology of this representation, which he divides into nine categories, and which he then uses in the subsequent chapters about the works of Samuel Beckett, Toni Morrison, Wole Soyinka, J.M. Coetzee and about the history of Robben Island. These nine types can be considered within the tensions that he identifies which work at three levels, as seen earlier. Thus, the first two types relate to the relationship between disabled and non-disabled characters in literary texts.13 The first is ‘disability as null set and/or moral test’, where disabled characters do not have an existence in their own right but serve as a means for other characters to prove themselves. The second is ‘disability as the interface with

13 The typology is presented in Chapter Two and the nine identified categories are also listed at the end, on page 52.
otherness (race, class, and social identity), where disabled characters also belong to other social minorities.\textsuperscript{14} The third type can be considered as operating at the second level identified by Quayson, that is the tension between plots, motifs, perspectives and the representation of disability. This is ‘disability as articulation of disjuncture between thematic and narratological vectors’, with disability serving as an analogy of social or narratological disruption. Such an analogy is similar to the concept of ‘narrative prosthesis’ developed by Mitchell and Snyder with reference to narratives and to the concept of ‘disability aesthetics’ developed by Siebers in relation to visual art.\textsuperscript{15} The next five types operate at the third level, between the reader and the text, since they refer to the different possible interpretations that readers can project onto the role of the disabled characters in the text. They are: ‘disability as bearer of moral deficit/evil’; ‘disability as epiphany’, that is when the disability of a character is only revealed at a key moment in the plot to highlight the significance of that moment; ‘disability as signifier of ritual insight’, that is the use of disabled characters who have superior insights, especially in folklore and myth; ‘disability as inarticulable or enigmatic tragic insight’ which, in contrast to the previous type, refers to the use of disabled characters to convey insights that are not clearly articulated; and ‘disability as hermeneutical impasse’, where disability signifies the failure of the narrative to reach a resolution or closure. To these eight categories, Quayson adds ‘disability as normality’. Very significantly, he does not include fictional texts in this category, but rather life writing by disabled people themselves or their close family members. These are the texts based on the lived experience and the materiality of disability as well as on its social construction, texts that provide the perspectives of those who have the experience of living with a disability on a day-to-day basis, perspectives that are woefully lacking in most literary and filmic narratives that include characters with disability. There are however also works of fiction that could be added to this category, many of which have been written by disabled people themselves.\textsuperscript{16}

In presenting this typology, Quayson is at pains to point out that it is intended as a heuristic device and ‘as a provisional mapping of the field only’ (\textit{AN}, 52). Additionally, he points out that the types can be used in combination with each other. Similarly, the disability representations that are typical in film discussed in Chivers and Markotić’s book are not meant to be exhaustive. These types are presented in the final chapter of the book, ‘Body Genres: An Anatomy of Disability in Film’, and have been drawn up by Snyder and Mitchell (\textit{PB}, 179-204). What these authors present is an ‘anatomy’ of ‘body genres’ which they created by adapting Linda Williams’ categorization of films from a feminist perspective.\textsuperscript{17} Snyder and Mitchell’s anatomy is split into nine genres of disability representation, each of which is then related to three films genres: comedy, horror and melodrama. They choose these as ‘the three foundational genres of film narrative’ (\textit{PB}, 188). The anatomy is presented in a table and is not explained in as much details as Quayson explains his typology. It is, nonetheless, a useful schema. The first genre identified by Snyder and Mitchell is Bodily Display, which refers to where the

\textsuperscript{14} It is worth noting that Chivers and Markotić also refer to the importance of considering disability within the context of intersections with other social groupings.

\textsuperscript{15} See Mitchell and Snyder, a book that is referred to by most of the contributors to \textit{PB}, and Siebers.

\textsuperscript{16} Examples include Anne Finger’s anthology of short stories \textit{Call Me Ahab} (Lincoln, NE: University of Nebraska Press, 2009) and Susan Nussbaum’s novel \textit{Good Kings, Bad Kings} (Chapel Hill, NC: Algonquin, 2013). \textit{PB} ends with a short story by Anne Finger, ‘Blinded by the Light, OR: Where’s the Rest of Me?’, which critiques the portrayal of disability in film (207-16).

\textsuperscript{17} Snyder and Mitchell refer to Linda Williams’s ‘Film Bodies: Gender, Genre, and Excess’, in \textit{Film Theory and Criticism}, eds Leo Braudy and Marshall Cohen (Oxford: Oxford University Press, 1999), 701-15.
impairment originates from – whether it is a faked impairment in comedy, an innate monstrosity in horror, or an impaired ability in melodrama. Like Quayson, Snyder and Mitchell consider the interaction between the viewer and the disabled character. For the second genre, Emotional Appeal, they identify the feelings aroused in the viewer: a feeling of superiority in comedy, disgust in horror and pity in melodrama. The authors next focus on the Presumed Audience of these films towards whom the representations of disability are mainly addressed: men for comedy, adolescent boys for horror, and girls and women for melodrama. The fourth genre, Disability Source, refers to how the disability is made visible to the viewer. Thus, in the case of comedy, it is performed (rising as it does from faked impairment), in the case of horror it is external, and in melodrama it is internal. The fifth genre, Originary Fantasy, refers to affect aroused in the viewer in terms of sadism (comedy), sadomasochism (horror) and masochism (melodrama). Next is Resolution, that is how the predicament of disability is resolved. Snyder and Mitchell identify humiliation for the disabled character in comedy, obliteration in horror, and compensation in melodrama. The seventh genre is Motivation, that is the force that motivates the disabled character to act as they do: in comedy it is duplicity, in horror it is revenge, and in melodrama it is restoration. The penultimate genres, Body Distortion, deals with how the disabled body is presented: as malleable in comedy, as excessive in horror, and as inferior in melodrama. The ninth and final category is Genre Cycles/‘Classic’ and focuses on the character types associated with each type of plot: the character of the con artist/bumbling ‘success’ in comedy, that of the monster in horror, and the long-suffering character in melodrama.

Snyder and Mitchell present their schema as a tool to understand the formulae generally used by film-makers in the use of disabled characters and the ways that the disabled body is used as short-hand that ‘prompts a finite set of interpretative possibilities’ (PB, 189). They then consider some examples of films that fall under the different categories they identify, in the same way that Quayson discusses his types in relation to various narratives, including Greek mythology, Shakespeare, Indian and South American literature, as well as the authors whose work he analyses in the next chapters. Together, Quayson’s typology and Snyder and Mitchell’s genres offer a comprehensive overview of how disability and disabled people are represented in textual and filmic narratives, including the ones analyzed in *Aesthetic Nervousness* and *The Problem Body*. Significantly, like Quayson, it is to narratives told from disabled people’s perspectives that Snyder and Mitchell turn as a way of challenging these formulaic and stultifying genres that only serve to reinforce stereotypes. In the same way that Quayson identifies lifewriting in this regard, Snyder and Mitchell pinpoint documentary as a genre that can foreground disabled people’s perspectives. Considering representations of disability from the perspective of disabled people emerges as an important approach for the analysis of these representations. It is by bringing in these perspectives that the disjuncture between codified representations based on preconceptions of disability and the lived reality of disability can be resolved.

This approach does not mean that analyses can only be carried out by disabled people but it does mean that they need to be carried out in a manner that is informed by the insights gained through the work carried out by scholars in disability studies. This is in fact the approach taken by Quayson in *Aesthetic Nervousness* and by the contributors

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18 A recently published edited volume that deals with this genre is Catalin Brylla and Helen Hughes’s edited collection *Documentary and Disability* (London: Palgrave Macmillan, 2017).
to *The Problem Body*. Given the huge number of films and literary texts that figure disability, as I previously pointed out, it would, of course, be impossible for either book to even attempt to provide a comprehensive analysis of filmic and literary portrayals of disability. The texts and films analyzed, and the ones that are referred to more briefly in the analysis, are as important as the ones that do not get a mention. In fact, it would be easy to criticize either book regarding what has been left out or to query the inclusion criteria used. However, such criticism would be unproductive not only because of the wide range of filmic and literary representations to choose from, but also because what is presented opens up the possibility for further analysis, especially when used in conjunction with the conceptual frameworks used in the two books. In this regard, Quayson’s choice of authors, including African writers, means that his volume provides a more global perspective than is usually the case, given that most analyses focus on Western-produced books and films. By choosing Nobel prize laureates, Quayson affirms the importance of considering the role of disability in the literary canon.

The following is a very brief summary of each of the remaining chapters in *Aesthetic Nervousness* and *The Problem Body*.

The first author whose work Quayson analyses is the Irish writer Samuel Beckett, with a focus on the novel *Molloy* and the play *Endgame*. Beckett’s characters share a remarkable list of ailments and impairments. Quayson reminds us that for Beckett bodily weakness was a reality, due to the different illnesses that he frequently suffered from. In order to explore Beckett’s use of disability, Quayson uses the eighth type of disability representation that he identifies in the earlier chapter – disability as hermeneutical impasse. The characters’ impairments and pain, Quayson argues, do not seem to have physical consequences. Sometimes the nature of the impairment is doubtful – the eponymous Molloy is not sure whether it is his left or right leg which is stiff and shorter than the other. In his discussion of *Endgame*, Quayson discusses how the bodily discomforts and pain experienced by Hamm and Clov are not necessarily perceived as having an objective reality by the audience. Disability in Beckett, then, is representative of uncertainty and the constant deferral of meaning, and ‘a cipher of the condition of frailty’ (*AN*, 82).

Disability in the work of African American novelist Toni Morrison, the subject of Quayson’s next chapter, is equally complex, even if in a different manner, including in *Paradise*, *Sula* and *Beloved*, the three novels considered in *Aesthetic Nervousness*. Consolata’s blindness in *Paradise* is linked to insight. 19 Eva’s self-inflicted impairment in *Sula* is never precisely described. This vagueness, Quayson argues, emphasizes the symbolism of her missing leg and the mythic qualities of Eva as disabled mother and as arbiter of life and death. In *Beloved*, disability directly references the trauma of slavery. Quayson notes that in this novel, the characters’ own consciousness and, therefore also their experience of disability, is brought to the fore. Quayson uses three elements from his typology to analyse Morrison’s characters – disability as epiphany, as enigmatic tragic insight and as normality – arguing that the three often work at different levels, without being sufficient to arrive at a comprehensive understanding of the role of disability in Morrison’s work.

Quayson next considers the Nigerian writer Wole Soyinka, especially the plays *The Strong Breed*, which centres around ritual sacrifice, and *Madmen and Specialists*,

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19 Attributing superior insight to blind personages is a trope that comes from a very long way, including Tiresias in Greek myth.
which has the Biafran war (during which Soyinka was imprisoned) serving as its backdrop. The Strong Breed opens on the night of a festival in which one person is offered as ritual sacrifice to expiate for the wrongdoings of the community. The choice falls on Ifada, a boy who has cognitive impairment, because he is considered to be already contaminated. He runs away and Eman – who occupies an equally liminal position in the community – offers himself for sacrifice. In Madmen and Specialists, disability becomes symbolic of the chaos of war as the protagonist, Dr Bero, holds his father captive and tortures him. These narratives tap into the disability as moral deficit/evil category but, Quayson argues, they are also more complex than that. Ifada and Eman’s action subvert the power of the community over them – the one chosen for sacrifice is supposed to meet his fate with docile passivity. In Madmen and Specialists, a group of disabled beggars serve as a Greek-like chorus that invites reflection on the tragedy of war and the actions of those caught up in it.

The last writer whose work is analysed in Aesthetic Nervousness is the South African-born J.M. Coetzee, especially the novel The Life and Times of Michael K. The novel is set in apartheid South Africa and even if Michael’s ethnicity is not specified, it is implied that he is not white. Michael was born with a cleft lip, is a slow learner, was institutionalized at a young age and has elective mutism. Quayson reads Michael’s conditions in terms of autism. I find this conclusion debatable, since Michael’s withdrawal can also be the result of traumatic experiences in his early childhood. Whatever the diagnosis, what is of interest is Quayson’s discussion of Michael’s silence within the context of Coetzee’s use of internal dialogues that his characters engage in. This dialogue takes on an added significance for Michael, since he does not speak to others. The interlocutor in Michael’s internal dialogues, Quayson argues, emerges from the rules of behaviour that he has imbibed from the institution he was in, and those pertaining to masculinity. These dialogues enable the reader to appreciate how Michael experiences his liminal social status. However, as Quayson argues, the character’s ethnicity and social class are never mentioned. Michael’s experiences therefore remain allegorical and his character symbolic of the ills of South African society at the time, and cannot be said to represent the lived experience of being a disabled person and an outcast.

It is in South Africa that Quayson remains for the last ‘text’ that he analyses. That ‘text’, Robben Island, may at first glance seem like an odd choice. The reason for that choice is that, long before it became a prison – and famously Nelson Mandela’s prison – it served as an asylum for the sick poor, people with leprosy (nowadays called Hansen’s disease), and those with mental illness. Robben Island’s history is therefore intimately connected with bodily difference. Quayson discusses this history with regards to Athol Fugard’s play The Island, which does not reference disability, but is based on the story of two convicts who actually served time in the apartheid-era island-prison. Quayson’s argument for including this analysis in his book is that it shows how interconnected questions of justice are for people who live on the edges of their own societies and also how literary and historic texts can both shed light on the reality of such persons as well as informing each other.

20 There are instances where characters have diagnosed with autism (or other conditions) by readers/viewers, without their being explicitly presented as having a particular impairment. One of the most notable characters is Sheldon, in the television sitcom The Big Bang Theory. See for example ‘The Problem with Sheldon Cooper and the “Cute Autism”’ by Lydia Netzer (2016), available at http://www.autismsupportnetwork.com/news/problem-sheldon-cooper-and-cute-autism-387783 [accessed 20 October 2018].
War and social conflict feature heavily in the texts discussed by Quayson in *Aesthetic Nervousness*. War is also referenced in the first film analysed in *The Problem Body*. War has a curious relationship with disability. Soldiers must be physically and mentally fit, and thus free from any impairments or medical conditions, before being allowed to go to the front, and yet going to the front highly increases their likelihood of returning home as disabled persons, whether it is through physical injury or post-traumatic stress disorder. Timothy Barnard’s chapter ‘‘The Whole Art of a Wooden Leg’’: King Vidor’s Picturization of Laurence Stalling’s ‘‘Great Story’’ deals with King Vidor’s 1925 film *The Big Parade*, which is based on Laurence Stallings autobiographical novel *Plume* and features Jim Apperson, a World War I soldier who returns home with an amputated leg. Barnard discusses how the film was made, including how the non-disabled actor who plays Jim (John Gilbert) was shown as having a below-the-knee amputation, long before the advent of computer-generated images. The realistic depiction of an amputation is related to the realism of the film more generally, especially with its attempt to debunk romanticizing myths about war. This attempt, Barnard argues, is only partly successful since the film does not escape melodrama and is a less bitter account of the ravages of war than the original novel it is based on. As with many of the works analyzed in the two books being reviewed, the focus is on how disability is used as a metaphor.

In the next chapter, ‘Phantom Limbs: Film Noir and the Disabled Body’, Michael Davidson looks at how this film genre uses disability. Davidson argues that, in film noir, disability is often linked to sexuality. In these films, Davidson argues, the disability of certain characters is linked with their sexuality or that of others. The crippled man whose wife takes a lover, for instance in *Double Indemnity*, *The Lady from Shanghai* and *Walk on the Wild Side*, serves to highlight the other man’s superior sexuality. The link with sexuality goes further, according to Davidson. The love triangle between crippled man, unfaithful wife and virile lover steals the limelight, thus allowing the director to introduce same-sex attractions into the plot, at a time when such filmic representations were heavily censured.

The third chapter in *The Problem Body*, ‘Seeing Blindness On-Screen: The Blind, Female Gaze’ by Johnson Cheu, explores how depictions of blindness on screen tend to be based on and also reinforce stereotypes and assumptions about blindness held by those who can see. Cheu chooses Terence Young’s 1967 *Wait Until Dark* for a more in-depth analysis. The character of Susy Hendrix, the blind female protagonist, feeds into two stereotypes: determined overcomer and helpless victim. These stereotypes may appear contradictory but both feature commonly in general assumptions about disabled people. Ultimately, it is the second stereotype that emerges more strongly. Susy’s agency in getting the better of those who drag her unwittingly into the selling of illegal drugs is undermined by the depiction of her as dependent on sighted persons for salvation.

Dawne McCance’s chapter ‘The Wild Child’ is about François Truffaut’s 1969 *L’Enfant Sauvage* is based on the true story of Itard’s work in early nineteenth century France with Victor, the ‘wild boy of Aveyron’, a feral child whom he took under his care. It is almost impossible to ascertain whether Victor’s developmental disabilities occurred before or after he was left to fend on his own in the wild. What is certain is that he was seen as not fully human by many of those who observed him, a stance which, as McCance notes, unfortunately applies for the way some disabled people are looked at even today.  

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21 Among the main proponents of seeing certain disabled people (especially those with profound and multiple physical and cognitive impairments) as not qualifying for human rights are Peter Singer and Jeff
Much like Coetzee’s Michael K., Victor can hear but does not speak. McCance argues that in Truffaut’s film, this inability to speak is what prevents the boy from attaining full human status because ‘he is incapable, in Jacques Lacan’s terms, of crossing the threshold into speech and autonomous subjectivity’ (PB, 93).

One of the issues that Quayson, as well as the contributors to The Problem Body, pinpoint is the lack of verisimilitude of the depiction of disabled people’s lives in narratives. Very often, they argue, this lack sustains the use of disability as a metaphor, trope, allegory or symbol – in short anything but the portrayal of the lived experience of disability. This issue very much features in Paul Darke’s chapter ‘No Life Anyway: Pathologizing Disability on Film’. Darke’s scrutiny is on John Badham’s 1981 Whose Life Is It Anyway, which tells the story of Ken, who becomes quadriplegic following a car accident. The film, Darke argues, requires Ken to be in a far more pitiable state than someone in his situation could have been. His need for long-term hospitalization, his remaining mostly in bed and his constantly wearing hospital clothes are among the techniques used to highlight the hopelessness of his situation, even if in reality a quadriplegic can live at home (albeit with intensive support), use a wheelchair and wear ordinary clothes. But Ken’s final choice to die, rather than living in his present state, would be undermined by a more realistic depiction of life with quadriplegia.

Death plays a more central role in the next chapter, “‘And Death – capital D – shall be no more – semicolon!’: Explicating the Terminally Ill Body in Margaret Edson’s W;t” by Heath Diehl. W;t is both a play and a film, and tells the story of Dr Vivian Bearing, a John Donne scholar, who is diagnosed with cancer, receives treatment for it and eventually dies. Diehl argues that this film works more as analogy than allegory, with scenes of Bearing’s doctor diagnosing and treating her illness being interspersed with her analyses of Donne’s metaphysical poetry. Ultimately, however, the analogy fails because the latter cannot substitute the experience of being treated for and dying with cancer, an experience that is dominated by pain and physical suffering not only from the disease but from the treatment for it as well. Unlike in the other narratives discussed in this review, the lived experience of bodily weakness is foregrounded, rather than being used as a vehicle for another theme.

The link between disability and sexuality, mentioned earlier, is returned to in the next chapter, Eunjung Kim’s “‘A Man with the Same Feelings’: Disability, Humanity, and Heterosexual Apparatus in Breaking the Waves, Born on the Fourth of July, Breathing Lessons, and Oasis’. Breathing Lessons is different from most of the other films discussed in this book, since it is a South Korean documentary film, the only one of the four films in which the disabled character is a woman. In the first three films, the disabled men seek to recover their sexuality through buying the service of prostitutes or, in the case of Jan in Breaking the Waves, prostituting his wife. Oasis highlights the very different way that disabled women’s sexuality is presented. As Kim says, its existence is hidden. In the film, Gongju, who has cerebral palsy, is raped by Jongdu, the man who had killed her father in a hit-and-run accident. Jongdu immediately regrets his action and the two develop a relationship. When later on in the film the two have consensual sex, Gongju’s family assume that she is being raped. In different ways, these films reinforce the perception that disabled people cannot find sexual fulfillment in the ways available for non-disabled people.

Sexuality also features in Chapter 8 of *The Problem Body*, the last one to focus on specific films, Robert McRuer’s ‘Neoliberal Risks: Million Dollar Baby, Murderball and Anti-National Sexual Positions’. Like Kim, McRuer analyses both a film and a documentary. In *Million Dollar Baby*, Maggie, a boxer, becomes quadriplegic and enlists the help of her former trainer to die.\(^{22}\) McRuer sees Maggie’s story as linked to neoliberalism, among other reasons because she took a risk, which could have paid off but did not, in a deregulated environment, and took personal responsibility for it, thus avoiding becoming a burden on the state. The quadriplegic rugby players who take part in the documentary *Murderball*\(^{23}\) portray a very different picture. They are active and trade on their masculinity. The narrative threading through the documentary is the sporting rivalry between the United States and Canada, but there is also a glimpse into the private lives of the US team, including their sexuality. The discussion on how a severely disabled man can have sex, McRuer argues, undermines the nationalistic streak of the documentary since it presents a different angle to life with a disability than the one that is generally sanctioned.

As mentioned earlier, these two books inevitably omit more representations of disability than they could ever hope to include. There may also be moments where one is not necessarily in agreement with the interpretations presented. Perhaps the most important message to take away from the analyses is that representations of disability are rarely what they seem to be at first glance and the reader/viewer does well to seek out the polyvalent nature of these representations not only to understand better the text at hand and to consider the dimension of disability in different narratives that is so often neglected by reviewers and critics, but also to appreciate more closely the reality of living with a disability.

**Bibliography**


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\(^{22}\) The plot is rather predictable and follows the same pattern as *Whose Life is It Anyway?* discussed above, as well as Alejandro Amenábar’s 2004 *Mar Adentro* and Thea Sharrock’s 2016 *Me Before You*, among other films.

\(^{23}\) The title of the documentary is the former name given to quad or wheelchair rugby and evokes the dangerous and violent nature of the sport.


**Interpretarea dizabilității în literatură și în film.**

**Recenzie**

**Rezumat**

Acest articol recreezează două studii majore din domeniul studiilor dizabilității, un volum editat de Sally Chivers și Nicole Markotic, intitulat *The Problem Body: Projecting Disability on Film*, și un volum intitulat *Aesthetic Nervousness: Disability and the Crisis of Representation* al cărui autor este Ato Quayson.
On Public Representation of Trauma: A Review of Jane Goodall and Christopher Lee’s 
Trauma and Public Memory (Houndmills, Basingstoke and New York: Palgrave Macmillan, 2015)

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Abstract

This is a review article of a collection of essays entitled Trauma and Public Memory, edited by Jane Goodall and Christopher Lee.

Keywords: trauma, public memory, memory studies, Jane Goodall and Christopher Lee

As this thematic issue has repeatedly shown, trauma studies have proliferated in the past decades, with a huge broad range of scholarship that spans disciplines such as critical theory, literary theory, psychology, sociology, memory studies, to name only a few. From this perspective, Jane Goodall and Christopher Lee’s Trauma and Public Memory brings a multidisciplinary approach that lends a sense of deeper thinking into this burgeoning field of inquiry. Made up of three main parts, one entitled ‘Overviews’, one containing ‘Interviews’ and the remaining part that is called ‘Reflections’, all covering topics that deal with situations in different parts of the world such as South-East Asia, Australia, Africa, Europe, Cuba and the United States, the volume shows how individual and collective traumatic experiences are transferred into the public memory. Goodall and Lee’s edited collection moves from the traditional understanding of trauma with its limitation to victims of violence, abuse or accidents that left disastrous injuries. As Peter Levine has shown, ‘[t]rauma does not have to stem from a major catastrophe’; some common triggering events include ‘automobile accidents […]; routine invasive medical procedures; loss of loved ones; natural disasters, such as earthquakes and hurricanes.’¹ It is exactly from reflections upon a natural disaster that this book started, more precisely the meetings Goodall and Lee had at the University of Southern Queensland in the regional Australian city of Toowoomba. The city was affected by massive floods that were transformed in an ‘inland tsunami’ in January 2011 and resulted in 35 casualties, over two hundred thousand people affected and damages of around 2.38 billion Australian dollars.²

Andrew Hoskins and John Sutton, the editors of the Palgrave Macmillan Memory Studies Series, where Trauma and Public Memory is included, draw our attention on the complexity of the way in which we remember traumatic events in the 21st century, when

¹ Peter A. Levine, Healing Trauma: A Pioneering Program for Restoring the Wisdom of Your Body (Boulder, CO: Sounds True, 2005), 14, original emphasis.
‘[g]enerational change and new technologies of memory are reshaping the ways in which memory works, and the influence of trauma narratives is a factor in this’ (1). There is always a gap between the way in which an individual who was directly affected by trauma recalls the respective event and its public reception. Thus, as Goodall and Lee make it clear, their volume is not concerned with ‘the politics of public memory per se, but rather with the relationship – or lack of it – between the experiential memory of traumatic events, and the kinds of narratives and commemorative practices embraced by a wider public’ (2) with the purpose of analysing how traumatic events ‘may register upon a wider public, distanced from them in time and place’ (3).

Structurally daring and deeply particular, this book aims to advance trauma studies as a discipline that exceeds the limits between theory and practice, unmooring itself from very strict theoretical and practical imperatives. As it proceeds, *Trauma and Public Memory* covers both the way contributing writers from the humanities and cultural history study trauma as an academic field and professionals primarily involved in healing traumatised people narrate and remediate trauma, informing one another.

Taking their cue from the French sociologist Maurice Halbwachs’s notion of collective memory where he included individual memories as mere fragments³ and from Jürgen Habermas who opened the discussion of the emergence of ‘the public sphere as a discursive domain’, the editors introduce the concept of public memory: that memory that ‘emerges when individuals, families and social groups encounter each other in time and space and negotiate a common view of shared events’ (4), thus ‘a memory disseminated’ and sometimes formed by sources and institutions that are often compromised, but constitute ‘various sections of the public sphere’ (5). Goodall and Lee think of the practices of relating to trauma which have all become standardized: traumatic events make front page or headlines in media, then they are mentioned in politicians’ speeches and then memorials, films, narratives, commemorative events appear. However, the sooner the event has been memorialized, ‘the sooner the community could be encouraged to move on’ (6). Such remarks are consonant with those expressed in the last years by many scholars within the field of memory studies.⁴

Goodall and Lee are also concerned with the huge gap between the narrative coherence of public memory and the individual memory of the victims of tragic events.


⁴ For instance, the German historian Martin Broszat has suggested that in spite of referring to history, instead of reminding people about events, monuments bury them altogether beneath and ‘coarsen’ historical understanding (‘Plea for a Historicization of National Socialism’, in *Reworking the Past: Hitler, the Holocaust, and the Historians’ Controversy*, ed. Peter Baldwin (Boston: Beacon Press, 1990), 129) and Pierre Nora has introduced the notion of *lieux de mémoire*, claiming that what ‘we call memory today is therefore not memory but already history’ and that ‘the less memory is experienced from the inside, the more it exists only through its exterior scaffolding and outward signs.’ (‘Between Memory and History: Les Lieux de Mémoire’, trans. Marc Roudebush, *Representations*, Special Issue: ‘Memory and Counter-Memory’ 26 (Spring 1989): 13). In his *Twilight Memories: Marking Time in a Culture of Amnesia* (New York and London: Routledge, 1995), Andreas Huyssen has suggested that in a contemporary age of mass memory that is produced and consumed, the proportion between the memorialization of the past and its contemplation and study has been inverted. James E. Young has coined the notion of ‘counter-monuments’ by which he understands ‘memorial spaces conceived to challenge the very premise of the monument’. See ‘Memory and Counter-Memory: The End of the Monument in Germany’, *Harvard Design Magazine* 9 (Fall 1999): 3.
While commemoration urges *Do not forget!*, victims need to work through their trauma and move on; at the same time, while commemoration urges to association ‘between the participants, between those assembled in the present and those remembered from the past, between historical causes and the ongoing convictions of a contemporary society’ (8), individuals live states of dissociation (like flashbacks, nightmares) that make them go back to the place of trauma and that affects personal relationships and wider social interactions’ (9).

Section one starts with Christopher Lee’s essay, “‘But Why Should You People at Home Not Know?’: Sacrifice as a Social Fact in the Public Memory of War’ which analyses Lieutenant J. Alec Raws’s *Letters* that were recorded by Charles Edwin Woodrow Bean in his *Official History of Australia in the War of 1914–1918*. Raws’s *Letters* depicted in vivid details the horrible deaths around him in the battle for Pozieres on the great Somme battlefield in 1916. 23,000 casualties were registered, including Raws himself and his younger brother, Goldy. Raws’s *Letters* exposed his family to trauma in different ways (to his sister he told the plain truth about the imminent death of their brother, to his parents he would mention his brother’s wounds but the possibility of recovery to give them hope). Lee identifies Bean’s dual role both as a liberal journalist and an official historian in fulfilling his task of handing down individual traumatic experience to the public. He points out that Bean’s use of ‘simple, dispassionate language’ and his straightforward style that recorded the thoughts of a simple Australian soldier is an indicator of his attempt to ‘communicate with an unlettered Australian public’ (25). Bean made a selection of Raws’s letters in *The Official History of Australia in the War of 1914–1918*, a reason why he was criticised for several omissions and relegations, which are regarded by Lee as a gesture typical of ‘the official historian whose determination to “stamp” the nation building achievements of war – “with some high moral purpose” markers of his deep concern for his historical duty – “stamp the war with high moral purpose”’ (31). Lee sees Raws’s letters as resonating with ‘new histories, new debates about war and nation, trauma and suffering, gender, race and class’ and claims that they contain what some may call ‘mythology’ or ‘ideology’ but he himself prefers to consider rather ‘a recurring trope, a common frame of incantation which consistently bundles this testimony in the forms of a resilient ritual’ (33).

Wendy Richards’s ‘Trauma, Dispossession and Narrative Truth: “Seeds of the Nation” of South Sudan’ focuses on editing the stories of refugees taking into account the way in which public imagination ‘functions as a marketplace, in which the refugee story must compete with other depictions of traumatic experience for empathy, legitimacy and the resources necessary for the construction of social belonging’ (41). Richards not only looks into the transference of private turbulent memory into the public sphere but also emphasizes the part this transference plays in emotion politics and necropolitics. She suggests that the filtration of traumatic dispossession lies both in its difficult settlement in a strange community and its struggle in representing the trauma experience imagined and constructed by that community, which asks for the delicate exposure of individual misery and tricky testimony of destruction. At the same time, invoking Julie Salverson’s work on the ‘erotics of injury’,5 she questions the role of the witnessing public, wondering whether we should guard ourselves against our ‘predilection for “innocent listening”, in which we avoid acknowledging the price imposed by trauma upon disclosure itself’ (41).

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She reflects on her work as co-editor of the Awulian Association’s Anthology containing both personal and communal traumas of destruction and displacement from the conflict between Sudan’s north and south, especially the narratives of ‘Lost Boys’ (42). Richards is sceptical about this ‘naive flight narrative’ (44) where adventure and resilience of refugees and benevolence and generosity of the host community are overstated, while violence and displacement of Sudan civil war are understated, pointing out that the commodification and sentimentalisation of the ‘Lost Boys’ leads to the ignorance of the domestic chaos in Sudan. In reality, the lost boys were orphans, unaccompanied and unaided by adults, ‘who endured long, arduous and life-threatening journeys on foot through the harsh landscapes of South Sudan’ where they were prey to diseases and animal attacks (44). The only support they received was in refugee camps operating across the region’s borders, where the international community stepped in ‘with programmes of resettlement to refugee-receiving countries within the Global North’ (44). Richards’ account attempts to give a comprehensive report on her role as the editor of the traumatic narrative with all the dissociative symptoms, including detachment and emotional numbing that the victims experienced, a narrative from which she maintained a detached position, yet connected distance while authors were making constant revisions to their texts, being aware that their works would become public.

Jane Goodall’s ‘Trauma and the Stoic Foundations of Sympathy’ examines experiences of violence, direct and witnessed, among individuals. Peter Bouckaert, Emergency Director of Human Rights Watch and photojournalists Jerome Delay and Marcus Bleasdale were witnesses to a horrible lynching of a man who dared disturb the speech of Catherine Samba Panza, recently elected interim President of the Central African Republic while she was demanding for a call for unity in her public address to the national army in 2014. The essay is written in the immediate aftermath of this horror (actually one day after it, as the author claims) and two days after Bouckaert and Bleasdale risked their lives in order to rescue the archive of photographer Samuel Fosso, whose house was in an area that was comprehensively trashed by looters (53). Permanently engaging with the other contributions in the volume, which is a unique feature of this edited collection, Goodall is interested in the way witnesses can bridge the ‘immense gulf’ between awareness and understanding of an event (54); that results from two tendencies: on the one hand, ‘the influence on public memory, so that it is accountable for the full spectrum of human reality’, on the other hand, ‘the need for a more fundamental kind of influence, on the cognitive and emotional range from which public memories are drawn’ (54). In order to address the second issue, Goodall resorts to examples from history, delving into the way in which ‘certain influential figures were concerned with the formation of memory in circumstances that test the capacities of human sympathy in the modern era’ (54). She offers a contrastive analysis between Abraham Lincoln’s 1861 inaugural presidential address that ‘sought to offer a vision of public memory drawn directly out of trauma to create the fabric of a wholesome nation through the bonds of sympathy’ and Adam Smith’s *The Theory of Moral Sentiments* (1759) which, in spite of their different agendas, were somehow similar in their embodying the principles of Stoicism, since they both rejected the cynical philosophical

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6 An association that helps refugees from sub-Saharan Africa who arrived in Australia.

7 The editors have structured their book in an unusual yet highly original dialogic structure. Not only do the editors comment on all essays in the *Introduction* and also in the introductions to each of the three sections, but also the authors relate to one another’s chapters and to the Introduction, keeping a conversational thread that is not common in edited books.
tradition of classifying human beings ‘as an inherently savage and combative species, whose mutually destructive tendencies can be quelled only through the control imposed by a ruthless leadership’ and both saw civilian concord ‘as the way out of a state of war and sectarian division’ (54). In spite of this, the difference between Lincoln’s and Smith’s views lies in the way in which they conceived the implication of witnesses of historical events. Smith practised the Stoic tradition, self-training himself to respect the principles of what is known as *apathæia* which refers to holding feelings at bay, refusing to embrace or identify with them (56). Questioning what kind of sympathy Smith envisages when ‘apathy, however particularly interpreted, is the precondition’ (56) of engaging with an event as a witness, Goodall engages with the way in which Lincoln’s speech was perceived by the public, discussing the highly positive way in which the renowned American poet Walt Whitman interpreted it. If Smith believed that sympathetic feelings expressed by a public in response to a private experience should be moderate and in correspondence with stoic practices, Whitman followed Lincoln’s conviction, stressing one’s need to identify with sufferers, a thing that he did himself while helping the wounded and the dying from the war with whom he spent his days during the American civil war. His *Memoranda During the Civil War*8 testifies to ‘the seething hell and the black infernal background’ (63). Yet, what made Lincoln a hero is in Goodall’s view his ‘visionary determination to influence how the future would look upon the present’ (67). To this extent, the people who never lived their predecessors’ traumas can be informed via image, cinematic portrayal of events and photography. There are two examples of photographic exhibitions with an impact at national level that Goodall uses to illustrate ‘the public deployment of historical images to re-shape public consciousness’ (68), examples that were used by Erica Lehrer and Cynthia E. Milton in their edited collection belonging to the same *Palgrave Macmillan Memory Studies, Curating Difficult Knowledge*:9 a massive assemblage of around 9000 photographs collected from Polish people and entitled ‘photographs of Jews before the Holocaust’, which evoked ‘a lost social world’ and ‘a collection of images by photojournalists in Peru recording “the faces of suffering, the visible proofs of the injustices committed” during the previous decades of civil conflict’ (68-9). Goodall’s essay ends symmetrically with the example of the photographers who rescued Samuel Fosso’s work from the ruins of his house in Bangu. Rescuing those photographs, they rescued public memory in the form of the defenceless against trauma, one who witnessed ‘to the harshest forms of reality’ (69).

Laurie Johnson’s ‘Unremembered: Memorial, Sentimentality, Dislocation’ deals with the ‘psycho-social’ function of collective memory in relation to trauma theory in an analysis on war memorials. The theoretical premises for this essay are Paul Ricoeur’s work on memory, *Memory, History, Forgetting* and Sigmund Freud and Josef Breuer’s *Studies on Hysteria* that showed that, even if after trauma the physical body might heal, the ‘foreign body’ which is the memory of the psychical trauma enables the trauma to persist until it can be removed to the unconscious (71-2). Moreover, Freud’s discovery of the process of mourning, in which the mourner expands his ego to include the lost object, partially in agreement with Sándor Ferenczi’s explanation of ‘introjection’ meant that once we mourn, we identify with the deceased, a gesture which, in Maria Torok’s view,

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'involves surrendering a portion of the ego to another' (72). Sociologist Erika Apfelbaum 'suggests that in populations defined by dislocation, a sense of community can be built in a new location around a "need for legacy"' (73); they are confronted with 'a lack of a past, and this is what enables them to regroup around a communal bond' (74). Apfelbaum’s ideas help Johnson to start a discussion on the psychosocial function of the war memorial in Australia which is the main focus of her essay. She defines it as ‘the artificial establishment of a need for legacy rather than a need arising from a forced dislocation’ (74) and compares it to some American memorials of large-scale traumatic events like the memorial for New York 9/11 or the memorial for New Orleans Hurricane Katrina. Laurie Johnson argues that ‘the memorial actually pushes the loss into the distance, as a moment defined by being elsewhere and in the past, by virtue of the fact that the memorial stands-in for the object of loss’ (76). Johnson invokes Tobias Döring who pointed out in The Performance of Mourning in Shakespearean Theatre and Early Modern Culture that the culture of Memorial appeared in Europe as early as the sixteenth century, after the Protestant Reformation and the abolition of Purgatory which meant ‘a mourning for the dead.’ Johnson’s conclusion is that ‘the monument functions, at least in psycho-social terms, in lieu of the past, to which end it ensures a break, which in the depth of feeling that is generated via widespread displays of sentimentality enables the break to feel like a trauma of memorial, here, now; the past unremembered’ (83). When it comes to trauma, medical specialists, rescue workers, police, counsellors and government officers play their role in helping the victims of trauma. The second section of the book consists of the editors’ interviews with professionals who are experienced in responding to traumatic events, including clinical psychologist Ross Anderson, emergency nursing specialist Therese Lee, disaster co-ordinator Norman Fry, chair of Human and Social Response Committee Tanya Milligan, recovery officer Sue Hewitt, and Foreign Correspondent Mark Willacy. A big part of the interviews is concerned with natural disasters such as earthquakes, large floods, hurricanes which – although not directly human-caused – were injury or death-producing environmental events that adversely affected a substantial number of people. This section does a brilliant job in articulating the different meanings of post-traumatic stress disorder and other related traumas in and after such disasters or during war or after physical assault or acts of terrorism as well as the huge gap between the way they appear to the ones who suffered the direct consequences of such disasters and their close circle (family, close friends) and the totally different way in which other people relate to the respective event. These interviews perfectly capture ‘insights into the stressed relationship between public accounts and experiential recollection in a disaster situation’ (85). The diversity and speciality of interviewees are the highlights of this section which guarantees the credibility of the trauma narratives included throughout the whole book and showcases the editors’ concern for humanity. Anderson mentions specific techniques of treating posttraumatic stress disorder like ‘normalising in the form of acceptance that the suffering after the event was valid’ (88) and general anxiety management techniques in treating trauma victims, making distinctions between primary victims (those who were physically present) and secondary

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victims (friends and family and co-workers not present at the time the traumatic event took place), explaining the necessity of peer support among disaster professionals. He is concerned with the cognitive management of the psychological impact during the initial period of shock. Considering ‘the modern entertainment media landscape’ a tool that leads to systematic violence desensitization, he believes this has led ‘to a desensitisation to the impact of trauma on others’ (92).

Therese Lee recounts her previous experiences as first aid provider who attended on site traumas at motor vehicle accidents, fires, incidents at building sites and moved on to helping in major disaster situations. She does not believe that media coverage of a disaster can actually make people comprehend what really happened. Recalling her experience with victims of tsunami in Banda Aceh, Indonesia, following the 2004 Indian Ocean earthquake – which was assessed as one of the deadliest natural disasters in recorded history and the deadliest of the 21st century – or that with victims from Vietnam, she makes it clear that private suffering cannot be rendered into public memory simply by images and reports. There are people, especially the ones who have never travelled overseas, who cannot comprehend the immensity of a catastrophe. However, in spite of witnessing the ‘horrible, the absolutely grief stricken and devastated’, she feels it was ‘a privilege to be with people in the highs and the lows of their life, even in those life and death situations’ (102, original emphasis).

Norman Fry, as one of the two disaster management coordinators for the Toowoomba Regional Council in Australia at the time of the 2011 floods, reflects on how accurate information was derived and circulated from the chaos of Toowoomba flood, but in its attempt to reach a wider public keen on reading and watching spectacular news, ‘any available information may be appropriated to support established generic modes of disaster reportage’ (86). Speaking about his own experience and the other coordinator’s, he shows how they were both affected to the point that they needed the help of other professionals; psychologists counselled the whole group and also spoke to individuals if these ones required. Fry also discusses the role of politicians in disaster situations. ‘Politics comes into a disaster situation right from the first minute’, he says, adding: ‘you can expect visits from the premier, visits from the leader of the opposition, visits from the government, visits from the governor general, visits from the prime minister’ (108). Although abstaining from commenting more and ending his interview on an inconclusive note, Fry voices a general truth: that politicians come to the site of the disaster not necessarily with the intention to help but with the desire to show to the world that they care.

Tanya Milligan and Sue Hewitt offer a detailed description of the floods from Lockyer Valley in South East Queensland in 2011. Tanya Milligan, herself a victim of the flood who was evacuated from her house, found herself in the position of helping the one hundred people who were in the same situation, while Sue Hewitt, a Red Cross worker, came from Brisbane to give a hand to the victims. Contrasting ‘local media that have […] done an excellent job’, really promoting the local events and the recovery story with the general coverage in national media, they criticize the former’s inefficacy in sharing public memory in news coverage which was highly inappropriate for those who were undergoing trauma. They also emphasize the need for greater community development in a wider frame to continue for a longer period than the two years after a disaster that NDRRA (National Disaster Relief and Recovery Arrangements) envisaged. That is needed in order to build something more sustainable and to keep going follow-up
stories that give people the feeling that they were not forgotten so soon after a disaster which ‘can be just damaging for a community’ (114).

In the next interview, Mark Willacy, a foreign correspondent with the Australian Broadcasting Corporation (ABC) who has reported numerous traumatic events from Israel, Japan, Korea, the Philippines, Thailand, Pakistan, Afghanistan, Iraq, such as the conflicts in the Middle East, terrorism, wars, revolutions and big natural disasters, shares his unique international work experience and admits that it is normal for journalists in war or natural disaster zones to be constantly on the move and to repeatedly probe into victims’ painful memory. He recounts how his job affects his loved ones, especially his wife who, in a sense, is a silent witness to what he experiences every day, and the pressures he experienced to report Australian stories because of the Australian involvement in the respective event, a duty that he has not subscribed to. He criticizes commercial television news for not covering events professionally, because they think ‘the audience has a short-term memory’ (122) and discusses the importance of micro-blogging on Twitter which can be ‘a valuable tool’ if used properly and can get several thousand followers. He also speaks about the advantage of radio as a medium that needs to use persuasive techniques and evocative stories in a world which is too much ‘bombarded by images’ on You Tube, television, movies (123). Willacy finally relates his experience of writing his book which was a great tool to share his experiences with his readers, even if his experiences do not always end with the Hollywood closure that people expect, admitting that what he wants to do is ‘to remind people that victims of trauma don’t always have a happy ending’ (126).

In the light of the examples that showed ‘how public memory can be governed by bad habits: sensationalism, fickleness, sentimentality, intrusive curiosity and selective amnesia’ (127), the third part of the book addresses the need to bring critical theory and memory studies closer, through a more theoretical approach of the concept of public memory.

Lindsay Tuggle’s ‘Unburied Trauma and the Exhumation of History: An American Genealogy’ discusses two disaster memorials: Ground Zero built after 9/11 and New Orleans Memorial after Hurricane Katrina. What they have in common is their metaphoric resonance with a ‘poetics of dust’ (132). Ground Zero houses real corporeal remnants of several thousand unidentified casualties. The forensic experts have unearthed from the ruins of World Trade Center around 20,000 body parts, out of which only 292 intact corpses were found, thus around 1592, or more precise 58 per cent of the 2789 casualties were identified.12 In an extremely interesting debate that builds its theory on Marita Sturken’s conclusions from Tourists of History13 as well as the work of prominent psychoanalyst (Sigmund Freud’s concept of ‘melancholia’14, Maria Torok and Nicholas Abraham’s theory of ‘incorporation’15 as well as Jacques Derrida’s notion of the spectre), Tuggle investigates the ‘disordered mourning’ at Ground Zero where the dust – ‘biologically rejected by the bodies it invades’, because it produces respiratory problems

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On Public Representation of Trauma

– becomes both the material trace of the dead and the toxic mixture of the towers that fell (134). Thus, Ground Zero caries in itself both an ‘unrealisable’ loss and ‘the other is encrypted within the psyche’ (134). The dust it kept from World Trade Center enacts, ‘in Walter Benjamin’s words, the “multiplication of traces” via its dispersal as airborne biological particles. Conceptualising the dust as traces of the dead, the entire reconstruction and memorial project is engaged in the banishment or enclosure of those traces’ (135).

According to Tuggle, the labyrinthine structure of the memorial that Jeffrey Rouse designed three years after Hurricane Katrina also internalizes trauma, inherently memorializing entrapment. At the same time, the cemetery on the site which was purchased by Charity Hospital in 1848 and ‘has historically been used to bury the unclaimed from throughout the city including victims of several yellow fever and influenza epidemics’ (137) testifies to ‘a collective refusal to whitewash the history of New Orleans, conjuring Katrina’s ghosts in defiance of the nation that left them behind’ (139). Such a tendency towards exhumation and preservation is traced back to the nineteenth century America, after Lincoln’s death, when Americans domesticized mourning in very personal ways. For Tuggle, at Ground Zero and New Orleans there is a whole ‘souvenir fetishisation industry’ (143). In fact, the feelings that one gets when confronted with the ‘poetics of dust’ can be framed in what Bryoni Trezise, the author of Performing Feeling in Cultures of Memory, called ‘memory practices that have, and are, particular cultural affects’. 16 Although not naming Trezise’s work, since that deals especially with virtual museums that recreate the familiar tropes of existing museums and memorials, when Tuggle gives a full account of the souvenir shops at Ground Zero and on Bourbon Street17 and of the ‘sacred preserv[ation]’ of Lincoln’s corpse, she actually describes what Trevize called ‘memory affect’. Indeed, perhaps what is missing from this collection of essays which claims to take into account that ‘[i]n a digital age of virtual worlds and instantaneous global communications it seems obsolete to insist on embodied presence for the constitution of a public’ (5) is precisely a chapter on the way in which emotions as cultural practices emerge in ‘virtual traumas’ which Trevise defined as ‘those cultural texts that have been produced by digital media in response to traumatic events’. 18

Lindsay Barrett’s ‘The Atrocity Tour’ charts complex spatial and temporal intersections of traumatic paths, starting from Alexander Platz, which in 1945 was a place in ruins where people used to walk down the streets as if nothing had happened (147), shortly visiting the city of Kassel, a former beautiful medieval town destroyed during the war by the British and the Americans ‘until it was ganz kaputt’, because in Hitler’s time it had become one of the Nazi Reich’s biggest and most important tank factories (148) to stop for a while at another place of atrocity: Wilhelmshöhe, a banal railway station where an unimaginable cannibalism case took place. Here Armin Meiwes, 40, who had picked up the announcement that Bernd Jürgen Brandes, aged 43, placed on a website called the Cannibal Café, came to meet his victim who wanted to be slaughtered and eaten. Barrett gives all the details of this horrible affair that ended up in Meiwes’s arrest at his next attempt to devour another victim, having as evidence the whole process of killing and butchering Brandes recorded. In this horrifying story, Barrett is not interested into

17 ‘9/11 souvenirs, including commemorative books, postcards, T-shirts, coffee mugs and playing cards’ and Katrina memorabilia consisting of ‘photography collections that capture residents stranded on rooftops, bodies littering the streets, displaced domestic objects strewn across the landscape’ (138).
18 Trezise, 116.
investigating this case of Meiwes’s serious mental illness but rather puzzled by an
entralling detail; while waiting for his victim to die in a warm bath, after the latter’s
penis was cut off, Meiwes went downstairs and behaved as if nothing happened; he read
peacefully a Star Trek novel, which reminds Barrett of a detail from the case of mass
murderer Adolf Eichmann: while being judged in Jerusalem, Eichmann was given Lolita
to read. As Hannah Arendt recalled in Eichmann in Jerusalem, Eichmann found Nabokov’s novel ‘a most unwholesome book’.

However, the tour does not stop here, but continues with what Barrett calls ‘a site
of infinitely greater horror than anything concocted by the lunatic, flesh-eating Trekkie
Meiwes’, which is one hour away from Kassel, the remains of the Mittelbau-Dora
concentration camp where the Nazis had ‘their underground rocket factory in which tens
of thousands of slave labourers were starved, beaten and worked to death by the morally
bankrupt Nazi state’ (152) under the command of the SS Sturmbahnführer Wehrner Von
Braun, who is also mentioned in Thomas Pynchon’s Gravity Rainbow. According to
Barrett, Wehrner ‘was a genius when it came to rocket science’ (152-3). That is why after
the defeat of the Nazi Reich, he was highjacked by the Americans and put in charge of
the American’s rocket design, being directly responsible two decades later for Neil
Armstrong’s small step on the moon (153), an atrocity in itself when we think how
Americans appropriated some Nazi brains, giving murderers the possibility to subtract
themselves from trials for the crimes against humanity that they committed. When stating
in passing that Eichmann was sincere when he asserted in court in Jerusalem ‘that he was
an honest man who always did the right thing and told the truth’ (153), although not
mentioning Hannah Arendt’s work, Barrett demonstrates a thesis she phrased in The Banality of Evil: what was most striking in the trial was that the Nazi criminal profile was neither a psychopath nor different from what we like to call a ‘normal’ person. Going on this tour while reading Jonathan Littell’s historical fiction novel The Kindly Ones which is narrated by the fictional protagonist Maximilien Aue, a former SS officer who helped the Nazi to carry out the Holocaust, Barrett considers the end of this ‘oneman sadomasochistic orgy in the Baltic hinterland […] both an homage to and a transcendence of Bataille’s classic The Story of the Eye, which in Jean Paul Sartre’s view epitomized the “destroying of all Literature”’ (155). Barrett’s conclusion is that a literary text is ‘just like a railway station, it’s a space of exchange, connection and transference, and the more effective these processes, then the more powerful the text’ (156). In this atrocity tour, the reader is finally dropped at Berlin’s Hauptbahnhof from where he arrives in front of the Natural History Museum with its piece representing ‘the most successful dinosaur excavation of all time’, the skeleton of a 13.27 metre-high and which can be a free ticket to what Barrett calls ‘an animal holocaust’ (158). Here the author encounters a busy

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19 ‘Serious mental illness’ was defined as ‘diagnosable mental, behavioral or emotional disorder […] of sufficient duration to cause serious functional impairment in an individual’s major life activities.’ Among serious mental illnesses SAMHSA includes ‘major depression, schizophrenia, and bipolar disorder, and other mental disorders that cause serious impairment.’ (See https://www.samhsa.gov/disorders [accessed 20 October 2018].)


ornithologist who identifies and classifies some of the ‘thousands of the surviving dead birds collected from the rubble’, seventy years after the war. At the end of this tour, the reader is almost relieved when the author declares: ‘I’ve had enough of this particular atrocity tour’ (161), a tour that caused reflections on the permanent need ‘to remember and acknowledge the traumas that live there, because they aren’t going to go away, and in the long run trying to repress them only makes their impact worse’ (161).

Robert Mason and Geoffrey Parkes’s ‘Regaining Lost Humanity: Dealing with Trauma in Exile’ draws upon the writings of the Cuban author Reinaldo Arenas, whose writings and openly gay life brought him into conflict with Fidel Castro’s communist government and made him end in jail because of his ‘ideological deviation’ and his publishing abroad without official consent. After a failed attempt to escape, he was imprisoned in the notorious El Morro Castle where murderers and rapists were detained, a place out of which he tried to smuggle his work. In 1976 he was released and in 1980 he fled to the United States. Mason and Parkes analyse Arenas’s novellas written while he was in Cuba: *Old Rosa* and *The Brightest Star*, his novels *Farewell to the Sea* (entirely rewritten after prison guards destroyed the sole manuscript (169). They also investigate the way in which the novels he wrote in the States, *Before Night Falls* and *The Color of Summer*, testify to the multiple traumas that Arenas had experienced. Mason and Parkes reject ‘the idea that trauma is a singular event’ and they contest that ‘trauma by definition necessarily involves dissociation’ (164). Political persecution prevented Arenas to share ‘a communal space of mourning’ but literature became for him ‘a testimony to the geographic and psychic effects of his trauma’ (164).

Victor Emeljanow’s ‘Popular Entertainments as Survival Strategies in Prisoner-of-War Camps During World War II’ discusses survival strategies used by war prisoners belonging to the British and Commonwealth troops to deal with psychological effects of trauma. When incarcerated in German camps, some succumbed, while others ‘developed strategies of mutual reinforcement’, by creating ‘communities of interest within which memory, both in its collective and public manifestations, played a key role’ (174). The most available means of keeping themselves tied to a community was the theatre that ‘has traditionally served as a site for remembrance and togetherness’ (174), as well as improvised cabaret with songs, poems, jokes (179). Even if one did not expect humour to have been one ingredient to temporarily forget the traumatic experiences of war camps, humour often made the difference between life and death and helped prisoners not to commit suicide or to go mad (180). Presenting journalist Noel Barber’s 1944 first readily accessible account of materials about prisoner-of-war camps, Emeljanow classifies and analyses the different plays that were performed in concentration camps. In the editors’ Introduction to Section 3, Emeljanow’s essay is presented as a ‘counterpoint’ for the volume, because it offers the reader a ‘case study of how the work of resistance may be conducted in a lighter register, through communally performed entertainments, and shows how the relationship between traumatic experience and public memory can cut both ways: there are situations in which public memory, far from offending against the traumatised subject, can provide a resource and a psychological support structure’ (128). Emeljanow’s work might be a valuable addition to work that has already been done on gallows humour at concentration camps.24

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24 See Chaya Ostrower, *It Kept Us Alive: Humor in the Holocaust* (Jerusalem: Yad-Vashem, 2014), and Lucia Ispas, ‘(Mis)Representing Trauma through Humour? Roberto Benigni’s *La vita e bella*,’ in *Arts of
Section 3 ends with Richard Gerhmann’s ‘A Soldier’s Perspective on Serving in Iraq and Afghanistan’ including reflections on his experience as an Australian soldier serving in Afghanistan and Iraq. Reading his essay shaped as a diary, we are just in the middle of tragic events, but also on the very reflexive side of things, since he is an academic, as he declares, probably the only one ‘who looked on the United Nations (UN) website to reassure themselves that their presence was in accordance with legally binding internationally endorsed UN Security Council resolutions’ (186). He tells us the story of the late Mathew (Hoppy) Hopkins, differentiating between the private side of things (his colleagues’, his relatives’ feelings) and the public memory of his funeral attended by Deputy Prime Minister Julia Gillard, as it was covered by television news. He also reflects on all recurrent traumatic flashbacks that war veterans live with and for which no clear remedies were found and about the soldiers’ need to see public recognition of ‘their sacrifice, trauma and suffering’ (201). Gerhmann’s conclusion is that in spite of the different categories of shared memory for veterans, for their families and friends, and for the wider community, there is always a common memory that is shaped (205).

At the end of the book, readers are somehow overwhelmed by the essays included in this collection, especially in the third part of the book which gave them a permanent sense of loss and suggested to them that the past intrudes belatedly upon the present through the numerous atrocities and disasters that were recapitulated in front of their eyes. Although readers were never there, they were given a sense of what Marianne Hirsch has called ‘postmemory’ which is the remembrance of things not witnessed.

The feeling we have when closing the book is well described by Robert D. Hicks in the book blurb: ‘Trauma and Public Memory breaks the comfortable and distanced mold of media-circumscribed public memory and exposes us to the complex, contradictory, and seemingly ineffable ways in which personal experiences of the traumatic become collective ones. We read of events so challenging as to defy naming, of events so searing that public memory demands a reassuring narrative, the harm obscured.’ Yet, when reflecting on how public memory represents trauma, we cannot avoid being confronted with events that take us out of our comfort zone and push us into an effort to come to terms with the negative legacy of the past and to learn its lessons if that is possible.

This book deserves a wide readership, proving to be equally beneficial to many other fields of study apart from memory and trauma studies like anthropology, history, sociology, psychoanalysis, to name only a few. With its potential to go beyond the realm of the academic research through Section 2, it charts new directions for a trans-disciplinary field of the study of trauma.


25 As he informs us, ‘most soldiers don’t kill, don’t see the dead, and don’t tend wounded – but they are soldiers nonetheless, and they are still part of the big military machine’ (197).
28 Director, Mutter Museum/Historical Medical Library, Philadelphia.
Bibliography

Despre reprezentarea publică a traumei. Recenzie

Rezumat

Acest articol recenzează volumul intitulat *Trauma and Public Memory*, editat de Jane Goodall și Christopher Lee.
Contributors

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Josephine Barnett is a Ph.D. student in the Sociology Department at The Graduate Center, City University of New York (CUNY) and an Adjunct Lecturer in the Sociology Department at Queens College (CUNY). Her research is in the areas of medical sociology, generational trauma, media studies, and visual sociology. She advocates for the use of visual research methods within the social sciences. Most notably, her piece entitled, Painting a Voice, explores how forms of art – such as graffiti – are used to raise awareness about illness, like AIDS and breast cancer, while simultaneously functioning as a way to reclaim public space and the body of the sufferer. Painting a Voice was awarded the Rachel Tanur Memorial Prize for Visual Sociology, which is funded by the Social Science Research Council and continues to be showcased by the International Visual Sociology Association. Her doctoral research aims to gain deeper insight into micro and macro sociological phenomena of generational trauma through the investigation of the significance of family photographs and photo albums in the construction of collective memory and personal-collective identity. A goal of this work is to bridge sociological theory and visual research methodologies in order to identify the integral role of the visual in aspects that underpin mnemonic battles used to conceal a traumatic past that may be rooted in systemic acts of violence across generations.

Kurt Borg is a PhD candidate in Philosophy at Staffordshire University. His current research draws on the work of Michel Foucault and Judith Butler to analyse the ethics and politics of narrating trauma in institutional contexts. He graduated with a BA and MA from the University of Malta, the latter with a dissertation on the relation between Foucault’s work on power and ethics. He lectures at the University of Malta on Foucault, Butler, ethics, feminist theory, medical sociology and narratives of illness, disability and trauma. He published articles on Foucault, Butler and trauma theory in Symposia Melitensis, antae, a book review in Foucault Studies and two book chapters in forthcoming volumes. An interview he has co-conducted with Judith Butler was published in CounterText 3.2 (2017).

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Arleen Ionescu is Professor of English Literature and Critical Theory at Shanghai Jiao Tong University. Her major research and teaching interests are in the fields of Modernist prose and, increasingly, in Critical Theory, Memory Studies and Holocaust Studies. She has published widely on James Joyce and other related aspects of modernism, as well as on Maurice Blanchot, Jacques Derrida, Samuel Beckett in reputed academic journals such as James Joyce Quarterly, Parallax, Partial Answers, Papers on Joyce, Joyce Studies Annual, Scientia Traductionis. Her books include Concordânte româno-britanică (Editura Universităţii din Ploieşti, 2004), Romanian Joyce: From Hostility to Hospitality (Peter Lang, 2014), The Memorial Ethics of Libeskind’s Berlin Jewish Museum (Palgrave Macmillan, 2017). At present, she is co-editing with Maria Margaroni (University of Cyprus) a volume entitled Arts of Healing: Cultural Narratives of Trauma (forthcoming with Rowman and Littlefield in 2020) and doing research on trauma issues related to the Piteşti experiment.

Douglas Kidd holds a Master in Liberal Studies Concentration in Disability Studies from the University of Toledo. As an independent scholar, his research interests are autoethnographies of himself and brother Richard as severe traumatic brain injury survivors. He has published in journals by Johns Hopkins University Press, Temple University Press and University of Hawai’i Press. He has also published works in anthologies about scars and poetry. Douglas Kidd presents research papers to universities and international conferences. He is employed as a case manager/peer supporter for a non-profit behavioural mental healthcare provider. In his current role on a civic commission and decade-long past service to a Center for Independent Living, he promotes the lives of individuals and improves the community. His non-profit safe-driving advocacy company is partnered with the National Safety Council. He leads a brain injury support group.

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Ann Millett-Gallant holds a PhD in Art History and serves as Senior Lecturer for the Bachelor of Arts in Liberal Studies program at the University of North Carolina at Greensboro. Her books include *The Disabled Body in Contemporary Art* (Palgrave Macmillan, 2010) *Re-Membering: Putting Mind and Body Back Together Following Traumatic Brain Injury* (Wisdom House Books, 2016) and co-ed, with Dr. Elizabeth Howie, *Disability and Art History* (Routledge, 2017). She has published a number of essays in academic journals and she is also an artist. Her website is annmg.com.

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Sarah Redikopp is a PhD student in the School of Feminist, Gender and Women's Studies at York University in Toronto, Canada. Her SSHRC-funded doctoral research undertakes a sustained intersectional analysis of self-harm as an embodied signifier of structural violence among Canadian women and trans populations, informed by a Mad studies perspective. Sarah received a Master’s Degree in Women’s Studies and Feminist Research from the University of Western Ontario (2018). Her SSHRC-funded research project ‘Revolutionary Flesh: Towards a Feminist Harm Reduction Model of Self-Cutting’ critically examined the construction of self-cutting in North American clinical literature and forwarded a depathologizing harm-reduction framework of self-cutting. Sarah’s broader research interests include Mad studies and epistemic politics, particularly at the site of psychiatric diagnostic categories, sick theory, critical race theory and the embodied materiality of trauma and structural violence.

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Tracy Anne Travis holds a Master of Arts in English with a concentration in Folklore from the University of Missouri. She tutors writing and lectures on writing ethics at The Pennsylvania State University-Harrisburg. A classically-trained flutist and traditional musician, she is interested in the interplay between cultural difference and aesthetics, the experience of authenticity, and Early Modern English literature and culture. Her interview with public sector folklorist Howard Marshall about the history of and issues in the field appeared in the Missouri Folklore Society Journal 33-34 (2011).