Disability, Pain, and the Politics of Minority Identity[1]

Tobin Siebers

1.

What is the trouble with minority identity? Minority identity is supposedly about pain.[2] Produced by coercion, clung to by subjects because the pain of coercion is hard to forget, minority identity is twice disabling. First, one is subjected; then the subject internalizes its suffering and lays claim to its own subordination. Pain serves as the glue that laminates the outside and inside of minority identity, ensuring that the violence enacted by society against individuals remains embedded in their psyche.

Such is the everyday experience of minority identity, according to many contemporary cultural theorists, but the trouble with minority identity grows worse when it is politicized. Identity politics apparently steeps the subject in pain by privileging the defective and weak identities produced by historical injustices like sexism and racism and by asking individuals to dwell on their suffering to produce political capital for themselves.[3] People given to identity

1 | This essay was originally published in *Foundations of Disability Studies* (eds. Matthew Wappett and Katrina Arndt. New York: Palgrave Macmillan, 2013. 17-28). It is reprinted with the kind permission of Palgrave Macmillan.

2 | This essay, along with my "Disability Trouble" and "Tender Organs," form part one of a two-pronged analysis of the representation of pain on the contemporary theoretical scene. Part one offers a counterargument to the pervasive belief that pain disables the ability of minority people to participate in politics. Part two, "In the Name of Pain," analyzes and takes issue with the use of pain in court decisions and legislation to justify unequal treatment of and violence against disabled people. The three essays together contribute to my ongoing correction of social constructionism by arguing that it ignores disabled bodies and their contribution to the knowledge base of society.

3 | For more on the notion that minority identity is supposedly injured or disabled in itself, and so inadequate for coalition building, see my *Disability Theory,* 34-95.

politics, according to Judith Butler, internalize the injurious names given to them by history and accept subordination to heal themselves, but the result is greater disability, not health or political power.[4] Either minority groups end up blaming themselves for their status as victims, which solidifies the sense of historical failure inherent in their minority status, or they avenge their pain by making scapegoats of others, which produces a morality of the powerless and resentful. Identity-based politics, Wendy Brown claims, thrives on "wounded attachments" (Brown 52 et seq.), and these affiliations, because linked to suffering, offer no alternative to subordination: "What kinds of political recognition can identity-based claims seek [...] that will not resubordinate a subject itself historically subordinated through identity?" (55). Pain apparently disables the ability of identity politics to form alliances based on self-affirmation, emancipation, and empowerment, producing instead a desire for recognition that "breeds a politics of paralysis and suffering" (55). "Politicized identity thus enunciates itself, makes claims for itself," Brown concludes, "only by entrenching, restating, dramatizing, and inscribing its pain in politics; it can hold out no future – for itself or others – that triumphs over this pain" (74). Friedrich Nietzsche, who is Brown's mentor in the theory of wounded attachments, uses stronger language to portray the identities created when oppressed people form political coalitions. He complains about being "condemned to the repellent sight of the ill-constituted, dwarfed, atrophied, and poisoned" (43).

The use of disability identity as a prop to denigrate minority politics has a long and pernicious history on the right, although it is bewildering to find the usage alive and well in Butler, Brown, and other cultural critics on the left.[5] (This surprising agreement between the right and left gives one small clue to the tenacious hold that ability as an ideology exercises over political thinking today.[6]) Indeed, the idea that the political claims made by people of color and women are illegitimate because their identities are disabled would be outrageous

4 | As Butler explains in *The Psychic Life of Power,* once "called by an injurious name" and "a certain narcissism takes hold of any term that confers existence, I am led to embrace the terms that injure me because they constitute me socially" (Butler 104).

5 | In "Disability Trouble," I trace the disagreement about minority identity during the last twenty-five years between the right and the left. On the right, I chart the continuum from Allan Bloom to Walter Benn Michaels. On the left worth mentioning are Brown, Butler, *Gender Trouble,* and Fraser.

6 | The ideology of ability establishes ability as the measure of human status, determining whether individuals are allowed to participate in a broad range of activities. Most important, in the context of politics, the degree of ability decides whether one is a rights-bearing person. Racism, sexism, classism, and other prejudices find justification in the argument that individuals lack ability, thereby establishing their inferiority and

if it were not such a familiar and successful ploy. Historical opponents of political and social equality for women, Douglas Baynton shows, cite their supposed physical, intellectual, and psychological flaws, stressing irrationality, excessive emotions, and physical weakness, while similar arguments for racial inequality and immigration restrictions involving particular races and ethnic groups invoke their apparent susceptibility to feeble-mindedness, mental illness, deafness, blindness, and other disabilities (see Baynton 33). Moreover, disability remains today, Baynton explains, an acceptable reason for unequal treatment, even as other justifications for discrimination, based on race, ethnicity, sex, and gender, have begun to fall away. It is no longer considered permissible to treat minority people as inferior citizens, although it happens all the time, unless that inferiority is tied to disability.

As long as minority identities are thought disabled, there is little hope for the political and social equality of either persons with these identities or disabled people, for there will always be one last justification for inferior treatment. There will always be the possibility of proving the inferiority of any given human being at any given moment as long as inferiority is tied to physical and mental difference. Moreover, that pain in itself leads to inferior identities, ones given to greater self-recrimination or frequent victimizing of others, relies on a fallacious psychological scenario prejudiced inherently against disability.[7] Once touching a person, pain is apparently transformative, to all intents and purposes serving as an organic and natural cause whose psychological formation evolves with little variation according to the internal logic of the psyche. First, the psychology of pain links mental and physical suffering inextricably, and, second, it names pain, opposed to all other causes, as transformative of individuals, compelling them to withdraw into selfish, narcissistic, and anti-social behavior. Any attempt to sketch a political theory, especially of minority identity, based on this misleading psychology will produce the same predictable and deplorable results.

Pain and disability are not equivalent, although prejudices against disabled people often reduce disability to pain, but both supposedly individualize the concept of identity. Disability is often misinterpreted as a personal misfortune, as inherently individual, and in a manner similar to pain. A major obstacle to the political organization of disabled people is the belief in the individuality

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excusing discrimination against them. For an extended definition of the ideology of ability, see my *Disability Theory*, 7-11.

7 | It would be worth writing a history of this misguided psychology, if only to understand one of the strongest cultural biases against disability. My contribution to this project concentrates on Sigmund Freud, although Nietzsche precedes him in the idea that pain and disability play defining roles in the constitution of individual psychology. See my "Tender Organs" and the expanded argument in *Disability Theory.*

of disability itself. What does a woman with a head trauma share with a male wheelchair user? On what basis, since their disabilities are so different, do they form a political alliance that speaks to their unique and different needs? While disabled people confront the same concerns as other minority groups about the authenticity of their experiences, an added problem supposedly arises because of the individualization of disability. It is often argued that women alone understand feminine experience or African-Americans black experience, and that only they should be allowed to represent the political concerns of their respective groups, but disabled people are required to represent the experience of disability in general and the experience of different disabilities in particular. The question posed to the disability community is not only how to design a unified political coalition for disabled people but how to determine whether a deaf person, for example, can represent a blind person in a political debate.

Such demands would arise less often if pain and disability did not serve as differentials in the creation of identity, if they were not thought to set off a mysterious organic and psychological mechanism that renders the individual person defective as a social and political agent. Pain does not spring from and differentiate the individual. It does not belong to one person alone. It is a social invention, external to people, that marks them as individual. The dominant social representation of pain in the West is the individual alone in pain, and it is difficult to find alternative representations, especially those that reveal pain's social origins.

2.

Although pain seems in most accounts on the right and the left to define minority identity, little attention has in fact been paid to what minorities experience as pain. The assumption seems to be that their pain is debilitating and all consuming, that pain prevents minorities from pursuing independent actions, and when they do manage to act, that pain brings out the worst in them, twisting their actions in the direction of selfishness, anger, and revenge. The model for defining minority pain is severe physical pain – its effects determined according to the dubious psychological scenario examined above – the very kind of pain supposedly exemplified by the disability community.

How accurate is this view? And what does the experience of the disability community tell us about minority pain? Now it is certainly the case that some disabled people experience severe pain on an hourly basis. This kind of pain deserves attention, but here I have set aside this focus to trace two ideas with enormous political weight on the current scene. First is the idea already examined above that critics of minority identity use disability to imagine minority pain. Second, I explore what pain means to the disability community.

Now, despite the fact that chronic pain is a plague upon disabled people, there exists relatively few accounts of organic pain in disability life writing. Rather, we discover accounts of another experience of pain, one that can be called with justice not organic but political and epistemological pain, that is, a feeling of suffering derived from the collision between two different worldviews, the worldviews of the nondisabled and the disabled. These accounts of pain stress a vision of the disability experience in which individuals derive new knowledge and self-understandings from the limitations placed on them by nondisabled society, while at the same time embodying in their interactions with other disabled individuals an alternative society in which people with disabilities feel at home.[8]

The array of disability life writings is now vast, as are the types of disabilities represented by them.[9] I will focus on only one narrative here, but I want to claim that it is exemplary in its vivid insistence on social location as epistemology. This narrative by Cheryl Davis focuses on the pain experienced because of her mobility impairment. She catalogues for the most part obstacles in the built environment and their impact on her everyday life. The story insists – like the majority of disability narratives – that disability confines affected individuals in social locations that carry negative meanings beyond those that the individuals are themselves capable of generating.[10] Because disabled people do not cause the meanings attached to them, their confinement in particular social locations is often arbitrary, experienced as violent and existentially absurd but also as a spur to awaken new perceptions about society.

Davis confesses that "Disability and the Experience of Architecture" was painful to write, and yet the essay is not about how much pain strikes her body. In fact, we know very little about the physical pain that she experiences on a daily basis. The central focus of the essay is the subjective experience of pain caused her by society. What makes Davis suffer is the clash between what she sees and what the rest of the world sees:

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8 | Of course, not all disabled people self-identify as disabled; nor are all disabled people politicized. I am speaking here and elsewhere in the essay about disabled people who have acquired an awareness of and desire to participate in movement politics. In *Disability Theory,* I trace the process of becoming a politically aware minority (see 11-22).

9 | Thomas Couser provides an introduction to the broad range of issues covered in disability memoirs.

10 | Sharon Snyder and David Mitchell make the case that the disabled are not excluded from society but held in specific "cultural locations" whose meanings both rely on disabled people and define them.

"I could tell you the objective facts of my life, but they would tell you little about me; to truly know me you must try imaginatively to enter the realm of my subjective experience. For example, in the objective mode you would learn that I went to a special school; in the subjective mode you would learn how I felt every morning as the bus drove into the schoolyard, past a sign that read School for Crippled and Deformed Children. That sign stabbed me to the core five days a week. It meant that society labeled me as different – Other – that able-bodied people did not consider me a child but a *deformed child,* and that I should be 'happier with my own kind.'" (Davis 19-20)

Davis concentrates on the minutia of everyday life, mapping the topography of society and cataloguing her emotions and those of the people around her – all detailed from her location as a disabled young woman living in a lower middle class family in Milton, Massachusetts. More significant than her observations, however, is Davis' understanding of her subjective experience as a contribution to the knowledge of her society. Davis claims "the value of the subjective mode, best entered through the analysis of experience, as a tool for understanding the interactive effects of society and the environment on the development of physically disabled individuals" (20). The value of Davis' experience is not complaint, energized by resentment, but the ability to expand the knowledge base of society, both for nondisabled and disabled people alike.

Here is the goal, then, for the best disability life writing, at least the variety that wants to claim its own distinctive point of view. Davis pursues this goal by recounting her own experiences, transmuting them into tools for measuring a different reality, one whose objectivity relies not on the subtraction of subjective experience but on the addition of one subjective experience to another. Davis records concrete details, specific conversations, and sequences of events, binding them into an epistemology shared by other disabled people. She is a determined cartographer of the social locations in which people with disabilities are represented as inferior, defective, contagious, and in physical pain.

One of Davis' stories explores what it means to occupy an inferior social location and to want to escape from it. The story recounts an experience at the visiting Moscow Circus where Davis dares to sit with her able-bodied friends in nondisabled seating. The account is long and builds slowly, accumulating details essential to understanding Davis' worldview, why it clashes with the worldview of the people assaulting her, and why the conflict is valuable as a contribution to knowledge:

"My friends were shown their seats, which were several feet beneath the level of the aisle, while I remained in my wheelchair, since a transfer to the regular seat below was too difficult for me. With their heads at the same level as my footrests, conversation was awkward, but at least we were together. The aisle, more than six feet wide, left plenty of room for people to pass me as long as I sat sideways. (My chair was less than twenty-

three inches wide.) The arrangement offered uncomfortable viewing, but I was willing to put up with it. The management, unfortunately, was less willing to put up with me. The young usher, who sported a rather self-important air, advised me that 'wheelchairs are supposed to sit over there,' indicating a spot only slightly closer than Siberia.
'That's fine,' I said, 'but I'm with two friends who walk; they haven't brought their own chairs.'
'You have to move. You're a fire hazard,' he said.
'I'll move if you'll put folding chairs down there for my friends.' I thought that sounded reasonable, and Marsha and Kent seemed agreeable.
'Impossible!' he snapped. 'I have other things to do.'
'Then I'm afraid I can't move.' I replied.
'Well,' said the usher, 'I'll let you stay, but the Chief Usher will be along soon. If you refuse to move for him, he'll throw you out.' ...
Inevitably, the Chief Usher materialized, a red-nosed, pudgy man of about sixty. ...
'You'll have to move,' he fairly barked at me. ...
'No,' I quavered in a small voice.
The veins in his forehead popped out. His face was purely purple. He shouted. 'I'm gonna get a policeman to throw you out,' and left. I sat there shaking. My friends were angry yet calm, but I was intensely upset. They urged me to hold my ground and not permit him to bully me. ...
While the Chief Usher summoned the law, I performed my own circus act in the stands. Dropping from my wheelchair to the floor, I crawled beneath the barrier, swung from it, and clambered up into a regular seat. Then I folded the wheelchair and brought it flush against the barrier. It now took up less than a foot of aisle space. ...
No sooner had I settled in than a policeman appeared. ...
'Ma'am,' he said softly, 'I'm afraid you'll have to move the chair, or leave. ...'
'Do you see all those people sitting in the aisles?' I asked. He did. 'Well, if you make me move, without making all of them move, that's discrimination.' Puffing out his cheeks, he lifted the bill of his cap, then expelled the air. Cheeks deflated, he looked depressed.
'I'm sure not going to be the one to make you move,' he said as he walked away.
The Chief Usher returned just then. ...The old man began to hector and bully me afresh. I had resisted all efforts to move for nearly an hour. The circus had been going on for half an hour and I hadn't seen any of it. I was tired, angry, and humiliated. Suddenly all I wanted to do was leave. ...
As we rose from our seats, a little girl in a wheelchair entered, escorted by her mother and a girlfriend. She was crying, and from her mother's words, it was clear that she too had been told that she had to 'sit with the wheelchairs,' apart from her mother and friend." (27-30)

It is important to note that Davis is not resentful, envious, or angry – at least not in the way that minorities are typically represented as being in the various attacks on identity politics. She does not want to limit her friends' freedom to enjoy the circus. She does not resent the ease with which other people move

through the aisles and choose their seats. She is angry not because other people are permitted to break the rules that she is compelled to obey. She is angry because the people surrounding her do not recognize her as a human being. To claim that Davis is angry because people do not recognize her as a human being may seem an extreme statement, but it is a crucial formulation to keep in mind. It exposes the fact that denying participation in everyday activities such as going to the circus, entering and leaving a restaurant, or choosing whether to sit in the front or back of a bus is an attack on human status more effective and serious than the insignificance of the activities suggest. For it is in everyday life that we win or lose our right to be recognized as a human being. The point is that Davis understands exactly why her disability limits her participation in the social world. It limits her participation not specifically because she is physically unable to participate and not because the built environment is inaccessible, although it is. Her disability limits her participation because other people do not welcome her presence sufficiently to make it possible for her to live among them.

Once Davis begins to use a wheelchair, her identity merges in the public mind with it. In fact, she literally becomes a 'wheelchair' – a social location that erases any trace of her identity as a person living among other persons. A social location is in this case a set of specific spatial coordinates – the space reserved for handicapped seating – but this social location, positioned among the array of other social locations comprising any given society, also represents a class of disqualified people. Among the many characteristics of the people in this social location are these modifiers: defective, unfit, inferior, diseased, contagious, pained, unsociable, angry, resentful, envious, selfish, etc. All wheelchairs must occupy this social location, one by which their inferiority is maintained, isolated, and exhibited, and any attempt to escape provokes a strong and violent reaction. It is almost as if Davis' desire to move out of her location causes the social edifice surrounding her to wobble on its foundation, setting off alarms to summon rescuers and police. That a tiny woman in a wheelchair represents a danger to society seems a comic proposition, but this is what the authorities tell her. The police and ushers call Davis a 'fire hazard' who must be isolated and confined for other people's protection. This official reaction draws its authority, meaning, and incentive from Davis' identity as a disabled person because her social location is stigmatized as inferior and undesirable. Supporting the organization of society is an architectural version of apartheid, a built environment that methodically excludes people with disabilities, and when a disabled person trespasses on able-bodied space, the social organization is threatened. The value of Davis' story derives from her discovery of this painful truth and from her ability to express it in a form recognizable as a contribution to knowledge.

3.

If current arguments among cultural critics are to be believed, minority identity is born, not made – born in the nest of pain. Pain as a natural cause, unfolding according to an unbending and unvaried psychology, supposedly takes control of minority individuals and dictates their behavior in and responses to the social world. Politicizing their identities only exacerbates the negative and painful experiences of minority people, endangering group cohesion and political action by giving power to individuals whose pain renders them too isolated and self-preoccupied to make responsible contributions to society. It is as if their nature makes minority people unfit for politics – that is, if we accept the current arguments. These arguments fail when we realize that the lack of political fitness ascribed to minority people depends on an analogy to disabled people and on the false belief that disabled people are biologically inferior.

The main trends of disability studies reject the idea that disability identity derives from biological pain or individual bodily properties. Disability identity is not based on impairment similarity but on social experience that includes a shared encounter with oppression, discrimination, and medicalization, on the negative side, and a shared knowledge of survival strategies, healthcare policy, and environmental conditions, on the positive side. According to Carol Gill, "disability culture" includes an emerging sense of its own history, art, humor, evolving symbols, and a "remarkably unified worldview" (Gill n. pag.). The woman with a head trauma shares with the male wheelchair user the knowledge of both the negative and positive sides of disability experience. A deaf person may speak for a blind person in a political debate because both people understand the social location of disability, including the fact that their disabilities represent sources of oppression and social knowledge not experienced by most people. The medical approach to disability treats each and every disabled person as unique, as an individual patient whose distinct pathology requires a treatment designed specifically for it. Disability studies exposes the fact that this difference between patients is a product of medicalization, and it need not form an unbridgeable political gap between disabled people. We are not naturally unfit for politics because we are disabled. In fact, our experience of and resistance to the medicalization of disability may make it easier for us to understand that people are never fit or unfit for political participation.[11]

Disability studies embraces the social construction of minority identity, not as a negative with which to dispense with identities as inauthentic, but

11 | This is a trick statement in that it invites the reader to think of arguments to deny participation based on disability, thereby demonstrating the degree to which disability represents the last frontier of unquestioned human inferiority.

as a mode of social integration that carries with it specific knowledge based on social location. Here the conclusion that an identity, because it is a social construction, is not an authentic identity on which to base political rights is a dubious proposition, because only an argument based on epistemology can demonstrate the value or lack of value of an identity claim. It may appear as if disability identity is based on natural or biological categories, but it is based in reality on an epistemology – a new knowledge about, and understanding of, what it means to be 'disabled.' This new knowledge lies at the heart of the disability rights movement, and it is what we have to offer to other political movements, whether they represent minorities or not.

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Responses to Tobin Siebers

Andreas Sturm

The Experience of Pain, Disability Identity and the Disability Rights Movement

Introduction

With regard to political mobilisation, Richard K. Scotch reasons that identification as a disabled person is not an automatic process, but rather that political involvement relies on whether the individual accepts or rejects this role (162). His deduction sheds light on a paradox that is linked to the so-called 'reification argument:' Refusal to identify as a person with disabilities prevents an individual from being politically involved, while accepting this identity implies possibly acknowledging "its handicapping connotations of dependency and thus also avoiding political involvement" (ibid.). Scotch's response to this dilemma is to strategically address disability as social oppression without adopting its negative connotations (162-63). Another option is to develop positive ideas that can become part of one's identity, for instance by rejecting negative stereotypes or challenging conventional ideas of normality. One classic example of this strategy is 'disability pride' which discovers "merit in the atypical, beauty in the uncommon, and value in the unusual" (Sherry 907).

Upon reading Tobin Siebers' essay, my impression is that his way of thinking is in line with these approaches. However, he tries to substantiate the argument by taking into account personal experiences of pain. Using a body theory and the concept of pain, as Siebers suggests, implies that the full range of (bodily) experiences shaping personal and political identities can be considered. By making use of disabled persons' biographical narratives, he describes how experiences of pain may lead to a political consciousness which forms the basis for political participation and activism. In responding to Siebers' essay my intention is, by applying a sociological perspective, to elucidate his approach and comment on its implications for disability identity and identity politics as prerequisites for the formation and proliferation of disability rights movements.

First, this response will explore different meanings of pain. Implicit in this exploration is the question of how a conceptualisation of pain can function as a point of reference when it comes to the identity politics of disability rights movements. Second, I will take into account the theoretical context of minority identity studies, which Siebers draws on in his study on pain, to investigate the pros and cons of collective identity politics that explicitly relate to the status of belonging to a socially oppressed minority. Third, this response will touch upon the relation between identity politics and recent developments in disability politics directly affecting the disability rights movement.

Pain – Linking the Individual and the Political

Siebers' approach is closely linked to the ongoing critical discussion of the social model of disability which has been of relevance for international disability rights movements since the 1970s. The idea that the social model of disability "perpetuates a *disembodied* notion of disability" (Beckett 735) and therefore is to be criticized can be found in many publications (see for example Schneider and Waldschmidt 138-43). At the same time, however, reintroducing the body into a social theory of disability runs the risk of opening up the discourse for naturalist and essentialist, medical and individualist perspectives on disability and identity (Hughes 684). Against this background, reflecting on the notion of pain in its full complexity is essential but somewhat problematic.

Pain is a broad term used not only in science but also in everyday language and implies various connotations that may favour political mobilisation but also transports negative stereotypes that may possibly hinder political or emancipatory struggles. As a first step, one needs to consider that everybody seems to know what pain means. In everyday situations, a person who experiences pain resembles a suffering victim deserving pity from 'others,' who usually regard this individual in need of medical treatment or as restricted in her or his abilities.

In the medical realm, pain is a bodily signal that is interpreted as a marker of an illness or disease. The International Association for the Study of Pain defines pain as "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" ("Iasp Taxonomy;" see also Glucklich 11). Typically, when making a diagnosis medical practitioners locate pain in a specific body part or organ and also qualify and assess pain, for instance its intensity and duration, in order to identify appropriate treatment. Understanding pain as described above implies considering pain as an individual condition that has to be overcome, a burden which makes the person dependent on medical treatment and the help of others. At the same time, the medical perspective makes us aware that feeling

no pain can also be dangerous, as it is the case with diseases involving sensory deficiencies.

However, in other life situations pain can also be viewed positively, for instance as a tool in religious rituals or a means for personal development and a kind of moral compass (Glucklich 34). Moreover, under certain conditions pain can be a solution instead of a problem (12): Experiences of pain are able to evoke new insights, decisions, and actions. There are more complex and paradoxical implications, such as in sadomasochistic practices or in the queer/crip art of Bob Flanagan and Sheree Rose, in which pain becomes a liberating tool to challenge notions of suffering and normalcy. These practices reveal that sensations of pain can be perceived as joyful or pleasurable, as well as enabling alternative ways of identifying as a disabled person (Kolářová 44).

There are also academic discussions with regard to pain in sociology, cultural studies and disability studies. In his text *The Culture of Pain*, David B. Morris refers to the "myth of two pains:" "You feel physical pain if your arm breaks, and you feel mental pain if your heart breaks. Between these two different events we seem to imagine a gulf so wide and deep that it might as well be filled by a sea that is impossible to navigate" (Morris 9). This differentiation is reminiscent of Helmuth Plessner's well known approach of criticising the 'crude' dichotomy between nature and culture, corresponding to the problematisation of the Cartesian division between the body and the mind in disability studies (see Gugutzer and Schneider 34-35; Hughes and Paterson 326).

As mentioned earlier, the social model of disability has been developed to overcome the individualisation and medicalisation of disability in favour of a perspective that allows for the definition of disability as an effect of a disabling environment. While this approach has proven capable of boosting the political activism of disabled persons, it fails to address the stereotype that disabled persons are suffering from pain, as Irving Kenneth Zola points out: "Similarly, the terms 'suffering from,' 'afflicted with' are projections and evaluations of an outside world. No person with a disability is automatically 'suffering' or 'afflicted' except in specific situations where they do indeed 'hurt,' are 'in pain' or 'feel victimized'" (170). Similar to impairment, pain is not theorised by the social model, and it is to Siebers' credit that he problematizes this weakness.

On the one hand, both pain and disability are easily reduced to bio-medical human conditions and may provide the basis for victimisation and (self-) blaming, despite the fact that pain and impairment are universal human experiences. On the other hand, disability, impairment and pain can also be used strategically to shape (self-)perceptions and identities. Concerning the latter, Siebers stresses its potential to unify diverse groups of persons (with disabilities) on the basis of shared personal experiences. In this view, pain becomes the vanishing point of unwanted or painful living conditions at

precisely the moment when a social group shares the experience of the same 'social' pain.

Pain and Minority Identity

Siebers employs the concept of 'pain' within the context of disability and minority conscious of the fact that terms and labels have the potential to either unite or divide minority groups fighting for political change. To understand why this author engages in a concept of pain with regard to minority identity, it is necessary to shed light on his theoretical background.

Siebers belongs to a group of minority studies scholars who pursue a post-positivist realist approach to conceptualise identity and identity politics. In the volume *Identity Politics Reconsidered*, Linda Martin Alcoff and her colleagues explicate this perspective by arguing that identities are neither an essence nor fictional, instead the complexity of "identity-based political struggles and the subjective experiences on which these struggles draw" must be considered (6). Furthermore, while according to Mary Bernstein most approaches to identity politics assume an essential core of identity[12] (Bernstein 49-56), for minority studies scholars identities resemble "social embodied facts about ourselves in our world" that may function as "*causal explanations* of our social locations in a world that is shaped by such locations, by the way they are distributed and hierarchically organized" (Alcoff et al. 6).

Against this conceptual background, Siebers confronts the idea that social minority groups such as persons with disabilities are unable to participate politically, since pain – if regarded as a 'natural' cause of inferiority – would prevent them from doing so. He shows that this so-called inferiority needs to be traced back to the internalisation of 'natural' pain as a part of self-perceptions and self-definitions which undermine the actual development of self-efficacy. Countering prevailing stereotypes, Siebers focuses on the concept of pain as a strategy of resistance. Precisely because pain is often used to victimise persons with disabilities and minorities in general, he reassesses this phenomenon from a critical disability studies perspective.

With this approach, Siebers also implicitly pursues a critical line on the social model of disability. While this model focalises disablement caused by

12 | This argument relates to Erving Goffman's ground-breaking study on stigma and 'spoiled' identity, as it focuses on the interactions between disabled persons and 'normal' people with respect to identity management (Goffman 1963). However, according to Waldschmidt, Goffman assumes a naturalistic core of identity as he does not question prevailing (body) norms, but perceives visible (bodily) defects as phenomena necessarily leading to stigma management, implying that the body is a natural source and basis for social interactions (5803).

society, it leaves out the question of how to locate or assess the actual disabling barriers. Siebers' approach, in contrast, highlights this question, thus not turning away from the (impaired) body in favour of a (socially constructed) disability, but rather avoiding labels of inability and inferiority for the benefit of a notion of pain inflicted on minorities by society and, at the same time, subjectively experienced. Such a perspective suggests that the political act of creating one's identity, searching for allies, and identifying as a socially oppressed person is closely linked to sharing 'pain' as a common experience with other disabled persons, an experience that enables one to address not only collectively but also very personally disabling barriers, discrimination, and the lack of rights. Siebers' argument also opens up the opportunity to refer to specific experiences of 'being in pain' (for instance, as a disabled person with learning difficulties).

Identity Politics and the Disability Rights Movement

In order to be able to understand the position from which Siebers conceptualises the relations between disability identity, minority identity and pain, it is also crucial to discuss which notion of identity *politics* he uses, in particular as a political practice employed by activists, groups, networks and organisations of the disability rights movement.

Reflecting on this notion of politics, the work of Erving Goffman comes to mind. Implying that identities can be managed and are part of social interactions, Goffman introduces the term "politics of identity" with regard to group alignments, and argues that the stigmatised person is identified "as a member of the wider group, which means he is a normal human being, but that he is also 'different' in some degree, and that it would be foolish to deny this difference" (123). The individual, in reaction, manages societal perceptions and expectations in relation to the group she or he belongs to and also with respect to the wider society. Drawing on Goffman's work, Renée R. Anspach defines identity politics as an act of "forging an image or conception of self and propagating this self to attentive publics" (66). Mary Bernstein also argues that identity politics is to be conceptualised in relation to "experience, culture, politics and power" (48).

While Siebers would certainly agree with these definitions, in his article "Tender Organs, Narcissism, and Identity Politics" he states that "identity politics is no different from any other form of political representation, since it is defined by ideological, historical, geographic, or temporal borders" (Siebers 42). In his view, the distinctive features of identity politics in comparison to other forms of political representation are, first, the goal of self-identification, second, the deduction of an identity "from a singular subjectivity," and third, possibly highlighting oneself as distinctively and/or individually suffering. The

last feature marks the focus of Siebers' critique, as identity politics centring on suffering runs the risk of provoking accusations of narcissism (ibid.).

Such disparagement can, in Siebers' terms, be avoided by transferring "the reality of disability into the public imagination," by "tell[ing] stories in a way that allows people without disabilities to recognize our reality and theirs is a common one" (51). He further elaborates that this would require a specific "symbolism," so "private emotions and thoughts are made compelling to the public imagination" (ibid.). Implicit in this approach is, in my understanding, the assumption that telling the larger public about experiences of 'social pain' needs to be done in a manner that overcomes the divide between the 'general public' and 'persons with disabilities.'

While it should be admitted that pain, just as suffering, carries connotations that might refer to 'deficient' subjects, Siebers might be right when he advocates for a 'symbolism' that enables the larger society to recognise the experiences of disabled persons as part of its own social reality, just as any other social group that makes effective use of identity politics. Thus, pain might be a metaphor which stresses the necessity of narrating or framing experiences of individuals or groups of (disabled) persons in ways that relate to universal human experiences, including the aspects of social oppression, discrimination, inequality, and lack of recognition.

Conclusion

This essay has attempted to provide a critical analysis of Siebers' approach to disability identity (politics) and pain. But there is one open question: Which lessons can be learnt from this concept for current disability rights activism?

At present, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is shaping disability policies across the world. It is, to a large extent, the result of political struggles, owing its main ideas and principles to the international disability rights movement. In future decades, the CRPD will play a crucial role in framing disability as a political concept and as a human rights issue, and it is not difficult to predict that it will also inform the identity politics and self-identification of persons with disabilities and their representative organisations. The CRPD appears to be a useful tool to frame personal experiences such as discrimination and to legitimise the removal of barriers that many disabled persons face every day around the globe.

However, this human rights Convention does not emphasise per se subjective experiences of social oppression in the way Siebers calls for. It tolerates the notion, but does not regard it as particularly relevant to tell personal narratives of painful experiences to catch the attention of societies and thus raise public awareness. Instead, the CRPD's value lies in drawing attention to the objective environmental conditions, adaptations and opportunities in

a given society. While it allows for an open-ended, processual definition of disability by describing it as an evolving concept, the Convention, as Karen Soldatic and Shaun Grech highlight, largely avoids the term "impairment" apart from the Preamble and Article 1. These disability studies scholars argue that as a result impairment cannot be discussed as a political issue and tends to be ignored within the human rights discourse. Against this background, Siebers' approach of using personal experiences (of pain) as a means to identify with the minority group of disabled persons could provide a stimulus for future disability rights activism, and even more so when the current human rights convention is reviewed and revised.

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Arta Karāne

Bob Flanagan: From the Pain of Disability to the Pain of Penis Torturing

Along with the concepts of the minority group and identity politics, one of the key categories that Tobin Siebers analyzes in his article "Disability, Pain, and the Politics of Minority Identity" is pain. Siebers criticizes the existing standpoint of many cultural researchers who believe that minority identity is founded on pain; because pain is enclosed within one's psyche, it is considered psychological and organic. When minorities enter the political realm their identities are supposed to become even more troublesome, for their political capital is based on projecting the suffering of historically imprinted injustices such as racism or sexism. Furthermore, precisely because minority group behavior in the social world is determined by this historically entrenched suffering, they are supposed to reproduce this pain in their political claims. This means that for the majority of cultural researchers, a member of a minority group is considered passive and subjected to pain; it is assumed that the only interaction he or she can have with his or her own suffering is to reproduce it. A final assumption is that pain is disabling. Pain leads a person of a minority group to inferiority, resulting either in greater self-victimization or accusation of others for their pain.

To deflate these arguments, the author compares the pain of minority groups to that of people with disabilities by discussing the pain experience of Cheryl Davis, a person with "mobility impairment" (Siebers, "Pain" 115). Analyzing her case study, Siebers concludes that what binds both disabled and minority people's identities and can serve as a basis for creating a political platform for a minority identity is the common epistemological experience of pain – that is, a shared social knowledge of both the positive and the negative everyday experiences of a person living with 'disabilities.'

Siebers interestingly shows the social nature of pain, yet, it occurs to me that the epistemological pain argument does not counteract all previously mentioned assumptions about pain. The Davis case does not answer whether, or how, a disabled person can avoid the reproduction of pain or escape the inferior position to which he or she is subjugated by society. Furthermore, Siebers' epistemological argument about pain opens questions that his paper does not touch on: What about the internal, bodily experience of pain as experienced by disabled people? How does such pain interact not so much in a political but in a cultural space? Can pain only be reproduced, or can it also be transformed into a resource, for instance, of sexual pleasure? Does pain simply disable and victimize a person or can it perhaps become a tool to challenge culturally constructed categories of normalcy and disability? After all, can a disabled person play an active role in transcending his or her own pain?

Siebers' argument focuses on the representation of the pain of disabled people in political space. I would like to echo yet also extend Siebers' discussion of pain and bring in another counter-argument to the previously mentioned assumptions about pain. My aim is to address the pain of disabled people as an expression within cultural space and to show how the experience of an active living with pain caused by disability can challenge the social construction of disability itself. In order to do so, I will focus on Bob Flanagan, an exceptional American performance artist whose physical pain and disability was at the centre of his life and art performances.

Bob Flanagan (1952-1996) was an American performance artist whose life centred around a physical impairment, cystic fibrosis[13] (see Hladki 269). Because of this incurable genetic illness, Flanagan's daily life was dominated by physical pain and suffering (see Jones 573). His disease caused constant coughing, weight loss, and regular breathing and digestion problems; it kept him under extreme pain and required constant medical treatment (see Kauffman 20; Hladki 269). In medical terms Flanagan had a physical impairment, in a cultural context his disease became a source of disability, in accordance with the social construction model of disability, which, furthermore, defines the normative body as invulnerable in its "wholeness, independence and integrity" (see Shildrick 757). Bodies different from it are subdued and excluded from the 'healthy' "social body" (see Shildrick 759), rendered as "not yet the 'subject'" (see Siebers *Theory* 56), and thus disabled.

Flanagan's disability occurs by failing the normative standards of sexuality and masculinity.[14] Following the dominant able-bodied normalcy discourse, sexuality is valid only for healthy, physically fit, heterosexual people and is assumed to involve sexual pleasure (see Cheng 114; Brodwin and Frederick 37). Perceived as 'the Other' of the cultural norm of able-bodiedness, disabled

13 | Cystic fibrosis is a fatal and incurable genetic disease that mostly affects the lungs, which overproduce mucus. The secretion settles deep in the lungs in that way creating a great environment for viruses and dangerous lung infections (see Juno and Vale 11). Although the medical technologies and treatment such as gene therapy of cystic fibrosis has advanced and thus improved life expectancy and quality of patients, in Flanagan's lifetime they were yet to be developed. Therefore, cystic fibrosis was treated mainly with the medicine that would dilute mucus and the therapy that would pump the overproduced secretion out (see Juno and Vale 10). The disease often led to the death of a patient who literally drowned in mucus or got a life-threatening lung infection. Unlike the majority of patients, who often died in their infancy or early adulthood, Flanagan became one of the oldest survivors of the disease in his lifetime. He died at age 43 on January 4th, 1996 (see Sandahl 97).

14 | For a lucid discussion of Bob Flanagan's art and life at the nexus of disability and queer studies see Robert McRuer's *Crip Theory* (181-198).

people are subject to myths about their sexuality and are most commonly even considered as asexual bodies, bodies that lack sexual desire and pleasure (see Brodwin and Frederick 37-38).

Intertwined with sexuality is also the phenomenon of gender performance, in this case masculinity. Theories of hegemonic masculinity (see Flood 391) presume that masculinity as a symbolic power of male gender is based on particular bodily manifestations such as strength, invulnerability, self-reliance, and excellent sexual performance (see Butler and Parr 169; Shakespeare 56; Brodwin and Frederick 39). Precisely because masculinity is viewed as embedded within a man's body, physical impairment emasculates a man. It is associated with medicalization, lack of sexuality, and an overall loss of power (see Shakespeare 56-57; Sandahl 97; Brodwin and Frederick 38-39). Physically sick, medicalized, and infertile because of cystic fibrosis, Flanagan fell into the disabled category as an asexual, sexually desireless, and therefore emasculated person: feminine, impotent, castrated, someone too weak to perform the 'accurate' gender (see Brodwin and Frederick 38; Bredenkamp 57; Shakespeare 56-57). And yet, although Flanagan did not fit into the norm of able-bodied sexuality and gender performance, he did not remain a passive victim of pain and disability. On the contrary, he consciously took his pain into his own hands and transformed it into a source of sexual pleasure.[15] To overcome the physical pain of disease, he began in his early childhood to experiment with torturing his own body, in particular his penis. Not only did this practice ease the pain, it also gave him sexual excitement and became a regular practice in his adult life both in private and in public art performances.

In Flanagan's rich and vivid performance art there were countless episodes of torture; inflicting pain by, for instance, tying, stretching, or nailing his penis, hanging heavy weights on it, piercing it and sewing it back up, etc. For the purpose of demonstrating the intensity of the pain Flanagan inflicted on himself and showing how he was able to transform this pain into a source of sexual pleasure, I would like to discuss three of his most well-known penis torturing acts. The first act that he often performed in front of audiences was sewing up his scrotum. In one such performance in San Francisco, he "pushed the penis head into the shaft of the penis and sewed the loose skin around it so it looked like it was totally cut off" (see Juno and Vale 63). Then the rest was sewed up in the scrotum (see Juno and Vale 63). The second act, called "Nailed", has been referred to by many authors as one of the most well-known examples of Flanagan's performance art. The movie *Sick: Life and Death of Bob Flanagan,*

15 | Flanagan in an interview for the volume *Bob-Flanagan: Super-Masochist* elaborates on how he could not control the cystic fibrosis, yet how he learned to organize and control his pain and transform it into sadomasochistic experience that led him to sexual excitement. For further reading see Juno.

Supermasochist offers the opportunity to follow one such performance. The spectator sees the close-up of a wooden board with Flanagan's penis placed on top of it. A nail teeters on the edge of his genitals until, with a few quick movements, it is hammered in. Seconds pass, then the nail is pulled out of the board, revealing a view of the penis pierced by a metal nail. In the final part of the episode Flanagan slowly pulls the nail out, which results in an outpour of blood filling the screen. As a third example, the "Butterfly Penis" performance displays Flanagan's penis literally stretched over a board in the shape of a butterfly. Placed in the hole of a board, the penis is stretched to all sides and fixed with pins while the scrotum is also spiked with medical pins.

Although these examples of genital mutilation might seem like extremely painful acts, Flanagan claimed and demonstrated through his frequent performances that penis torture was a way of transcending his physical pain to the point where it became a source of sexual satisfaction. For instance, Flanagan described the act of sewing the penis into the scrotum as "auto-eroticism" (cited in Juno and Vale 62), or during one performance of "Nailed" accidentally missing the nail and hitting the head of his penis as sexual excitement: "[E]verything was cleaned up and I started getting hard. I [...] started masturbating against the sheets in a real frenzy; now I was really turned on by what had just happened to me! I had a really good orgasm" (cited in Juno and Vale 22). While he affirmed that piercing his penis was a painful process, his sexual sensations performing "Butterfly Penis" surpassed the pain. As he says:

> "[...] I play Cupid to my stupid love-sick dick, each fiery pinprick another shot of adrenalin coursing through the veins of my porcupine pal, thick and purple, bobbing in front of me like a festive party balloon just begging to be popped." (Cited in Juno and Vale 59)

Flanagan's testimony contradicts the notion of pain as something that an individual must simply accept and remain passive toward. Instead of subjection to pain, Flanagan's sexual pleasure while nailing the penis shows that he can stay actively involved with his pain, controlling and transforming it into a resource of another bodily experience. The body is not only physical but also has a "social skin" (see Schildkrout 321), even more in disability art where the body turns into "self-representation" and "autobiography" (Garland-Thomson 334), which incorporates both visual and narrative layers. The disabled body is more than a medium – it becomes the "content of performance" (ibid) that can counteract "cultural images of disabled people" and "social construction of disability identity" (335). Displaying the transformation of the pain of disability into a pain of bodily torture in his public performances, Flanagan lives out his disability (see Sandahl 98); his body becomes a statement that challenges his own disability by calling preconceived categories of able-bodied sexuality and masculinity into question.

Although he does not fit into the normative social constructs of sexuality and masculinity, Flanagan's penis torture deflates the notion of disabled people as asexual and emasculated. On the contrary, the penis torturing acts display Flanagan as sexually functioning, actively involved in sexual exploration and intensively receiving sexual pleasure. Similarly, Flanagan challenges dominant notions of masculinity through phallic torture. If the 'penis' is a symbolic carrier of phallic masculinity,[16] i.e., the notion of masculine power by show of dominance, strength and sexual performance, then this masculinity is precisely what Flanagan embodies during his penis torturing acts. He does not simply nail, sew up or pierce his penis, but he embodies phallic power. All three examples of penis torture reveal Flanagan's ability to go beyond and interrogate normative gender performance. For instance, in the sewing performance Flanagan consciously enacts sex inversion and gains "temporary castration" (see Anderson), which serves as a way to deconstruct gender (see Juno and Vale 63) and to ridicule it (see Kauffman 26). Similarly, he exerts control over the pain of his disability and exceeds its limits. Spectators are inevitably forced to ask, "Why does Flanagan do that?" "Could I be able to do that?", "How does that feel?" (see Kuppers 89), thereby challenging individual limits of corporeal knowledge of pain as something one cannot control and would never want to inflict on oneself. Flanagan not only exceeds pain but he, moreover, turns it into sexual experience. Flanagan's masculine strength is recreated through this ability to surpass the limits of pain. His dominance occurs through control over his own gender category, symbolically embodied in the penis. By living out the pain and confusing the normalcy categories of sexuality and masculinity, Flanagan shows that pain is not disabling and victimizing. Rather, he disables the pain and gains power and superiority over his disability.

In his article, Siebers has initiated a discussion about the category of *pain*. He opposes current arguments among cultural researchers who approach pain of minorities mainly as organic and psychological, as something that subjugates and exposes those who feel it to inferiority and victimization. What can serve as the basis for minorities to build their identity in politics, Siebers claims, is an epistemological knowledge of pain. In order to refute these

16 | Psychoanalysis, Sigmund Freud's and Jacques Lacan's work in particular, has influenced the prevailing notion of 'phallic masculinity.' They view the phallus as a symbolic signifier and the penis can be its physical dimension. A man during childhood adopts and learns the phallic and paternal law, thus the Freudian 'Father-in-the-head' or Lacanian 'Name-of-the-Father' stands for the masculine power of the man in culture. Thereby, the notion of the phallus from childhood transferred to adulthood embodies masculinity (see Bredenkamp 62) and functions as the symbol of "power, authority and fertility" (see Flood 475). The phallus goes beyond its corporal physicality and represents male superiority, intellectual, political and cultural authority (see Tuana 7).

current assumptions that Siebers is critical of, I attempted to extend his pain argument further. Shifting the perspective from the political to the cultural field, I focused on the exceptional case of Bob Flanagan, whose disability and experience with penis torture provides a new and alternative perspective on understanding pain. Flanagan's performance acts allow us to read pain not simply as something psychological and externally constructed or as something that subjugates and can only be reproduced. On the contrary, his case shows a person with a disability who can take agency over physical pain and thereby transform his experience into something different, even into a source of pleasure. For Flanagan and for us, this transformation of pain and living it out publicly is a form of power, a manifestation that challenges constructed categories of sexuality, masculinity, and disability.

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