

Preface

This volume gathers the papers presented at three Seminars¹ featuring Dr. Margrit Shildrick, visiting professor from University College Dublin at York University in the year 2004. A well-known scholar in the areas of feminist philosophy and bio-ethics, Dr. Shildrick uses a deconstructive, post-structuralist framework to rethink the nature of embodiment. Her phenomenological approach challenges modernist assumptions about the split between body and mind, self and other, normal and abnormal, inviting us to recognize the intrinsic unpredictability, instability and ambiguity of all bodies. Through this novel conception of the embodied subject, Shildrick opens way to a renewed ethic of relationship that disrupts traditional power relations because it fundamentally asserts our common and universal vulnerability.

It is this theme that traverses and links Shildrick's three papers, whether she is interrogating the place and meanings of the "monstrous body", discussing the experience of pain, aging and dying, or addressing the contested issue of sexuality and disability. At stake is always our (in)ability to connect with one another, "not as static channels of communication, but as dynamic and fluid networks" (30). Rather than providing sure answers, Shildrick reminds us that "it is only by reconfiguring thought that we can move on to potentially more creative modes, both of becoming in ourselves and of encountering others, whatever form those others might take" (11).

In their comments, Catherine Frazee, Roxanne Mykitiuk and Lorraine Code reflect upon and expand this project. Frazee evokes her own experience of disability to reclaim the point that "monsters matter" – no longer as objects of the public gaze as in the freak show, but because in their quest for social justice, disabled people have "pushed back against the forms and structures of oppression" and assert themselves today as active subjects and integral members of the human family.

Mykitiuk takes the discussion to the complex terrain of genetics and law. Current genetic discourses, she argues, expose the leakiness and boundaryless of all subjects. In that sense, they question legal conceptions of the autonomous, self-sufficient individual, which reflected and reinforced the power position of the white able-bodied male. To the extent that, in the era of the gene individuals become "fundamentally connected" to each other, a new legal framework is necessary to take into account, not the bounded self, but transgressivity and vulnerability as norm.

Finally, Code draws on Shildrick's work to develop a critique of Evidence-Based Medicine, which she claims casts out the notion of vulnerability as "subjective, unquantifiable and messy". She proposes instead a model of patient-centred care that acknowledging the embodied

¹ The York Institute for Health Research would like to thank the National Network on Environments and Women's Health, the York University Centre for Practical Ethics and the York University Centre for Feminist Research for co-sponsoring these events.

experiences that patient and physician bring to their interaction, ultimately postulates our “commonality, heterogeneity and social responsibility” (36).

With *Vulnerability*, the York Institute for Health Research initiates a series of Monographs, dedicated to explore innovative and multidisciplinary approaches to health and well-being. It is our hope that this initiative will stimulate further discussion and research, and contribute to inspire others in pursuing inventive ways to address and improve the health status of populations.

York Institute for Health Research

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Why Monsters Matter: Ethics, Anxiety and Difference.***Margrit Shildrick.***

The theme that threads through this paper and links to other aspects of my work is the notion of vulnerability as it emerges through various material foci, and discursive approaches. As elsewhere, the paper addresses the issue of embodiment as always and everywhere unpredictable and unstable, so that the overall purpose is to shift the focus of vulnerability away from its authorized designations to the bodies of each one of us. More specifically, *Why monsters matter: ethics, anxiety and difference* explores some of my recent work on the body that confronts the question of differential embodiment. As I see it, the flesh and blood experience of living in the world through the body throws up not only issues of materiality, but also those concerning ontology, and for me the hugely important area of ethics. And of course all of those are intricately concerned with the practices and deployment of power.

In the context of conventional ethics, and even to a large extent within bioethics itself, which deals directly with bodily matters, the question of how we should act for the good has been conducted as though it concerns only disembodied subjects, or at best subjects for whom their own bodies are merely the medium of agency. The ideal subject is fully autonomous, separate from others, and encounters between such subjects are mediated either by pre-determined rights and duties, or else by the rational calculation of harms and benefits. The dominant discourse of western liberal humanism, which characteristically reproduces the Cartesian split between mind and body, devalues corporeality in general, or at least sees it as a neutral given self-complete, closed and consistent. It is only those who do not match the standard parameters of masculinist normativity, women, and a range of others, who are defined in terms of the actual unruliness and disorderliness of all bodies. In contrast, what I'm interested in is a fully embodied ethics, a true bioethics, which requires us to analyze the relations between differential bodies. What's new here is that the present post conventional turn to a body-centered ethics, almost a revival of ethics, is no longer about abstract rights and interests in the traditional sense. Instead it rejects the modernist rules founded on abstract autonomy, and mounts a sustained attempt to recover a corporeal ethics.

That approach is particularly clear in feminist ethics that has typically worked on the basis that the participants in any ethical encounter do not meet as non-specific *disembodied* subjects but as living, dynamic human beings whose corporeal specificity and location cannot be discounted without loss to ethical valency. Nonetheless, I want to suggest that there are some categories of difference that are still addressed inadequately, and particularly in ethical discourse. Despite a real attempt to overcome the distinction between mind and body, feminist theory in general remains centered on a highly normative model of embodiment that fails to deliver an ethics adequate to embodied

difference except when that difference is reducible to the big structural markers of gender and race. The exceptions, whose work informs my own, are theorists like Liz Grosz and Judith Butler, who position themselves within a poststructuralist, even postmodernist, framework.

The ethics that I propose, then, make a further break with the conventions, and operate, broadly speaking, from a deconstructive and poststructuralist framework. In other words, I'm not referring to morality as such, but rather an ethic of relationship. It's not questions of good and bad, or right and wrong, or of equality or freedom that primarily concern me, but the more nuanced and uncertain terrain of how to be open to the other, how to value our own becoming with others, rather than being distinct from them. The ethical encounter with the other is no longer one between individuated, abstract subjects, but one in which the uncertainties of both embodiment, and psychic interaction, play an equal part. The important point is not to see those uncertainties as negative, but as signaling the very possibility of theorizing a more adequate ethics. And, unlike conventional models of ethics that are organized around the doer and the done-to, as for example in health-care encounters, the ethics I propose is highly disruptive of power relations.

So what has all this to do with monsters? What is it that the supposedly radically different body tells us about ethics? and what does it have to do with anxiety? My use here of the term 'monster', or 'the monstrous', carries no negative charge, but on the contrary signals a point of contestation of ontological and ethical values. And my question is: what would it mean to take account of those excluded others who are categorized as monstrous, or whose bodies radically disrupt morphological expectations?

As is by now well-established, there have always been close connections made between the monstrous and the female body – Aristotle, for example, saw the female as a deformed male - but *sexual* difference is not the only important parameter here. The cultural imaginary of each age differentially constructs its monsters in response to both socio-political and psychic anxieties, so that gender operates alongside other determinants of normativity such as race and physical or mental ability. Now if the task is to establish an alternative to a disembodied ethics by recuperating the body, we need to engage with the issues arising from morphological diversity in a way that does not just reduce to the binary of sameness and difference, in other words to those whose bodies meet normative expectations and those who do not. What is needed is a strategy of queering the norms of embodiment, material and ontological, where what is put into question is not just the limits of a given category, but the notion of distinct and bounded domains at all. And to queer the norms, not once and for all, which just establishes new norms, but as a continuous process, might be the only way to give a place to monstrous difference. Note that this is a strategy that views all bodies as unable to comply with the norms through which they enter the space of

discourse. It is not that some bodies are reducible to the same while others figure as the absolute other, but rather that *all* are excessive to predetermined norms. The security of categories, whether of self or non-self, is undone by a radical un-decidability. The issue is not just one of revaluing differently embodied others, but of rethinking the nature of embodiment itself.

So how does the monstrous point the way? If normative embodiment seems to guarantee individual autonomous selfhood, what is monstrous in all its forms, hybrid creatures, conjoined twins, those born without limbs, human clones, cyborg embodiment and others, disrupts the notions of self-sufficiency and separation that underlie such a paradigm. So long as the monstrous remains the absolute other in its corporeal difference it poses few problems; in other words it's so distanced by difference that it can clearly be put into an oppositional category of not-me. Once, however, it begins to resemble those who lay claim to the primary term of identity, or to reflect back aspects of ourselves that are repressed, then its indeterminate status, as neither wholly self nor absolutely other, becomes deeply disturbing. The monsters that concern us most are always human or quasi-human beings, for they both mark the boundaries of normalcy, and closure of the self, and *simultaneously unsettle them*. So what is at stake is not simply the status of those bodies which might be termed monstrous, but the being in the body of us all. The being, that is, in which body and mind are indivisible.

It is precisely that phenomenological approach, which sees corporeality as inseparable from subjectivity, that can expose the deep flaws in modernist conceptions of the self that seek to erase and devalue the specificity of bodies. By reflecting on overtly disordered or monstrous bodies, we are forced to accept both that no *form* of embodiment is fully secure, and that the sense of *self* cannot be isolated from embodiment. We become who we are by living in the world through the medium of our bodies, both our own and those with whom we come into contact. Certain bodies, those of conjoined or congregate twins, for example, clearly demonstrate the inadequacy of conventional models in which the body is merely the housing of an autonomous and controlling sovereign self. Conjoined twins in particular evoke confusion between one and two and cannot be resolved by modernist paradigms that rely on clear cut boundaries between self and other, and on the line up between one mind and one body.

Below I will present an arbitrary selection of images of monstrous bodies. I am acutely aware that to show the monstrous body runs the risk of encouraging a kind of voyeurism. Just as the term 'monster' itself is freighted with sexist, racist and ableist connotations which must be constantly challenged and undone, the deployment of visual imagery also requires delicate negotiation. The issue here is that even making allowances for the historical distance, what initially strikes us is that these figures are *not like us*, they are *other*, the *not-self* against whom the majority defines their own embodied normativity.

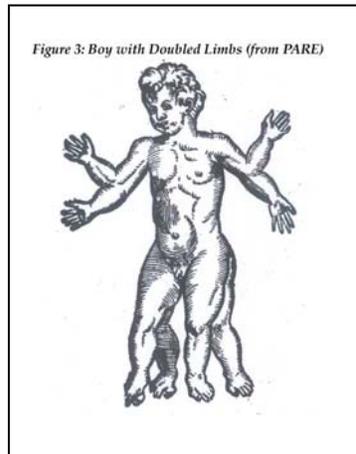
- Monster of Ravenna (1573 Early Modern period). The Monster of Ravenna is not even clearly human, but displays an improper mix of horn, fur, scales and skin; the arms are replaced by wings; the legs have fused into a clawed tail; and there are two sets of genital organs - male and female. The creature is fundamentally hybrid (Figure 1).



- Daisy and Violet Hilton (20th century) were vaudeville artists who were conjoined along the lower spine. The Hiltons clearly *are* human but pose the impossible question as to whether they are one or two selves. The point is that conjoined twins habitually unsettle not just material bodies but identities too (Figure 2).



- The Boy with Doubled Limbs (16th century). He is perhaps a single self, but he is also excessive because both his arms and legs are doubled.



What I would like you to consider is that the morphological uncertainties manifested here are all the more troubling because the other is encountered not simply as an absolute other, as a member of a counter-category, but as monstrously indeterminate. In a sense, the monsters are half us, half something else. What matters is the way in which each defies normative form, and functions beyond predetermined limits as a fluid signifier. And in them, we can almost see ourselves morphing into something else. The images uncover the relation between the monstrous and standards of normativity as one that cannot finally be fixed. It is never a simple case of the binary opposition between two clearly defined categories, as in the normal and abnormal. The monstrous here throws the binary logic of self/not-self, and the values associated with it, into doubt.

Far from being an exception beyond significance, the limit case of the monstrous body serves to uncover some pertinent aspects of all forms of embodiment that must force us to rethink both the nature of the self, and the intrinsically ethical relation between self and other. Could it be then, as postmodernism insists, that the problem is the standard itself, what we name as 'normal', rather than its variants? If all bodies and subjects are uncertain and insecure, we should think again about the anomalous body, and make normative embodiment part of the problematic rather than a taken-for-granted standard. It is a similar move, if you like, to the realization that we have to problematise whiteness as the standard against which blackness is posed.

I want to be clear that the 'reality' or otherwise of monstrous creatures has no bearing on my

argument. The point I am making here is the familiar postmodernist insight that *all* bodies are discursively constructed, but I also want to go further. Not only is corporeality a dynamic process that undoes the static givenness of bodies, but, I'm claiming, all bodies are in some sense phantasmatic. They are products of a cultural imaginary that expresses our deepest hopes and anxieties. In saying this, I am clearly concerned with the meaning of the corporeal, but we should not neglect the substantial and tangible. Postmodernism contests the dominant body image of modernity both through a theoretical concern with meaning, and simultaneously by engaging with material practices, both of the monstrous bodies of the past, and the radically new possibilities of embodiment that are emerging in the era of post modernity, through such techniques as cloning, transsexual surgery, genetic engineering and xenotransplantation. The point of taking up the theoretical alongside the material is to suggest that the standard body is not just challenged by the contemporary practices, but has been unstable all along.

The image of the monster always circulates in popular culture, from the early historical representations through to contemporary cyborg figures, but it operates as a deeply disruptive force. And the disruption is not because it represents an oppositional and external threat to well-being, the alien who would abduct or destroy us, but because it shows that as selves we are always and everywhere vulnerable, precisely because the monstrous is not only and always an exteriority. When I first started studying the monstrous body, initially in archival texts, it was to ask just what the monster signifies that gives rise to a curious trans-historical intermingling of fascination and fear. In other words, why is it that, like the feminine or racial others for example, monsters are both silenced by western discourse, and at the same time always haunting its margins, simultaneously seductive and threatening? And often those categories come together in specific cultural and historical forms of the monstrous. We could cite for example, images of the so-called Monstrous Races which stretch back at least to the time of the Roman writer Pliny, and were still current in the early modern period. The figures were there to be discovered on the most distant boundaries of the human world.

Now we know that the strength of the western logos as a symbolic system, the whole system of power and knowledge, depends in large part on defining those who are other, those who escape normative identity, as marginal and dangerous. It is a process that works particularly well with regard to the body itself. Yet even in popular discourse, the monstrous is neither rarely simply negative nor fully outside; it is always a figure of ambiguous identity, such that we might question the denial of any likeness between self and other. Historically, the monster has been destroyed or persecuted, or has sometimes functioned as a scapegoat, carrying the taint of all that must be excluded from the ordered community. But doesn't the anxiety that promotes such strategies, doesn't the need for barriers between us and them, doesn't the very force of rejection, suggest a level of disturbing familiarity, even similarity? In other words, we are made anxious not by

absolute difference but by what evokes resonance within ourselves. We can see something similar in the structure of homophobia for example, or the current moral panic about paedophiles. The monster is not just abhorrent, it is also enticing, a figure that calls to us, that invites recognition. Simultaneously threat and promise, the monster embodies those things which an ordered and limited life must try, and finally fail, to contain or disavow. What is in operation is a very material manifestation of the Kristevan concept of the abject.

Differential embodiment always exposes the fragility of what Julia Kristeva calls 'the clean and proper body' that is the normative body that is ideally bounded, impermeable, and self-complete. The problem with monsters is that they show bodies to be unreliable, in other words unstable and leaky. Monstrous bodies cannot be categorized by form, indeed they are characteristically hybrid, both human and animal, male and female, or self and other, or they have too many orifices that defy the closure of normative bodies. Faced with the monstrous other, the fear of the modernist subject is of the threat of contamination, a sure sign of the intrinsic vulnerability that we seek to disavow in ourselves. By keeping the other at a distance, and making her an *object*, we set up a relationship of power that belies both our own fragility and our commonality with the less than normative. The other we assure ourselves is *not like us*. And yet think: all of us were once part of a maternal-fetal dyad, part, in other words of a fundamentally hybrid structure that does just what monsters do. It mixes genetic material, possibly conjoins male and female bodies, confuses inside and outside, and certainly problematises the boundaries of self and other. In similar unexceptional ways, the instability of the body is unavoidable: none of us can escape the everyday operation of ageing and degeneration.

Despite that, those with congenital deformities or who become disabled are frequently treated as curiosities, as monstrous, and devalued as persons. The freak shows of 19th and 20th centuries are one particular manifestation of that impulse, but the devaluation has a much longer history and lives on today in all sorts of seemingly benign outlets such as telethon charity appeals. Whatever form it takes, strange embodiment is marginalised as a safely distant object of attention, rather than sharing a space in which our own assumed corporeal stability might be compromised. The concern of the normative subject is to preserve the invulnerability of her own boundaries, illusory though those boundaries may be.

So what exactly is the issue? The problem is that vulnerability is a quality that deeply undermines the security of closure and self-sufficiency that characterizes the modernist self. Although any of us may experience it, vulnerability is characterized as a negative attribute, a *failure* of self-protection that opens the self to potential disintegration. The supposedly autonomous self cannot acknowledge its own vulnerability to the extent that vulnerability must be projected on to the other. And those monstrous bodies that already display a lack of closure or self-sufficiency must

be constructed as the not-self, to be held at bay. Consider, for example, these images of the Monster of Cracow, who leaks from multiple orifices, whose body displays a clear lack of closure (Figure 4); or the concolorate Colorado Brothers, whose form of twinning is medically called parasitic, indicating a lack of self-sufficiency (Figure 5). What is at issue in both cases is the disavowed permeability of the boundaries that guarantee the normatively embodied self.

Figure 4: Monster of Cracow

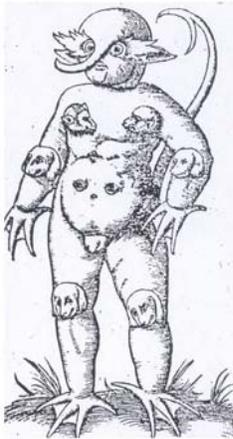


Figure 5: Lazarus and John Baptista Colorado



Monstrous embodiment may be the overt source of anxiety, but all corporeality has the power to disrupt expectations of the modernist sovereign self. The encounter with the strange is not a singular and external event, a meeting between opposites, but the constant condition of all becoming. It is because neither being nor the materiality of bodies is fixed, that we find the corporeality of the monstrous so disturbing. In other words, the significance of the monstrous is as much about the problematic ontology of human being as about the contested terrain of a particular historical moment where images of the monstrous might be deployed for highly political purposes. Monstrous others are deeply unsettling because even as we define ourselves in opposition to them, we feel a tug of recognition. Think again about the intriguing Monster of Ravenna. Such monsters are both necessary and feared, the focus of a highly ambivalent response that cannot quite decide on the question of sameness and difference.

Indeed, the ideal humanist subject of modernity, the self-sufficient, autonomous figure, can be maintained only on the basis of a series of putative exclusions. That which is different must be located outside the boundaries of the proper, in black people, in foreigners, in animals, in the congenitally disabled, and in women; in short in all those labelled monstrous. We know ourselves and others within an economy of sameness and difference where the security of borders

mark out the places which are safe and which are unsafe, who is due moral consideration and who is not, and who has power and who does not. Yet, in seeking confirmation of our own secure selfhood in what we are not, what we see mirrored in the monster are the leaks and flows, the vulnerabilities in our own embodied being. Despite a persistent desire, stretching from Aristotle through to present day medical discourse, which seeks to categorise and control the monstrous through the pathology of abnormal corporeality, in other words to put it into a neat box, there is always that other more disruptive intuition that monsters cannot be confined in the place of the other.

But the boundaries of the normative self are never finally secure, *not* because the excluded might overflow us, but because exclusion itself is incomplete. As poststructuralists like Derrida have shown, the uncontested belief in full self-presence cannot be maintained even by the violent hierarchy of the binary which defines the self against what it is not. At the very moment of self-definition, the subject is marked by its excluded other, an absent presence which it must deny, and yet on which it relies. So, for all that the monster represents not-me, the outside, it is also the other within. It is always there as a trace, the spectra of the other who haunts the selfsame, what Derrida would call a figure not of difference but *différance*. This suggests that if the monstrous cannot be fully contained within the binary structure of the western logos, then its operation can transform the relation between self and other. As such it is a figure of hope which ensures that change is not only possible but perhaps inevitable. The encounter with the monstrous other opens up both a putative risk of loss of self-certainty, and the hope that oppressive identities might be interrupted.

Monsters, then, are deeply disturbing; neither good nor evil, inside nor outside, not self or other. On the contrary, they evade classification by refusing to stay in place; they are always liminal, transgressive and transformative. They disrupt both internal and external order, and overturn the distinctions that set out the limits both of the sovereign self, and the bounded body. And they demand a new ethics of relation. Despite that, the force of normalization that is directed towards them should never be underestimated, and I do not want to suggest that successful resistance to the standards of sameness and difference is assured. The norms of modernity are deeply entrenched. The persecution of those who are classed as monstrous may operate within historically changing parameters, but it is as persistent as it is intolerable.

Nonetheless, it is in the very ambiguity of the monstrous that we may begin to discern different ways forward. The monster is a figure of fear and fascination because it is never wholly other. For all that it remains excessive of any category; it matters because it tells us things about ourselves. Though it may evoke anxiety and loathing, it always claims us, always touches us and implicates us in its own becoming. The responses of disavowal of *and* identification with the

monstrous arise equally because we, all of us, are already without boundaries, already vulnerable. I am not claiming that every form of the monstrous effects the same counter-logic, but in challenging the strategies by which the self is secured, all may be effective in mobilizing new ways of thinking not simply the binary encounter between self and other, but the very impossibility of such a determined relation.

So despite its familiarity in cultural history, can we rethink the significance of the monstrous from the start? During my own research, I have studied dozens of images of the monstrous, as well as many video documentaries. Inevitably the dual responses of repulsion and fascination that I analyze are as much my own as those of the abstract modernist subject. None of us is innocent. Nonetheless, while we may all teeter on the brink of a voyeurism that in its lack of (self)-recognition reduces the focus of our gaze to merely an object of curiosity; a more reflexive engagement will provoke just those questions that I want to ask of the ambivalent nature of the encounter with the monstrous. What exactly is it that we are looking for? And even as I question my own motives in looking, as I explore the theorizations that will move thinking beyond the boundaries that structure what seems possible, I am struck, especially in the face of video and photographic material from the present, not by any academic insight into the concept of vulnerability but by my own emotions. But if I have sometimes shed tears in the face of the monstrous, it is because it does indeed touch me. Despite the distance that visual representation entails, something reaches out and breaches my own boundaries. And that capacity of the monstrous to evoke unexpected emotions extends to all of us I think.

Against normative reactions then, the questions we need to ask ourselves would be: what forms of imaginary are being put into play? What anxieties are being expressed and why? We need to open up the problematic to unanticipated insights, to find new channels of exploration, to allow ideas to flow and overflow into unexpected configurations. Whatever our own starting point, normative or already resistant, it is time to unsettle and go beyond *all* our conventions and expectations. As such, we need to *undo* the singular externalized category of the monster, and find a new form of ethics that is both *of* the body, and answers more fully to the multiplicity of embodied difference. In place of a morality of principles and rules that speaks to a clear cut set of binaries setting out the good and the evil, the self and the other, normal and abnormal, the permissible and the prohibited, we could turn away from such normative ethics to embrace instead the ambiguity and unpredictability of an openness towards the monstrous other, who is both the same and different. The question of value here is not so much made irrelevant, but suspended in the face of an encounter which cannot be known in advance. It is a move that acknowledges both vulnerability *to* the other, and, more importantly, the intrinsic vulnerability *of* the self. In other words, it confuses and complicates the flow of power.

The terrain of the monstrous offers a radical and potentially traumatic challenge to the scene of the embodied self, but out of that rending of the ontologically and ethically known and certain, space is created for movement and transformation. The ongoing task, then, is to open up the question of how to develop, at least provisionally, other more ethically adequate structures that can accommodate corporeal undecidability, and defuse power relations. Perhaps allowing ourselves to be touched by difference, both literally and metaphorically, is one way forward. We might begin to see vulnerability as positive, a link between ourselves and others that sees danger not in the flow across boundaries, but in the isolation peculiar to the sovereign subject. There are no certain answers here, but I believe that it is only by reconfiguring thought that we can move on to potentially more creative modes both of becoming in ourselves and of encountering others, whatever form those others might take.

Commentary by Catherine Frazee.*Portrait of the Activist as a Young Monster*

On a summer day in 1967 in Winnipeg I lost my innocence. Canada was 100 years old and I was 13. I was a student in reasonably good standing at the Allan Douglas School for Crippled Children. Reasonably good standing means that my marks were good but my reputation was bad. This apparently was because I was smart. Although it made no sense to me I knew this was so because of the way that Dr. Crosland, bless her heart, had tightened her face and hissed when she told the rest of the class to ignore me because I was being “smart”. Now whereas in other contexts, being a crippled child with a moderately precocious tongue was a preferred asset redeemable in the capital of adult attention and regard, a classroom filled with crippled children is a buyer’s market and Dr. Crosland wasn’t buying. My tarnished reputation was collateral damage. It was not my intent to estrange Dr. Crosland. They were intended to amuse, those smart remarks that I used, and if they missed the mark on Dr. Crosland they were marvellously successful in other quarters. With a single smart remark delivered at just the right moment, I could wrap robust arms of hilarity around the handsome 14 year old subject/object of my heart’s desire, Brian. Brian was Sandra’s boyfriend. That was because they both had cerebral palsy. But time and smart remarks would take care of that.

Summer brought sweet reprieve from Dr. Crosland’s disfavour and dates with Brian. First a movie, then a visit to the Winnipeg summer fair. The former, *Wait Until Dark*, I now understand to be a classic in what was at least in 1967 a still unproblematized genre of stocker versus blind victim films. The latter, that’s the trip to the Winnipeg summer fair, emerges in 2004 as the memory of a mostly restless and unsatisfying day, decorated with the usual featureless swirl of rides and thrills for bodies unlike mine, when we came upon a tent with a marquee of superlatives. It was thus the promise of untold astonishment and mystery and more the simple fact of a step-free entrance that lured us inside. This was my first and only direct encounter with a freak show. Like pictures at an exhibition, the freaks of nature were arranged in sequence, their individual stalls spaced to permit small clusters of gawkers a good, close look before moving on to the next enclosure. The elephant man was first. He had some kind of skin condition. He returned my stare from a raised platform a few feet away from me, where he sat in his wheelchair. Seal boy was next. Seal boy was younger than the elephant man and he had hands like Eddy, Eddy who sat beside me every day on the crippled children’s school bus. Seal boy too occupied a four-wheeled throne. I remember only those first two strangers although there were others, and I remember an unfamiliar voltage of Brian’s twitching grip upon the handles of my manual wheelchair. I remember that we left the tent in silence and that by some strange alchemy we returned into the late afternoon light as strangers ourselves. I remember that there were no smart remarks on what remained of that day.

The people that Brian and I encountered inside that tent on the Winnipeg fair grounds had none of the aristocratic carriage of the 19th Century freaks who are captured in Charles Eisman's photographs and I'll wager anything that their earnings came nowhere near the 1967 equivalent of the reputed wealth of folks like William Henry Johnston, a.k.a. Zoot from Tie Brannick's film 'Freaks' who presumably acquired this wealth in the service of P.T. Barnum. This was a two-bit fair and the freaks were bored at best, profoundly degraded at worst. I do not know what they thought or felt as they stared out at me. I can scarcely even today name my own response, a bitter blend of betrayal, shock, and shame. These were my people given over to the casual gaze of so many two-bit fair goers, a gaze that would now slide toward me.

The insistent return of this memory as I began writing this paper uncorked an eruption of more questions than I have had time to explore thoroughly. I had always imagined monsters as, well, upright beings for one thing. Powerful beings, fierce and raging. Was this some projection of my own ablest impulses or antipathies? How could an inversion of the monsters, those silent, passive, shadowy strangers, how could this encounter imperil a teenage monster attitude and wit? How closely linked were the crippled child's impulse to amuse and the crippled adult's choice to entertain as a performing freak? Could I, can I presume that there was neither beauty nor wit to behold there? Where did the power reside in relations between spectator and spectacle? Well those are the questions I won't address now. But for today's purposes what I have salvaged from this many-headed beast is simply this. In that first encounter with enfreakment we see ourselves as we are seen, whether in a tent at the fair, in a paediatrician's office, in a charity advertisement, a family gathering, an academic text, wherever. The unravelling of identity begins when we see its monster in the mirror. We meet ourselves as other, deviating from the natural order, malformed, defective, and unwelcome. The imaginary body, writes Todd Tolken Sebers, that undergirds not only medical science but also architectural theory, employment law, and conceptions of citizenship.

Like the movement that has sustained me, I have grown and matured since 1967 from a place somewhere outside of the Winnipeg fair grounds and somewhat distanced from the corrective attentions of Dr. Crosland. Brian and I and others of our tribe, many of whom are perhaps in this room, have pushed back against the forms and structures of oppression. We have spoken through sound bites and slogans and court rooms, board rooms and classrooms with vocabularies of argument, critique and negotiation. We have high roaded and prostrated, we have made friends and enemies. We have reframed and regrouped, and we have always pressed onward. All of this we have done because we know that monsters matter and that the sidelining of our interests has never been fair. With visions of justice dancing in our heads, we have advanced toward equitable, social, and political arrangements toward enrichment of limitarial conditions of disabled people's

minds. Our progress has been incremental and sporadic, but it has been real. And we have launched a still more ambitious enterprise. Coming up behind and penetrating through our campaign for participation and opportunity is another quest, a deeper quest, a quest for human recognition. Not only is our social positioning unfair, but the justificatory theories relied upon to account for our disadvantage are without substance. We have not been treated fairly but nor have the deprivations of our lives been natural, been a natural consequence of our impairments. Our bodies do not explain the problem of disability. They are the site upon which this problem is invented. For the purpose of this particular odyssey we must and we do take up the monster's place, claiming the monster's power, uniqueness, and seduction. We are, we now assert, integral beings, authentic, viable, and worthy of life. In a process of reinventing and self definition, we assert our beauty and our strength and our particularity as part of the asymmetrical, dissident, chaotic, interdependent, lumpy, leaky, and dappled natural world. No longer the monstrous object contained within the circus tent or the death camp, disabled people now step centre stage into a subject position as artists, creators, and agents of culture.

Commentary by Roxanne Mykitiuk.

What I will discuss here builds on the film *Gattaca* and on work that I have been doing with Isabel Karpin, a colleague at the University of Sydney, on inheritable genetic modifications. I will try to relate it to some of the prohibitions that are going on now on a regulatory scale with respect to not permitting the creation of chimeras and hybrids and the sort of panic that has ensued about that and our questioning about what is really being regulated here in this sort of moral panic about a creation of chimeras given that we could sort of put on hold the health considerations and possible exploitation issues. We think that there is actually something else going on.

Much feminist legal scholarship, and I am coming out of a legal discipline and so much of my work will focus there, has attempted to critique the legal concept of selfhood for its reliance upon artifice of physical boundedness and unity. Feminists who reject the law's embrace of this legal construction of self, do so because the political, social and legal consequences that follow from this ascription of self work against the bodies of women and others of course. Women's bodies, it is argued, are least able to perform or one of the kinds of embodiment that are unable to conform to an optics of the skin particularly in the context of pregnancy. This is not however confined to women's bodies. Harroway, for example, points out that in these days of biotechnological seeing, even the most reliable Western individuated bodies neither stop nor start at the skin, which is itself something of a teeming jungle threatening illicit fusions and view the self as a construct that extends beyond the limits of the physical by simply being in the world. Its situated extension in time and space underlines the alleged autocracy of the individual self.

So part of what Isabel and I have been trying to do is to argue that genetics discourses, which arguably can be indifferent to the surface of the body as a marker of identity, demand a more complex understanding of the self in law. What happens for instance when genetic discourses reveal that we are all leaky and boundaryless subjects? In her discussion of conjoined twins, she describes this conception of the leakiness of self and says that above all it is the corporeal ambiguity and fluidity, the troublesome lack of fixed definition, the refusal to be either one thing or the other that marks the monstrous as a site of disruption. Genetic discourses which emphasize shared identity and participation in the common genetic pool have a potential to reveal this monstrousness or monstrosity in all of us. But what we try to suggest is that this is challenging to law because these discourses expose the impossibility of the autonomous, self-sufficient individual which lies at the normative centre of liberal legalism which we live and inhabit every day. There is the potential then that the individual in the age of the gene is fundamentally connected and vulnerable. The individual in the age of the gene always contains the trace of the other.

It is this central anxiety, the loss of self through the exteriorization of the interior that propels the narrative in the film, *Gattaca*. We see the failure of law because individuals are not recognized in that way anymore. I will present a summary of the film *Gattaca* to help you better understand the discussion. *Gattaca Corporation* is an aerospace firm in the future. During this time society analyzes your DNA and determines where you belong in life. Ethan Hawkes' character was born with a congenital heart condition which would cast him out of getting a chance to travel in space. So in turn, he assumes the identity of an athlete who has genes that would allow him to achieve his dream of space travel. Vincent, the Ethan Hawke character and now our so-called hero, is one of the last so-called natural babies born into a sterile, genetically enhanced world where life expectancy and disease likelihood are ascertained at birth. Myopic and due to die at 30, he has no chance of a career in a society that now discriminates against your genes instead of your gender, race or religion. Going underground, he assumes the identity of Gerome who was disabled in a car accident (we find out later in fact that it wasn't a car accident but it was actually a suicide attempt) and achieves prominence in the *Gattaca Corporation* where he is selected for his life-long desire, this manned mission to Titan. Constantly passing gene tests by diligently using samples of Gerome's hair, skin, blood, and urine, his now perfect world is thrown into increasing desperation, his dream within reach when the mission director is killed and he carelessly loses an eyelash at the scene. Certain that they know the murderer's ID, but unable to track down the form of infant, the police start to close in with extra searches and new gene tests. With the once in a lifetime launch only days away, Vincent must avoid arousing suspicion while passing this test, evading the police, and not knowing who he can trust.

Allan Mason has written that the autonomous self is produced as an optical effect as the body attempts to conform to an encoded visual surface and to inhabit a landscape constituted as a field of the other's gaze. It is this differentiated self, certain of its limits that we are taught to prize. The failure to articulate and determine fixed and impenetrable boundaries is a failure of selfhood. And it is nowhere more evident than at *Gattaca*, where people routinely and without complaint open their mouths for swab tests, offer their thumbs for prick blood spot tests, and piss on demand in the presence of the testing technician. Not only is the body's boundary compromised through the extraction of its fluids, but its very heart is splayed open when the heartbeat is monitored during physical exercise. This is why in *Gattaca* the main character, Vincent, never offers any of his own bodily fluids. Nothing that comes off Vincent is wet. Nothing comes from inside. Nothing comes from inside him. He only ever removes what is already on the surface, his dead skin, loose hair, loose eyelashes, and fingernails.

In order to take on Gerome's identity, Vincent must have his legs lengthened, wear contact lenses, and attach pouches of Gerome's blood to his fingertips and pouches filled with his urine to his inner thigh. Every day he must scrub the dead skin from his body so he doesn't shed any at

Gattaca and he must comb his hair and eyebrows and eyelashes so that nothing is loose, his obsessive boundary policing activity. He must make sure that his body does not leave a trace of itself. Gattaca is the visualization of a paranoid future in which the body is the source of abundant and excessive traces of itself. Vincent though represents the triumph of liberal individualism. By an obsessive maintenance of the surface of his body, he maintains his limits against all incursions. He alone in this movie maintains his selfhood. Even those who are at the very top of the pecking order are flawed because they cannot keep themselves to themselves. Vincent's boss is ultimately caught for the murder of the director because his saliva is found in the eye of the dead man. Apparently he was unable to control his contempt for the man and spat in his eye before he killed him. All the workers at Gattaca must succumb to their fluidity. They allow their thumbs to be pricked every day, their urine to be tested every week and so on. But Vincent never cedes to this invasion of his identity. Even when Vincent must have his own urine tested because he failed to anticipate a test at this stage, the technician refuses to read it. He tests it and flicks a button which brings up the valid Jerome Morrow, not the invalid Vincent Freeman. The reason for this collusion is his own so-called flawed son who didn't turn out quite as he was supposed to. Thus Vincent is allowed to pass without ever ceding his interior bodily self. Together the technician and Vincent cooperate in the liberal individual project.

Gattaca should be a film of great uplift. Here we have the triumph of the will. Jerome says to Vincent at the end of the movie 'I gave you my body and you gave me your dream over the intrusion of the state'. But the truth is that the narrative does not provide uplift because it offers only one way out, namely the shutting of the body. Bodies are what hold you back. If you can transcend your body then you will still make it. Nothing has changed then in the not too distant future world. The mind/body split is still the source of selfhood and those of us trapped in our bodies are still destined to fail. In Gattaca, as in law, the liberal subject is still the pre-eminent mode of selfhood. This rights bearing subject find its greatest recognition in those moments when it fends off encouragements by others. These are boundary defining moments that carry with them the promise of invulnerability and autonomy but is the kind of autonomy that is characterized by self interest. Even though Vincent is an invalid, his white male able-bodiedness still seems to be what enables him to succeed. Those who demand an autonomy of self that incorporates care, responsibility, connection, dependence, and even immersion with the other are seen as a definition of paradox, transgressive, messy, mixed up failures. It is not as if Jerome, who uses a wheelchair, would fare any better if people weren't genetically engineered and in the movie suggests that the only way that genetic engineering can be flawed is through the intervention of fate, namely disabling car accidents. In the not too distant future, Jerome must be feminized because he is truly subject to his body through his disability. That is why he can never really be free until he is dead according to the movie. Until then he is simply body. When

Vincent Freeman scrapes off his skin and his hair, he throws the waste into the incinerator. When Gerome decides to be a free man, he must incinerate himself.

There is no room for women either in this selfhood maintained through closure of body boundaries. We are not allowed to care whether Irene, one of the female figures, makes it on to the space ship. Instead we are to assume she'll wait for Vincent to return. Apart from Irene, women have infrequent presences in the film. There is Vincent's mother and there are the midwives who delivered him, and there is the woman who runs the childcare that refuses Vincent entry due to lack of insurance. All these women continue to occupy places traditionally reserved for women but more than that, the film demands a return to natural maternity in order to ensure the possibility of male selfhood. It is Vincent's mother who enables the creation of a real self in Vincent first by allowing his conception and second by believing in him. When his fate is read out at his birth, it is Vincent's mother who says 'He'll do something. He will. I know he will.' Similarly when there is a chance that Vincent might have to give up a bodily fluid it is Irene, the Uma Thurman character, who allows herself to be cast as a contaminator that saves him from exposure. And it is the feminized Gerome, who protects Vincent's privacy and ironically his greatest act of will, when he drags himself up steps to answer the door to the police who have come seeking Vincent at home. Vincent cannot be a self-sustaining self without all of these women and Gerome helping him. And this is the essential point. Nobody is truly self-sustaining. And so this return to an ideology of natural birth is really a call for maintenance of a fantasy of male, white, able-bodied selfhood at the expense of the other. The ideology of the movie is that women's maternal role must be reinstated. What is going wrong in *Gattaca* is not just the excessive surveillance of the state but that bodily exchanges are deviant. What is going right is that Vincent never really has to give up any of his bodily fluids.

Some of our recent work was to use genetic discourses to generate anxiety about the stability of liberal identity so that its current beneficiaries find themselves at the margins along with the rest of us. And to do this, Isabel has posited what she considers to be this law, this legal norm of transgressivity. So, law in this new frame must take as its base unit a subject that is inevitably connected, vulnerable and dependent. Because the transgressive is by definition that which goes beyond the limits, normative transgressivity is both an oxymoron and a standard state of being. *Gattaca*, on the other hand, identifies the transgressive self as that which is intolerable. It is not therefore a film that offers much in the way of radical and progressive imaginings. It does however offer an interesting and popular vision of a paranoid future and it is this kind of vision that we are trying to argue partly informs recent legislative attempts in Canada, in the U.K., and in Australia to restore the visual surface of the body as the marker of individual identity, primarily through privacy legislation with respect to the way that genetic information is treated. What we are finding in several pieces of legislation is that there is an attempt to secure one's rights, to keep

one's genetic identity to oneself without turning it into property which, of course, if you did so would lend to the self being a subject of exchange. It is worth noting probably that privacy in itself as a concept is not a model that indigenous groups and indigenous peoples have found particularly useful in their attempts to protect indigenous knowledge and indigenous property, and they in fact would prefer to resort to a recognition of indigenous knowledge and the concept of property as a way of protecting that information.

We also suggest that the primary anxiety that motivates these regulatory impulses is to protect that one individual who up until now has been able to utilize his or her body state to garner power and that, of course, is the sort of normative legal subject who is the white able-bodied male who lies at the heart of liberal legal discourse. There is the sense that you cannot pass for a white, able-bodied male if you are wearing your DNA coat on the outside where everyone can see it. Indeed, there is a scene in the movie where Vincent's parents are ordering their second baby where a black geneticist claims to know the value of whiteness. When he notes that they want a fair child, he raises his eyebrows and says 'Of course' suggesting that the Michael Jacksons of the future might be able to get their white children his way too. His surface is always already leaky. He can't hold his blackness back. It is self revealing. Whereas for Vincent he can hold all of his vulnerabilities back by internalizing them and making his surface impenetrable. And this bears out the view that the real problem with genetic discourse is that there are equalizers for the white able-bodied male and what is not exposed can now be exposed while the rest of us have already had to live exposed in our very embodiment. So, arguably, this is why in *Gattaca* it was necessary to continue to mediate reproduction through a heterosexual parental couple. In this way, the deviant involvement of others could be more clearly illuminated. When the black genetic counselor says to Vincent's parents 'Bear in mind this is still you, simply the best in you', it's not clear what is being imagined. As in fact any effective genetic engineering will require more than two genetic progenitors. Genetic engineering fragments bodies producing offspring from the genetic material of more than two people. There is I think the suggestion that the genetic counselor empowered with creating their offspring is a deceiver and not a conceiver. The suggestion that there could be racial mixing also is made much of in this moment. Not only is a black man involved in the production of a white child but he seems to be offering them a choice of the color of that child.

In the comparative legislation that we were looking at, with respect to the genetic modification issue, we are seeing certain practices were being prohibited and others were not being prohibited. This possibly was an implicit instantiation in the legislation of a heterosexual couple norm into reproductive law that has also led to the formulation of certain sections in cloning acts where it becomes an offence to create an embryo with genetic material from more than two people. It is interesting that the act (Australian legislation) does not say that the requirement is a genetic male

and a genetic female, but merely the combination of two genetic sources. It may be an oversight on the part of the legislators who cannot imagine a future where you can actually combine two same sex genes to create anything other than a clone. But this could possibly be mistaken because fairly recently Professor Bill Sykes, of Oxford, has suggested in his latest book that men are on the way out because the Y chromosome is not up too much and because women have two X chromosomes and can reproduce just as well themselves.

So what we have been trying to do is that what we need to be moving towards this recognition of ourselves in others. Isabel and I want to be able to use genetic discourses to reveal the individual in biomedical moments of self recognition in the other. We do not do away with individuality but complicate it. Indeed in doing this, we can suggest that what makes us individual also joins us to others. This will offer a radical solution, not the kind of obsessive boundary maintenance that Vincent undertakes. So we are actually troubling the idea that we should in fact be banning chimeras or hybrids, not suggesting that we necessarily embrace it, but that we really need to be taking a look at where the anxiety of the sort of instinct to prohibit is coming from.

Reconsidering the Evidence: Healthcare Bioethics and the Body.***Margrit Shildrick.***

The theme of this paper centers on the experience of bodily distress as it arises in the experience of pain, and dying - with the everyday transformations of ageing serving as a less dramatic scenario for similar considerations. My choice of those areas is not because I think they are singular moments of vulnerability in a life otherwise secure, predictable, and controlled, and I shall go on to reiterate the vulnerability of all embodied being, but because they so clearly set out the limits and shortcomings of modern western biomedicine and conventional healthcare. The claims to impartiality and objectivity, the reliance on clear and distinct empirical evidence, that mark the positivist enterprise of biomedicine in particular have long been subjected, especially by feminist theorists, to a sustained critique that could well be extended to the recent officially sanctioned love affair with evidence-based medicine. I shall not take up those concerns directly, but rather suggest a different way of understanding the body that has implications not only for my own area of bioethics, but for the operative models of many substantive areas of health care.

Now, one of the most remarkable things about pain, ageing, and death is that despite their ubiquity as life experiences, very little attention has been paid either to the meanings involved, or to the materiality of those conditions, by which I mean that any real sense of embodiment tends to be left out. With few exceptions, we will all age, and experience pain, and all of us will die, as an intrinsic part of the life course, and yet those experiences are threaded through with forms of silencing, not simply in the realm of biomedicine, which is strongly oriented to threats that are temporary and manageable, but as a kind of denial that operates widely in everyday life. And where they are spoken, it is as an external description, rather than as the phenomenological experience. Although death, for example, is a necessary topic in bioethics insofar as it relates to the relative value of life or involves interventional procedures, it is customary to hide it away. As something that is finally unpredictable, and irreversibly transformative of the embodied subject, it remains a disturbing point of ambiguity and disorder that grounds both anxiety and denial. Indeed, I cannot really think my own death, and am reluctant to think my dying.

Equally pain is at the centre of much biomedical research and clinical practice, but it remains poorly understood even in those limited contexts, and largely unspoken in the wider medical encounter. If as Kathryn Montgomery Hunter remarks, biomedicine 'is characterized by its varied and ingenious defenses against uncertainty' (1991: 47), then it becomes clearer why a condition like pain, that we should expect to be central to the endeavor, is so marginalized, even covered over within the positivist and objectifying ideals of medical enterprise. Corporeal unpredictability or fluidity in any form is a severe embarrassment to a discourse that has worked

traditionally through classification, normalization and regulation. In particular, chronic pain contests the imposition of definitive strategies by frustrating the legitimating search for localization and causal connections. But even beyond the rationalism of the clinic, pain, as we'll see, struggles to find adequate expression. Like the experience of ageing, it is both a matter of outward and public display, and an interior transformation of the embodied subject that remains largely unacknowledged. And perhaps ageing is most silenced of all. Older people in our culture are both denied a voice and scarcely spoken of except as somewhat troublesome others. Their experience is so effectively privatized, so alien to socio-cultural normativities, that the ordinary effects of ageing can come as a surprise.

What sets pain, ageing and death apart is that each challenges normative conceptions of the embodied self as somehow properly self-determining, predictable and ordered. We all know, I suppose that it cannot really work like that, and yet we continue to hold onto the ideal of always being in control of both mind and body. It is of course the post-Enlightenment fantasy, the cultural imaginary, of the invulnerable self that biomedicine has taken as its own ideal. The problem is that the more our own potential vulnerabilities are made manifest, albeit in the bodies of others, the more those others are held apart. As the feminist philosopher, Susan Wendell, who has Chronic Fatigue Syndrome, puts it:

If we tell people about our pain, for example, we remind them of the existence of pain, the imperfection and fragility of the body, the possibility of their own pain, and the inevitability of it. ...They may want to believe they are not like us, not vulnerable to this; if so they will cling to our differences, and we will become 'the Others'. (1999: 91-2)

The point is not simply that we habitually refuse to see and acknowledge the distress of others, but that it cannot be seen without risk because it threatens the stability of the normative self-image. In particular, everything about the western modernist tradition demands that bodies are at our disposal, subject to our will, under control, not liable to cause us doubt about our ontological security.

I am not suggesting that people really do live the mind/body split in quite the way that the critique of Cartesian binaries would claim, if only because most of us are one way or the other obsessed with our corporeality and never quite certain of it. What matters is the tension between the normative standards of control to which we aspire and the actual struggle that goes into maintaining that control. Our society's preoccupation with keep fit regimes, dieting, cosmetic surgery, weight training and the like, speaks to a constant need to discipline the body in order to circumvent its own inherent lack of order and discipline. The problem is that as we age, the body increasingly evades self-determination and becomes visibly more limited in its physical capacities. Alongside the negative perception of any inability to participate fully in the capitalist labour

market, the representation of the physical and mental changes of old age as decline can only be understood within the normative standards of specific socio-cultural contexts. Long before actual death, old people commonly experience social death, a culturally mediated shrinking of horizons that is both real and metaphorical. On a phenomenological level, the external context in which a self takes shape and is continually transformed becomes increasingly limited so that old people are invisibilised, and yet simultaneously made subject to increased surveillance and management. Either way, their ageing bodies must not be allowed to disrupt the comfortable norms of society.

Certainly changes both in health care and social policy could alleviate some of the distress borne by older people, but my argument is that that process of othering, properly called gerontophobia which the Oxford Companion to Medicine defines as ‘a morbid dislike of old people or a dread of growing old’, is entrenched as much at a psychic, as material levels. The underlying issue is our refusal to accept the instability of the body and the embodied self whatever its material condition. It is not that bodies in extremis are the problem, but that all bodies are inherently vulnerable. As feminist philosopher Jean Grimshaw notes:

At most the body is only ever in a precarious and temporary state of equilibrium, and all negotiations of its states are temporary. The body is always a problem in human life....
(2002: 71)

In other words, the ambiguity of ageing is no more than the ambiguity that informs all bodies. It is the unspoken meaning of ageing, the intimation of instability and uncertainty, not the condition itself that is unacceptable and must be disavowed. And the situation is further complicated in that older people inevitably internalize the same cultural norms that mobilize the experience of alienation.

In her autobiographies, Simone de Beauvoir tackles both death and ageing. In the account of her mother’s terminal illness with an aggressive cancer (1965), the death is eased only insofar as Françoise, the mother, with the collusion of Simone, her sister, and the attending physician, tacitly refuses to acknowledge that death is imminent. To the end Françoise clings to some semblance of control, even as her body dis-integrates. In the later books too (1968, 1972), Beauvoir often seems repelled by her own ageing, experiencing a protective sense of self-distancing. As she puts it:

Old age is something beyond my life, outside it - something of which I cannot have any full inward experience’ (1972: 291).

But if one strategy of holding onto control is to deny the materiality of ageing and death, then we might notice that the alternative of acceptance, which is often urged on older people, perhaps

represents only another form of control, a conscious willing that would cover over the embodied anxiety of impending death.

The ethical difficulty with all this is not that of resolving the tension between the control of denial and the control of acceptance, but that the ambiguity and uncertainty of the embodied self is so impossible to bear. Insofar as death has meaning both as a materiality and in the cultural imaginary, the impetus of all those involved is to intervene to settle on one or another path, not so much for the sake of the one dying as for the need to exercise control. Amongst terminal patients, and dying is usually institutionalized, the 'good' ones are those who are docile and manageable, who have suspended their doubts about everything being under control. As with the lay public, the medical profession itself seems singularly unwilling to openly face uncertainty. The urge to impose order and rationality in the face of disorder, and to give hope where none is justified, finds expression in biomedical procedures that may postpone the moment of dying, but fail to attend to the on-going changes to the being-in-the-world of the patient. The two extremes of heroic high-tech intervention to preserve life at all costs, and the shutting down attendant on the decision of clinical futility, are both about the appearance of rational control. Neither is necessarily wrong in any particular instance, but while the imperative to do something - to exercise a determining agency - may settle professional anxieties, it can override other less reductionist alternatives.

In the case of Beauvoir's mother, her daughters' implicit agreement to support her denial could not in the light of our shared investments in disavowing anxiety be wholly altruistic, but it is very different from the detached control of the medical staff who authorize a supposedly life-saving operation, even though its effects are extremely short-lived. Beauvoir worries about agreeing to participate in the whole scenario of deception, but in the end she compromises in order to meet the bodily needs and desires of her mother. In other words, hers is an ethics of relationship which does not simply fall back on abstract principles in order to enact the good. In contrast healthcare professionals are trained to resist that emotive, affective relation, to chart instead a way through the messiness of life and death. The biomedical encounter is one in which, conventionally, the one acts, within his or her own moral framework, on the other. The material and psychic embodiment of the professional is considered irrelevant. In effect, the rigid hierarchical structure, faith in technology, and emotional detachment of modern western medicine, combine with an understanding of death as adversarial to mobilize procedures that are broadly unreceptive to human needs and desires. I do not mean that conventional approaches are always morally inadequate, but that often they fail to respond to the embodied specificity of a given situation.

In contrast, a phenomenological approach, and indeed Beauvoir's own ethics of ambiguity, more readily lends itself to a corporeal ethics that might acknowledge the insecurities and vulnerabilities on both sides of any encounter. Whilst no patient should be compelled to partake of a different relationship, and some might prefer the convention of 'doctor knows best', that does

not diminish the value of exploring different ways of openly negotiating the medical encounter to more productively account for the overt and hidden needs and desires at stake. The difficulty for bioethics is that the change to a radically less objectifying attitude demands a reconsideration of the entire Western intellectual tradition and its investments in evidential certainty. In relation to death, there is already a substantial body of literature on the significance of self-determination around dramatic issues like euthanasia, compliance or non-compliance with living wills, or recently the ethics of organ and tissue disposal, but little of it shows awareness of the mutually constitutive relation between patients and practitioners. And though feminist bioethicists have led the way in rethinking the biomedical encounter in general, they too remain largely silent on the materiality of dying.

To turn our attention now from death to pain invokes similar difficulties, for as Elaine Scarry notes, severe pain is a rehearsal for death. What she means is that like death, overwhelming pain obliterates the world, the self, and the voice, and, like dying, nullifies the external interactions of living in the world, and destroys the context of consciousness. For Scarry, the analytic of pain serves to ground her reflections on torture, but, as she makes clear, it is not only at the extremes that pain functions to ‘unmake the world’. As she explains it, pain, unlike all the other affects, love of, hate for and so on, has no external object. Instead, it is interiority, experienced from within the boundaries of the individual body. Even though it may produce outward signs in identifiable and discernible behavior, it always retains an inward quality that resists expression or description. As Scarry puts it:

‘having pain’ may come to be thought of as the most vibrant example of what it is to ‘have certainty’, while for the other person it is so elusive that ‘hearing about pain’ may exist as the primary model of what it is ‘to have doubt’. Thus pain comes unsharably into our midst as that which cannot be denied and that which cannot be confirmed. (1985: 4)

This paradox of certainty and doubt is clearly a conceptual gap of some importance, not least for both biomedicine and bioethics, and seems on the face of it to resist the very ethics of embodied relationship that I am proposing as appropriate to health care. In *The Body in Pain* (1985), Scarry makes clear that the inexpressibility of pain, and hence its resistance to direct observation, is not a contingent feature, but the very core of what pain is.

Physical 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. The task for the sufferer, then, is to find a way to force pain outwards, to voice it in the world of others. A consistent feature is the use of a metaphorical language of agency, as in ‘my head is being split apart’ or ‘it feels like a knife in the guts’, expressions which as

Scarry puts it, 'begin to externalize...and make sharable' what has been an interior and unsharable experience.

This urgent searching for expression is exemplified in Audre Lorde's efforts to come to terms with the pain of her cancer, as the following two journal entries in *The Cancer Journals* (1985) show:

26 Jan. 79

I'm not feeling very hopeful these days, about selfhood or anything else. I handle the outward motions of each day while pain fills me like a pus-pocket and every touch threatens to breach the taut membrane that keeps it from flowing through and poisoning my whole existence....

22 April 79

If I resist or try to stop it, it will detonate inside me, shatter me, and splatter my pieces against every wall and person that I touch.

Like Scarry, Lorde is acutely aware of the destructive dangers to the sense of self of pain borne in silence, but rather than understanding it only as an intrinsic quality of pain that it obliterates language, Lorde is equally concerned with the silencing that is imposed on sufferers from the outside, and then internalized. As she puts it in the preface to *The Cancer Journals*:

I do not wish my anger and pain and fear about cancer to fossilize into yet another silence, nor to rob me of whatever strength can lie at the core of this experience openly acknowledged and examined. For other women of all ages, colors, and sexual identities who recognize that imposed silence about any area of our lives is a tool for separation and powerlessness...I have tried to voice some of my feelings.

And we might note that the same awareness of the destructive power of silence is evident in one of the most politicized campaigns around HIV/AIDS where ACT-UP adopted the slogan SILENCE=DEATH.

Lorde is never dismissive of the fear and often hopelessness that she and others with cancer feel, but she sees survival in terms of the subject's capacity to make meaning out of the experience, and in her own case to integrate it into her political project for changes in the lives of women. After her mastectomy operation, Lorde is swiftly faced with the normalizing forces of society, that seek to cover over bodily difference, and particularly those that signal vulnerability, by the expectation that she will wear a breast prosthesis, not least to maintain her attractiveness to men. And on another occasion, a phone call from her consultant's office urges her to use a prosthesis, on the grounds that her evident breastlessness is bad for the morale of others who attend the office. Not surprisingly, Lorde rejects such disciplinary overtures and comments:

certain other people feel better with that lump stuck into my bra, because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference (1985: 56).

She is, she declares, more interested in maintaining her own control over ‘the new me’. As with Beauvoir’s mother, Lorde’s desire for self-control is scarcely surprising, it is the ideal of both post-Enlightenment culture in general, and in Lorde’s case very specific to the early agenda of Women’s Liberation, where women explicitly sought to wrest control of their bodies and lives. What is different, however, is that where Françoise desperately tried to deny that her embodied self had changed, Audre is determined to celebrate the new self, or as she puts it at one point, to ‘live myriad selves’. Her words go instinctively towards the theorization of embodiment as unfixed, unstable, and, despite the desire for control, ultimately ungraspable.

Before looking at another feminist account of the experience of breast cancer that productively pushes that analysis into the uncertain territory of deconstruction, I want to review the more widely accepted phenomenological account of the body in distress. Broadly speaking, phenomenology sees embodiment as a concept in which both mental and physical components are always intimately intertwined as the structure of all lived experience. I live not in my body as though the ‘I’ were somehow already existent: I am my body to the extent that all the experiences and changes of my corporeal interface with the world of others constitute and continually reconstitute my self. For the greater part of time, while my body is operating within the normative limits of biological function, social intercourse, affective experience and so on, my acquired habitus is so familiar that I am unaware of my corporeality as such. In other words, when I do something like use a computer, I know without conscious reflection exactly how much pressure to apply to the keyboard, or, without looking, where to extend my hand to lay hold of the mouse. In a similar way, in mainstream phenomenological theory at least, the body in good health and pain-free is not a conscious presence for me, but simply the unquestioned ground of my well Being. It is the body that is forgotten. But I think we need to be cautious here. I increasingly feel that the normative body itself does require ongoing conscious maintenance to avoid slippage beyond the norms. That everyday performative awareness may be substantially different from the awareness that imposes itself when the body shows signs of putatively ‘biological’ breakdown in terms of illness, aging, pain and so on; but we do not suppose that the embodied self is ever in a state of static integration.

The usual phenomenological understanding is that the body that fails to work as expected demands attention, by opening up a dissonance between self and body. It becomes an unwelcome presence that makes us aware of our limitations and vulnerabilities. Arthur Kleinman provides the classic phenomenological account in *The Illness Narratives*:

The fidelity of our bodies is so basic that we never think of it...illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair. (1988: 45)

In effect, the previously taken-for-granted integration of embodiment is challenged by a scenario in which the security and stability of the self appears to be threatened by the otherness of bodily effects. Body and mind appear antagonistic.

Now if body and mind are irreducibly intertwined as phenomenology suggests, then the restoration of well Being, call it good health, cannot finally rest on strategies that privilege the one over the other, but only on re-incorporation. But the goal of modern health care is more likely to attempt to once more cover over the uncertainty of the body, by restoring self-control over corporeality, and by renewing the illusion of invulnerability. And even when, as Kleinman insists it must, biomedicine assists in the ethical task of re-embodiment, that too is misdirected if the ultimate goal is to sideline the body once again by restoring normative forgetfulness. If, as I've been suggesting, the body is already unstable in the normal course of events, and not simply at extra-ordinary moments, then disorder is a dimension of embodiment that is not susceptible to remedial practices. Beyond certain limited procedures that at most restore ordinary disorder, embodiment cannot be settled once and for all.

How can these reflections provide insight into the problematic of pain? Unlike a disease process or bodily trauma, which may result in pain, pain as such is already clearly psychosomatic in its nature. Although an external belief in the reality of pain is strongest when it can be supported by clinical evidence such as tissue damage, the old biomedical model is far from adequate. In recent years the Gate-Control theory of pain has gained widespread acceptance, and backs up the idea that whatever the neural impulses, their intensity can be either diminished or exaggerated by psycho-cognitive factors. That is not to say that the biomedical establishment is necessarily more empathetic in its approach to pain, more willing to accommodate the fluctuations that resist categorization, or likely to abandon the search for measurable evidence. Without radical changes, bioscience, with its grasping after certainty based on repeatable and regular evidence, is ill-suited to address the intrinsically variant and unpredictable nature of its object. A friend who attends a leading pain clinic, for example, is regularly asked to rate her severe chronic pain on a scale of 1-10, and is firmly assured that hypnotherapy would be of no benefit because her pain 'is real'. There is no opportunity for her and others to give voice to what, as Scarry indicated, is an intensely personal and interior experience, and as a result pain is frequently delegitimized.

Although the Gate-Control model goes some way towards explaining the potential gap in perception between a sufferer and observer, the imposition of what is effectively another impersonal and rationally-based model scarcely satisfies the phenomenological understanding of pain as part of the structure of lived experience, where what is at stake is the embodied ontology of the self. Like the body itself, pain is unstable, and eludes the disciplinary impulses of positivist science. As with illness, disability or simply ageing, the body in pain can be experienced as alien, or estranged, and yet so overwhelmingly present that it threatens to disintegrate the self. And in order to escape that condition of vulnerability, the internal response is to dichotomize the abstract self as a would-be controlling agent, and the materiality of the body that resists control. It is as though the sheer unpleasantness, or unbearability, of pain can only be comprehended as something other than the 'I'. For the sake of maintaining the supposed integrity of our selfhood, we make an object of the body and an abstraction of pain.

On the face of it, the reiteration of the mind-body split appears to be a characteristically masculinist way of dealing with the dis-ease of an ontological vulnerability, and I leave it to you to speculate why both sexes apparently believe that 'women are better able to cope with pain'. What does seem clear is that however much we might wish to transcend the body, our being in the world is always embodied, and therefore intrinsically vulnerable and uncertain. In an account of her violent rape, the philosopher Susan J. Brison, who characterizes herself as someone whose self-image had been highly abstract, writes:

My body was now perceived as an enemy...a site of increased vulnerability. But rejecting the body and returning to the life of the mind was not an option, since body and mind had become nearly indistinguishable. My mental state (typically, depression) felt physiological, like lead in my veins, whereas my physical state (frequently, one of incapacitation by fear and anxiety) was the incarnation of a cognitive and emotional paralysis resulting from shattered assumptions about my safety in the world. (1997: 17)

Brison's ordeal compels her to accept that the fragility of the embodied self is a permanent condition of being, and that she cannot regain an old self by further objectifying her body. Instead she must heal the dissonance of mind and body and remake her self by forging the embodied connections of living-in-the-world-with-others.

I want to close, however, by questioning whether the phenomenological model itself perhaps implies too great a possibility of an integrated bodiliness. For a rather different way of understanding embodiment that acknowledges the impossibility of ever settling it, I turn briefly to Eve Kosofsky Sedgwick, the so-called queen of queer deconstruction, who had written extensively about AIDS and death, before her own unexpected encounter with breast cancer. Whilst acknowledging that the experience is 'draining and scary', Sedgwick also characterizes it as

‘an adventure in applied deconstruction’ (1994: 12). In other words, she makes it her project to trace out the imbrication of her now ‘turbulent’ material embodiment with her theoretical resources. As she puts it, she must reflect on:

The phenomenology of life-threatening illness; the performativity of a life threatened, relatively early on, by illness; the recent crystallization of a politics explicitly oriented around grave illness: exploring these connections has...to mean hurling my energies outward to inhabit the very furthest of the loose ends where representation, identity, gender, sexuality, and the body can’t be made to line up neatly together (1994: 13)

Sedgwick’s acceptance of dislocation as an intrinsic dimension of human embodiment arises out of suffering and the threat of death, but that dislocation marks every aspect of living-in-the-world. What Sedgwick’s approach illustrates is that while body and self are surely indivisible, that does not imply any neat correspondence of the multiple elements that constitute lived experience. Things fall apart in ways that defy conscious control. For Sedgwick, survival depends not on reintegrating an illusory wholeness, but on an appreciation that her self-displacement could not be otherwise.

All this is deeply problematic not only for the operation of biomedicine, and especially evidence-based practice where the fundamental drive is to eliminate uncertainty, but also for the cultural context in which our values, expectations and uncertainties are constructed. Ageing, pain and dying are all about uncertain transformations in which distress is to a greater or lesser degree inevitable, but the desire to impose some kind of order, to reintegrate a secure self, is bound to end in failure. The problematic is finally the ethical one posed by the encounter with those in distress. Beyond the limits of material relief, the task is to remain open to the varying needs and desires of differential embodiment, and to engage in remaking connections, not as static channels of communication, but as dynamic and fluid networks. Yet, it is less about an empathetic reaching out to otherness, than of contesting the corporeal normativities that structure the embodied self. For those involved in healthcare and the rest alike, it means acknowledging those internal anxieties that so often compel us to silence, or attempt to impose order on, distress. To resist the self-assuring lure of stability, certitude, of evidence itself, is a move towards a necessary tolerance for vulnerability and ambiguity as the very condition of life.

Commentary by Lorraine Code.*Vulnerability: Contesting the Evidence*

This paper will offer some free associations prompted by Margrit Shildrick's paper. Because I admire the paper itself, and am largely in agreement with what she says, I will explore some ideas related to hers. It will have virtually nothing in common with the standard philosophical commentary and critique. The two issues that have caught my attention from Margrit's analysis are, as my title suggests, the issues of vulnerability and "evidence": and of places where the two intersect.

In a compelling article with the title "February 22, 2001: Toward a Politics of the Vulnerable Body", Debra Bergoffen presents a meditation on the implications of the 2001 UN war crimes trial at the Hague, where three Bosnian soldiers charged with raping and torturing Muslim women and girls were found guilty of crimes against humanity (2001; 116-34). Bergoffen characterizes the decision as a landmark event, not just because the acts were prosecuted and condemned but, most dramatically in her view, because rape was classified "as torture, a crime against humanity" (116). The decision thereby links "women's dignity to their 'fundamental human right to sexual self-determination'": a judgement that disrupts an entrenched pattern of charging crimes against humanity only according to a tacitly invoked standard of "the normative 'neutral' body" (117), assumed to be white, male, and in the prime of life. In a passage worth quoting in full in light of Margrit Shildrick's analysis, Bergoffen comments:

In adopting the standards of pain and suffering, we have set the bar too low. Uncritically accepting patriarchal myths of male and female bodies, establishing the mythical male body as the normal human body, and establishing that a violation of this normal human body occurs only when its "natural" invulnerable, closed shell is "unnaturally" forcibly breached, opened, wounded, courts have made it difficult for the charge of rape to stick. The Hague court's verdict changed this. Its judgment leads us to challenge the myth of the male invulnerable body and to interrogate the ways in which this mythical body has come to represent the human ideal (120).

Striking in Bergoffen's essay is a reconfigured conception of humanity with which it proposes framing the discourse of bodies, suffering, and responsibility: humanity defined not by its sameness, nor by autonomous homogeneity, but by the "heterogeneity of ... mutual vulnerability" which "identifies woman's otherness and vulnerability with a universal human obligation to acknowledge and abide by the virtue of trust" (133). This is a large and a generous idea both less cloying than some of the language produced by the ethics of care, less minimalist than the language of rights, and thoughtful in requiring 'us' to rethink issues of justice when substantive

equality can be neither presupposed nor achieved. What might the implications be of thinking about human beings not as rational self-conscious agents, most perfectly realized in the Enlightenment “man of reason”, but as vulnerable creatures who can live their vulnerabilities well only in climates of trust and mutual responsibility? These are some of the questions that, for me, bring Margrit Shildrick’s paper and Bergoffen’s together.

Since I too have thought and written about Susan Brison’s writings, I want to draw on some of that work to think about how Brison’s analyses of her rape (1993; 5-22, 1995; 37-40, 2002) contest the stability of a dominant social imaginary and the limitations of what is thinkable within it; and how they too expose human vulnerability as integral to, constitutive of ordinary lives and subjectivities, at least as fully as autonomy is imagined to be. Her essays reveal that professional philosophy’s professed unconcern with the material-corporeal specificities of subjectivity conceals processes by which some specificities, in their urgency, have tended to draw its attention after all, but merely self-protectively; have prompted philosophers to relegate such events and testimonials to the category of the non-rational, the merely particular; to cast them as aberrant episodic disturbances, and often to disqualify their tellers as reliable testifiers to the stories of “their own” lives. The autonomy-of-reason presumption fosters such moves. But the Hague decision, as Bergoffen reads it, may count as a first step toward a better way.

In Brison’s analyses of self and subjectivity in disarray, striving for viable cohesion in post-traumatic stress following sexual violence, the personal in its affective, corporeal particularity is as philosophical - as epistemological - as it is political in the better-known feminist sense. Speaking in the first person, Brison refuses the comfortable option of distancing herself from the story in the interests of generality or objectivity, thus breaking a philosophical taboo that keeps the subject, as knower or as known, hovering silently in the wings, speaking dispassionately in the third person, as though into a void. She addresses her readers, offers them “imaginative access to what is, for some, an unimaginable experience” (1993, p. 5), asks them to listen, to try to imagine how an event that fractures prototypical imaginings of “ordinary lives” can disrupt a self in whatever assuredness of (liberal) self-ownership it might avow. Her writings show that it is not only or even principally the dreaded deconstructions of postmodernity that fragment the presumed unity of this subject, but everyday events for which the polite liberal Enlightenment imagination rarely has adequate conceptual resources.

Crucially, Brison reminds her readers of “the every-dayness of sexual violence”: a reminder that should dislodge residual certainties about the matter-of-course safety of “ordinary lives”. Yet ironically, she observes, its very every-dayness “leads many to think that male violence against women is natural”; even though - compounding the irony - “while most people take sexual violence for granted, they simultaneously manage to deny that it really exists” (p. 7). In my view,

such thoughts highlight the persistent complacency of beliefs in the settled order and orderliness of a society so privileged as to enable (some of) its citizens to imagine violence - and other “unfortunate events” - as mere blemishes on an otherwise unsullied social surface; they affirm the tenacity of the liberal model with the polite imaginings that comprise its standard repertoire. Traumatic, albeit “ordinary”, events in women’s lives count merely as extraordinary for a social imaginary nourished to uphold expectations of a smooth journeying through “life”, and to discredit evidence showing that “life’s journeys” are commonly not so smooth, by relegating that evidence to the aberrant, to places where a woman has “asked for it” by having failed to play by the rules. An ecology of incredulity maps the terrain surrounding such episodes, to sustain the dream of affluent, andro-centred safety, all evidence to the contrary notwithstanding. Yet as Berghoffen shows, in consequence of the Hague tribunal’s landmark move, a new epistemology of rape has to be instituted, in which issues of consent and female sexual integrity come to displace violence as the sine qua non defining characteristic of rape as a crime. The convictions on the charge of crimes against humanity, she argues, show that “we cannot forget that human bodies are abused when their intentionalities, specifically the intentionalities of integrity, are violated” (p. 121). In so dramatic a move away from equating “self integrity with the integrity of the unmarked autonomous self” (p. 127), the court initiates a conceptual breakthrough that denaturalizes male violence against women, after all.

Brison’s theme is “the disintegration of the self experienced by victims of violence” (1993, p. 7; “the undoing of the self” in the undermining “of its most fundamental assumptions about the world” (1995, p. 38); the severing, when trauma is of human origin, of “the sustaining connection between the self and the rest of humanity”(1997, p. 14). Her writings chronicle the willed unknowings too much particularity - and too much suffering - evoke within professional philosophy marked, as it is, by a “disciplinary bias against thinking about the personal” (1995, p. 38); and assured of its power to achieve the exclusions of corporeality and affect necessary to keep particularity off its agenda. More disturbingly, she finds that secular listeners, too, tend to filter out experiential details too difficult to accommodate within the assumptions they live by; try to “explain the assault in ways that leave [their].. world view unscathed” (1993, p. 11). In short, orthodox knowers as Anglo-American epistemology represents them are trained to know only instances not particulars; and to fit those instances into ready-made universals, generalities, however uneasy the fit may be.

Here, drawing together a perhaps unlikely cluster of ideas - vulnerability, trust, ready-made universals, and evidence - I want to forge a connection from these thoughts to medicine and medical evidence. I hope it will not come across as forced. I make the connection with reference to some work I have done with two feminist family physicians, one Norwegian - Dr. Kirsti Malterud - and one American - Dr. Lucy Candib, both of whom are committed in their clinical practice to

responding to women's particular vulnerabilities; both of whom evince an ongoing scepticism of Evidence Based Medicine (EBM).

There is of course a certain shock value in the rhetoric of EBM on which its champions undoubtedly trade: it reminds me, although the link may seem a little far-fetched, of tales about the introduction of tinned tuna fish to the North American market, with the advertising slogan "guaranteed not to turn pink in the tin!" - an indirect assurance to consumers whose tinned-fish tastes would accommodate only salmon. Stretching the point a little, EBM assures its customers (for such they are) that unlike forms of medical treatment currently proposing to offer personal, individual attention, they are offering the real thing, guaranteed not to be tainted by the vagaries of subjective interpretation, thus bound to appeal to a science-venerating culture because it is based in evidence. The clear implication - and hence its shock value - is that EBM prompts an unsuspecting public to believe that other forms of medical treatment ignore the evidence, are inadequately scientific (both normatively and descriptively), are careless or frivolous, and therefore not to be trusted. So EBM comes across as the best, most reliable option, capable of replacing (soft) conjecture and tentativeness with (hard) evidence.

Now the point is not to discredit EBM outright, but to recognize how its pretensions have grown to exceed its reach. Initially, Malterud notes, things had been happening in medicine that had not been adequately documented, but just done - such as, in breast cancer surgery, cutting off the breast without determining whether survival rate was thereby improved. Examining rates of survival made it possible to evaluate the evidence more closely, about correlations between levels of the disease and prospects of survival. In such circumstances, many people were shocked to realize that experience-based medicine had not been as scientific as it pretended to be (forthcoming). So EBM was able to claim what we might call an epistemological high ground. But its subsequent hegemony is the problem.

Malterud has been working with what she calls "medically unexplained disorders": a diverse group of complaints that present variously. The patient - usually a woman - tends to experience persistent disabling symptoms: chronic pain, loss of energy, sleep problems, hypersensitivity, for which no pathological evidence can be found. Descriptive labels such as fibromyalgia, chronic fatigue syndrome, glossodynia, whiplash disorder, temporomandibular joint disorder, or irritable bowel syndrome are often applied. But Malterud, as both a practitioner and an academic, attests to her increased discomfort with the so-called objectivity attributed to medical knowledge and diagnosis. She encounters women in her practice who not only suffer from medically unexplained disorders, but also bear the burden of incredulity conveyed by a discipline which insists on a sharp dichotomy between the subjective and the objective. Those who can present only subjective

narratives that fail to fit the objective template EBM offers are frequently blamed or discredited; their symptoms dismissed as merely psychological.

Similarly, Candib contests the central assumption of evidence-based medicine (EBM) that all the important questions can be answered by random control trials (RCTs): problems that cannot be formulated in the proper format (i.e. a specific question answerable by an adequately powered RCT) are not worth asking. If she, for example, maintains that a physician's relationship with the patient is a crucial factor in successful treatment, EBM experts will deny the very possibility of evidential support for such a claim, and - strongly reminiscent of the positivistic verificationist credo - conclude that her claim is therefore meaningless, mere folk medicine.

Evidence-based medicine prioritizes what can be demonstrated in randomized controlled trial, while disparaging any epistemological claims for the validity of specifically embodied experiences - and vulnerabilities. Patient-centred medicine, by contrast, places the patient at the centre of inquiry. At its best, it regards the patient's experiences of illness, her vulnerabilities, and what I want to call the political and ecological specificities of her situation as pivotal to understanding how to approach and treat her symptoms. By contrast with EBM, the patient-centred care Candib and Malterud advocate is enriched by understandings both of the patient's particular, material, embodied experiences and the clinician's experiences of that patient. But in a medical culture where EBM is powerfully positioned to determine both how doctors are trained, and how they are encouraged to view the world, "alternatives" such as these are consistently relegated to the margins, condemned as risky, merely flaky. Adherents to evidence-based medicine rarely acknowledge that in privileging research based on numbers of patients in controlled trials, it too exposes a cultural preference which endorses entrenched stereotypes of gender, illness, health, and science, all carelessly essentialized. Patient-centred medicine, focussing on this patient, taking seriously her conjectures and causal hypotheses about her symptoms, has the potential to acknowledge and evaluate the background assumptions both patient and clinician bring to any interaction, and to examine the values implicit in their diagnoses and proposed treatments.

Returning more closely to the theme of today's session, I want to conclude with two thoughts: Evidence Based Medicine, I am suggesting, has had the strange effect of prising illness and vulnerability apart, redefining illness positivistically via a quantifiable "correspondence" reading of a collection of visible, quantifiable, scientifically diagnosable symptoms. It generates a politics of knowledge that fails to serve people well in the particularity of their suffering, while casting vulnerability off into the realm of the subjective, the unquantifiable, the messy - where women and other Others have always been, albeit with small exceptions and brief interruptions. As a thought experiment worthy of being more than just an experiment, I wonder how it would be if the autonomy obsession of the affluent western world, the perversion of autonomy, in Willard

Gaylin and Bruce Jennings's words (1996), were displaced from the central, all-encompassing position it has occupied in post-Kantian moral and political theory, and if vulnerability - vulnerabilities - were to claim the share of the analytic, epistemological, moral and care-giving attention that contortions around preserving an overblown autonomy ideal have claimed, to the peril of the vulnerable - of all of us. Something of this sort seems to have happened in the Hague trial decision, as Debra Bergoffen reads it; analogously, Susan Brison's narrative analyses call a society/political system/global order to account for holding open places for acts of violence against women, condoned by a social imaginary that sustains harsh, gender-inflected hierarchies of vulnerability and power. Thus hers is not just a claim for women's sexual autonomy and self-ownership. It is individual in insisting on the full particularity of each woman's "own" lived, embodied vulnerability, yet not starkly individualistic, for the case it presents amounts to a plea for a renewed acknowledgement of commonality, heterogeneity, and social responsibility.

Sexuality & Disability: Normative Anxiety and the Denial of Pleasure.

Margrit Shildrick.

The topic for the third paper in the series on vulnerability is focused on sexuality and disability and the way in which that conjunction generates normative anxiety which in turn results in a widespread societal silencing or denial of the sexual pleasure of people with disabilities. My point is not however to highlight any unique vulnerability of disability itself, but, as in the two previous papers to uncover the conditions, in this case the issue of sexuality, that cause such discomfort to the normative majority. I will argue that what is at stake is precisely the fragility, the vulnerability, of the standards by which the majority names its own embodiment as normal. In consequence, those bodies labeled as abnormal or anomalous, those which fall outside the standards of morphological acceptability, are disqualified from the full attributes of personhood, particularly with regard to issues of sexuality.

Let me start with an initial reflection on the conditions of vulnerability. When we think of vulnerable bodies in everyday parlance, what comes to mind are those who are sick or diseased, congenitally deformed or disabled, but also the young, the old, and certain conditions like pregnancy. And in some senses, of course, women are always seen as weak and vulnerable, because like the other categories I have mentioned, their bodies compromise western ideals of the embodied subject. The linking condition is often about being seen as dependent, particularly in the sense that the autonomy of the self is compromised. At the same time, the ideal standard demands that our bodies are whole and complete, that they are predictable, and certainly under our own control. So entrenched are the normative expectations of our society that any display of vulnerability makes us deeply uncomfortable. It is seen as a somewhat shameful condition in others, and something that most of us probably want to deny, or at very least avoid, in ourselves. For those who think they more or less approximate to the standards, who claim a certain invulnerability, there's a very real desire to keep any differences that transgress the norms at a distance, because they tend to make us anxious about ourselves.

My claim, then, is that in the west, all forms of aberrant embodiment, those that blatantly contest the discursive ideal of normative embodiment, are highly productive of anxiety, particularly insofar as they threaten to overflow the boundaries of 'the self's clean and proper body'. The specific fear, which I identified in my first paper as a socio-cultural and psychic fear of the monstrous (Shildrick 2002) - is that the putative lack of self-containment, and the failure to occupy a delimited space, signal the disturbing possibility of engulfment and contamination. The overtones of the Kristevan abject (1982) are fully intended, and as that analysis makes clear the issue is not that the body of the other is horrifying in and of itself (though it may be), but that it

will enter the space of my own body and effect the very transformations that would disturb my claim to autonomous selfhood. For all that our embodied subjectivity depends on a phenomenological interface with a world of others, there remains a clear perception of bodily limits and boundaries. In seeking to maintain the self-possession and control that the modernist ideal of embodiment demands, we continually make the distinctions, between self and other, and between categories of others, that mark out both psychic and cultural assessments of safety and danger. Given that no interaction is entirely without risk to our fragile sense of self, the relations between self and other operate largely within a scopic economy that privileges separation and self-sufficiency. The problem is that the breakdown in some bodies makes everyone question whether the capacities and boundaries of all bodies are as solid and secure as we would like to imagine.

We are all aware I think of the observation that western societies are inhibited about touch, and it is indeed when the safe distance of the scopic economy gives way to actual or anticipated physical contact that anxiety is heightened. To touch another is in some sense always to compromise control, to feel my sense of wholeness and self-sufficiency dissolve, for even where the intent is outward and aggressive, we are also touched in return. An undecidable moment of exchange occurs, a crossing of corporeal boundaries that unsettles the dimensions of the embodied self. In other words, the socio-cultural mores that overtly regulate physical contact intersect with the interiority of psychic investments. My point is not that all such exchanges are unwelcome, on the contrary, affective life in particular depends on the closeness of others, but that they are openings which inevitably involve risk. To minimize that risk, we are wary of physical contact in general, and have well-developed strategies of avoidance when faced not only with the overtly dangerous, but also with the unknown or unpredictable. In particular, the implicit anxiety that characterizes any corporeal interaction is condensed and projected outward on to those others whose bodily disconformity unsettles the ideal of embodied selfhood. It is a short step to realizing that sexuality, which necessarily closes down the interval between self and other is already fraught with risk, and that sexuality in association with bodily anomaly is especially disturbing.

The varied possible responses to such anxiety all have grave consequences for the sexual well-being of people with disabilities. First there may be an exercise of normative power cloaked as benign concern or even protection which operates under the rubric of acting in the best interests of the other. It may manifest in the paternalistic control and regulation of the sexual possibilities of disabled people, whereby issues such as adequate sexual education and information are limited, privacy is denied, and social relationships are closely monitored. Far from being seen as a fundamental facet of the embodied self, sexuality in the context of disability is often viewed as a problem to be managed and is both explicitly and implicitly discouraged. For young people growing up in institutions, or in closely controlled parental care, the restrictions can stifle sexual

development and leave them unaware of both the pleasures and dangers of sex. Several recent studies for example have shown that people with disabilities are at much higher risk of contracting sexually transmitted infections, including AIDS, possibly because of a low awareness and take-up of safe-sex practices.

The intrusive surveillance of sexual activity experienced by people with disabilities should remind us of Foucault's analytic of the operation of normative power through a system of disciplinary measures and regulatory controls aimed at the body (Foucault 1977, 1979). Although no-one, however they are embodied, escapes the various discourses that construct and regulate sexuality, many people with personal experience of disability implicitly assent to systems bounded by generalized categories and highly normative expectations. In particular, those both in institutions, and sheltered housing, or living at home often experience sexual monitoring as a way of life. Sexual expression or relationships, particularly non-normative ones, may not just be discouraged, but materially obstructed. Indeed, the normative attitudes of helpers are often highly repressive. As Valios notes,

A not uncommon scenario....is disabled men being threatened with the removal of home care because staff found pornographic magazines and videos. (2001: 20)

Similarly, a friend working at a well-respected care home with supposedly independent bungalows told me, for example, that staff were routinely expected to report any suspicions of overnight visitors. Part of the problem, identified by the feminist disability scholar Jenny Morris (1995), is that many helpers tend to see their task as one of care and control, rather than of assistance.

The issue of controlling sexuality is far more complex than my brief reference indicates, and although I do not want to deny that there are circumstances in which external protection may be justified, I would nevertheless argue that control is more about protecting the authoritative figure from their own unease than promoting the well-being of the disabled person. Alongside the impetus to 'protect' differently embodied others, an equally familiar response is to enact real violence, including sexual violence, against them. All those who are seen as vulnerable, babies and children, older people, and of course women, especially those who are pregnant where levels of assault are three times as high as for other women, all are subject to everyday abuse and violence perpetrated not by strangers, but particularly by those in caring roles.

Precisely the same is true of disability, where disabled people of both sexes suffer higher than usual levels of sexual abuse. At its worst, the resultant relative ignorance of sexuality can leave people with disabilities vulnerable to sexual abuse which, despite the desire of progressive disability activists to emphasize the positive pleasures of sexuality, is so prevalent that it cannot

be ignored. The incidence of abuse seems particularly high in institutional care where power inequalities are at their strongest. Margaret Kennedy (1996: 127) for example claims it is up to four times higher than in the general population, with women again being most at risk. The few surveys done indicate that an exceptionally high proportion of adult women with disabilities have experienced abuse at some point in their lives, most usually by sexual partners, family members, or statutory carers. Tom Shakespeare (1996) gives a figure of 48% (and claims that men experience similar levels of abuse). Margaret Nosek's far more extensive study, however, found that sexual abuse was fairly evenly between disabled and able-bodied groups of women, but she adds:

Women with disabilities tended to experience abuse for longer periods of time, reflecting the reduced number of escape options open to them due to more severe economic dependence, the need for assistance with personal care, environmental barriers, and social isolation. (Nosek et al. 2001: 27)

The responses of either violence or control are perhaps both less likely, however, than the equally damaging voyeurism directed to disability and sexuality, or on the other hand, the failure to acknowledge the sexuality of disabled people at all. Although the experience of disability covers a huge range of differences with anything from a profound physical affect on sexuality to virtually none at all, the overall tendency in the latter response is to silence the idea of sexuality altogether, especially any recognition of desire. And I should perhaps note in view of the sponsorship of today's event, that although feminism has insisted on the importance of embodiment and explored sexuality in increasingly sophisticated ways, disability has not generally been one of the differences that count. A comprehensive collection of articles on feminism and sexuality edited by Stevi Jackson and Sue Scott (1996), for example, makes no mention of disability. Even more surprisingly, Lennard Davis' *Disability Studies Reader* (1997) is scarcely less silent on the subject of sexuality, unless linked to reproduction. The real danger is to start thinking that the silence or negativity of the imagery simply reflects the facts of life for disabled people. Even those working within feminist theories of the body which have promoted an acute awareness of the social construction of gender, class or race bias, may regard the sexuality of people with disabilities as an unchanging unnatural condition, rather than as yet another discursive construction.

Within disability activism, too, the problematic of sexuality has often been lost by the overriding claims of advocates of the social model of disability that what is disabling is not so much the physical limitations or impairments of individual bodies, as contingent obstacles set up by an uncomprehending society that insists on operating within narrowly defined normative standards of physical well-being. The approach is very plausible and has undoubtedly made a difference to social policy, but it fails to offer a convincing explanatory model that both attends to the particularity of bodily experience, the phenomenology of disability, in which personhood exists

only as an element of embodied being, and to the feelings of anxiety, even disgust, that anomalous bodies invoke. There is no sense that what is at stake in differential embodiment is far more complex than society's ineptitude in catering adequately to a range of physical differences.

Now, we shouldn't suppose that silence is neutral. As Foucault notes:

Silence itself, the things one declines to say or is forbidden to name, the discretion that is required between different speakers, is less the absolute limit of discourse...than an element that functions alongside the things said...(silences) are an integral part of the strategies that underlie and permeate discourses. (1979: 27)

This is highly significant in view of Foucault's parallel claim that sexuality is regarded as the prime site in which identity is discursively inscribed, as he puts it 'the privileged place where our deepest truth is read and expressed' (1988: 110). In other words, sexuality isn't simply a potentially pleasurable bonus, but the very heart of self-becoming. And as Foucault understands it, both the highly negative attributes attached to the sexuality of disabled people, and the silencing itself are constitutive of personal identity. What we must understand then, is that to strip away the significance of sexuality, both as a practice and in terms of pleasure and desire, is to do damage to the very notion of human becoming.

The extent of the power to silence that operates under the dominant normative discourse is made particularly clear in the light of recent research which is beginning to uncover precisely what has been hitherto disavowed. One influential large scale empirical study conducted by Margaret Nosek (2001) and her colleagues found that the lifetime experience of sexual relationships of disabled and non-disabled women showed little variation, and that although the percentage of disabled women in a relationship at any given time and their levels of sexual satisfaction were lower, there was no difference at all between the groups in terms of sexual desire. But of course, it is precisely the concept of desire that is likely to be silenced, even where functional sex may be recognized and tolerated under the rubric of need, signs of pleasure and desire are still considered improper, even perverted. As Robert Murphy notes, disabled people are seen as 'either malignantly sexual, like libidinous dwarfs, or more commonly, completely asexual' (1987: 83).

I'm not going to talk here about the controversies surrounding facilitated sex, but I would suggest that part of the difficulty of it being accepted as an option available to people with disabilities relates not simply to the cultural urge to disregard disabled sexuality in general, but more specifically to both the idea that desire might be involved, and entails intimate contact with the fluidity of other bodies. The potential undermining of what are considered appropriate gender roles, in particular, of the notion of masculine sexual self-sufficiency that facilitated sex entails, is

deeply disturbing to the cultural imaginary. I do, however, want to pick up on how gender difference feeds into the question of disability and sexuality more generally. As Russell Shuttleworth notes, disabled women's sexuality has been disproportionately disavowed:

(the) obsession with sexual and reproductive function ... seems part of a larger cultural anxiety that views any lessening of penile potency as a diminishment of masculinity....(The) early research largely ignored women, and completely ignored racial and sexual minorities, reflecting that white, heterosexual masculinity was prioritized. (www.nsrc.sfsu.edu)

Until recently, that silencing in the context of women has reflected the cultural stereotype that sexuality is of greater importance for men than women. Research and discussion have been heavily skewed towards the male experience, with particular emphasis, not on the capacity for sexual feelings or even activity, but on the putative loss of self-directed independence. In contrast, even within disability politics, the 'tragedy' of disability for a woman has been not the assumed effect on sexual identity or activity, but on her ability to become a mother, the presumed goal of all 'real' women. As a result, disabled women can feel literally desexed, as one female polio survivor quoted by Nosek puts it: 'I always felt like a neutral sex. It's like I'm not a woman, not a man. I don't know what I am because I was never approached like a woman' (Nosek et al 2001: 5). Nonetheless, in recent work, many disabled women, often supported by feminist ideals, have challenged the conventions. Rosemarie Garland Thomson, for example, has usefully identified the disabled woman as 'a cultural third term':

Seen as the opposite of the masculine figure, but also imagined as the antithesis of the normal woman, the figure of the disabled female is thus ambiguously positioned both inside and outside the category of woman. (29)

And others have sought to undermine the rigidity of sexual normativities. If full physical autonomy is impossible because of morphological difference, then one way forward is to rethink sexuality outside the convention of male dominant heterosexuality. The result is an opening up of sexuality that disrupts gendered expectations, and deconstructs the primacy of genital contact to explore a range of alternative sexual pleasures like touch and fantasy. For gays and lesbians with disabilities, this may be no great change, but for more conservative heterosexual men and women, it may partially ground what many theorists see as the queering of disability. In other words, the conjunction of disability and sexuality has the potential to shine a critical light on the organization of normative sexuality, to highlight its exclusions and excesses.

I want now to turn to the specific intercorporeality of the sexual relation in order to explore further the material and discursive devaluation of corporeal difference that cannot be encompassed within the normative parameters of sexuality. Given that any tactile relation is a

potential point of disturbance to the normativities of everyday life, sexuality, as I have indicated, especially invokes uncertainty and risk. The intentional exchanges of penetrative sex are merely the most overt instances of what is in essence a corporeal modification; every instantiation of erotic touch breaches the boundaries of embodied being. In consequence, sexuality is paradigmatically a site that invokes feelings of vulnerability, feelings that be either positive or negative. The bodily exchanges are never merely contingent, but the very basis of an engagement figured as both pleasurable and dangerous. And it is precisely because of such ambivalence, that the sexual relation is also bound by an imposing set of regulatory practices and normative values which seek to mitigate the potential instabilities and vulnerabilities of the encounter. Desire is constrained by a broad disinclination to engage in any sexually coded corporeal exchange unless there is already some knowledge of the nature of the participants. Now, I don't think this is simply a matter of rational prudence, but a less explicable feeling of aversion against bodily contact with the strange or the stranger. In addition to those whom we do not yet know, they are, I suggest, all those considered intrinsically unknowable in the sense that they are positioned outside the norms that govern what can be grasped and controlled: in other words, those marked by difference, corporeal and otherwise.

In her essay 'Intolerable Ambiguity', Liz Grosz briefly questions why those who are labeled freaks are both so fascinating and repulsive to society at large. So what exactly does the term imply? Grosz offers the following definition:

The freak is an ambiguous being whose existence imperils categories and oppositions dominant in social life. Freaks are those human beings who exist outside and in defiance of the structure of binary oppositions that govern our basic concepts and modes of self-definition. (1991: 57)

Freaks then transgress the limits of clean and proper embodiment in which body boundaries are assumed to be closed and impermeable, but their challenge is directed to the normative body itself. The anxiety is not that those others are 'out there', but that faith in the integrity and impermeability of normative bodies is put in doubt. Taking the case of conjoined embodiment, Siamese twins, she suggests that interest is motivated primarily by the age-old sexual question of how do they do it.

Now I think Grosz is unjustifiably reductive: it is not simply a matter of sexual performance as such, but of the performativity of the self through gender identification, the naturalization of sexual preference, and ultimately sexuality as the truth of the self, in Foucault's sense. In normatively embodied sexuality, a combination of medical, social and juridical discourses constitute and regulate its 'proper' expression, but where morphology itself frustrates the performance of normative certainties, sexuality is potentially more open and, at the same time

more troubling. The uncertainty of all modes of embodied being are exposed (Shildrick 2002). Contrary to Grosz, my claim, then, is that a concern with the sexuality of those with aberrant bodies is not simply prurient, though that may be the overt motivation; rather it masks an anxiety about questions of identity, bodily integrity, and even autonomous agency. The enormous popularity of freak shows in the nineteenth and twentieth centuries, which build on venerable traditions of publicly displaying monsters and re-emerge in the present via the medium of 'educational' documentaries, has often been concerned with the sexual, but the issues raised speak to the ontological vulnerability of the viewer as much as to the putative difference of the objects of perception. In any case as Susan Steward observes:

It is the imaginary relation, not the real one, that we seek in the spectacle (1993: 111)

We can see such issues play out in many everyday encounters with disability and sexuality, but I want now to focus on the limit case of conjoined twins, precisely because the extremity of the condition casts further light on why the image of disability and sexuality causes such discomfort and denial. Moreover it picks up some of the gender complications that are always threaded through the problematic insofar as masculinity and femininity are always in a different relation to sexuality. I am going to show just a couple of images here to contextualize the discussion, but I am acutely aware that to show the anomalous corporeality in this way always skirts on the edge of voyeurism. Just as the term 'freak' is freighted with negative connotations which must be constantly challenged and undone, so the same is true of the deployment of visual imagery. Whatever our analysis, none of us is transparent in our motivation. Nonetheless, while voyeurism thrives on a lack of (self)-recognition reducing the focus of the gaze to merely an object of curiosity, a more reflexive engagement will provoke just those questions that I want to ask of the ambivalent nature of the encounter with the bodily anomaly. We must keep asking: what exactly is it that we are looking for?

So here are the most famous pair of conjoined twins, Chang and Eng Bunker, the original 'Siamese twins', who frequently appeared in the freak shows of nineteenth century US and Europe. As in this studio portrait from their maturity, carefully managed images discreetly show their short conjoining ligament. As the twins entered sexual maturity, their orderly appearance, personal attractiveness, and heterosexual appeal were stressed to construct them as quasi-normative figures. Nonetheless, despite the attempts to normalize their *corporeal* image, an unresolved tension erupts in that their radical otherness, the self that is neither one nor two, remains always a site of discursive disorder. The clean and proper body so carefully constituted in popular discourse is undone by its own irreducible excess which becomes all the more apparent in the ultimately confused representation of the twins' sexuality.

Although promoted as eligible, albeit somewhat exotic, young men, their own expression of sexual

desire caused consternation. So long as they remained detached objects of the gaze, all was well, but once the twins wanted to *marry*, to enter into heteronormativity, the intriguing sexual narrative constructed around them took on a distinctly disruptive meaning. Not only did they share a phenomenology of affect and desire, the brothers were already effectively positioned in a life long (auto) union. The doubleness of the putative groom disrupted the prospect of marriage not simply with regard to the impossibility of enacting a legal contract as a singular subject, but in terms of putative bigamy or adultery on the part of both the twins and their brides. And not only was monogamy at stake, but given that one brother might experience vicarious desire through the body of the other, the hint of both homosexuality and even incest. In the event, Chang and Eng did marry two sisters, yet despite each fathering many children, and a life of bourgeois respectability, they never fully escaped the label of freaks. The tensions and ambiguities that they embodied, and the combination of fascination and repulsion which they attracted, mark them as highly disruptive. They remained neither inside nor outside existential and socio-political norms, but always transgressive of the very stability of sexual normativity.

Such anxiety-provoking disruptions equally mark the lives of Daisy and Violet Hilton, who were also conjoined in a relatively simple way that encouraged the illusion that their bodies were self complete, with nothing overtly anomalous about their initial appearance. By the mid 1930s, the Hiltons had moved from vaudeville to become Hollywood stars, but what interests us now are not their accomplishments as paid performers, but their performativity of a normative femininity. Throughout their well-documented career, the twins were constructed as the epitome of feminine desirability, framed at a safe distance from their viewing public, as two sexually alluring women, often posed in the embrace of handsome young men. But does their performativity conceal a different truth? Certainly their sexual identities as normative women are fissured by the congenital specificity of their embodiment, but like all of us, Daisy and Violet both conceal and reveal not fixed truths, but a series of ambiguous and even contradictory constitutions of self-becoming. As Butler (1990) points out, the performativity of the self, in which the operation of sex/gender is central, is not an unconstrained process, but one exposes the inescapable mechanics of normativity. In any case, the Hiltons deliberately blurred life and art, where in both the irreducible excess to their display of normative femininity, their conjoined status, was not simply a negative counter-identity, but was constituted precisely as part of their sexual intrigue.

Their best known film, Todd Browning's *Freaks* (1932), makes the point. Although the film's preamble insists on the emotional normality of freaks, the narrative plays on a sexual voyeurism directly linked to their radical disability. The tension of an excessive and ambiguous display of feminine sexuality is clearly evident in one scene where the supposed privacy and contractual privilege of the marriage union is undermined when the 'unmarried' twin mocks the impotence of the husband who cannot hope to control the doubled female body. It epitomizes a moment of the

cultural anxiety that always attends the failure to maintain a proper relationship between the sexes, whether in performance or performativity. A later Hilton film, *Chained for Life* (1951), which places the issue of incorporation centre-stage explicitly exposes the limits of normative femininity. The film publicity is completely upfront about the prurient appeal, 'Joined together, how can they make love to separate husbands?', and indeed in the plot, the promise of love gives way to murder.

In their own lives too, the sister's sexuality was at stake, for though each was portrayed as romantically involved, as with Chang and Eng, the titillating fantasy turned sour in the face of apparently real desire. Daisy's wish to marry was considered scandalous and she was refused a license in 20 different States on various grounds including public decency, the fact that 'answers to the usual routine questions were in the plural', and unspecified moral concerns. Both sisters did eventually marry, but the events were regarded as publicity stunts, and each ended in annulment. Unlike the Chang and Eng who achieved a high degree of normalization, the Hiltons' bodily contestation of socio-legal mores disqualified any regularization of their sexual identities. The destabilization of 'proper' sexuality is one shared by all conjoined twins, but perhaps what made Daisy and Violet unacceptably transgressive was their exploitation of the gap between the highly successful performativity of femininity and their radical disability. Their putative desire was both a matter for a distancing public gaze and that which must be forbidden. As such it was rendered irrecoverable. And interestingly not much has changed since the 1930s. A 1990s Broadway production, *Side Show*, based on the Hilton's life was highly praised critically, but failed to attract audiences. As one reviewer put it:

Broadway audiences were simply unwilling to see a musical about a subject they considered distasteful, that a kind of mass squeamishness overrode all the old barometers of good reviews.. (*NYTimes* 04.01.1998).

And we might also speculate that the difficulties faced by the Hilton's reflect not only their own transgressive embodiment, but an existing fear of female sexuality that makes their expression of desire all the more threatening.

Why should the anomalous body as sexual remain broadly unacceptable? I have already invoked the Kristevan concept of the abject, which posits one psychic explanation, and I want now to briefly mark the psycho-cultural significance of the Lacanian view of the infant body. As Lacan (1977) makes clear in his seminal paper 'The Mirror Stage' the coherent sexed and gendered subject emerges only as the inherent dis-integration of the infant is covered over. Moreover, the undifferentiated maternal-infant dyad is an originary relation lacking in boundaries, a state for the infant of 'motor incapacity and nursling dependency'. That fragmented body must be denied, and the mirror stage heralds instead the emergence of the embodied self as a seemingly closed

identity reliant on the clearly defined limits of a fully integrated body that is distinct from others. What matters is that self and other are both whole and separate, held apart by a scopie drive that overrides the originary phenomenological connection. In short, the unity and order of embodiment in the symbolic entails a high degree of repression that entails a life-long repudiation of all elements of non-identity, including the maternal figure herself, concorporeality more generally, and those forms of embodiment that recall the disavowed ‘corps morcélé’, the body in bits and pieces.

It is in these fragments that we can see the significance of the psycho-social aversion to disabled bodies in general, and to the interface of sexuality and disability more specifically. As all psychoanalytic theory indicates, the unity of the embodied self remains always precarious, an illusion of singular wholeness and self-sufficiency that is deeply threatened by the memories of disorder and dependency evoked by the disabled body. The fear of indifferenciation becomes a wariness about intercorporeality that is at its most acute in relation to the sexuality of people with disabilities.

So does the deployment of theory shed light on an ethics of disability? If we agree with Foucault, then sexuality is an intrinsic component of self-becoming, then to delegitimize it or deny its significance is to do grave damage the very notion of personhood. Within the modernist model of the putative autonomy for self and other, sexuality may generate rights-based equality claims, but that appeal to the normative order cannot account for the psychic significances of irreducible differences in embodiment. If, however, we accept that sexuality is never simply a material reality but a complex and fluid mix of corporeal, psychic, and social components, then what matters is not just a more nuanced understanding of the operation of normative constructions of sexuality, but of the reasons for their emergence. Only in recognizing that sexual relationality devolves on constituted meanings that always entail anxiety, specifically the anxiety of a disavowed vulnerability, can the way be opened to moves that encompass all those with anomalous bodies.

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