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7.3

BREAKING THE BOUNDARIES OF THE BROKEN BODY

Margrit Shildrick and Janet Price

Theories of postmodernism and the tool of deconstruction are not often associated with the kinds of substantive issues with which an everyday living feminism concerns itself. They may be fine – though never less than controversial – for laying bare the construction of knowledge, or for posing new theorisations of the subject, but it is less obviously clear how they might contribute to an issue-based feminist politics, such as might surround women’s health. What we intend to talk about in this article is, nonetheless, just one such area. Our topic is disability; and we want simultaneously to hold in mind the experience of disability as an experience of a supposedly ‘broken’ body, and disability as precisely one of those transgressive categories that demands that we rethink not simply the boundaries of the body, but equally those between sameness and difference, and indeed self and other. We want to bring together some hard practical concerns with the (con)textual interplay of postmodernism; to show, as Eve Kosofsky Sedgwick says of her own experience of cancer, how ‘deconstruction can offer crucial resources of thought for survival under duress . . .’ (1994: 12). [. . .] And where postmodernism can come to the aid of a feminism attempting to end its own past indifference is in two ways: first in deconstructing all and every identity, and second in laying bare the ways in which the body itself is constructed and maintained as disabled.

It is not that we think there is no distinction to be made between those women who experience themselves as disabled, and others who are able-bodied, but that, from a postmodern perspective, those are always provisional and insecure categories which can never be entirely separate. What we are contesting are the fixed dichotomies – of health/illness, able-bodied/disabled, whole/broken, them and us, and so on – that constitute the very ground of our embodied selves. Indeed, it is through appeal to those hierarchical and apparently stable binaries that we are able to maintain a sense of definition, of the boundaries between sameness and difference, and thus of safety, bodily integrity and (self)identity. Tom Shakespeare identifies the problem as one of the privileged term of the binary: ‘. . . it is not us it is non-disabled people’s embodiment which is the issue; disabled people remind non-disabled people of their own vulnerability’ (Shakespeare 1994: 297). Nevertheless, it is our contention, that although the exclusionary/othering process is usually seen as the prerogative of the dominant, the ‘able-bodied’, the same move is made in reverse in radical disability politics. As we shall show, the boundaries of what constitutes disabled identity is policed every bit as strongly against its others.

[. . .] DISCIPLINARY PRACTICES

Following Foucault’s problematisation of the human body and of the epistemology surrounding it, we may see the body not as the point of departure for a bio-psycho-social science of health and illness, but as the very locus of knowledge production. Foucault’s concern is with medicine as a disciplinary regime through which the embodied subject is inscribed and brought into being, and with the circulation of power/knowledge as the indivisible condition of discourse. In other words, notions of health, of physical ability, are not absolutes, nor pre-given qualities of the human body, but function both as norms and as practices of regulation and control that produce the bodies they govern.

[. . .] While we would agree that Foucault’s analysis is flawed by his gender omissions, his deconstructive approach to the episteme of the body and to power is a stepping stone of great significance to a specifically feminist contestation of the politics of disability. It should not be forgotten, of course, that while the body is always marked by gender, it is crossed too and mediated by a variety of other categories such as class, ethnicity, sexual preference and indeed (dis)ability which may both bind and separate women and men. Above all power circulates in the procedures of normalisation by which on the one hand the body is inscribed with meaning (the intelligible body) and on the other rendered manageable (the useful manipulable body) (Foucault 1977: 136). Together these two modes constitute the docile body which ‘may be subjected, used, transformed, and improved’ (Foucault 1977: 136). Insertion of bodies into systems of utility – be they at the service of capitalism or patriarchy – devolves on forms of power that are localised over the singular body, and that rely not on brute force but on quasi-voluntary acquiescence. The disciplinary and regulatory techniques practised on the body exemplify the productive nature of power in that they not only set up systems of
control, but call forth new desires and institute new normativities. In this, medical science is exemplary in that it constitutes the individual in terms of a series of norms, while at the same time inviting the subject to produce truths about herself. It is not simply that 'the female body became a medical object par excellence' (Foucault 1988: 115), but that the external gaze is complemented by a complex mesh of techniques of self-surveillance and confession.

Though the clinical encounter is a paradigmatic site for the technologies of the body which both shape and control, in the modern welfare state the effects of healthcare as a disciplinary regime can extend to other most private and personal aspects of life. The demand to know intimate details about the individual is a common feature of state bureaucracy, but is nowhere more apparent than in the transaction between the welfare claimant and the multifarious over-seeing benefit agencies. In recent years, the trend in Great Britain has been towards various forms of self-certification to replace in-person interview and examination; but, far from liberating the claimant from an authoritarian and intrusive situation, the locus of power/knowledge has merely shifted to equally or additionally onerous forms of surveillance. The gaze now cast over the subject body is that of the subject herself. What is demanded of her is that she should police her own body, and report in intricate detail its failure to meet standards of normalcy; that she should render herself in effect transparent. At the same time, the capillary processes of power reach ever deeper into the body, multiplying the norms of function/dysfunction. As with confession, everything must be told, not by coercive extraction, but 'freely' offered up to scrutiny. The subject is made responsible, and thus all the more cautious and manageable, for her own success in obtaining state benefit. And, should benefit be withheld, then it may be attributed to a failure of reportage as much as to a denying external agency.

These particular modes of disciplinary practice are exemplified with great clarity in the procedures surrounding the benefit currently known as Disability Living Allowance (hereafter DLA). As a benefit directed towards a state of being that affects both men and women of all ages, classes, sexualities, ethnic groups and so on, DLA might seem to illustrate the general operation of power/knowledge in and over the body without specific relevance to gender. We have chosen it as an example, however, precisely because of the way in which disability imbricates conceptually with the wider issue of the existential disablement of the female body in western society. Our concern is not simply that female bodies are the privileged target of disciplinary practices, but also that state-defined disability mirrors the phenomenological experience of women generally. Given that all women are positioned in relation to and measured against an inaccessible body ideal, in part determined by a universalised male body, the experience of female disablement as such may be seen as the further marginalisation of the already marginal. Where all women’s experience of their corporeal integrity is generally under threat or inadequately addressed (Young 1990), then those who are additionally defined as disabled may find their bodily experience even more likely to be invalidated (Wendell 1992). In relation then to the ‘whole’ body of phenomenology, women with disabilities may be seen as doubly dis-abled.

None of this is to imply any pre-existing strategy to position ‘empirical’ disability as a peculiarly feminine condition, and, indeed, male claimants of DLA are subjected for the most part to the same extraordinary procedures as female ones. Nonetheless, insofar as the category of disability is constructed through such practices, it is – and this is a point we would want to make about broken bodies in general – as a condition that is en-gendered as feminine in terms of its implied dependency and passivity. Bearing in mind that the docile bodies produced by disciplinary techniques are an effect in every instance of power/knowledge, what is additionally striking about the shifting and heterogeneous set of conditions named as disability is that in its construction the disciplinary process is laid bare. And, moreover, that heterogeneity, paradigmatically exemplified by the multiple states that fall into the diagnosis ME, is itself masked in the production of a regulatory category that operates as a homogeneous entity – disability – within the social body. Despite the emphasis given to what appear to be very singular determinations of a state of disability, it is in the very gestures of differentiation and individuation – as exemplified by the innumerable subdivisions of the questions posed on the DLA form – that the claimant is inserted into patterns of normalisation which grossly restrict individuality. Ultimately, what the technologies of the body effect, while appearing to incite the singular, is a set of co-ordinated and managed differences.

For the specific benefit of DLA, intended for those who need help with ‘personal care’ or ‘getting around’, self-assessment plays a particularly large part in the claims procedure. Nonetheless, the limits of reliability of non-authoritative discourse are marked in that the subject’s own report must be supplemented by statements from two other people who will be most usually health care professionals. In other words, the gaze is multi-perspectival. What is remarkable about the claims pack (Benefits Agency, 1993) sent to potential claimants is its sheer volume, in which four pages of initial notes are followed by 28 pages of report, the vast majority of which consists of a detailed self-analysis of personal behaviour. The introductory instructions are quite clear about what is expected from claimant self-surveillance: ‘(t)he more you can tell us, the easier it is for us to get a clear picture of the type of help you need’ (Section 2:1); and they suggest: ‘keep a record for a day or two of how your illness or disability affects you’ (Section 2, 1).

In focusing on singular behaviour, the state sponsored model of disability promotes individual failing above any attention to environmental and social factors. The DLA pack rigidly constructs and controls the definitional parameters of what constitutes disability in such a way that those who need to place themselves within that definition are obliged to take personal responsibility in turning a critical gaze upon their own bodies. The claimant is constrained to answer questions not just on her general capacity to successfully negotiate the everyday processes of washing, dressing, cooking and so on, but on the
minutiae of functional capacity at every differential stage, and moreover at differential frequencies. The implication of such a demand is that disability is a fixed and unchanging state which pre-exists its observation. In contradistinction, our point is that not only is disability a fluid set of conditions but that the body itself is always in process. Yet again, ME specifically contests the possibility of predictable performance. A single page (see Figure 1) illustrates the extraordinary complexity and detail in which the claimant is expected to freely confess to her own bodily inadequacy. The questions for each discrete function follow a similar format and many, like those on toilet needs, are duplicated to establish night-time behaviour as well. What this amounts to is an astounding display of power/knowledge and of the capacity to proliferate discourse in accordance with Foucault's dictum: 'the exercise of power creates and causes to emerge new objects of knowledge and accumulates new bodies of information' (1980: 51). No area of bodily functioning escapes the requirement of total visibility, and further, the ever more detailed subdivision of bodily behaviour into a set of discontinuous functions speaks to a fetishistic fragmentation of the embodied person.

In the absence of any sufficient justification that could arise from the declared intentions of the welfare process itself -- to provide financial help with personal care or getting around -- one must assume that the extent of the benefit agency's 'need' to know is indeed an expression of the power/knowledge complex that underwrites the modern social body. In the section on cooking a main meal, for example, the claimant is asked to distinguish between the inability to use a cooker and the inability to cope with hot pans (DLA 580: 16); while in the toilet needs section, women are subjected to a supplementary gaze that requires them to report on their difficulties around menstruation: 'Tell us as much as you can ...' (DLA 580: 12). The welfare claimant is controlled not by a display of external coercion but by continuous surveillance and by the insistent demand for a personal accounting that fits the rigidly constructed parameters of disability. The subject herself effects a normalising judgment on her own modes of being by submitting to what Foucault calls a power that 'produces domains of objects and rituals of truth' (1977: 194). Moreover, she acts not as a pre-existent bounded being, but constructs her very selfhood in the process of normalisation. In terms of the DLA claim form, she produces herself as a disabled subject. What this display of the productivity of power signals is how control of the social body is effected through disciplinary technologies targeted on the individual body.

Where Foucault was concerned primarily to deconstruct the power relations between the singular, but universalised, body and a series of institutional forms -- the prison, the clinic, the school -- and to expose the symbiotic links between the individual disciplinary practices and the manipulation of population, feminists have been constrained to emphasise that disciplinary economies are gendered. The interplay of power and knowledge produces difference in just such a way that the bodies of women are the ground on which male hegemony and, at least in part, the power of the state in the service of capitalism are elaborated. For all of us, the polymorphous forms of domination to which we are subjected are frequently masked so as to appear freely chosen, that is,
expressive of personal desire or consented to as necessary for individual or social good. What is not always apparent is that those goods and desires circulate within a system of normativities which, although never inevitable, imposes nonetheless a powerful urge to behave in certain ways, to mark out the boundaries of the proper. Indeed, the efficacy of disciplinary practices may be greatest when they appear not as external demands on the individual but as self-generated and self-policing behaviours. These internalised procedures constitute what Foucault calls the technologies of the self. In other words, the objectifying gaze of the human sciences, which fragments and divides the body against itself, has its counterpart in a personal in-sight, which equally finds the body untrustworthy and in need of governance. Moreover, each form of surveillance incites the other, and renders its subjects wholly transparent.

While it is clear that diverse groups of women, including those classed officially as disabled, are marginalised by many operations, like slimming and keep fit, which are directed at 'whole' bodies, the point remains that all women are positioned vis-à-vis an inaccessible body ideal. The reiteration of the technologies of power speak to a body that remains always in a state of pre-resolution, whose boundaries are never secured. Indeed, repetition indicates its own necessary failure to establish any stable body, let alone an ideal one. In the phallocentric order, the female body, whether disabled or not, can never finally answer to the discursive requirements of femininity but remains caught in an endless cycle of bodily fetishisation. In other words, it is a body that always exceeds control.

What we would suggest is that it is precisely that which escapes femininity, the embodied but gender resistant female subject, which provides the moment of contestation. The claim is not that the bodies of women are ever outside the relations of power/knowledge, but that there is potential slippage between what is possible for them and what is required of them by even the most adaptive patriarchal state. Just as disciplinary power incites certain practices in which external expectations are internalised in forms of self-surveillance, so too, those same practices may ground resistance. One example might be the way in which wheelchair athletes subvert expectations of weakness by consistently outperforming non-disabled runners in marathon races.

Given, then, that the construction and quasi-stabilisation of the disabled body is achieved through the continual procedures of both internal and external disciplinary power, might that indicate how a resistant feminism could respond? Foucault’s insistence on the absolute interconnectedness of power and resistance – (t)here is no power without potential refusal or revolt’ (1988: 84) – indicates the disabled body is never simply passive. But is the struggle ever a successful one, or rather what would constitute success amid the relentless relations of power? As an individual with ME, I do not understand our analysis of DLA as a ‘personally liberatory experience’ but as resistance which ‘continually seeks to uncover the constitute mechanisms of truth and knowledge as they construct and position the individual within social and scientific fields’ (Shildrick 1997). Foucault himself speaks always of local and discontinuous points of resistance, and recommends the recovery of ‘disqualified, illegitimate knowledges’ (1980: 83). Perhaps, for feminists and for those others concerned with disability politics, that might point to the obscured histories of bodies. If we can demonstrate that what has been naturalised as the truth of the body is merely the discontinuous outcome of a complex series of normalisations, in which health care has been pre-eminently implicated, then it becomes possible to dissolve devalued identities and theorise new constructions of embodiment. In contesting the universal signification of the living body our aim should be to acknowledge the plurality of possible constructions and the multiple differences which exceed imposed normativities.

For all that, however, final self-identity eludes the embodied self, for the boundaries which organise us into definable categories are in any case discursively unstable, such that constant reiteration is needed to secure them. Just as we perform our sexed and gendered identities, and must constantly police the boundaries between sameness and difference, so too the ‘purity’ of the ‘healthy’ body must be actively maintained and protected against its contaminated others – disease, disability, lack of control, material and ontological breakdown. As Diana Fuss puts it:

Deconstruction dislocates the understanding of identity as self-presence and offers, instead, a view of identity as difference. To the extent that identity always contains the specter of non-identity within it, the subject [and we would stress here the embodied subject] is always divided and identity is always purchased at the price of exclusion of the Other, the repression or repudiation of non-identity. (1989: 102-3)

In a reworking of the separation of self and other, there can be no understanding of, for example, able-bodied, unless there is already an implicit distinction being made that to be able-bodied is not to be disabled. Yet because able-bodied carries within it the trace of the other – a trace which must be continually suppressed if able-bodied is to carry a delimited meaning – such closure is not possible. To deconstruct binary difference, then, to point up all those oppositional categories which begin to undo themselves at the very moment of defining identity through exclusion, disrupts both ontological and corporeal security. In other words, the specter of the other always already haunts the selfsame: it is the empty wheelchair that generates dis-ease in the fully mobile.

Though the disability movement has both challenged and reconceived the relationship between able-bodied and disabled, its flirtation with identity politics precludes any understanding of how those categories are complicit with one another, and of how each might be radically destabilised. Interestingly, however, one strategy recently advocated in disablement politics is to push the ‘healthy’ majority to a recognition that they are merely temporarily able bodies (TABs). Although that is intended to mark no more than the material precariousness of health, the notion can be extended to provide just that thorough-going critique of health/ill-health, able-bodied/disabled that a poststructuralist
The regulatory and disciplinary regimes which impose and maintain normative standards of bodily and mental well-being are necessary precisely because of the inherent leakage and instability of those categories, because the spectre of the other lurks within the selfsame.

A radical politics of disability, then, might disrupt the compulsory character of the norms of abled and disabled, not by pluralising the conditions of disability, as the notion of TABs intends, but rather by exposing the failure of those norms to ever fully contain or express their ideal standards (Butler 1993: 237). And it should be stressed that while disabled and ill people—their bodies are deemed as broken—are labelled as other, they do not escape the regulatory apparatus of norms, but are forced to negotiate a set complementary to those of able-bodiedness. In illness and disability, what can be called performative acts—that is the corporeal signs, gestures, claims and desires elicited in embodied subjects—serve no less to produce effects of identity, coherence, control and normativity.

But the very need for the reiteration of the regulatory process, through which the materialisation of bodies is compelled, simultaneously destabilises the body, revealing that which exceeds the norm. The discontinuities continually break through, opening up a gap between bodily form, appearance, function and ability: the deaf person who can hear you perfectly, till you turn your back on them; the woman who uses a wheelchair and has just qualified as an aerobics instructor; the visually impaired woman who greets you in the evening on the street but cannot see you in the light of day. These disruptions speak not to the apparent limits of an impaired body, but rather of a break with the normative identities of those who are blind, deaf, disabled, and so on. For just such reasons, performativity may evade normalisation and move instead into transgressive resistance. Speaking of her experience of breast cancer, Eve Sedgwick writes of the 'performativity of a life threatened ... by illness' and of herself 'hurling her major energies outward to inhabit the very farthest of the loose ends where representation, identity, gender, sexuality and the body can't be made to line up nearly together' (1994: 12).

**ME AND PERFORMATIVITY**

We want now to return to look more specifically at the ways in which the woman with ME, the 'ME sufferer', has been produced through the reiteration of regulatory norms which have materialised the ill and/or disabled body, and in particular at the discursive practices of the medical system and self-help groups which have produced differing reinscriptions of the bodies of those with ME.

[...]

What is at stake for coherent diagnostic closure is that the body should be constructed either as stable or as predictably changeable. Professional theorisation relies, therefore, upon that body being open to investigation—to the invasive waves of ultrasound and the electrical impulses used in muscle tests, to the needle drawing blood, and to the structured psychological questionnaire—and to revealing 'truths' in standardised ways. The patterns of ritualised medical exchange that form the clinical examination permeate the boundaries of the body in fixed and certain ways, to reveal information that might explain and reinscribe a stabilised, though ill, body. The medical gaze seeks to establish an empirical, material 'broken' body but, as with the DLA assessment, the individual is incited at the same time to become an instrument of that ever-extending gaze. She turns it on herself, carrying out her own self-regulation, thus becoming complicit in the process of constituting herself as embodied subject.

A questionnaire produced by the Department of Medicine of the University of Liverpool—for completion by the 'patient'—is an example of how such self-surveillance operates. Through the reiteration of a series of implicit criteria contained in the questions, norms for ME are established. Twenty-six pages of questions cover everything from fatigue and pain, to sex life, sleep patterns, emotional state and social contacts. We can look at one example. A series of questions on pain, which attempt to categorise it and relate it to functional ability—levels of walking, sleeping, having sex, socialising—is followed by a silhouette of the human figure which the patient is asked to complete by precisely mapping where and how she experiences pain (University of Liverpool 1993). The act of marking it down, making it visible, serves to bring a sense of coherence. A pattern emerges through the questions. In answering the questionnaire, those with ME become a part of the process of the inscription of the body, establishing norms without which organisation of the condition has to start afresh each time.

[...]
from new members, clearly providing support and a sense of shared experience to other members. Through the reiteration, repetition and categorisation of symptoms in this and other self-help forums, a normalising process occurs through which some symptoms are accepted as indicative of illness, others not. The process of monitoring remissions, relapses and other changes has become a necessary act for the person with ME, such that the very instability of the condition has become incorporated as a stable feature of a new norm. Members are constrained to 'perform' their illness or disability in ways that fit in with the norms adopted by the self-help group. But the point here is not so much that the performativity of disability is something a subject may freely choose, but that disability itself is performative in the sense that it constitutes as an effect the very subject that it appears to express' (Butler 1991: 24). At an uncontested individual level, the deployment of norms offers a fantasy of control, a way of pinning down, categorising and assuming the ability to manage a condition which constantly escapes attempts at closure, which continually produces new symptoms, or which returns to previous symptoms after a respite of weeks or months. They offer a way of adapting to the functioning of a body which suddenly runs out of energy, leaving you stranded in the middle of a shopping expedition, or half-way up a flight of stairs, or in the middle of making love. They create an illusion of mastery, never completely absent but never totally achieved.

In campaigning ME groups, the normative identity claimed relies on the recognition of a physically induced impairment, and there is strong resistance to any suggestion of non-somatic causation. The ME Association in particular perceives itself as having made a major breakthrough in achieving recognition for ME in the International Classification of Diseases, the definitive list of recognised conditions. The belief in an underlying viral illness is an article of faith in most ME self-help groups, and there is no place for the woman who has similar symptoms, but relates them all to stress. Part of the operative norm is that of the tragic victim, suffering from a physical illness and yet dismissed by the medical profession and by society. The 1993 Annual Report of the ME Association entitled The Burden of Proof reiterates this norm both visually - through the cover image of a drooping, wheelchair-bound figure - and in its contents, which focus on research undertaken into the viral origins and pathological markers of ME. This process of reinscription of the body of illness, through knowledge circulated and legitimised by self-help groups, acts as a strong cohesive link in the maintenance and success of such groups.

The ME Association’s imagery - and this is true of some other groups - mirrors conventional media representations in which ‘disabled people are portrayed as helpless, needy victims of illness and the plucky, courageous and brave cripple fighting adversity’ (Ralph 1993: 9). In contrast, other disability rights groups have strongly critiqued such negative accounts (Corbett 1994; Shakespeare 1994). Nonetheless, however much self-help and campaigning groups have challenged the medical and charity models, familiar in cultural representations, their intention and achievement has been only to replace one set of functional norms with another. Either way, what matters is a stable identity and the discovery of the ‘true’ self.

The denial of our reality ... is a suffocation of what makes us exist as unique individuals. It disempowers and weakens us. To gain a proud label, we need to fight this denial and use the language of our ‘actual’ identity. (Corbett 1994: 347)

What a deconstructionist approach suggests, on the contrary, is that all identities are constantly shifting and developing, both through resistance to existing norms, and through the incitement of new norms. But the process is never complete, and nor is there any final truth of the body at which to aim.

The task of the postmodernist feminist is to lay bare and contest the discursive construction of all seemingly stable categories. It is - to brazenly paraphrase Judith Butler writing on heterosexuality and homosexuality - as though disability ‘secures its self-identity and shores up its ontological boundaries by protecting itself from what it sees as the continual predatory encroachments of its contaminated other’, ability (1991: 2). Now that, of course, is a reversal of the usual relationship between ability and disability, but our point is that both categories are concerned to police their boundaries. [...] Indeed, the failure of feminism in general to respond adequately to issues around disability must surely reflect the difficulty of thinking beyond the binary of sameness and difference. By deconstructing both the regulatory processes of normalisation which map out the divisions between bodies, and by contesting the stability of the able-bodied/disabled subject herself, we hope to break down the boundaries of the broken body. There are neither homogenous categories, nor fully self-present individuals. In rethinking difference in terms of irreducible and multiple differences, we advocate not liberal tolerance but a radical openness to the disruptive otherness within.

NOTES
1. Parts of this section are taken from Shildrick (1997) Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio)ethics.
2. The analysis we make of DLA is equally true of the new Incapacity Benefit, introduced by the Department of Social Security in 1995 to replace Invalidity Benefit.
3. For a detailed analysis of how such a move operates with regard to the colonial state, see Price and Shildrick (1995).

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